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Decision-making among adolescents prescribed antipsychotic medications: Interviews to gain perspectives of youth without psychosis or mania

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Abstract

Objectives: This study aimed to understand the experiences of youth who had been prescribed antipsychotics but did not have psychosis, mania, autism spectrum disorder, or developmental disability. Methods: Twenty-three qualitative telephone interviews were conducted with youth aged 11–18 who had been prescribed an antipsychotic medication but did not have a diagnosis of psychotic disorder, bipolar disorder, autism spectrum disorder, or developmental disability. Participants were recruited from four U.S. healthcare systems participating in the pragmatic trial Safer Use of Antipsychotics in Youth (SUAY). Interviews were recorded, transcribed and analyzed using template analysis techniques. Results: Prior to initiating an antipsychotic medication, most participants experienced behavioral health crises; many felt that they had no options other than to start the medication. Other core themes included: (1) antipsychotics had both positive psychosocial outcomes, such as improvement of family life, and adverse effects, such as drowsiness or weight gain, (2) antipsychotics were only one part of a broader treatment plan, (3) efforts were made to maximize benefits and minimize side effects through careful titration, (4) feedback from friends and family was important in the decision to continue. Conclusions: The findings provide valuable insights into how to engage youth in conversations around the use of antipsychotics.

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Adolescent, antipsychotic agents, decision-making, off-label use, qualitative research

Background

The vast majority of antipsychotic use in youth aged 4–17 years is not for psychotic disorders, mania, irritability associated with autism, or tic disorders, which are the regulatory indications for antipsychotic use. Rather, antipsychotics are most often prescribed for youth diagnosed with attention-deficit/hyperactivity disorder, conduct disorder or oppositional defiant disorder, and/or impulsive aggression (Bushnell et al., 2021; Chen et al., 2021; Crystal et al., 2009; Loy et al., 2017; McKinney & Renk, 2011; Naslund et al., 2016; Rettew et al., 2015). Clinicians prescribing medications for youth with these conditions must contend with a trade-off between risks and rewards (Loy et al., 2017; McKinney & Renk, 2011; Penfold et al., 2013). Specifically, they must weigh the known adverse side effects of these drugs against improvement in patient symptoms and function. They must also make recommendations in the context of resource-constrained health systems including poor access to behavioral health services for many youth (Murphy et al., 2016). Clinicians may experience pressure from parents and school administrators to prescribe medications so that youth can return to routine activities such as school attendance as soon as possible. Some clinicians report prescribing antipsychotics to help both patients and their families while waiting for psychosocial therapies, but report feeling conflicted about putting youth on "chemical leashes" (Murphy et al., 2016). In this complex milieu of decision-making, the voice of the child or adolescent patient is usually missing.

Studies of adults and youth with psychotic disorders report that individual experiences with taking antipsychotics are varied and complex (Morant et al., 2018). This variation makes developing guidelines and resources for shared decision-making among patients, families and providers about antipsychotic use a challenge (Gray & Deane, 2016; Moses, 2011). Although there are several diagnosis-specific guidelines regarding antipsychotic prescribing, (American Academy of Child and Adolescent Psychiatry, 2011; Pappadopulos et al., 2003; Pliszka et al., 2006) recent work advises a targeted symptom approach for youth (Penfold et al., 2021) precisely because most guidelines do not incorporate the complexity of co-occurring disorders and patient history.

Despite the complexity of prescribing antipsychotics to youth and knowledge of potential clinical risks and benefits, little is known about the experiences of youth taking antipsychotics. No study that we know of has specifically explored this topic for non-psychotic disorders, for which the trade-offs between risks and rewards are less clear than using the medications for psychotic disorders. Youth perspectives are important to research (Head, 2011; Schelbe et al., 2015). This paper aims to understand the experiences of youth who do not have a mental health disorder for which antipsychotics are recommended as first-line treatment but who were prescribed antipsychotics. We explore the circumstances that led to the prescription of an antipsychotic and how youth describe the benefits and drawbacks of antipsychotics. The findings are intended to facilitate patient-centered dialog with providers and improve shared decision-making with providers about initiation, continuation, titration, or discontinuation of these medications.

