Adolescents with Chronic Conditions:

Engagement with Children's Mental Health Systems During the Covid-19 Pandemic

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Abstract

Purpose: The Covid-19 pandemic contributed to adverse adolescent mental health outcomes globally. Adolescents with chronic conditions have four times the odds of self-harm than peers. Little evidence exists to guide pediatric nurses on how to engage this vulnerable population with mental health supports as the pandemic continues. In adults with chronic conditions, positive health assets (health access literacy, health self-efficacy, and emotional wellbeing) are directly related to improved patient engagement. The objective of this study was to gain a deeper understanding of engagement with mental health supports in adolescents with chronic conditions to inform practice.

Design and Methods: Using mixed methods, we surveyed and interviewed adolescents with chronic conditions aged 10-20 years. Random sampling was applied to avoid bias. Valid and reliable scales were used to measure health access literacy, health self-efficacy and emotional wellbeing. Textual data was collected using a semi-structured interview guide. Integrated data analysis was conducted using structural equation models and interpretive phenomenology.

Results: 154 participants provided numerical data and 17 participants provided textual data (mean age 15.5 years; 56% female, 5.8% agender; 56% white; 16.9% Black or African American, 4.5% Asian; 51.9% Hispanic or Latinx; 23.4% LGBTQ+). The structural model was an acceptable fit for the data (CFI = 0.97, TLI = 0.95). Participants reported higher levels of health access literacy (M=3.88, SD=0.848) than health self-efficacy (M=2.98, SD=.646), and engagement (M=1.78, SD=1.71). Health access literacy predicted emotional wellbeing (β = .33, $p < .001$, 95% CI [.20, .50]) and health self-efficacy (β = 0.52, $p < .001$, 95% CI [0.42, .062]).

Emotional wellbeing positively predicted health self-efficacy ($\beta = 0.21$, $p < .003$, 90% CI [0.10, .033]). Health self-efficacy predicted engagement ($\beta = 0.20$, $p < .01$, 90% CI [0.07, .034]). Participants reported not engaging until "it was really, really bad" citing fear, stigma, and lack of connectedness with providers as barriers.

Practice Implications: Regardless of health access literacy and health self-efficacy, adolescents with chronic conditions may not engage until crisis levels. Pediatric nurses can aim to engage with this vulnerable population proactively.

Keywords: children/adolescence, mental health, chronic illness, quantitative/qualitative

What is currently known?

- The Covid-19 pandemic contributed to poor mental health outcomes for adolescents across the globe. Adolescents with chronic conditions (ACCs) are four times likely to self-harm than peers. Supporting ACCs to engage with mental health supports is a priority. In adults with chronic conditions, positive health assets (health access literacy, health self-efficacy, and emotional wellbeing) are directly related to patient engagement and improved mental health outcomes.

What does this article add?

- This study is the first to examine the impact of positive health assets on patient engagement in ACCs. We found regardless of health access literacy and health self-efficacy, ACCs reported not engaging with mental health supports until crisis levels. Barriers to engagement include fear, stigma, and lack of connectedness with providers. Innovative nurse-led models of adolescent care delivery that proactively establish and foster patient-provider connectedness is a priority for pediatric nurses globally.

The Covid-19 pandemic exacerbated a mental health crisis in the United States (U.S.) for adolescents aged 10-21 (Children's Hospital Association, 2022). The crisis was compounded by a shortage of primary and mental health providers. In a letter to the U.S. Senate and House of Representatives, the Children's Hospital Association (CHA), the American Academy of Pediatrics (AAP), and the American Academy of Child and Adolescent Psychologists (AACAP) acknowledged the pandemic contributed more than a 50% increase in adolescent mental health hospitalizations from pre-pandemic levels (Children's Hospital Association, 2022). By October 2021, suicide became the leading cause of adolescent death in Colorado. A state of emergency was initiated citing all mental health access points across the system exceeded crisis levels— including emergency medical services, transport, partial and intensive hospitalization programs, and ambulatory treatment programs (Children's Hospital of Colorado, 2021). These trends were not isolated to one state; rather, were experienced across the country prompting the declaration of a national child mental health crisis (Children's Hospital Association, 2021). In January 2022, the CHA requested urgent investments in the adolescent mental health workforce to meet the demand (Children's Hospital Association, 2022). The request specifically cited the need for primary and mental health services for adolescents with chronic conditions (ACCs), i.e., those requiring treatment for physical conditions for more than one year (Children's Hospital Association, 2022). The odds of self-harm and suicide is four times greater in ACCs than peers without chronic conditions (Children's Hospital Association, 2022; Health Resources & Services Administration Maternal Child Health Bureau, 2020; National Survey of Children's Health, 2020). The adolescent mental health crisis, the shortage of providers, and the unique vulnerability of ACCs is a problem that U.S. children's health systems are urgently adapting to.

