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Linking Primary Care to Community-Based Mental Health Resources via Family Navigation and Phone-Based Care Coordination

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Abstract

Family navigation (FN) and phone-based care coordination may improve linkages from primary care to community-based mental health referrals, but research on their differential impact is limited. This mixed-methods study compared FN and phone-based care coordination in connecting families to mental health services from primary care. Families of children (56.3% male, mean age = 10.4 years, 85.4% Black) were sequentially assigned to either receive FN through a family-run organization or phone-based coordination via the child psychiatry access program (CPAP). Caregiver-reported children's mental health improved in both groups and both groups were satisfied with services. More families in the CPAP group had appointments made or completed (87%) than families in the FN group (71%) though the difference was not statistically significant. Future research with a larger sample that matches family needs and preferences (e.g., level and type of support) with navigation services would be beneficial.

Keywords Mental health referrals · Family navigation · Child psychiatry access programs · Primary care

Introduction

Pediatric primary care clinicians (PCCs; e.g., pediatricians, nurse practitioners) play a critical role in identifying mental health concerns, which are experienced by approximately one in five youth (Foy & American Academy of Pediatrics Task Force on Mental Health, 2010; Kessler et al., 2005; Stagman & Cooper, 2010). The COVID-19 pandemic has further exacerbated mental health problems and access to treatment among youth (Racine et al., 2021; Samji et al., 2022). Indeed, an increasing number of PCCs are identifying mental health concerns at routine well-child visits (Beers et al., 2017), as PCCs are often the first point of access for children with mental health concerns (Foy & American Academy of Pediatrics Task Force on Mental Health, 2010). While many PCCs report that they are increasingly comfortable with their role in the identification of mental health concerns and subsequent referral to a specialized mental health provider, many continue to report discomfort with providing in-office interventions themselves or treatment with psychiatric medications, with the exception of ADHD (Bettencourt et al., 2021; Heneghan et al., 2008; Horwitz et al., 2015; Stein et al., 2008). Additionally, some youth with more severe mental health concerns require specialized support outside of primary care due to the complexity or severity of their condition (Horowitz et al., 2015). Yet many (48–62%) youth referred for outpatient mental health services fail to present for their intake (Harrison et al., 2004; Ofonedu et al., 2017), despite families expressing a desire to connect to services (Harrison et al., 2004).

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Theoretical and empirical models suggest several barriers to mental health engagement including the following: caregiver beliefs (e.g., social norms), motivation (e.g., caregiver priorities), skills and knowledge about help-seeking, environmental barriers (e.g., transportation), institutional/system-level factors (e.g., inadequate insurance cover for mental health services), caregiver well-being (e.g., stress, [lack of] social support), and child symptom functioning (Cyr et al., 2019; Foy & American Academy of Pediatrics Task Force on Mental Health, 2010; Harrison et al., 2004; Larson et al., 2013; McKay & Bannon, 2004; Ofonedu et al., 2017). Barriers to care may be even more pronounced for youth who have been historically underserved, such as those in the foster care and juvenile justice systems, immigrants, those who identify as BIPOC (Black, Indigenous, People of Color), and those experiencing poverty (Stagman & Cooper, 2010).

Primary care practices and states have grappled with ways to increase engagement in mental health care in general and linkages to care following PCC referrals more specifically. Across many states, child psychiatry access programs (CPAPs) have been used to fill in gaps, gaining traction as an effective way to address mental health concerns among youth (Foy & American Academy of Pediatrics Task Force on Mental Health, 2010). Starting with the Massachusetts program in 2004, CPAPs now exist in 46 states, the District of Columbia, and 6 tribal communities and US territories (https://www.nncpap.org/map). Programs vary based on factors such as funding, geography, and existing child mental health infrastructure (Bettencourt & Plesko, 2020; Spencer et al., 2019), but generally aim to increase the ability of PCCs to directly address the psychiatric needs of their patients. Many CPAPs provide a core set of services that includes PCC training and education, rapid phone access to advice from child and adolescent mental health clinicians, and referral assistance. While many CPAPs address referral support by providing a cultivated list of referral options to the PCC (specific to the type of service needed, accepted insurance and wait time; Maryland Behavioral Health Integration in Pediatric Primary Care, n.d.), some programs provide care coordination directly to patients and families in recognition of the barriers many families face when navigating a complex mental health system (Massachusetts Child Psychiatry Access Program, n.d.). Evaluations of CPAPs have been primarily descriptive in nature, with most studies describing high levels of PCP enrollment and utilization, high acceptability and feasibility, and improvements in PCPs' confidence in addressing their patients' mental health needs (Bettencourt & Plesko, 2020; Spencer et al., 2019).

To our knowledge, no studies have examined rates of connection from CPAPs to mental health services following referral from primary care to community-based resources nor are there studies specifically examining care coordination. We know of only two studies that have examined family satisfaction with CPAP services (Cama et al., 2020; Dvir et al., 2012). However, both studies focused on the Massachusetts program and one study focused on parent satisfaction with PCP's use of MCPAP rather than on their experiences with care coordination to community-based resources (Cama et al., 2020). Dvir et al. (2012) reported high levels of parent satisfaction with MCPAP staff and services, though satisfaction with care coordination to community-based resources versus satisfaction with MCPAP psychiatry consultations was not delineated.

In addition to CPAPs, peer support models have been put forth as another way to increase linkages with recommended mental health services (Chinman et al., 2014). In this model, caregivers of children with mental health needs or knowledge of community-based resources (referred to as "navigators") support families who are newer to the mental health system in accessing services and understanding the system of care. Navigators can potentially address many of the aforementioned barriers to accessing mental health care by reducing families' sense of isolation, stress, and self-blame; helping families clarify their own needs; teaching skills, coaching families, modeling effective advocacy; personalizing the approach to accessing healthcare; and bridging the gap between providers and families (Chinman et al., 2014; Mullen et al., 2023). Peer navigation has been deemed an evidence-based model of care by the Centers for Medicare and Medicaid Services and many states and health plans are increasingly reimbursing for this service (Eiken & Campbell, 2008). While the use of navigators has been cited as a promising way to better connect families from primary care to mental health care (Acri et al., 2016; Godoy et al., 2019), research is limited. Notably, much of the research has focused on navigation for adult patients with chronic health concerns or serious mental illness (Ali-Faisal et al., 2017; Freeman & Rodriguez, 2011) and few studies on mental health navigation have used randomized control methodology (Waid et al., 2021).

Within a pediatric population, peer navigation research has focused more on management of chronic illness or broader developmental concerns rather than mental health concerns (Cavaleri et al., 2011; Hoagwood et al., 2010). For example, a systematic review of empirical studies examining navigation for youth referred to behavioral health services found only 8 studies (Petts et al., 2021), with four of the studies targeting developmental diagnostic assessments, including three that focused on autism (Feinberg et al., 2016, 2021; Roth et al., 2016) and one that focused on connection with Early Intervention (Guevara et al., 2016). Research examining the use of family navigation for children with autism has found that families are more likely to complete an autism diagnostic assessment (Feinberg et al., 2016, 2021), have greater likelihood of connection with recommended services after an autism diagnosis is made (Roth et al., 2016), and demonstrate decreased caregiver stress (Jamison et al., 2017). However, this body of research is limited in its focus on autism rather than on referrals from primary care to community-based mental health referrals more broadly. Another study focused on referral from primary care to Early Intervention found that use of a navigator was feasible and there were good rates of connection (83% initiated referral; Guevara et al., 2016). However, there was no use of control arm, the navigator did not have lived experience, and the focus was on Early Intervention rather than mental health referrals more broadly.