Methods

Study sites and recruitment

Participants were recruited purposively from four health systems, Kaiser Permanente Washington, Kaiser Permanente Colorado, Henry Ford Health System, and Nationwide Children's Hospital, in preparation for the pragmatic trial Safer Use of Antipsychotics in Youth (SUAY). Each site's Institutional Review Board approved the qualitative study, and all participants gave verbal consent. Electronic claims and health system data were used to identify and recruit youth aged 11–18 who had filled an antipsychotic prescription in the last 6 months (first generation or second generation). We excluded anyone with a diagnosis of a psychotic disorder, bipolar disorder with mania, autism spectrum disorder, or intellectual disability. No other diagnostic or patient history criteria were used in recruitment. In accordance with qualitative research standards, factors including the specificity of the research question, size and specificity of the population of interest, and anticipated quality of the obtained data were used to predetermine the sample size (Malterud et al., 2016). Qualitative methods are meant to generate new insights, not to generalize to a larger population. For this reason, this paper focuses on broad themes and experiences and not on quantifying those experiences.

Data collection

We developed a semi-structured interview guide with input from clinicians who work with youth (see Supplementary Information). Interviews lasted 30–60 minutes and ended with a demographic survey. Interviews were recorded and transcribed for analysis. Youth were interviewed by telephone by experienced qualitative researchers at each site after oral consent was obtained from the parent followed by oral assent of the minor. Our methods were consistent with rigorous criteria in qualitative research, as documented by the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007).

Analysis

Interview transcripts were analyzed using a template analysis approach (Corbin & Strauss, 2008; King, 2004) that employs both inductive and deductive approaches to code development and analysis. An analysis team of three researchers, two of whom had conducted interviews with youth and one who was the lead qualitative researcher for the entire study with over 20 years experience conducting qualitative research, developed an initial code list after reading the transcripts. The code list was refined using iterative rounds of each analysis team member independently coding the same transcript, followed by comparing codes to identify areas of agreement and divergence in coding approach and understanding of code definitions. After four rounds of this process, a high level of interrater reliability was established between coders upon comparison of the independently coded transcripts. Remaining transcripts were coded by a single researcher. When coding was complete, prevalent themes and subthemes were summarized into a coding memo (Saldaña, 2021) that contained participant quotes that were edited for clarity. To reach consensus on findings, the entire team discussed several iterations of the coding memo, yielding a final version that informed the results.

Table 1. Participant characteristics (N = 23).

Characteristic	n (%)
Health systems	
Health system 1 (15–18 yrs)	7 (30)
Health system 2 (15–17 yrs)	3 (13)
Health system 3 (11–14 yrs)	11 (48)
Health system 4 (12–14 yrs)	2 (9)
Gender	
Female	15 (65)
Male	8 (35)
Race	
White	19 (83)
African American	2 (9)
Asian	1 (4)
Other	1 (4)
Ethnicity	
Hispanic or Latino	6 (26)

Results

Interviews were completed with 23 participants aged 11 to 18 years (Table 1). Participants had a history of behavioral health issues; many reported disciplinary issues in school and all reported accessing counseling or psychotherapy at some point prior to beginning antipsychotics (Table 2).

Five major themes emerged: (1) antipsychotic use was initiated during times of crisis, (2) participants experienced positive psychosocial outcomes with antipsychotics, (3) they acknowledged that antipsychotics were only one part of a behavioral treatment plan, (4) they described adverse effects of taking antipsychotics, and (5) they used a complex set of factors to decide whether to continue or discontinue taking antipsychotics. Within these themes, we examined variation in participants' experiences.

All youth reported taking at least one type of antipsychotic and some had tried more than one. Antipsychotics mentioned were: risperidone (n = 15), quetiapine (n = 11), aripiprazole (n = 10), ziprasidone (n = 6), and olanzapine (n = 4). Duration of antipsychotic use varied from several weeks to years. Most participants described taking an antipsychotic in addition to a stimulant, anticonvulsant, antidepressant or antianxiety medication.

Participants most commonly reported having diagnoses for attention disorders and depressive disorders; however, participants reported a broad array of reasons for taking antipsychotics including problems with sleep, problems with school, emotional outbursts, arguing with friends and family, and suicidal ideation. As has been reported elsewhere (Penfold et al., 2021)the evidence supporting the effectiveness of antipsychotic prescribing for issues related to sleep, eating, and suicidal ideation is very weak.

Context of prescribing: Antipsychotic use initiated during times of crisis

The situations and symptoms that participants described as precipitating the use of an antipsychotic generally involved acute mood and behavioral symptoms including mood swings, uncontrollable rage resulting in violent outbursts, self-harming, depression and suicidal ideation or attempts.