To address this problem, decision makers need a clearer understanding of factors that impact engagement with mental health services among ACCs.

In adult populations, positive health assets such as health access literacy, health self-efficacy, and emotional wellbeing have been demonstrated to positively impact patient engagement and other disease-specific and system-level outcomes. Emotional wellbeing in youth has been described as an umbrella construct that extends the subjective wellbeing concepts – positive affect, life satisfaction and meaning and purpose – and can be measured with patient reported outcome instruments (Forrest et al., 2019; Forrest, Devine, et al., 2018; Forrest, Ravens-Sieberer, et al., 2018; National Institutes of Health, 2021). Health access literacy has been studied in youth and described as knowledge of where to get care and confidential services; while health self-efficacy has been described as incorporating elements of self-advocacy, effective communication with providers, and the ability to follow through at home on plans made with providers (Sebastian et al., 2014). Engagement with health services has been operationally defined as the number of recalled conversations with a healthcare provider in the past 12 months that purposefully assessed and guided healthy emotional development and disease prevention (Sebastian et al., 2014). These purposeful conversations, known among adolescent healthcare providers as anticipatory guidance, are standard of care recognized by leading professional associations for adolescent healthcare (American Academy of Pediatrics, 2021; National Asssociation of Pediatric Nurse Practitioners and Providers, 2020). These positive health assets have been well studied in youth (Bröder et al., 2017; Sanders et al., 2009); however, no studies to our knowledge examined relationships between them, nor their impact on engagement, in ACCs. The existing literature base focuses on youth in general (Bröder et al., 2017; Sanders et al.,

2009). This gap in knowledge may limit the actions that policy makers could take to address the mental health crisis exacerbated by the pandemic. This study addresses the knowledge gap.

The overarching aim of this research was to gain a deeper understanding of the phenomenon of engagement with mental healthcare systems in ACCs that would inform clinical practice and health system policy. The specific research objectives were 1) to explain the relationships between health access literacy, health self-efficacy, emotional wellbeing, and patient engagement; and 2) to explore the nuances of engagement with mental health systems in this vulnerable population.

Methods

Design

A parallel convergent mixed methods approach was used throughout the planning, conduct and analysis to enhance significance of results from both quantitative and qualitative arms (Leech & Onwuegbuzie, 2010). Structural equation modeling (SEM) and interpretive phenomenological approaches were applied to integrate the collection and analysis of quantitative and qualitative data (Bazeley P., 2018). SEM was conducted with MPlus version 8.4 to examine direct and indirect relationships between health access literacy, health self-efficacy, emotional wellbeing, and engagement (Ferketich S.L. & Verran J. A., 1990). An interpretive phenomenological qualitative inquiry was used to interpret lived experiences of these same variables. Atlas.ti software version 22 was used for qualitative data management (ATLAS.ti Scientific Software Development, 2021). The study is reported according to professional standards for reporting mixed methods research in mental health services research (Leech & Onwuegbuzie, 2010).

