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LETTER
MONTHLY REPORTS ON THE PROBLEMS OF CHILDREN AND ADOLESCENTS GROWING UP

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Highlights…

Our page 1 stories this month look at the linkages between anxiety, OCD, and engagement in treatment; and at the effect of lockdown on memory based on the age of the child.

Inside

Anxiety

Who calls, who engages? Families seeking treatment for anxiety and OCD

Emma Jenkins, B.A., Josh Kemp, Ph.D., Kristen Benito, Ph.D., Erin O'Connor, Ph.D., Lesley A. Norris, Ph.D., Jennifer Herren, Ph.D., & Jennifer Freeman, Ph.D.

Pediatric anxiety is among the most common mental health diagnoses for American youth, yet few youths diagnosed with anxiety/obsessive-compulsive disorder (OCD) receive treatment. The majority of parents nationwide report at least some difficulty accessing mental health care for their child. Within the state of Rhode Island, where 12.7% of youth experienced anxiety concerns during 2021, 59% of caregivers reported difficulty accessing mental health care of any kind (Child and Adolescent Health Measurement Initiative, 2021-2022). Access to exposure-based CBT (exposure therapy), despite strong evidence as a frontline treatment for anxiety/OCD, is especially limited.

Randomized clinical trials (RCTs), which inform interventions such as exposure therapy, are often lacking substantial racial and ethnic diversity, due in part to significant barriers to care. Barriers that patients and families face when seeking mental health treatment include attitudinal (e.g., stigma, past experiences of discrimination, trust in provider/healthcare system) and structural barriers (e.g., access to transportation, flexibility of caregiver work schedule, affordability), which differentially influence access to care. Health insurance coverage is a particularly salient

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Pandemic

Lockdown's effect on memory and mental wellbeing based on age and gender

Alison Knopf

Lockdown under COVID-19, involving children in an effort to prevent transmission of the virus, had negative effects on the children's emotional wellbeing afterward, even though they didn't remember all of the details. It turned out that the younger the child, the less likely depression was to ensue due to the way memory works at different ages, and also due to having less information about the pandemic.

Memories of what happened during the pandemic lockdown weakened over time for children. A study of 247 students, aged 8 to 16, found that, in addition, psychological well-being decreased over time. The adolescent females fared the worst.

The memories did fade in terms of detail, but the fact of being locked down did involve higher levels of negative affect. The researchers suggested that there are aspects of autobiographical memory that might help attenuate negative consequences of the lockdown.

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Anxiety

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barrier for historically marginalized youth who utilize public insurance at a greater rate than their White, non-Hispanic counterparts (Lu et al., 2021).

To ensure equitable treatment access, it is imperative for researchers and clinicians to better understand who is currently seeking services and what barriers and facilitators exist in this process. To this end, the present study aims to (1) characterize the youth seeking services through an RCT at one center and (2) explore factors, including referral source, youth's racial/ethnic identity, and insurance coverage, which may relate to a family's likelihood of continued study participation (i.e., engaging in treatment).

Methods

The current project used data collected as part of the Improving Access to Child Anxiety Treatment (IMPACT) study, a large RCT funded by the Patient-Centered Outcomes Research Institute (#IHS-2017C1-6400). IMPACT was designed to purposefully address known barriers to treatment by offering a treatment arm where the majority of sessions took place in the home/community, accepting all insurances, including public insurance, and partnering with an extensive network of community partners who helped inform equitable recruitment and enrollment practices.

Between 2020–2024, 514 caregivers contacted the Pediatric Anxiety Research Center (PARC), located in Riverside, Rhode Island, seeking mental health services for their child ages 4–18 years (M=11.26, SD=3.37). PARC staff then explained the IMPACT study and offered interested caregivers a chance to complete a phone consent and a 20-minute initial phone screen to assess their child's symptoms, demographics (gender identity, age, race, and ethnicity), referral source, and insurance coverage. Additional demographic information was collected at subsequent assessment time points for interested families who progressed through the study.

Study inclusion criteria were: a) age 5–18, b) primary or co-primary diagnosis of anxiety or OCD, c) symptom duration of at least 3 months, d) appropriateness for outpatient treatment (i.e., no acute suicidality or psychotic symptoms), and e) presence of a caregiver able to participate in treatment. Youth could not receive treatment through IMPACT if they were receiving concurrent psychotherapy or were on an unstable dose of psychotropic medication (defined as an initiation of a medication within four weeks, or a dose change within 2 weeks prior to enrollment).

Results

Aim 1

Of the 514 youth, 386 (75.10%) identified as White, 30 (5.84%) as mixed-race/ multi-racial, 17 (3.31%) as Black or African American, 10 (1.95%) as Asian, five (0.97%) as other race, one (0.19%) as American Indian/ Alaska Native, and 64 youth (12.5%) were missing race data. Additionally, 32 youth (6.23%) identified as Hispanic or Latino, and 286 youth (52.14%) were missing ethnicity data. The high rate of missingness within the ethnicity data is likely due to the open-ended nature in which caregivers were asked to report on their child's demographics. As such, caregivers frequently opted to provide either their child's race or ethnicity, instead of both. The majority of callers and their children (N=415; 85.02%) moved on to subsequent assessment time points.