Table 2. Youth School and Household Characteristics (*N* = 23).

School characteristics	n (%)
Grade level starting the fall that interviews took place	
8th	1 (4)
9th	5 (22)
10th	5 (22)
11th	5 (22)
12th	4 (17)
Already graduated from high school	3 (13)
Type of school currently attended	
Public school–standard track	11 (48)
Public school–special needs track	2 (8)
Public school–alternative program	3 (13)
Private school–general program	3 (13)
Home or online school	4 (17)
School-related issues experienced	
Detention or other forms of school-based discipline for disruptive behavior	10 (43)
Suspension from school	11 (48)
Expelled from a school	4 (17)
Attendance/truancy issues	14 (61)
Household characteristics	
Youth lived with	
Mother and/or father	21 (91)
Grandparent	7 (30)
Other family members	14 (61)
Children living in household	
1	9 (39)
2	12 (52)
3	1 (4)
4+	1 (4)
Services used to manage behavioral health issues	
Individual counseling/psychoanalysis for youth	23 (100)
Individual counseling/psychoanalysis for one or both parents	9 (39)
Family counseling	9 (39)
Parenting classes	14 (61)
Support group (for youth)	9 (39)
Support group (for parents)	14 (61)
School-based programs	7 (30)

> I know if I didn't have [health care organization] I probably wouldn't be here talking to you today. My family would be living without me, and my life would be over…My life was so dark, I didn't ever think I would be able to see light through it. I would not have been able to get through that without the help from the doctors and the help and the medication I got. (Health System 4, Youth-02)

> When I was thinking of suicide and when I was cutting, it was just like let the feelings go, but those feelings always came back. And then they got me on the medication. (Health System 1, Youth-07)

A number of youth reported that they were started on antipsychotics while hospitalized for behavioral issues.

> My parents got really scared that I was going to take more serious actions. I was feeling really suicidal. They called my therapist, who just recommended that they call the cops. Cops picked me up from school and I had to go to a hospital and then they sent me to the rehab center and that was where I started the medication. (Health System 3, Youth-06)

Many participants had extensive experience with psychotherapy prior to and during their use of antipsychotics. Youth and parents generally made the decision together to take antipsychotics and youth were often influenced by parents' level of concern. Given the acuity of their behavioral health issues at the time of starting antipsychotics, some youth could not recall having a conversation with their health care provider about the benefits and harms. One youth described the circumstances of being prescribed antipsychotics as follows:

> Well, it was over the phone and he had to talk to my mom over the phone because I was kind of having a depressive episode where I was crying and I was on the ground and I was going through this giant like panic attack and so it wasn't really explained to me quite. I remember my mom telling me more about it than he did. But I don't really remember him saying anything to me about it. (Health System 2, Youth-01)

Positive psychosocial outcomes with antipsychotics

Many youth described positive outcomes when taking antipsychotics (e.g. improved mood and outlook, improved social/family dynamics and improvement in school). Common phrases included '*more regulated,' 'outbursts controlled,' 'levels me out,' 'controls extremes,' 'calms me down,' 'less irritable,' 'helps me deal with emotions,'* and *'stops my suicidal moods.'* Most participants stated that they continued antipsychotic use because of these positive outcomes. Some of the specific benefits participants described included more controlled moods, describing the medications as '*reducing the distance between the deepest lows and the highest highs*.'

> It helps stabilize my mood, because I have a bunch of mood swings, it helps keep my mood at a stable place. I can get angry easily, I can get sad easily. It helps with keeping me calm and I feel calm, I'm ok, which is nice. (Health System 3, Youth-06)

> It helps me stabilize my highs and my lows to keep it not as huge mountains, but little waves. Helps me feel like just a normal teenager. (Health System 3, Youth-08)

Youth stated that medication helped them take on a positive outlook and brighter thoughts while diminishing anxiety and depression.

> I like the fact that it helped me not get so, like, depressed. I used to be really, really depressed and I didn't know what to do. So when I started taking medication, I felt I really liked taking medication because it helps me not be depressed. It helps me calm down and it helps me not cut. And I like the fact that I'm not suicidal. (Health System 3, Youth-10)

Some described feeling more organized. These participants were considering their future in decision-making about school and extracurricular activities.