Participants and Procedure

Quantitative

Survey participants were recruited between January and March 2022 from three ambulatory sites across a children's health system on the east coast of the U.S. Patients were included if they were age 10-21 years, had a chronic condition and, triaged to an emergency severity index level two to five if sampled from the emergency department (Green et al., 2012). Parent proxies speaking for their child were excluded to ensure the voice of participants was optimized (Creswell J.W. & Poth C. N., 2018). Providers with established relationships with potential participants approached every third patient meeting inclusion criteria to minimize bias. They introduced the study using a flyer. If patients indicated interest, the provider communicated this to a study team member trained in human subjects' protection who then conducted the informed consent and assent process. No incentives were given to participants for participation other than contributing to advancement of science on adolescent mental health. A power analysis was conducted using SPSS® software version 27 with a priori criteria including a power of 0.8, effect size (0.8), statistical significance of $p < .05$ with a 90% confidence interval. Sample size was estimated by using well-established method of at least ten participants per parameter, plus fifty, to detect a moderate effect size (Ferketich S.L. & Verran J. A., 1990). This method aligns with contemporary studies applying SEM with sample sizes under 200 (Barbeau K., 2019; Grossoehme et al., 2020). Further, we consulted with a PhD prepared statistician with specific expertise in SEM in designing and conducting all statistical analyses. Accordingly, a final sample size of at least 150 was sought.

Purposive sampling from the participants who completed the survey was concurrently applied to recruit the sample to be interviewed. The same inclusion and exclusion criteria applied. A sample size of 10-20 of patient volunteers willing to share their experiences was sought (Creswell J. W., 2018).

Data Collection

Quantitative measures

A survey including valid and reliable psychometric instruments examining health access literacy, health self-efficacy, emotional wellbeing, and engagement was used. We accounted for developmental differences across the stages of adolescence, by employing instruments with strong reliability (Cronbach's α = 0.76 - .98) and construct validity (mean factor loading = .61 - .94) in adolescents over age eight years, developed using item-response theory (Forrest et al., 2019; Forrest, Devine, et al., 2018; Forrest, Ravens-Sieberer, et al., 2018; Ramos et al., 2017; Ravens-Sieberer et al., 2014; Sebastian et al., 2014). The Youth Engagement with Health Services Scale (YEHS!), developed for use in a federal Child and Adolescent Health Measurement initiative uses items adapted with permission from the American Academy of Pediatrics Bright Futures questionnaire, also designed for use in adolescents aged 10 years and over (Ramos et al., 2017; Sebastian et al., 2014). The age range in these studies reflects the movement toward youth friendly health services in the U.S. to engage early adolescents in their own health promotion (Sebastian et al., 2014). Emotional wellbeing was measured as a latent variable by using three instruments from the National Institutes of Health (NIH) emotional wellbeing toolkit and Pediatric Patient Reported Outcomes Measures Information System (PROMIS®) to measure three observed variables in children over eight years old: positive affect,

life satisfaction, and meaning and purpose (Forrest et al., 2019; Forrest, Devine, et al., 2018; Forrest, Ravens-Sieberer, et al., 2018). In these instruments, positive affect is defined as emotional experiences resulting from pleasant engagement with the environment; life satisfaction is defined as an individual's evaluation of their life in general and across specific contexts such as self, family, friends, living conditions, school, and work; and meaning and purpose is defined as an appraisal of life as having meaning, purpose and hope. Construct and face validity were previously reported (Forrest et al., 2019; Forrest, Devine, et al., 2018; Forrest, Ravens-Sieberer, et al., 2018). Instrument responses were measured using item-level calibrations and response pattern scoring using REDCap® autoscore feature as a preferred method by PROMIS®. The T-score was used in the analysis. The survey included demographic questions of age, gender identity, race, and ethnicity. Socioeconomic and disability status were not asked of the mostly minor participants to reduce participant burden as recommended by the institutional review board.

Qualitative Interviews

An interpretive phenomenological inquiry was conducted using a semi-structured interview guide consisting of one primary research question and five open-ended questions, available as a supplementary file. The guide was premised on the theoretical framework and developed with the assistance of an expert in qualitative health systems research methods.