Sprecher et al. (2018) conducted a retrospective descriptive cohort analysis of patient navigation in an urban academic pediatric primary care practice and found that navigators were fully successful (65% of the time) or partially successful (21% of the time) in completing the referred task and closing the loop with the PCC. Referrals for help with logistical barriers (e.g., assistance with transportation) were more likely to be successful when compared with referrals for developmental concerns (e.g., Early Intervention), referrals to promote treatment adherence, or referrals focused on transition to adult care (Sprecher et al., 2018). However, there was no comparison group and referrals were for a broad range of issues and not specifically for mental health concerns. Pantell et al. (2020) randomly assigned caregivers of youth seen in primary care and urgent care clinics to either in-person navigation or control (provision of resource list) to address social needs and found that navigation was associated with decreased risk of hospitalization in the year following, but there were no differences in emergency department utilization. While promising, this study focused on social needs and not on mental health navigation specifically.

For children experiencing mental health concerns, several studies have documented the benefits of telephone-based family navigation (FN), including connection with mental health services, especially for families in which parents were highly strained (Kutash et al., 2011, 2013). However, participants were families of children enrolled in special education programs and findings may therefore not generalize outside of the school setting. In a sample of families with limited financial resources referred for mental health services (from various referral sources including but not limited to primary care) in three counties in Oregon, a FN program demonstrated high rates of initial connections to mental health services and increased family empowerment compared to a control group receiving usual care (Koroloff et al., 1996). Notably, this study also provided a cash fund to support families in accessing mental health services, which may have provided additional benefit to families in the navigation condition potentially confounding outcomes. Furthermore, the majority of families in this study were White (82%), which may limit generalizability of findings to a region with greater racial and ethnic diversity.

We know of no research examining navigation from pediatric primary care to community-based mental health referrals nor research comparing navigation to CPAP care coordination support. This study addresses the identified gaps in the literature by expanding on this knowledge base with an examination of how navigators can be used to enhance mental health referrals from pediatric primary care and how navigation compares to the phone-based care coordination provided in some CPAPs.

Objectives

This mixed-methods study had 3 primary aims: (1) Determine if FN was more effective than phone-based care coordination for accessing community-based mental health services following referral from primary care; (2) Describe changes in key outcome variables related to the child (e.g., improvements in mental health), caregivers (e.g., depression, perceived social support), and the help-seeking process (e.g., barriers to care) between groups 3 months after referral from primary care; and (3) Describe families' perceptions of accessing mental health care with the support of a peer navigator or CPAP phone-based care coordinator via surveys and interviews. We hypothesized that receipt of FN would increase the likelihood of connection with care compared to phone-based care coordination.

Methods

Study Setting

The District of Columbia joined the growing list of states with a CPAP in 2015 to promote mental health within primary care with increased collaboration between PCCs and mental health providers and to improve the identification, evaluation, and treatment of child mental health problems. The DC CPAP, "DC MAP" (Mental Health Access in Pediatrics) offers core services including (1) real-time phone-based consultation for PCCs with a child mental health specialist, (2) a one-time in-person or telehealth patient visit with a psychiatrist as clinically indicated, (3) support for PCCs in identifying community treatment referrals, (4) direct phone-based follow-up support for families to support resource navigation, (5) technical assistance on implementing routine mental health screening within a pediatric primary care practice, and (6) education for PCCs on mental health topics. Clinical questions were directed to a team of child psychiatrists and psychologists, whereas intake calls and care coordination were provided by a team of non-clinical, bachelor or master's level program staff.

When PCCs called the DC CPAP to inquire about community-based mental health resources for families, as part of standard of care, the Care Coordinator provided information directly to patients and/or their caregivers about these resources and then followed up with the family via telephone at regular intervals to support the family in accessing care. Separately within the District of Columbia there has been a focus on increasing peer navigation for families of children with mental health concerns. The DC CPAP partnered with a local family-run, not-for-profit organization founded and led by parents of children with mental health concerns, that offers mental health FN. Prior to the study, the organization was receiving referrals directly from the community, but was not regularly receiving referrals from PCCs or the local CPAP.

Participants

Caregivers of youth between one and 18 years of age referred for DC-based CPAP care coordination (i.e., PCC had requested that the family be provided with referral resources) from February 2017 to November 2018 were initially eligible to participate. The recruitment period, which had already been extended beyond initial planned recruitment dates, was limited due to funding and resource constraints. Families were excluded from participation if the caregiver was not the custodial caregiver, the caregiver was younger than 18 years of age, the family did not reside in DC, or the caregiver was not comfortable completing surveys and interviews in English.

Recruitment and Informed Consent

Families who met eligibility criteria were asked via phone by the CPAP Care Coordinator if they wanted to learn more about the study. Research staff then contacted interested and eligible families via phone to provide further information, obtain informed consent, and set up a time to complete the baseline questionnaires. Caregivers were given the option of completing assessments at their home, at a public location (e.g., library), or at the hospital. They were compensated for their time in completing assessment measures/interviews.

Group Assignment and Intervention Descriptions

Participants were assigned alternately to the CPAP phone-based care coordination or FN groups. Immediately after completing informed consent and baseline surveys, families were informed of their group assignment and the CPAP team and FN team were notified accordingly so that they could follow up with the family to provide referral information and family support.

Family Navigation Group: Description of Services

Caregivers in the FN group could contact the navigator at any time, though navigators aimed to contact caregivers every few weeks when they did not hear from families to ensure regular contact. Caregivers and Navigators were able to communicate in-person, via phone (calls/texts), or via email depending on caregiver preferences and needs. Most FN family contact was in-person with sessions typically lasting an hour in length. While Navigators aimed to assist families in connecting with specific mental health resources to which they had been referred, they also were able to support families more broadly. For example, Navigators could support caregivers in accessing additional services that may be relevant to their child’s mental health (e.g., housing). Navigators working at the family-run organization, who have a minimum of a high school diploma or GED, all have “lived experience” in navigating youth mental health and/or substance use disorder systems. Navigators receive formal external trainings (e.g., local Department of Behavioral Health Certified Peer Training program, Mental Health First Aid and Recovery Coach trainings) as well as internal training and ongoing support and coaching within the organization from licensed clinicians. Navigators tend to have small caseloads (7–10 families) so that they can spend up to several hours per week with families if needed.

Child Psychiatry Access Program Group: Description of Services

At the time of the study, families referred to CPAP care coordination services received email or phone outreach from the Care Coordinator with information about mental health resources (e.g., agency telephone numbers). Following the initial contact, the Care Coordinator then attempted to contact the family 2 weeks, 1 month, and 3 months post-referral. During these calls, the Care Coordinator supported families in their efforts to access care, though typically this was limited to providing referral information again. Care Coordinators had advanced degrees (e.g., bachelor’s or master’s degrees) though did not have formal clinical training. During the course of the study, they maintained a relatively small caseload similar to that of the FN group (7–10 families).

Procedure

Participants completed a caregiver-report baseline assessment following informed consent (prior to group assignment) and a post-intervention assessment 3 months later. Families were notified about group assignment upon completion of informed consent and gathering of baseline assessments. Information about family contact with the mental health agency was gathered during each contact between the family by either the Care Coordinator or the Navigator depending on group assignment. Participants also completed a brief interview about their experiences trying to access mental health care at the end of the study. Quantitative data were entered into REDCap (Harris et al., 2009, 2019), a secure, web-based data capture application. Interviews were audiotaped, transcribed, and imported into Dedoose for analysis (Dedoose Version 9.0.17, 2021).

Measures

Caregivers completed questions about demographic characteristics for their child (e.g., race, ethnicity) and for themselves (e.g., parent education level). This included a question about the total number of *ACES (Adverse Childhood Experiences)* caregivers had experienced (range 1–10; Felitti et al., 1998). ACEs reflect children's experiences with negative life events, such as family conflict, physical abuse, and sexual abuse. The ACEs questionnaire has acceptable internal consistency and test–retest reliability (Dube et al., 2004).

Family connection with mental health services was measured by whether the family had contact with any of the mental health agencies to which they were referred with the opportunity to indicate the nature of the contact (e.g., seen for a visit, on a waitlist). These data were gathered during calls between the family and either the Care Coordinator or Navigator and during endpoint interviews and questionnaires.