> …I feel happier than I used. My thoughts are just about getting myself together for the future and getting ready to go to college and stuff. Like I am getting my things together and I'm just really thinking about work, school, and doing what I have to do at home. (Health System 2, Youth-04)

Participants noted improvements at school since taking antipsychotics, such as greater focus and better relationships with teachers.

> School actually went well this year. I was very surprised because before last year, my 11th grade, I was taking other medicines and I wasn't really doing as well. But this year I am doing really well with talking to people, and getting my things done. And I used to get into confrontations with teachers, but I'm not now. The teachers love me. They like this. They like this new person. Abilify helped me a lot. (Health System 2,Youth-03)

With improved mood and less anxiety and depression, many youth reported better social communication and relationships.

> My friends started noticing a change and they asked me, 'I know you go to the doctor. What new prescription did you get?' They're very concerned friends. They say, 'I think this medication is better for you because you're acting way more sensible than you used to be. You're actually having a decent conversation with us and not arguing with us.' (Health System 2, Youth-01)

Antipsychotics only one part of treatment plan

Some noted that while the medication helped, it wasn't a cure-all. Several youth attributed their improvement to coping skills learned through therapy; they felt that improvements were not attributable to APs alone.

> I don't think that the fact that I'm doing better with my mood is mostly because I'm on medication, it would be because through therapy, I'm starting to understand that I need to stop overexaggerating my negative thoughts. (Health System 3, Youth-08)

> When I look at my overall journey, I feel like I still feel the same, but I'm in a better head space than I was, so I think it's a combination of the medicine that I'm currently taking and then the therapy and just like the coping methods and just being able to talk to somebody. (Health System 1, Youth-03)

Adverse effects of antipsychotics and calculus of continuation

The side effects reported by youth included: headaches, dizziness, '*feeling in a daze,*' '*feeling high,*' sleepiness/drowsiness, difficulty falling asleep, overeating, lack of appetite, weight gain, stomach aches, suicidal/homicidal thoughts, body sweats and sweaty palms, cold feet/hands, shaking, increased irritability, heart palpitations, breast development and lactation. In a number of cases, adverse effects outweighed the benefits of the antipsychotics.

> So in the beginning it was really helpful with my twitching and I really wasn't noticing anything bad happening. But after a while of me taking it, in a few months I gained around 40 pounds; I actually started to semi-develop breasts and I was having these really abnormal pains in my head. (Health System 3, Youth-11)

I got really angry about body image because I gained, like, a lot of weight. I was sitting in the kitchen just eating all the time. I was so angry because I didn't advocate for myself and say I needed a medicine that doesn't do all of these things, that doesn't make me hungry. (Health System 3, Youth-01)

I told my doctor I was pretty sure it's making me fall asleep because during the day, I'd get really tired and I would straight up fall asleep in my classes, which I never had done before. I think that was one of the main reasons we decided that I couldn't be on the pill anymore. (Health System 1, Youth-03)

I know that I'm not allowed to [take the antipsychotic] anymore…because I made a bad decision and I took a full bottle of it or two, I can't remember much, and it kind of erased my memory. (Health System 3, Youth-04)

Yeah, I think the fact that I was too tired – I mean also we felt like it wasn't, it didn't have like the effects that we wanted it to, I guess. Because, like, obviously if it was really helping me, we might have, like, toughed it out, but we didn't really notice anything that was so prominent that I should keep taking it. Yeah, the sleeping thing was a really big problem. (Health System 1, Youth-03)

In other cases, youth felt ambivalent about the pros and cons of antipsychotics.

I don't necessarily like it, but I don't dislike it. I just think it's better for me and my family. I guess it doesn't bother me like it used to, so I just take it. When I take it I do notice a difference, because I take it regularly now. But when I miss a dosage or whatever, I don't take it one day, I get really angry and then I'm just irritated about everything. If someone says something I don't like, I'll snap at them and then no one wants to be around me. (Health System 1, Youth-06)

A number of participants described ongoing efforts to titrate and adjust their medications to maximize benefits and minimize adverse effects.