The research team consisted of a PhD prepared expert in qualitative and healthcare systems research, a PhD prepared psychiatric mental health practitioner, a PhD prepared nurse executive, a PhD candidate with formal training in healthcare systems research using quantitative and qualitative methods, a PhD prepared methodologist, five physicians with expertise in adolescent medicine and research assistants with project specific training in human subjects'

protection. Half of the research team identified as female. Weekly team meetings were conducted. Quantitative recruitment data informed the qualitative purposive sample selection to optimize a demographically diverse sample (Bazeley P., 2018). The qualitative sample size was determined inductively after information saturation was achieved (Creswell J.W. & Poth C. N., 2018). The interviews were conducted virtually via Zoom® due to constraints caused by the pandemic, and in person once those constraints were lifted. Privacy was maintained by asking parents and guardians to temporarily leave the room during the interview. All interviews were recorded after parental consent and participant assent (for those <18 years) was obtained. In one interview, the parent of 10-year-old with high-functioning autism listened in on the conversation and added commentary. To minimize influence, additional participants of the same age were recruited with purposive sampling.

Reputable methodological strategies (member checking, separation of a priori assumptions, field notes, reflexive journaling, and meticulous record keeping) were employed to ensure overall trustworthiness of findings, including transferability, dependability, credibility, and confirmability (Bazeley P., 2018; Creswell J. W., 2018). Self as instrument was used to ensure internal validity (Mulholland, 2007). Peer debriefing was performed on a weekly basis until information saturation was achieved.

Analytic Strategies

In this concurrent explanatory/exploratory mixed methods study, quantitative analysis was integrated into an inductive and deductive qualitative analysis.

Quantitative Data Analysis

Descriptive statistics were conducted on demographic variables using SPSS® version 27 (IBM Corp., 2020). SEM using maximum likelihood estimation was conducted with MPlus

version 8.4 to examine relationships in the hypothesized model (Muthen & Muthen, 2019). The recursive model is supported by systems theory and recent conceptual and qualitative research (Courtwright S. E., 2020; Courtwright et al., 2022). The model was considered a good fit for the data if the comparative fit index or Tucker Lewis Index was > 0.90 (Bentler, 1990).

Qualitative Data Analysis

Thematic analysis of the qualitative data was performed using a mixed inductive and deductive approach. Atlas.ti software version 22 was used to manage the data (ATLAS.ti Scientific Software Development, 2021). Analysis was informed by quantitative results and the theoretical model. Analysis was conducted in three phases: inductively to identify participant priorities within and across transcripts; deductively to assess study variables in context; and finally, integrating model fit with interview data. A codebook was developed iteratively. Two researchers conducted independent analyses on 384 pages of transcripts. They met weekly to ensure contextual authenticity and reach consensus through iterative review and discussion. The qualitative analysis, in all three phases, resulted in explanatory statements and enhanced understanding of the quantitative data analysis (Bazeley P., 2018).

Ethical Considerations

The study was conducted in alignment with national and international standards for human subjects' research and was approved by the institutional IRB where the study was conducted (#Pro2021-1006). Informed consent was obtained for all participants over 18, and both participant assent and informed parental/guardian consent was obtained for all participants under 18.

Results

Participants

The final sample size for quantitative data analysis was n = 154 and n = 17 for qualitative data. Descriptive statistics of each sample are displayed in Table 1. Most participants were in middle or high school between 6-12th grades, with a mean age of 15.5 years and 9th grade. Approximately half identified their race as white (56.5%) and nearly one third (29.8%) as black. Half identified their ethnicity as Hispanic or Latinx (51.9%) and half identified their gender as female (56.5%). Demographic results mirrored the demographic diversity of the state's population according to the most recent census (United States Census Bureau, 2020). One-quarter (23.4%) identified as lesbian, gay, bisexual, queer, transgender (LGBQT+). Interviews lasted between 12 and 60 minutes (mean = 34). The sample represented participants with the following chronic conditions: diabetes (types I and II), epilepsy, congenital heart disease, irritable bowel syndrome, anorexia, Crohn's disease, cancer, scoliosis, bulimia, polycystic ovarian syndrome, anxiety, depression, HIV, and asthma.