Parent perceptions of children's mental health were assessed using several 5-point Likert scale questions developed by the study team focused on overall child mental health (1-excellent to 5-poor), child mental health changes (1-much better to 5-much worse), and concern about child mental health (1-not at all worried to 5-very worried).

Barriers to Children's Mental Health Care (Larson et al., 2013), a 23-item survey that uses 6-point Likert scale questions (rating the extent to which they consider something a problem and agree with statements) was used to assess caregiver perceptions of mental health treatment and potential barriers in seeking mental health care, including tangible barriers (e.g., transportation problems, difficulty navigating resources; "The clinic is too far away from my home") and intangible barriers (e.g., stigma, fears about medications; "I would be embarrassed if my family and friends found out I was taking my child to the mental health center"). Subscale reliability is adequate (Cronbach alphas > 0.7; Larson et al., 2013).

Parental self-efficacy was measured using the eight-item efficacy subscale from the Parenting Sense of Competence (PSOC) scale (Johnston & Mash, 1989). Parents rate each item (e.g., "Being a parent is manageable, and any problems are easily solved") using a 6-point Likert-type scale (from *Strongly Agree* to *Strongly Disagree*). Previous studies have demonstrated strong reliability and validity (Ohan et al., 2000; Rogers & Matthews, 2011). Internal consistency of this scale is good across both mothers (0.68) and fathers (0.74).

Caregiver perceptions of social support were measured with the widely used Multidimensional Scale of Perceived Social Support (Zimet et al., 1988), which has been demonstrated to have good internal reliability (Osman et al., 2014). This 12-item scale uses a 7-point Likert scale (Very Strongly Disagree to Very Strongly Agree) to explore social support from family, friends, and significant others. The scale's psychometric properties, including internal consistency ($r = 0.85$) and test–retest reliability (alpha = 0.88), are good.

Parental stress was assessed via two items ("I feel too stressed to enjoy my child" and "I get more frustrated than I want to with my child's behavior") that are included on the Early Childhood Screening Assessment (Gleason et al., 2010). These items have been validated by the US Preventative Health Task Force to evaluate parental stress. Internal reliability of the scale is good (0.76; Gleason et al., 2010).

Parental depression was assessed via the 2-item Patient-Health Questionnaire (PHQ-2; Spitzer et al., 1999), which assesses depression symptoms over the previous 2 weeks (Kroenke et al., 2003; Staples et al., 2019). The widely used tool has strong psychometric properties, including 87% sensitivity and 78% specificity for Major Depressive Disorder and good internal consistency (0.86–0.89; Löwe et al., 2004).

Interviews were conducted by trained independent interviewers and lasted approximately 20 min. Interview guides used 20 semi-structured questions focused on perspectives on mental health (e.g., "How do you think other people in your family and community might react to you taking your child to the children's mental health center?"), mental health integration in primary care (e.g., "Do you feel like your PCP plays an active role in getting your child the help they need?"), families' experiences with trying to access mental health services (e.g., "Tell me about your experiences trying to access mental health services for your child or yourself. What were some positive or helpful aspects? What were some difficult or challenging aspects?"), and their experiences working with either the Navigator or CPAP Care Coordinator (e.g., "What could be done to improve the experience?").

Data Analyses

This mixed-methods study employed separate strategies to address quantitative and qualitative aims. Quantitative analyses were conducted using SAS 9.4 with two-sided tests using a p value of < 0.05, and 95% confidence intervals (CI). A power analysis conducted prior to study implementation assumed a power of 0.80, $\alpha = 0.05$, and a 30% greater rate of mental health appointment completion for the FN group compared to the CPAP group which yielded a sample size of 38 families per group at the time of follow-up. Independent relationships between variables at baseline and month 3 (e.g., child and caregiver well-being variables such as parent depression and social support and child mental health improvements) as well as the difference between the control and intervention groups (e.g., mental health referral completion status) were examined using Chi-Square, Fishers Exact Test, McNemar's Chi-Square, Wilcoxon Rank Sum, and Wilcoxon Sign Rank significance tests. Intangible and tangible barriers to care were summed for each individual and the significance of the difference between baseline and month 3 was assessed using the Wilcoxon Rank Sum test, and the significance of the difference between intervention and control was assessed using the Wilcoxon Sign Rank test. These analyses were selected based on the nature of data collected (e.g., continuous versus categorical variables) and they accounted for repeated measures.

Qualitative interviews were audio-recorded and transcribed. Verbatim interview transcripts were analyzed using Dedoose qualitative data analysis software (Dedoose Version 9.0.17, 2021). We used constant comparative qualitative analysis, an inductive, iterative process exemplified by simultaneous data collection and analysis (Braun & Clarke, 2006; Hsieh & Shannon, 2005). Initially, codes were induced from line-by-line analysis using the participants' words to name codes. Codes were created based on qualitative interviews with families describing their perceptions of mental health, barriers and facilitators in accessing care, and satisfaction with FN or CPAP services. Codes were then grouped based on content similarities (Thorne, 2008). Informational redundancy (i.e., not hearing new data from caregivers) was achieved after completing analysis of all the interviews. The coding scheme was developed jointly by several of the authors (LG, RW, LD, HF). Coding revisions were made using consensus agreement. In place of formal reliability analyses due to the small sample size, every interview was double coded to ensure consensus was reached.

Results

Study Participants

Figure 1 provides information about families approached and recruited into the study, as well as data about family completion and attrition. Of the 48 families who completed baseline questionnaires, 75% ($n = 36$) completed endpoint questionnaires and/or an interview at 3-months follow-up (62.5% from the CPAP group, $n = 15$; and 87.5% from the FN group, $n = 21$). Of the 48 participating families, we found no significant difference in the demographic characteristics of those who completed the study and those who did not complete the study. Demographic variables are described in Table 1. Child participants were 10.4 years old on average ($SD = 3.8$ years), 56.3% ($n = 27$) were boys, 87.5% ($n = 42$) identified the child's race as Black/African American, and 10.0% ($n = 5$) identified the child's ethnicity as Hispanic/Latinx. Most of the children (76.3%; $n = 29$) had public insurance. Caregivers were predominately biological mothers (92%) and they reported experiencing an average of four Adverse Childhood Experiences. There were no significant differences between the CPAP group and FN group in terms of demographic characteristics.

Family Connection with Mental Health Services

Of the 32 families with known referral status information, 78% ($n = 25$) made and completed appointments with mental health resources. Families in the CPAP group (87%) were more likely to have appointments made and completed than families in the FN group (71%), though the difference was not statistically significant ($p = 0.090$).

Child and Caregiver Well-Being

Child and caregiver well-being variables are described in Table 2. There were no significant differences in caregiver-reported responses to a question about their child's Overall Mental Health from baseline to follow-up, though there was a trend toward significant changes: baseline Median response = 4 (*Fair*) vs follow-up Median response = 3 (*Good*), $p = 0.071$. Caregivers reported improvements in children's mental health from baseline to follow-up ($p = 0.02$) in response to a question about changes in their child's mental health status (Median response at baseline = 3, *About the Same* vs Median response at 3 months follow-up = 2, *A Little Better*), though there were no significant differences between the CPAP and FN groups. There were no differences in caregiver-reported social support, efficacy, stress, or depression nor in caregiver-reported concern about child mental health across the study period or between groups.