Yes, they said they'll take it down a notch, but I say I don't know. I might want to keep it at this level so it can keep me to where I am. But I don't want to go any higher (laughs)…my mom…was really worried about me one month and I went in to go see [my provider] and she asked my mom, "Does she want it higher?" And my mom said, "I don't know about that yet because" she don't know how it'll react to me if it's higher….I really think that I wouldn't be—like I would just be in a daze to me because this already keeps me calm enough … but I don't want to be in a complete daze. (Health System 2, Youth-03)

Um, I remember talking about like how my anger was. The first time I took it, it didn't really seem like it helped a lot, so I decided to go off of it, and then I guess I started getting really angry and getting into fights all the time so they put me back on it. It seems to help now when I take it, I noticed it now. Pretty much all they talk about is how I'm doing and what my anger's like. (Health System 1,Youth-06)

I have auditory hallucinations and so we decided we needed more, like we need medication to specifically target that. So we went to him and he started on risperidone and took me off what had been Lexapro to Effexor, and so far that was going pretty good. We were seeing a lot more of a result than we had with the previous two medications I was on. And then around May I started to take trazodone to help me sleep because I've had a series of issues with like sleep and insomnia and then around – when I was in the hospital for a bit, around August, they introduced me to Wellbutrin, like 150 mg, I think, and then two weeks later after that, it was upped to 500 – no, not 500 – 300 mg. But then as we increased on the dose, I had some side effects, like I was having these seizure-like spells. They didn't call it a seizure but it sounded a lot like a

seizure, so because of that, I was taken off of it. And I've been off of it for about four days now. So far those seizure-like episodes have stopped. (Health System 1, Youth-02)

Youth often formed their impressions of antipsychotic-associated benefits based on social feedback. Many decided to continue taking antipsychotics when family, friends, and schools responded favorably to their improved behavior while taking them. Youth also described a sense of duty to continue use to protect loved ones and themselves from the unmedicated self who could cause physical or emotional harm.

I want to take it to make sure I won't hurt myself and I won't hurt other people. Because if I hurt myself then it will hurt my parents and my sister and even a couple of my friends. I'm encouraged to take it because I don't have to feel like I want to hang myself or I want to cut or any of these because it hurts me and it hurts other people as well. (Health System 3, Youth-08)

I want to keep taking it because I know that when my mood swings are around I risk possibly hurting someone in my family if I boil over, and hurting myself if I go under. I don't want that to happen again. (Health System 1,Youth-05)

Discussion

Youth reported a variety of positive, negative, and ambivalent experiences taking antipsychotics, and had varying reasons for continuing or discontinuing use. Several acknowledged that antipsychotics were only one part of the treatment plan. The reported sense of ambivalence towards taking antipsychotics highlights the need for ongoing communication between provider and youth about both physical and psychological risks and benefits of continuing antipsychotic medications. Study participants initiated antipsychotic use during periods of crisis, in some cases with little recall of discussions with either their health care providers or their parents about risks and benefits.

Further, the severity of their circumstances or reports by youth of '*being out of options*' suggest that youth and parents' processing and retention of information about specific treatment decisions may be limited by high-stress levels at the time of antipsychotic initiation. If supported by future research, this interpretation emphasizes the importance of providers taking time at follow-up visits to elicit young patients' antipsychotic experiences and adjusting their treatment plan accordingly.

Only three previous studies have conducted qualitative research on youth antipsychotic experiences, (Floersch et al., 2009; Gray & Deane, 2016; Murphy et al., 2015) despite scholarly discourse advocating for inclusion of youth in research (Head, 2011; Schelbe et al., 2015). Some of our findings are consistent with these previous reports. Floersch and colleagues found that youth referred to their bodies, emotions, behavior, thoughts, self, and expectations when making sense of medication treatment (Floersch et al., 2009). Murphy and colleagues reported that youth describe taking antipsychotics like a '*double-edged saw'*, (Murphy et al., 2015) and Morant found that youth described antipsychotics as the '*least worst option'* (Morant et al., 2018).

Compared to previous studies, we found far greater diversity of experiences; in many cases, antipsychotics engendered an improved sense of well-being and balanced mood states that allowed improved function in many facets of life, including perceptions of the future. We also noted contradictory experiences. For example, school performance was bolstered for some because their mood was regulated, improving focus. However, others described how medication made them so drowsy that they could not participate in class. We found difficult experiences with the physical side effects of antipsychotics, similar to those reported in previous studies (Murphy et al., 2013).