Quantitative Results: Positive health assets predict health self-efficacy but not engagement

All 154 participants participated in the survey. Five cases missing > 75% of data were excluded after determining data was missing completely at random using expectation-maximization estimated statistics and an independent samples T-test using pairwise deletion resulted in no statistically significant differences in the means of the sample with or without those five cases. The remaining sample had < 2.5% of missing data handled with multiple imputation in MPlus (Muthen & Muthen, 2019). On average, participants reported higher levels of health access literacy (*M*=3.88, *SD*=.848) than health self-efficacy (*M*=2.98, *SD*=.646), and even less on engagement (*M*=1.78, *SD*=1.71). Descriptive statistics for study variables are

Table 1. Demographics of participant pool as a percentage of the sample

Characteristics	Quantitative n = 154 Percent	Qualitative n = 17 Percent
Age (years)		
10-12	20.7	23.6
13-15	27.2	23.5
16-18	27.2	23.6
19-21	26.5	29.4
Grade		
4-5th	11.0	17.6
6-8th	25.9	11.8
9-12th	37.0	41.3
College	14.9	17.6
Not in School	11.7	11.8
Race		
American Indian or Native American	5.8	11.8
Asian	4.5	11.8
Black or African American	16.9	58.8
Native Hawaiian or Pacific Islander	2.6	17.6
White	56.5	
No response	13.6	64.7
Ethnicity		29.4
Hispanic or Latinx	51.9	5.9
Non-Hispanic or Latinx	45.5	
Gender Identity		52.9
Female	56.5	35.3
Male	37.7	5.9
Other (neither male nor female)	5.8	
Sexual Identity		
Identify as LGBQT+	23.4	23.5
Do Not Identify as LGBQT+	70.1	70.6
Not Sure if Identify as LGBTQ+	5.8	5.9
Location		
Emergency Department	68.8	76.5
Pediatric Primary Care Office	22.1	23.5
Adolescent Medicine Office	5.8	

displayed in Table 2. Relationships between variables are displayed in Figure 1. The model was

an acceptable fit for the data (CFI = 0.97, TLI = 0.95). Health access literacy positively predicted

emotional wellbeing (β = .33, p < .001, 95% CI [.20, .50]) and health self-efficacy (β = 0.52, p <

.001, 95% CI [0.42, .062]) while emotional wellbeing positively predicted health self-efficacy (β

= 0.21, p < .003, 90% CI [0.10, .033]). Health self-efficacy predicted engagement (β = 0.20, p <

.01, 90% CI [0.07, .034]). No statistically significant direct relationships were demonstrated