Help-Seeking

Help-seeking variables are described in Table 3. Families in both groups reported significant improvement in having the information needed to manage their child's mental health ($p = 0.014$) and there was a trend toward increases in family reports of being given information about treatment options ($p = 0.096$), though there were no significant differences between groups. There were significant decreases in intangible barriers to help-seeking over the course of the study

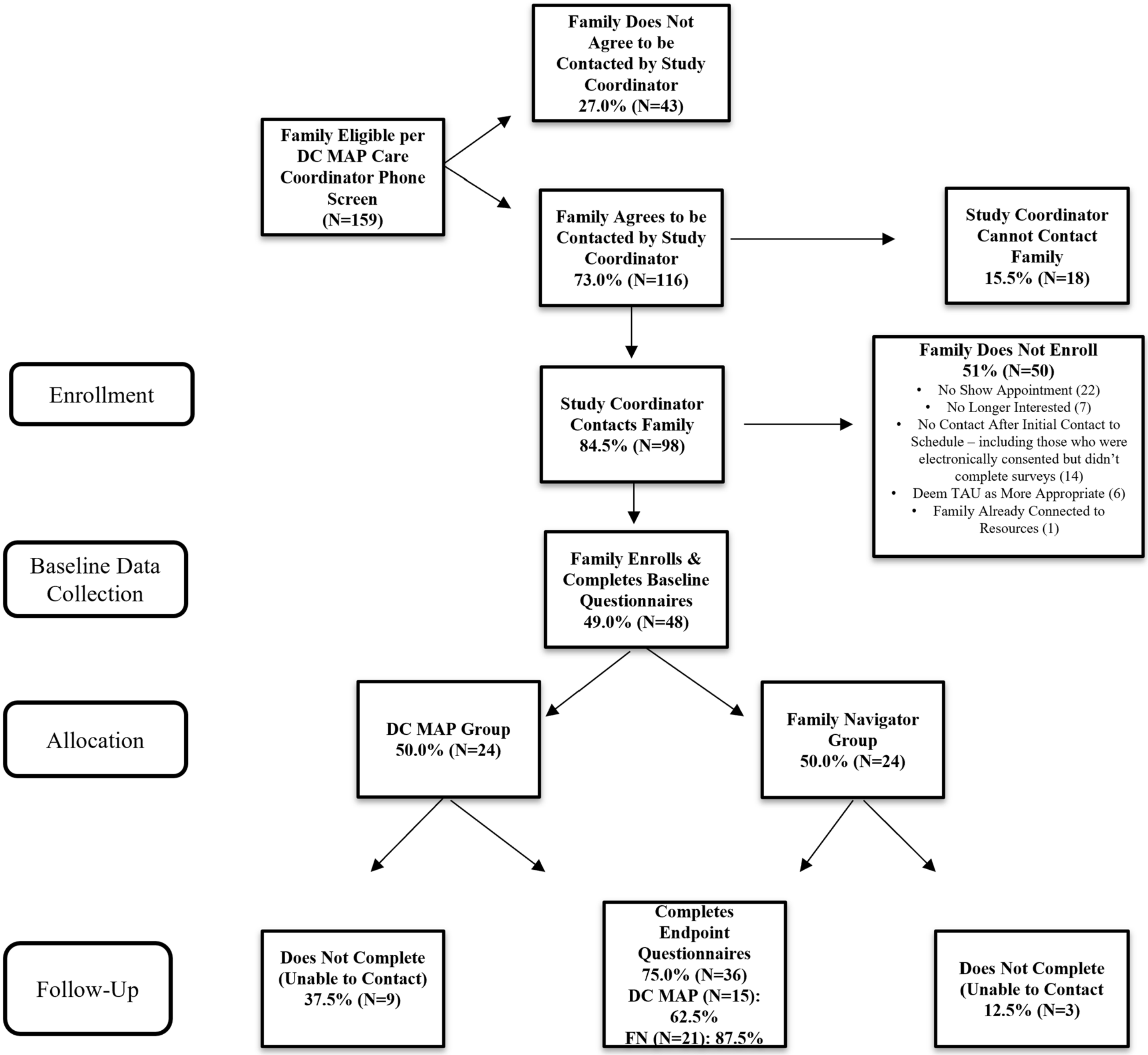

Fig. 1 Study flow chart

($p = 0.016$) and there was a trend in decreases in tangible barriers from baseline to follow-up ($p = 0.054$). There were no significant changes across the study period or between groups in several other variables, such as whether the family got the professional help they wanted, the efficacy of any treatment received, and the difficulty of getting treatment.

Qualitative Data Results

Family experiences with either CPAP or FN are described in Table 4. Families in both groups reported positive experiences about their relationship with the professional (i.e., the Navigator or CPAP phone-based Care Coordinator) with whom they worked and the focus and approach of the work. Families in the FN group reported a higher degree of overall satisfaction than families in the CPAP group ($p = 0.037$), though across both groups, high levels of satisfaction were reported.

Tables 5 and 6 summarize qualitative findings. At some point during the interview, the majority of families expressed neutral (80.0%) and/or negative (65.7%) attitudes or perceptions related to past experiences with mental health care, with only a quarter of families (25.7%) expressing positive attitudes, perceptions, or previous experiences. Barriers and facilitators of accessing mental health care were coded into different categories. It was then noted whether the family

Table 1 Demographic characteristics

Variable	CPAP % (*N*)	FN % (*N*)	Overall % (*N*)	*p* value
Child gender				1.00
Male	29.2 (14)	27.1 (13)	56.3 (27)	
Female	20.8 (10)	22.9 (11)	43.8 (21)	
Child race/ethnicity				.77
Asian/Pacific Islander	0 (0)	0 (0)	0 (0)	
Black/African American	45.8 (22)	41.7 (20)	85.4 (41)	
White	4.2 (2)	2.1 (1)	4.2 (2)	
Hispanic/Latino	4.2 (2)	6.3 (3)	6.3 (3)	
Other	0 (0)	4.2 (2)	4.2 (2)	
Mean child age	10.7 (3.7)	10.0 (4.0)	10.4 (3.8)	.50
Child insurance status				.65
Public	34.2 (13)	42.1 (16)	76.32 (29)	
Private	7.9 (3)	5.3 (2)	13.1 (5)	
Both	5.3 (2)	0 (0)	5.2 (2)	
Uninsured	2.6 (1)	2.6 (1)	5.2 (2)	
Caregiver relationship to child				.23
Mother	43.8 (21)	47.9 (23)	91.7 (44)	
Father	6.3 (3)	0 (0)	6.3 (3)	
Other	0 (0)	2.1 (1)	2.1 (1)	
Caregiver education				.69
Did not complete high school	6.5 (3)	4.4 (2)	10.9 (5)	
High school graduate/GED	17.4 (8)	17.4 (8)	34.8 (16)	
Some college/post high school	17.4 (8)	21.7 (10)	39.1 (18)	
College graduate	10.9 (5)	4.4 (2)	15.2 (7)	

CPAP child psychiatry access program, *FN* family navigator, *GED* general educational development test

had indicated that the barrier or facilitator was something perceived to be an issue for families broadly (coded as "community" access barrier or facilitator) or something perceived to be an access barrier or facilitator for their individual family (coded as "personal" access barrier or facilitator). While about a third of families described their own persistence and prioritization of help-seeking (i.e., value [or lack thereof] caregivers place on accessing mental health services, particularly in relation to other competing priorities, perseverance/motivation [or lack thereof] in trying to access resources) to be both a community (34.3%) and a personal (34.3%) access barrier, over half of participating families (54.3%) expressed their persistence and prioritization of mental health issues as a facilitator in their access to care. One family described their persistence in obtaining mental health care stating, "All I know is I guess I was on top of it and they see that it was a problem also and instead of letting it get worse, we addressed the needs so it could get better." The majority of families (67.1%) noted they had personal difficulties related to the mental health provider's availability (e.g., not offering evening or flexible times) and other characteristics of services provided (e.g., long waitlists, not accepting new patients, limited patient age range). More families perceived education and knowledge of mental health issues to be a community access barrier to mental health care (37.1%) than to be a personal barrier (17.1%) that they had experienced. Families also cited external factors, such as financial status (20.0%), insurance issues (20.0%), and transportation/distance from resource (20.0%) as obstacles to their own personal access to care. In qualitative interviews, almost all families (88.6%) discussed favorable views about their PCC, expressing feelings of support, trust, and comfort. One family reported that their experience with their PCC was "very positive, and she reassured me that it's not an isolated situation. That many children have those types of issues, so she let me know that I wasn't alone."