The authors recognize that each racial and ethnic group experiences unique barriers and facilitators to accessing mental health care. However, due to limited diversity in the sample and insufficient power to conduct statistical tests, race and ethnicity variables were collapsed into minoritized racial or ethnic identity (youth identifying as Black or African American, Asian, mixed-race, other race, and/or Hispanic or Latino; 16.73%) and non-minoritized racial or ethnic identity (youth identifying as White, non-Hispanic; 71.40%).

Referral sources were distributed as follows: 125 youth (24.32%) were self-referred (online search, social media, family/friends), 107 (20.82%) were internally referred (previously received treatment at PARC; referral made by PARC provider), 101 (19.65%) were referred by a behavioral health provider, 77 (14.98%) were referred by a pediatrician, 30 (5.84%) were referred by a school, and 20 (3.89%) were referred by another medical provider. Fifty-four (10.51%) youth were missing information on referral source.

Insurance coverage was distributed as follows: 373 (72.57%) reported having primary private insurance, 49 youth (9.53%) had primary public insurance (Medicaid), four (0.78%) had primary military insurance (TRICARE and affiliates), and 88 youth (17.12%) were missing information on insurance coverage.

Aim 2

A Fisher's exact test did not find a statistically significant relationship between referral source and continued study participation (p=0.31), suggesting that being referred by a specific source (i.e., internal referral versus self-referral) did not affect the likelihood of completing later assessments. Minoritized racial or ethnic identity was also not significantly related to continued study participation (p=0.85).

A chi-square test found that continued study participation was related to insurance coverage (p<0.01), such that youth with public insurance were less likely to continue on to later assessments compared to those with private insurance. This relationship remained statistically significant after accounting for referral source, and the youth's minoritized racial or ethnic identity (p=0.01). The primary reasons youth with public insurance did not move to the next phase were that they were lost to follow-up (36.36%), the enrollment window closed (12.12%), or they were no longer interested (12.12%).

A chi-square test also revealed a statistically significant relationship between minoritized racial or ethnic identity and insurance coverage (p<0.01), with youth holding a minoritized identity being more likely to utilize public insurance.

Discussion

The present findings highlight the continued lack of racial and ethnic diversity of families who call specialty anxiety clinics and express initial interest in research services. Even in the context of intentional community-informed recruitment efforts to increase the diversity of this sample, the demographics of youth seeking services aligned more closely with the state level census data which remains disproportionately White.

This expands upon previous research, finding that youth utilizing public insurance were less likely to participate in research. This finding points to the possibility that those utilizing public insurance

may share other commonalities which influence study participation but were not assessed in this sample. For instance, given that many youth with public insurance did not complete later assessments after being lost to follow-up, future research might consider exploring how caregiver stress, family financial stress, and wellbeing relates to study participation. Holding a racially or ethnically minoritized identity may be another commonality influencing study participation. The present study's null association between minoritized identity and continued study participation should be explored in a sample with greater racial and ethnic diversity.

There are several limitations within the present study, including that the data is derived from one center, and may not be representative of referral dynamics for treatment outside of a research context. Future research should focus recruitment efforts on increasing sample diversity to allow for more nuanced inferences about who is affected by which types of barriers and facilitators to access. Researchers should also consider how caregivers are asked to report on their child's demographics, as some caregivers may feel reluctant to report on such information at the first point of contact, as they were asked to do in this study.

While the rates of racial diversity in this study loosely align with census numbers for the city and state in which it took place, they do not match rates of diversity in more urban settings such as Providence — only a few miles from the study center. Efforts to better represent areas of increased diversity in the community may include bringing intervention research to those communities, rather than expecting families to travel. Accordingly, PARC was recently awarded funding to bring the team-based model of exposure therapy to certified community behavioral health centers (CCBHCs) throughout the state, including those serving high rates of minoritized youth, to shed further light on the process through which Rhode Island families seek and obtain treatment for anxiety and OCD. The project is called IMPACT-RI and it involves a robust set of partners, including patients and caregivers, providers, hospital administrators, community engagement experts, state-level policy officials, and experts in statewide dissemination efforts, with the goal of increasing equitable access while continuing to learn more about which barriers and facilitators affect whom. ■

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Pandemic

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Background

The measures taken to prevent COVID transmission caused increased anxiety and disruptions in children's everyday social lives, researchers have found. In addition, the fear of contagion and the news on television and elsewhere may have increased children's perceptions of safety and increased their anxiety.

One of the most distinctive aspects of the pandemic lockdown is that it may have affected the very ability to remember the past — and certainly, the ability to reminisce about positive experiences. There is evidence that "autobiographical memory" provides a foundation for emotional wellbeing.

Many studies were conducted early in the pandemic, and these suggested that prolonged restrictions had a negative effect on mental health. But longitudinal studies were needed to determine