between health access literacy or emotional wellbeing and engagement within a 95% confidence
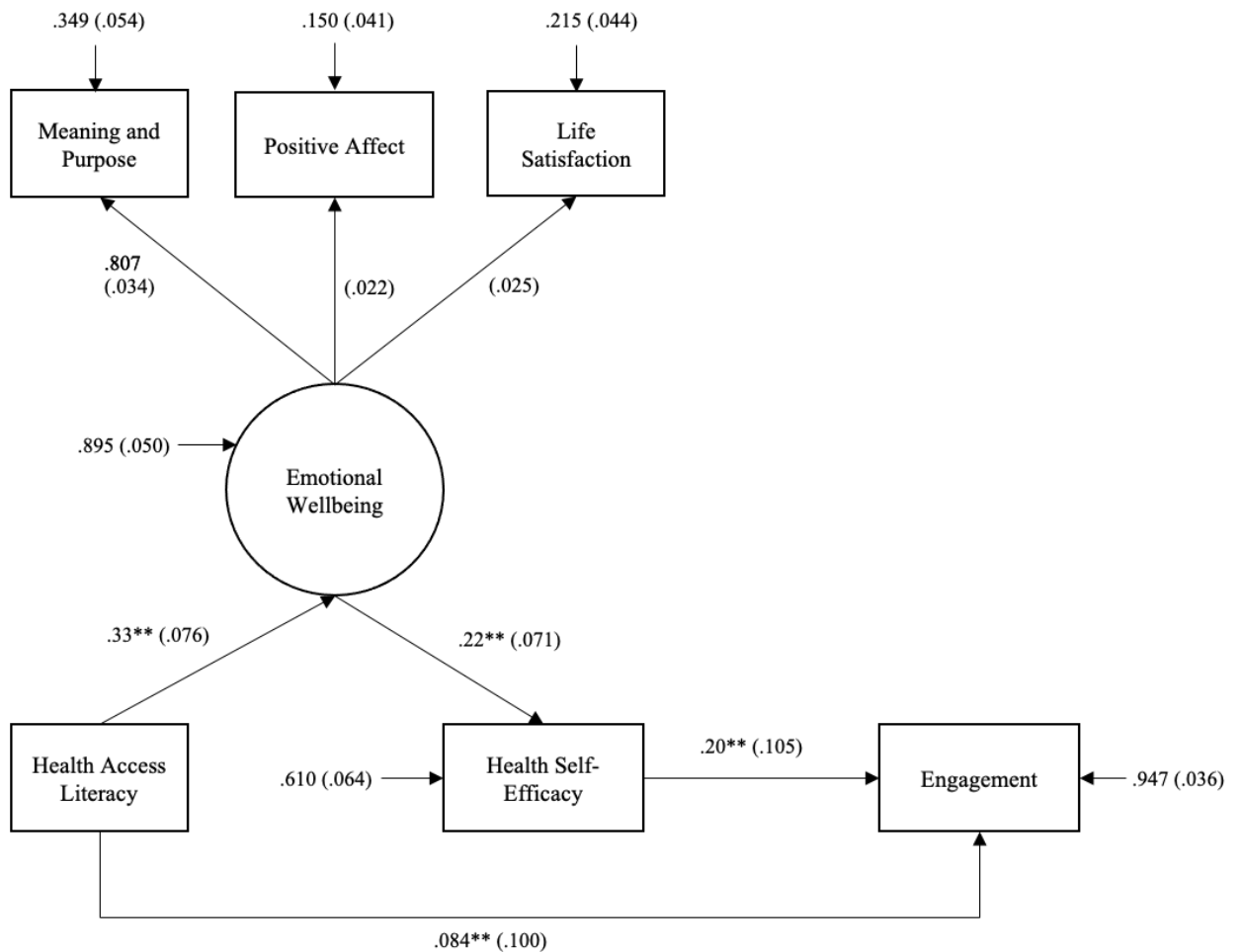
interval.

Figure 2. Structural model with Emotional Wellbeing as a latent variable and standardized path
coefficients. *p < .05; **p < .01

Table 2. Descriptive Results of Quantitative Analysis

N = 154	Min	Max	Mean (M)	Std. Dev (SD)
Health Access Literacy	1.80	5.00	3.88	.848
Health Self-Efficacy	1.40	4.00	2.98	.646
Positive Affect	27.7	66.2	44.28	9.63
Life Satisfaction	22.6	62.5	43.49	10.8
Health Self-Efficacy	1.40	4.00	2.98	.646
Engagement	0	5	1.78	1.71

Qualitative Results: Engagement doesn't happen until "it's really, really bad". Trust is key

Participants did not report that engaging with health services was a challenge due to the pandemic, citing telehealth as expanding access to care. However, participants reported waiting to engage until their emotional wellbeing was "really, really bad"[36, 42, , 62, 97, 99, 134] before engaging support (Table 3). The researchers adapted to this finding early and iteratively and employed a mental health barometer to measure participants' perceptions of when they would engage (Phoenix Children's Hospital, 2022). The average score was 2.5 on a scale of 1-10 between "I'm in a really dark place" and "I am completely lost and broken". This finding was confirmed in subsequent deductive analysis that demonstrated "somebody you can really trust"[36, 42, 62,,96] is a "big deal and has to be built over time"[106] to move from health self-efficacy to engagement sooner than later (Table 3).