Overall, the majority of families discussed positive experiences receiving either FN (84.2%) or CPAP care (87.5%) during their interviews. Although the majority of families expressed positive experiences with both groups, over half (52.6%) of the families in the FN group expressed at least one unfavorable experience with the program (e.g., inconsistent access to the Navigator). Families in the CPAP group did not express any negative experiences with the program. Furthermore, the majority of families receiving CPAP services described a positive perception or experience with

Table 2 Pre- and post-study differences across groups: child and caregiver well-being

Variable	Overall sample median (IQR)		Difference in overall sample baseline to month 3	Difference between change in CPAP and FN—baseline to month 3
	Baseline	Month 3	*p*	*p*
Overall child mental health *Excellent (1) to Poor (5)*	4: Fair (1)	3: Good (2)	Signed Rank Test .071	Fishers Exact Test .32
Child mental health changes *Much better (1) to Much worse (5)*	3: About the Same (2)	2: A Little Better (1)	Signed Rank Test (S): .023*	Fishers Exact Test .50
Parent concern about child mental health *Not at all worried (1) Very worried (5)*	3: Worried (1)	3: Worried (2)	Signed Rank Test (S): .35	Fishers Exact Test .86
	Mean (*SD*)		*p*	*p*
Caregiver stress *Possible range: 0–4*	1.2 (1.1)	1.2 (1.3)	Signed Rank Test (S): .82	Wilcoxon Rank Sum Test .18
Caregiver depression *Possible range: 2–8*	3.6	3.9 (2.2)	Signed Rank Test (S): .45	Wilcoxon Rank Sum Test .92
Social support *Possible range: 7–84*	55.43 (22.08)	57.67 (21.15)	Signed Rank Test (S): .92	Wilcoxon Rank Sum Test .91
Self-efficacy *Possible range: 1–10*	7.02 (2.56)	6.62 (2.26)	Signed Rank Test (S): .31	Wilcoxon Rank Sum Test .85

CPAP child psychiatry access program, *FN* Family navigation

*$p < .05$; ***$p < .01$

Table 3 Pre- and post-study differences across groups: help-seeking variables

Variable	Overall sample median (IQR)		Difference in overall sample baseline to month 3	Difference between change in CPAP and FN from baseline to month 3
	Baseline	Month 3	*p*	Table Probability (P) *p*
Got the professional help you wanted *Never (1) to Always (4)*	3: Usually (2)	3: Usually (2)	.59	.36
Given information about treatment options *Yes (1) to No (0)*	1: Yes (1)	1: Yes (1)	.096	.83
Information to manage *Yes (1) to No (0)*	1: Yes (1)	1: Yes (0)	.014*	1.00
Care responsive to child’s needs *Yes (1) to No (0)*	1: Yes (1)	1: Yes (0)	.16	1.00
Efficacy of treatment (How much child was helped) *Not at all (1) to A lot (4)*	3: Somewhat (2)	3: Somewhat (1)	Signed Rank Test .66	.89
How difficult to get treatment *Big problem (1) to Not a problem (3)*	2: Small Problem (2)	2: Small Problem (1)	.28	1.00
Barriers to help-seeking: Intangible *Possible range: 12–72*	2 (3)	1 (3)	Signed Rank Test .016*	Wilcoxon Rank Sum Test .45
Barriers to help-seeking: Tangible	2 (4)	0 (3)	Signed Rank Test .054	Wilcoxon Rank Sum Test .69

CPAP child psychiatry access program, *FN* Family navigation

*$p < .05$; ***$p < .01$

Table 4 Post-study differences between groups: experiences with FN and CPAP

Variable	Median (IQR)		Test statistic Fishers exact test (P) *p*
	FN group	CPAP group	
Relationship *I do not feel heard, understood, respected (1) to I felt heard, understood, and respected (5)*	5: I felt heard understood and respected (2)	5: I felt heard understood and respected (1)	.045
Goals and topics *We did not work on or talk about what I wanted to work on and talk about (1) to We worked on and talked about what I wanted to work on and talk about (5)*	4(2)	5: We worked on and talked about what I wanted to work on and talk about (2)	.0066
Approach or method *The [care coordinator/navigator] approach is not a good fit for me (1) to The [care coordinator/peer specialist] approach is a good fit for me (5)*	5: The approach is a good fit for me (2)	5: The approach is a good fit for me (1)	.11
Overall *There was something missing in my work with the [care coordinator/ navigator] (1) to Overall, my work with the [care coordinator/navigator] has been right for me (5)*	4(3)	5: Overall, my work has been right for me (1)	.12
I was satisfied with [navigator/care coordinator] *Strongly disagree (1) to Strongly agree (5)*	5: Strongly Agree (2)	4: Agree (1)	.037*

CPAP child psychiatry access program, *FN* family navigation, *IQR* interquartile range

$^{*}p<0.05$; $^{***}p<0.01$

help-seeking (81.3%) during the interviews. Speaking on their experience with the program, a family in the CPAP group stated, “I appreciate her … following-up, the contacting, kind of checking-in here and there, seeing how everything goes, do I need anything, anything like that.” Only about half (57.9%) of the families receiving FN services described a positive experience with help-seeking. Many CPAP families cited service or provider availability (56.3%) and good coordination or follow-up (68.8%) as a facilitator to receiving services. In contrast, fewer FN families cited both service and provider availability (21.1%) and good coordination (31.6%) as an access facilitator.

Discussion

This study focused on ways to improve connection with mental health services following referral from primary care. The findings overall demonstrated the potential benefit that either phone-based care coordination or family navigation can play in accessing services. Follow-up connection rates in the present study (78% overall) were higher than prior literature on unassisted follow-up (48–62%; Harrison et al., 2004; Ofonedu et al., 2017). While families in the CPAP group (87%) were more likely to have appointments made and completed than families in the FN group (71%), the difference was not statistically significant and in the opposite direction from what we had hypothesized. In addition, families in both groups reported significant increases in their knowledge of how to address their children’s mental health problems, and both groups reported that the assistance they received had reduced barriers to receiving care, which is consistent with some other studies on navigation (e.g., Feinberg et al., 2021; Koroloff et al., 1996). Families in both groups reported positive changes in some key child and family well-being factors from baseline to follow-up, such as improvements in children’s mental health status, with no significant differences between the CPAP and FN groups.

Qualitative findings elucidated help-seeking processes and strengthen the limited research examining family outcomes and satisfaction following receipt of care coordination services (Bettencourt & Plesko, 2020). Families in both the CPAP and FN groups reported positive experiences and high levels of satisfaction with the professional with whom they worked via survey questions and interviews. This compares favorably to prior studies of caregiver satisfaction