Implications for Clinical Practice and Future Research

The findings highlighted in this paper have several important implications for clinical practice and future research, particularly for how and when providers in an outpatient setting engage youth in the decision to start or continue antipsychotics. First, our findings reinforce the need to discuss the risks and benefits of antipsychotic use broadly – including not only mood changes and physical side effects, but also social well-being, thoughts about the future, effects on school participation, and individual motivations to continue or discontinue use. Given the importance youth placed on the impact of their behavior on family and friends, providers might want to emphasize potential or observed improvements in relationships to youth who may be considering stopping treatment due to physical side effects (such as weight gain). Providers might also consider sharing the positive and negative experiences of other youth to engage patients in treatment planning and medication monitoring. These shared experiences are often powerful in shaping attitudes towards treatment (Naslund et al., 2016; Rupert et al., 2016; Simmons et al., 2018; Ziebland & Wyke, 2012). There may also be a need for additional emphasis on physical health monitoring for youths and parents and workflow to ensure that monitoring is factored into conversations about the continuation of antipsychotic medications – particularly for youth who take antipsychotics long-term rather than for acute stabilization. Some health systems have implemented best practice alerts in the electronic health record to encourage clinicians to have such conversations at regular intervals and to order laboratory tests and vitals measurement (Nadine Schwartz, personal communication, January 20, 2022).

Second, psychiatrists, pediatricians, and family practice physicians are often asked to extend medications started as part of an inpatient stay. Transitions from inpatient to outpatient care provide an opportunity to have longer, broader conversations about continued use of antipsychotic medication as part of a holistic treatment plan once a crisis has passed. These transitions are times when youth and their families have a chance to assess the risks and benefits of antipsychotics in a less charged context, when they may appreciate the range of treatment options more fully than during a health crisis.

Research needed in conjunction with these changes includes developing and testing shared decision-making tools, educational materials and provider training methods for off-label antipsychotic prescribing in youth, as well as finding innovative ways for youth to share their experiences of treatment with a variety of supportive individuals including parents and providers. Although there is an emerging literature on shared decision-making for antipsychotic use, it is not focused on youth or on off-label use (Morant et al., 2016; van Dijk et al., 2018) (Kaar et al., 2019) and needs to take into account the complex nature of prescribing decisions for psychiatric issues (Morant et al., 2016).

This study has several strengths. First, we designed a unique study that gave much-needed voice to youth experiences. In addition, participants varied by health system, geographic region, age and sex. Unlike previous studies, we used a targeted approach to identify youth with non-psychotic disorders, to address the experiences of the majority of youth taking these medications. However, this study also has limitations. By its nature, qualitative research is not expected to be generalizable to larger populations. Although we have considerable demographic variation in our sample, it is not broadly representative of the U.S. population or of all youth on antipsychotics and may be missing perspectives, especially those of youth whose race and ethnicity is not white.

Conclusions

Results from this study highlight the challenges of youth participation in decisions related to the initiation and continuation of antipsychotics. Findings suggest that providers should have broad conversations with youth about the advantages and disadvantages of taking antipsychotics related to a wide range of factors including physical health, social well-being and ability to participate in school and that these conversations need to happen regularly after starting the medications to allow for more patient-centered decision-making – particularly for youth who take antipsychotic medications long-term.

Clinical significance

The findings highlighted in this paper reinforce the need to have regular, meaningful discussions with youth about the risks and benefits of antipsychotic use including impact on physical health, social well-being, effects on school participation, and individual motivations to continue or discontinue use. Also, given that many youth begin antipsychotics during inpatient stays, transitions from inpatient to outpatient care are a critical time to have longer, broader conversations about continued use of antipsychotic medication as part of a holistic treatment plan with the goal of discontinuing antipsychotics once the crisis has passed and other resources are in place to support the youth and their family.

Declaration of conflicting interests

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Availability of data and materials

The authors declare that the data supporting the findings of this study are available within the article. However, additional data are available upon request from the corresponding author [CH]. The data are not publicly available since they contain information that could compromise research respondents' confidentially that was promised in the consent process.

Ethics approval and consent to participate

This research was reviewed and approved by the Kaiser Foundation Research Institute IRB #4 (IRB00010902, FWA00002344) of Kaiser Permanente Washington and by the IRBs associated with each health care system that participated in the data collection process. An invitation letter was first mailed to the family. Study staff then called to speak to the parents and describe the study. IRB-approved procedures were used to obtain verbal

consent from study participants. Willing parents gave oral consent for their minor child/guardian to participate and the minor was then informed about the study and, if willing, gave oral assent.

Trial Registration

ClinicalTrials.gov, NCT03448575

Consent for publication

Not applicable. Consent for publication was provided during the interview consent process.

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Supplemental Material

Supplemental material for this article is available online.

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