Integration: "I'm scared and I'm faking it. Please Don't Analyze Me – Just talk to me like I'm human"

Despite high levels of health access literacy and health self-efficacy, participants reported not engaging until "it's really, really bad" [36, 42, 62, 96], i.e., crisis. Three themes identified from the integrated analysis explained barriers to engagement: fear, stigma, and lack of connection with providers. Fear was a clear theme that explained the delay in accessing emotional supports, despite reporting knowing where to go, who to go to, and that they would tell providers even if

Table 3. Results of Qualitative analysis

Qualitative overarching theme: *I didn't seek help… not until it was really, really bad*
"Well, if it's really bad, like, isolating myself being all, all, all dark and I feel like there's no hope"[42]; "Yeah, it was really bad, like I wanted to kill myself" [134]; "Really bad, just that ending point of depression, I was very suicidal and had cuts, that's when it was really bad for me"[99] "The thoughts were so overwhelming… like dark…really bad, like was…going to kill myself[62]"; "Really bad, a zero…I was suicidal and I didn't want to talk to anyone[97]"

Qualitative data informing integrated results	
Fear	***I was afraid… that my parents would be upset with me, that something was really wrong with me.***
	"Sometimes you're scared"[131]; "It's like a scary movie. I was afraid something was wrong with me. I was terrified."[96] ; "The guidance counselor sends kids away to an insane asylum. I was afraid she'd send me too"[99]; "I was afraid my parents would be upset with me"[134]; "Sometimes you're scared. Like, you might know you need the help, but like you're scared to ask for it"[62]
Stigma	***"I'm able to hide it. … I fake it"[11]; "I just put on a façade."[101]***
	"There's definitely a stigma in my community. We don't really believe in mental health"[97]; "My mom doesn't talk about things like that, nobody talked about things like that"[62]; and "Depression is a weakness. I would put on a brave face all the time. I was going through the motions every day— physically, but not mentally."[100].
Lack of Connection with Providers	***Don't analyze me. Talk with me like I'm human.***
	"It seemed like I was being analyzed … that she was looking for things that were wrong with me, and not trying to talk to me or listen"[11]; "That feeling you get when you're in their office and like you're being evaluated, like we need more. Talk to me like I'm a human"[99]; "He was asking these kind of questions…like, forget the script, we are humans, yeah, generally, talk to me like I'm a human"[62] "It just seemed like the woman was a blank slate. I couldn't interact with her. It was just that relationship that I was looking for, it wasn't reciprocated"[11]; "I felt like I was being analyzed, like a robot"[98] "Maybe if they took away just a little bit of the professionalism, like we are humans, just talk to me like I'm a human being"[97].

they didn't ask. Fear of disappointing parents, fear that something was 'wrong with their brains', fear of being sent away to a facility or asylum, and fear of the emotions themselves were all described. Participants explained that courage was needed to overcome their fears before engaging supports; however, even if fear was overcome, concerns about stigma delayed action. Participants explained: *"I'm able to hide it. ... I fake it"*[11]; *"I just put on a façade."*[101]; *"There's definitely a stigma in my community. We don't really believe in mental health"*[97]; *"My mom doesn't talk about things like that, nobody talked about things like that"*[62]; and *"Depression is a weakness. I would put on a brave face all the time. I was going through the motions every day—physically, but not mentally."*[100]. After mustering courage to overcome fears and stigma to actively engage with supports, many participants described feeling analyzed instead of supported (Table 3). The importance of human connection—to be seen and heard as a human having an emotional experience—was determinant factor in participants' choice to return for follow-up.

Discussion

This study sought to examine the relationship between positive health assets (health access literacy, health self-efficacy, emotional wellbeing) and engagement with mental health services in ACCs during the pandemic. This study is the first to examine these relationships in ACCs, establish that emotional wellbeing predicted health self-efficacy in this population, and characterize the significance of the patient-provider relationship on engagement with mental health services in ACCs. Importantly, regardless of high levels of health access literacy and health self-efficacy, ACCs reported delaying engaging mental health supports until crisis levels – not because of pandemic restrictions, rather because of fear, stigma, and a lack of human connectedness with providers. Our findings support growing theoretical evidence on the

relationship between emotional wellbeing and health self-efficacy in ACCs (Courtwright S. E., 2020).