Table 5 Coding themes and illustrative examples

Code	Specification	Examples
Thoughts/feelings about mental health and help-seeking		
Perceptions/definitions of mental health *Descriptions of mental health; the ways in which the interviewee explains mental health issues*	Negative attitudes/perceptions/definitions/stigma *Descriptions with a negative valence (e.g., see mental health issues in overly negative light, describe stigma)*	"I don't judge anything with mental health. It's just some people aren't blessed to be able to actually function on their own. Some need assistance, and that's just how I look at it."
	Neutral attitudes/perceptions/definitions *Descriptions with a neutral valence (e.g., statements that are fact-based and do not have a negative or positive tone)*	"Well, someone that's getting help far as mentally, they could be some issues as far as depression or … It can really be anything that's mental." “If you're referred to an asthma specialist, you need to get assistance with your asthma so I guess it would be the same because a mental health specialist you need assistance with your mental health”
	Positive attitudes/perceptions/definitions *Family describes mental health issues with a positive valence (e.g., see mental health issues as a strength)*	"I think everyone deserves to have their mental health checked out. It shouldn't be as big of an issue as it is, it's the same thing as going to get a physical. So, I don't think it should be a hassle for people to go and get really checked out."
Mental health education/literacy *Knowledge (or lack thereof) about mental health, including aspects such as diagnosis, etiology, intervention, and help-seeking*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"Not being able to identify signs of mental health or just behavior patterns. A lot of parents are just like, ‘Oh, that child is just like, they over there playing. They probably had a lot of candy.’ It's not always that, or ‘Oh, that child, I don't know what's wrong with that child. She moody today.’ It's not always about that. It literally could be something wrong."
Non-issue *Perceptions that mental health-related behaviors are not problematic, abnormal, or something worthy of specialized intervention; Denial of concerns about mental health*	Community access barrier Personal access barrier	"There's always going to be a lot of parents who's just defiant at the fact that there's mental health issues."
Persistence/Prioritization of Help-Seeking *The value (or lack thereof) caregivers place on accessing mental health services, particularly in relation to other priorities they have; perseverance/motivation (or lack thereof) in trying to access resources*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"All I know is I guess I was on top of it and they see that it was a problem also and instead of letting it get worse, we addressed the needs so it could get better.”
Nobody’s Business *Belief or attitude that the opinions or judgments of others (i.e., general public, friends, family) does not have an effect on their propensity to seek mental health care for their child. Interviewee endorses the idea that others should not be involved in their child's mental health care or the decision to seek care. Interviewee endorses the idea that they do not seek approval or opinion of others in making decisions about mental health care for their child*		"It's none of their business, so their opinion doesn't really matter."
External Factors: Individual/Family		

Table 5 (continued)

Code	Specification	Examples
Financial Status *Ability (or lack thereof) to pay for mental health services (i.e., copays, insurance premiums, payment for transportation to appointments)*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"This provider, she is only charging $10 a visit. But I've had times where I've had no job and I couldn't pay any co-pay and the co-pays were higher and I just said forget it because I've even had providers who've said they charge per family member and I wanted family counseling. So money"
Insurance Issues *Insurance coverage (or lack thereof) or other insurance issues that impact the ability to access the preferred or recommended mental health services*	Community access barrier Personal access barrier	"I was actually having problems with my insurance company so I didn't have insurance for some time. I had to go to court to be able to fight to see what was going on. I literally just got it reinstated about a week ago."
Transportation/Distance *Issues pertaining to making it to appointments, including access to (or lack thereof) cars, public transportation, parking. This may also include how far the service is from the family's house*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"A lot of the insurance, they offer transportation. So I feel like transportation is a big help especially parents that don't have their own transportation or sometime the weather doesn't permit. So they get the help to get to their appointments."
Experiences with Mental Health Referrals and Intervention		
Effectiveness of Treatment *Perceptions about the extent to which (if any) mental health interventions for the child or caregiver impacts mental health and helps the child/family to address their needs*	Perception of effectiveness of Treatment *expression that mental health intervention had or will have positive results in terms of improvements in mental health*	"I just think about professionals helping me to minimize those symptoms that I've been having, the diagnosis that I've been given. I just, I think about them kind of decreasing it so I would have a stable life. I would be … I can have ways to, like if I'm triggered, I can have ways to cope through all of that."
	Perception of ineffectiveness of Treatment *expression that mental health intervention has not had or is unlikely to have positive results in terms of improvements in mental health*	"Although we started a couple of months ago, it's still not at the point where I feel like this is working."
Fit of Therapist/Referral *The extent to which the mental health provider or resource to which a family is referred matches the needs and desires of the family and is able to address potential or general mental health needs in the way that would be most helpful*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"[Child] did get a good case manager…. when I tell you she was good, she was good. She was at that age. She had the patience. She didn't tolerate. She was stern, but she was loving at the same … she was just what [Child] needed. And they worked on their goals and stuff."
Trust/Comfort with Health/Mental Health Clinician or Agency *Perceptions about the confidence and ease (or lack thereof- i.e., feelings of discomfort and distrust) a family feels towards the health or mental health institution or provider to which they are referred or connected or about the general process for obtaining healthcare services*	Community access barrier Community access facilitator Personal access barrier Personal access facilitator	"Sometimes, we feel like we're being judged. I mean, it's probably not the case but in your mind, you feel like, 'Oh my god. I'm tellin' all of this to a stranger.' I think reassuring the families that everything's confidential or it's okay to talk about it."

Table 5 (continued)

Code	Specification	Examples
Experience with Mental Health Agency *Family's perceptions of their interactions with mental health agency*	Negative experience with mental health agency *Unfavorable impressions of the Mental Health agency/clinical with whom they worked (separate from CPAP/FN)*	"This particular agency, we scheduled the intake, we did the intake… As far as their actions of following through, we never had another appointment. I reached out to them a couple of times… Sometimes they would answer, sometimes they wouldn't,… It was just like running around in a circle. When I totally got fed up and I'm like this is taking too long. It was supposed to take a week for them to get back to me, they never got back to me. A month and a half later, I just decided to start all over with the original list and contact another agency."
	Positive experience with mental health agency *Favorable views about the Mental Health agency/clinician with whom they worked (separate from CPAP/FN)*	"This week, she had two anxiety attacks. The first thing she went to do is talk to her therapist, the mental health therapist. She was so nice. She helped her calm down until I arrived, until the ambulance arrived. I think there's one of my experience that I think it's not what I thought it was."
Characteristics of the Mental Health System		
Characteristics of the Mental Health System *Issues pertaining to agency or systems-level factors that impact help-seeking and care*	Co-located services *Experiences accessing mental health support integrated into places the child already accesses (e.g., primary care, school)*	"His primary care physician, and she told me the next step to take was to talk to the psychiatrist that was already placed within the clinic that he goes to, so the only thing I had to do was set up an appointment."
	Lack of co-located services *Mental health support is not integrated into places the child already accesses (e.g., primary care, school)*	"Yes. Because I come here for everything else, so why not just come here. She could see the pediatrician. I would make it, not only would it be a mental health appointment as well, but it would be a pediatrician appointment."
	Good coordination/ follow-up *Members of the care team communicate well with one another and provide seamless care and contact with family related to referrals and intervention*	"Keeping the communication open between the school and her pediatrician and everything, it was excellent. They exchanged information so if anything went wrong, emails were always connected or phone calls or paperwork."
	Poor coordination/follow-up *Fragmentation of the mental health system; For example, members of the care team do not communicate well with one another or with family*	"The negative is that they don't … It's like a miscommunication between primary and mental health services, physicians, psychiatrists, and therapists."
	Inconsistent care *Experiences with staff turnover (e.g., changing therapists or PCPs) and lack of care continuity*	"One of the issues that I have is I have a problem with the high turnovers. I would have one person that I'm working with and next thing I know that person is no longer there then I have another person. In a year, I've probably had about 7 people and that's beyond ridiculous. It's already hard to be able to pour out yourself to one person but to keep doing that, that's very traumatic."