While fear and stigma are known barriers to engagement with mental health services in youth, particularly those from underrepresented groups (Aguirre Velasco et al., 2020; Raymond-Flesch et al., 2014), this study is the first to characterize the impact of the patient-provider relationship on engagement in ACCs. Specifically, our findings suggest that ACCs desired pre-established relationships with providers, characterized by human connectedness, before they felt comfortable even accessing care for mental support. These findings support a recent metasynthesis that identified the patient provider relationship is a key factor in ACCs' emotional wellbeing (Courtwright et al., 2022), and confirms this relationship is indeed a critical antecedent for ACCs to engage. While literature described the utility of telehealth services to increase access to face-to-face care during the pandemic, most participants described experiences with school-based resources as the first access point, and not telehealth. This finding is consistent with a recent systematic review demonstrating most adolescents receive mental health services in the school setting more than ambulatory or primary care settings (Duong et al., 2021). Still, regardless of access to virtual or in-person care, participants' engagement was premised upon their relationship with their provider. Many expressed feeling evaluated, analyzed, lacking connection, and a desire to have providers "talk to me like I'm a human" with a reciprocal relationship. These experiences influenced participants' decisions to not engage or reengage, despite demographic background. These findings confirm theoretical relationships between positive healthcare provider relationships as an antecedent to emotional wellbeing and self-efficacy in ACCs (Courtwright et al., 2020; Courtwright et al., 2022).

Fear has been described as a symptom that ACCs experience more than peers without chronic conditions, placing them at higher risk for delayed engagement with mental health supports (Barker et al., 2019). Participants described fear of disappointing parents, fear of being sent away, and fear that "something was fundamentally wrong"[11] with their brain – and reported fear as a barrier to engagement with available resources. Fear can be addressed by facilitating preventative patient provider relationships that normalize discussions of emotions, provide health information, and build human connection before crisis levels. Eliminating fear also requires addressing the known stigma associated with accessing mental health services (Aguirre Velasco et al., 2020)

Stigma, recognized by the Centers for Disease Prevention and Control as a social determinant of health, is a known barrier to seeking mental health supports in healthy adolescents and this study extends that knowledge base to include ACCs (Aguirre Velasco et al., 2020; Centers for Disease Control and Prevention, 2019; Kaushik et al., 2016). A recent meta-analysis demonstrated that while increased access to school-based mental health initiatives improve mental health literacy, perceptions of stigma associated with mental health services do not change (Amado-Rodríguez et al., 2022). The need for innovative, effective solutions to reduce stigma associated with mental health persists. The capacity to address stigma may be hindered by national shortages of adolescent primary and mental healthcare providers.

The results of this study contribute novel and significant findings on factors influencing engagement with mental health services in ACCs during the pandemic. Despite positive health assets and access to pandemic-era telehealth, ACCs may not engage until crisis levels if human connection is lacking in the patient provider relationship. Our findings fills an important

knowledge gap in the literature base for this vulnerable population that can inform future research, practice, and policy.

Limitations

This study has limitations. The cross-sectional observational design limits the generalizability of findings. The sample size, while meeting a priori parameters, did not detect small effect sizes. Engagement with mental health supports was measured by participant recall which some critics claim is subject to bias; however, the field of adolescent engagement with health services lacks robust instrumentation highlighting a need for future instrument development. Socioeconomic and disability status were not collected to reduce participant burden on mostly underage participants who may not have known that information. Findings should be interpreted with these limitations in mind.

How Might this Information Affect Nursing Practice?

This study has important implications for pediatric nursing practice in all healthcare settings and at all levels of practice. Primary care pediatric nurses should consider reconnecting with ACCs lost to follow-up to reestablish the human connection while conducting psychosocial and depression screening. Acute care pediatric nurses might identify ACCs as being at higher odds of self-harm, screen for antecedents to wellbeing during an inpatient stay, and connect patients with psychosocial support post-discharge (Courtwright et al., 2022). Pediatric nurse leaders and nurse scientists should consider designing, leading, and testing innovative care delivery models with specific nursing interventions that foster the nurse-patient relationship and human connection for ACCs. These novel models and interventions have potential to decrease fear and stigma and improve engagement with mental health systems early. Pediatric nurses

across the globe can apply these findings to their practice, administration of healthcare systems,

and programs of research.

Declaration of Competing Interest

The authors have no actual or competing interests to disclose.

Data Availability Statement

The data that support the findings of this study are available from the corresponding

author upon reasonable request.

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