Table 5 (continued)

Code	Specification	Examples
Services/ Provider Availability *Experiences of waitlists/wait times, whether mental health resources are locally available and accepting new patients, and issues pertaining to appointment times (e.g., agency's ability to offer evening or weekend appointments)*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"I feel some of the challenges is the time of the appointments. Most of the appointments are between eight and four and a lot of parents, we work and it's hard. The hours, it's kind of hard because you have to miss work hours or to take the kids. They go to school. You don't want them to miss school too."
Help-Seeking Experience		
Experience with PCP *Family's perceptions of their interactions with the child's primary care providers*	Negative experience with PCP *Expresses unfavorable views about the PCP and their interactions with them*	"When you go to a [PCP], …you as a patient just got to be like, besides going through what you're going through physically, you have to tell them right away what's going on with you and then sometimes it's really hard… to put it in words because… they're just telling you, "Okay, I only have 15 min. You have to hurry up."
	Positive experience with PCP *Expresses favorable views about the PCP and their interactions with them*	"When we came back, a week later, she went through them and went from there. She said it wasn't anything detrimental. But as far as the behavioral, she said it could get out of hand, and we want to nip it in the bud. Yeah, it was very positive, and she reassured me that it's not an isolated situation. That many children have those type of issues, so she let me know that I wasn't alone. Yeah, I think that was positive and reassuring to me as the parent."
Experience with FN *Family's perceptions of their interactions with peer specialist*	Negative Experience with FN *Unfavorable impressions of assigned Peer Specialist/agency, including perceptions of inadequacy/ineffectiveness*	"She came one time to talk to my sons in March. And then, after that, she would call to say she would come, and then not come. And I ain't seen her since September."
	Positive experience with FN *Favorable impressions of assigned Peer Specialist/agency, including perceptions of adequacy/effectiveness*	"Or if he'll say, "I just want to walk down there and walk back". He'll do that with him… He definitely checks on us every day, asks how school is going, homework is going, tutoring…It's good. My son really likes him. It's a good thing."
Experience with CPAP *Family's perceptions of their interactions with CPAP*	Negative experience with CPAP *Unfavorable impressions of CPAP, including perception of inadequacy/ineffectiveness of CPAP*	(Not coded)
	Positive experience with CPAP *Favorable impressions of CPAP, including perceptions of adequacy/effectiveness*	"[CPAP Care Coordinator] is very helpful… She told me lots of programs and how they work. … She keeps me updated, she let me know what I have to do, she asked me if I needed any other resources. Everything I tell her, she gets right on top of it and if I … need any other thing, she lets me know how to get into it

Table 5 (continued)

Code	Specification	Examples
Perceptions/Description of Help-Seeking *Beliefs, feelings, or experiences pertaining to the process of obtaining professional mental health services for their child or themselves*	Negative perception/description of help-seeking *Unfavorable beliefs, feelings, or experiences*	“If you were to ask me the services my child has received already, do I think that they're working or anything like questions like that right now, I wouldn't be able to answer you or it would be a negative answer because of what I've experienced.”
	Neutral perception/description of help-seeking *Beliefs, feelings, or experiences that do not have a positive or negative valence*	“In the beginning, I was given a list from an email and it was four different types of services/agencies that I could use. One was they only come to your house… One of them was the regular city, mental health access hotline, which I didn't want. Two were … private agencies… I went online and I googled the two different agencies. One stood out as far as the verbiage on the website, one stood out a little better than the other. I called them, scheduled an intake”
	Positive perception/description of help-seeking *Favorable beliefs, feelings, or experiences*	“When we first started—when I first got the numbers and everything to call for him, the people I spoke with was very helpful. Like I said, I had got an appointment as soon as possible for him”
Psychosocial Factors		
Parenting Stress *Interviewee reports experiencing strain, potentially related to addressing mental health concerns or more generally in their life*	(No subcodes)	"That makes it a little bit more stressful on a parent, because they're trying to pay attention to the child that needs to receive services, but at the same time, they still have to focus on their other responsibilities as far as the other kids so that's overwhelming, and frustrating"
Social Support for Help-Seeking/Mental Health Needs *Family is encouraged in their journey with mental health issues and obtaining resources by individuals, including:*	Community *Those around patient aside from family and school (e.g., friends)*	"I'm blessed to not have a family or community that's judgmental. They help. They're supportive.”
	Family	"Actually, they told me to get the help for my kids before any of this started. They're really supportive. My family's supportive.”
	School	"The thing that helped me connect with receiving outside services outside of Children's was the school. The school social worker"
	Other *Other person/organization (including faith-based) encourages family's journey with mental health issues and help-seeking*	"The caseworker was just on board with everything that was taking place and everything that I was working towards doing, she was very supportive…”
Youth Involvement *Extent to which the child or adolescent is a part of the help-seeking process and treatment*	Community access barrier Personal access barrier Community access facilitator Personal access facilitator	"I keep her informed about everything. I just don't make decisions about her without her being there or without her giving her opinion about what she thinks is best for her, especially when it comes to her medication. I don't take it, she takes it, so I don't know how she feels. She has to tell me. She had one medication that just made her groggy all day, and she didn't like that feeling, so we immediately had it changed."

Table 5 (continued)

Code	Specification	Examples
Suggestions		
Suggestions *Explicit recommendations the interviewee makes to improve services*	Improving FN experience *Family offers ideas for ways to enhance work with peer specialists*	"So, I think it should be openness and transparency in that relationship, because this is somebody trying to help your child, but it's also his job. So, the parent, the client, and the peer specialist need to be able to work together. For sure. Or it's not gonna work. So, I think that that should be something that is worked on, or added, that, it be kind of like a mandatory kind of relationship, even though it's a voluntary program."
	Improving CPAP experience *Family offers ideas for ways to enhance work with CPAP*	"Probably more emails and less phone calls. I can do emails and text messages better than talking on the phone."
	Improving mental health help-seeking *Family offers ideas for ways to enhance the process of seeking/obtaining mental health services*	"I feel like they should focus also on parents and not just the child." "I don't feel like medicine should be the first option. It should be counseling, give them more options of what they can do for parents who may not necessarily want to do the medicine option."
	Other *Family offers ideas for ways to enhance something not captured by the other suggestion categories*	"Let them just explain to them how this goes, to make them feel that the support is not really about being crazy, but things that will help the family and the child. In school, at home. Things like this could affect, not only in school but at home too. It really affect, especially they have siblings."
Other		
Other	Other code not captured *Something else the interviewee says that seems important to code but is not captured in the ones above*	"I think it's just a little more compassion. A little more empathy toward their parent"
	Other community access barrier *Other factor that serves as barrier to care that has not been categorized above, perception of barrier to community*	"Families with multiple children, they have to worry about okay, well is this child going to be able to sit in on a setting… if I had more than one kid and they were rowdy or they start interjecting, that wouldn't be beneficial to the child receiving services."
	Other community access facilitator *Other factor that facilitates care that has not been categorized above, perceived that it would be helpful to other families*	"You have to have people with the right heart, passion, have a desire to go into the mental health service to help families or individuals that's like really dealing with mental health issues"
	Other personal access barrier *Other barrier not captured in other codes that was problematic for this family*	"With myself, I had been out of work for a while and just recently started working back."
	Other personal access facilitator *Other facilitator perceived that it would be helpful to the family*	"I guess giving… a wide array of providers; providers with different specialties, providers who take different insurances, and who are in all 8 wards."

CPAP child psychiatry access program, *FN* family Navigation, *PCP* primary care provider

Table 6 Family endorsement of key themes

Code	Percentage of families who discussed (% (N))
Thoughts/feelings about mental health and help-seeking	
Perceptions/definitions of mental health	97.1 (34)
Negative attitudes/perceptions/definitions/stigma	65.7 (23)
Neutral attitudes/perceptions/definitions	80.0 (29)
Positive attitudes/perceptions/definitions	25.7 (9)
Mental health education/literacy	65.7 (23)
Community access barrier	37.1 (13)
Personal access barrier	17.1 (6)
Community access facilitator	22.9 (8)
Personal access facilitator	20.0 (7)
Non-issue	22.9 (8)
Community access barrier	11.4 (4)
Personal access barrier	5.7 (2)
Persistence/prioritization of help-seeking	91.4 (32)
Community access barrier	34.3 (12)
Personal access barrier	34.3 (12)
Community access facilitator	22.9 (8)
Personal access facilitator	54.3 (19)
Nobody's business	31.4 (11)
External factors	
Financial status	22.9 (8)
Community access barrier	8.6 (3)
Personal access barrier	20.0 (7)
Community access facilitator	0 (0)
Personal access facilitator	0 (0)
Insurance issues	20.0 (7)
Community access barrier	5.7 (2)
Personal access barrier	20.0 (7)
Transportation/distance	20.0 (7)
Community access barrier	22.9 (8)
Personal access barrier	20.0 (7)
Community access facilitator	20.0 (7)
Personal access facilitator	8.6 (3)
Experiences with mental health referrals and intervention	
Effectiveness of treatment	62.9 (22)
Perception of effectiveness of treatment	42.9 (15)
Perception of ineffectiveness of treatment	22.9 (8)
Fit of therapist/referral	65.7 (23)
Community access barrier	11.4 (4)
Personal access barrier	40.0 (14)
Community access facilitator	0 (0)
Personal access facilitator	40.0 (14)
Trust/comfort with health/mental health clinician or agency	57.1 (20)
Community access barrier	5.7 (2)
Personal access barrier	14.3 (5)
Community access facilitator	14.3 (5)
Personal access facilitator	31.4 (11)
Experience with mental health agency	57.1 (20)
Negative experience with mental health agency	22.9 (8)
Positive experience with mental health agency	42.9 (15)

Table 6 (continued)

Code	Percentage of families who discussed (% (N))
Characteristics of the mental health system	
Characteristics of the mental health system	80.0 (28)
Co-located services	31.4 (11)
Lack of co-located services	14.3 (5)
Good coordination/follow-up	48.6 (17)
Poor coordination/follow-up	42.9 (15)
Inconsistent care	34.3 (12)
Services/provider availability	82.9 (29)
Community access barrier	25.7 (9)
Personal access barrier	67.1 (20)
Community access facilitator	20.0 (7)
Personal access facilitator	37.1 (13)
Help-seeking experience	
Experience with PCP	97.1 (34)
Negative experience with PCP	28.6 (10)
Positive experience with PCP	88.6 (31)
Experience with FN	100.0 (19)
Negative experience with FN	52.6 (10)
Positive experience with FN	84.2 (16)
Experience with CPAP	93.8 (15)
Negative Experience with CPAP	0 (0)
Positive Experience with CPAP	87.5 (14)
Perceptions/Descriptions of Help-Seeking	68.6 (24)
Negative Perception/Description of Help-Seeking	68.6 (24)
Neutral Perception/Description of Help-Seeking	45.7 (16)
Positive Perception/Description of Help-Seeking	68.6 (24)
Psychosocial Factors	
Parenting Stress	22.9 (8)
Social Support for Help-Seeking/Mental Health Needs	65.7 (23)
Community	25.7 (9)
Family	37.1 (13)
School	14.3 (5)
Other	20.0 (7)
Youth Involvement	51.4 (18)
Community Access Barrier	8.6 (3)
Personal Access Barrier	14.3 (5)
Community Access Facilitator	5.7 (2)
Personal Access Facilitator	20.0 (7)
Suggestion	
Suggestions	97.1 (34)
Improving FN Experience	28.6 (10)
Improving CPAP Experience	11.4 (4)
Improving Mental Health Help-Seeking	88.6 (31)
Other	20.0 (7)
Other	
Other	45.7 (16)
Other Code Not Captured	11.4 (4)
Other Community Access Barrier	5.7 (2)
Other Personal Access Barrier	14.3 (5)
Other Community Access Facilitator	14.3 (5)

Table 6 (continued)

Code	Percentage of families who discussed (% (N))
Other Personal Access Facilitator	8.6 (3)

CPAP child psychiatry access program, *FN* family navigation, *PCP* primary care provider

with child mental health access programs (Cama et al., 2020; Dvir et al., 2012). However, this is the first study to our knowledge that examined satisfaction with direct care CPAP coordination services specifically. Prior research has either been limited to survey responses (Dvir et al., 2012) or was gathered via interview but was similarly focused on close-ended responses and did not incorporate extensive open-ended qualitative data (Cama et al., 2020). Moreover, prior research was focused on satisfaction with CPAPs more broadly and not with care coordination services specifically.

While follow-up interviews with participating families found many positive reports about both forms of assistance, there was more variability in feedback among families in the FN group. Given the range of navigation options (e.g., team composition, types of supports offered), it could be helpful to match family needs and preferences with service type (Godoy et al., 2019). For example, some families may desire and benefit from peer support (e.g., those who prefer more support or who may have experienced previous difficulties trying to access care), whereas others may prefer phone-based Care Coordination alone. Furthermore, differences have been found in the appropriateness and acceptability of models of care depending on the youth's presenting concern, thus highlighting the need to gather preliminary information about the child and family prior to matching families with a coordination service type (Spencer et al., 2019). Future research that assesses how to best match family needs and preferences (e.g., prior experiences trying to access care, level and type of support family desires) with navigation services could be beneficial.

This study should be understood in light of several limitations that can be addressed in future research. Our sample size was small (despite extending enrollment for seven additional months) and underpowered to detect potentially meaningful differences across our study outcomes. Additionally, our sample was limited to families who we could reach and enroll in the study and may therefore not generalize to a wider spectrum of families. We were unable to obtain endpoint data for 25% of families, including a significantly higher proportion of families in the FN group. While there were no significant differences in demographic characteristics between those who completed and did not complete endpoint data, dropout rates limit our ability to draw conclusions for families who may be at most risk of not connecting with mental health resources. The small sample size also prevented us from examining characteristics of specific navigators, nesting data by navigators, and examining potential mediators and moderators of change, which would be important to do in future research. Prior research with both parents of young children (Diaz-Linhart et al., 2016; Jamison et al., 2017) and with adults (Corrigan et al., 2017) suggests that the potential benefits of navigation may be more robust after the first several months. Thus, our study was limited by the 3-month follow-up period and future research that examines outcomes over a longer period (e.g., 6–12 months) would be beneficial.

We compared phone-based care coordination with FN provided from a particular organization in Washington, DC. The nature of FN services offered and the context for navigating services are limited and may therefore not be generalizable to those receiving services through another organization or outside of DC. Future work that includes other FN models or looks at connection with services in other geographic areas will be beneficial. Additionally, future research should expand upon the use of FN models targeting populations with specific mental health concerns (e.g., autism spectrum disorder; Broder-Fingert et al., 2020). Our study was limited to families who could respond to questionnaires and surveys in English, which limits generalizability. Future research that includes a broader spectrum of participants and can speak to the unique challenges of navigating mental health services when a caregiver's primary language is not English would be beneficial.

Despite these limitations, lessons can be learned from these results. Many families struggle to connect with community-based mental health services following referral from primary care settings. This study documented several benefits to families working with a phone-based care coordinator or family navigator, which may be helpful in efforts to increase family connection with mental health services and ultimately lead to improvements in child and family well-being. Our findings suggest a benefit from either CPAPs providing direct phone-based care coordination to families or connection with local family navigation services. In this study, we were unable to compare either of these interventions to provision of a mental health resource list alone, which is standard of care for some CPAPs. Given prior research studies showing live navigation to be superior to written resources in some settings (Pantell et al., 2020), CPAPs may consider providing more intensive follow-up support to at least a subset of families. Our findings are especially relevant as access to CPAPs continues to expand and states may be increasingly relying on CPAPs to address gaps in pediatric mental health care.

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Author Contributions LG was involved in all aspects of the study, including funding acquisition, study conceptualization, qualitative analysis, and drafting and revising the manuscript. RW led data collection and management, oversaw CPAP care coordination for the study, and contributed to qualitative analysis. LD and HF contributed to qualitative analysis and original draft preparation. SB completed quantitative analysis. GA oversaw family navigation group programming. AR, MGB, LSW, LSB, and ML contributed to funding acquisition and study conceptualization. All authors contributed to manuscript preparation, commented on previous versions of the manuscript, and read and approved the final manuscript.

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Data Availability N/A.

Code Availability N/A.

Declarations

Conflict of interest Leandra Godoy, Renee Williams, Lindsay Druskin, Hailey Fleece, Sujatha Bergen, Gail Avent, Adelaide Robb, Matthew G. Biel, Lawrence S. Wissow, Lee Savio Beers, and Melissa Long declare that they have no conflicts of interest to disclose. The authors have no financial relationships relevant to this manuscript to disclose.

Ethical Approval This study was approved by the Children's National Hospital IRB.

Consent to Participate Participants completed informed consent prior to participating.

Consent for Publication N/A.

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