What Do Adolescents and Their Parents Need From Mental Health Integration in Primary Care? A Qualitative Exploration of Design Insights

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Introduction: The design of integrated adolescent mental health care should address needs and preferences of patients and parents/guardians.

Method: We conducted interviews and focus groups with adolescents aged 13−17 years who received care at Kaiser Permanente Washington in 2020 and interviews with parents of such adolescents. We sought to (1) understand the challenges of primary care-based mental health and substance use screening and care for adolescents and (2) identify program design solutions. Sessions were audio-recorded, transcribed, and coded. Thematic analysis was applied to identify key challenges and design solutions.

Results: Emerging themes from interviews ($n = 41$) and focus groups ($n = 10$) were summarized in five overarching design principles: Engagement, Privacy, Communication, Choice, and Ease.

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Each design principle was expanded for operationalization within a new health system program.

Discussion: Health systems serving adolescents in primary care may consider application of these design principles to the development of mental health integration programs. J Pediatr Health Care. (2022) 36, 570−581

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INTRODUCTION

Adolescent depression and substance use cause significant morbidity and mortality over the life course (Erskine et al., 2015). Suicide is a leading cause of death among adolescents and young adults in the United States, and substance use disorders among adolescents are often underdiagnosed and undertreated, leading to a lifelong risk for health and psychosocial consequences (National Center for Health Statistics, 2021a; National Center for Health Statistics, 2021b; U. S. Department of Health and Human Services Office of the Surgeon General, 2016). Timely screening and assessment of depression, suicidal ideation, and substance use among adolescents can improve treatment initiation and reduce negative health outcomes (Hagan, Shaw, & Duncan, 2017; Siu & U.S. Preventive Services Task Force, 2016). However, most adolescents are screened and assessed in the context of routine preventive health visits in primary care. This scheduled approach, in contrast to opportunistic, "Catch-Up" screening and assessment at nonpreventive health visits, may fail to reach historically marginalized populations, such as rural-residing, Black and Latinx youth, who experience disproportionate barriers to routine preventive care and face health inequities as a result (Burns & Leininger, 2012; Elliott & Larson, 2004; Elster, Jarosik, VanGeest, & Fleming, 2003; Klein, McNulty, & Flatau, 1998; Society of Adolescent Medicine, 2004).

In 2018, the Kaiser Permanente Washington (KPWA) integrated health system completed the successful implementation of a population-based integrated mental health (IMH) screening and assessment program in primary care for adult patients (Bobb et al., 2017; Glass et al., 2018; Richards et al., 2019). The effectiveness of this system change subsequently inspired a quality improvement initiative to expand the program to patients aged 13−17 years. This initiative was supported by a growing evidence base that pediatric mental health integration improves health outcomes (Richardson, McCarty, Radovic, & Suleiman, 2017). A research-care delivery partnership between Kaiser Permanente Washington Health Research Institute and KPWA set out to understand the design and implementation considerations unique to adolescent patients, including those related to (1) privacy and confidentiality practices to obtain and document screening results and related assessment or treatment plans, (2) minor consent for mental health and substance use services in Washington state's legal context, (3) format of dedicated 1:1 time and parent involvement in care, (4) documentation of screening and assessment results in the electronic health record, and (5) linkages to follow-up care when indicated. This initiative was supported by KPWA's Center for Accelerating Care Transformation, which conducts learning health system research, aligning health system and research priorities (Allen et al., 2021).

Ensuring confidentiality and protection of patient privacy are critical to screening and treating adolescents for sensitive health concerns, such as mental health symptoms or substance use behaviors (National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division, Division of Behavioral, & Social Sciences and Education Board on Children Youth and Families, & Committee on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications, 2019; Pathak & Chou, 2019). Adolescent-serving professional organizations support adolescent access to confidential care without parental consent for select services, including sexual and reproductive health services, mental health care, and substance use disorder treatment (Ford, English, & Sigman, 2004). In Washington state, adolescents aged 13 and older have a legal right to consent for their mental health or substance use disorder care without parental notification or involvement in most circumstances (Revised Code of Washington 70.96A.096, 230; Revised Code of Washington 70.96A.235; Revised Code of Washington 71.34.530). This legal context intends to reduce barriers to youth needing critical services but may challenge health systems to balance emerging youth autonomy, parent/guardian involvement, and patient safety and quality priorities. Health systems serving adolescents must be designed in alignment with these patient-specific priorities.

A growing body of evidence supports the value of engaging patients and families in designing mental health and substance use screening interventions and disseminating their findings, but few initiatives have involved youth and parents to date (Bombard et al., 2018; Moore, Wilding, Gray, & Castle, 2019; Orlowski et al., 2015; Scholle, Torda, Peikes, Han, & Genevro, 2010). To design an adolescent IMH program that addresses the needs and preferences of patients and families, we interviewed adolescents and parents of adolescents, exploring their experiences, concerns, and preferences for adolescent confidentiality, screening, and 1:1 time with their providers. Our objectives were to (1) understand the challenges faced by adolescents receiving mental health and substance use screening and care and (2) identify patient-informed solutions that could be integrated into the design of an adolescent IMH program, synthesizing them into overarching design principles that provide a framework for the adolescent-centered design of IMH. This paper summarizes our findings to inform pediatric clinicians and health system leaders who implement or improve adolescent mental health integration approaches.

METHODS

This work was conducted as part of a quality improvement initiative. The KPWA Institutional Review Board designated

the project as not human subjects research. We nonetheless applied routine human subjects protection standards to all data collection and analysis aspects.

Participants

Our sample included adolescents aged 13−17 years and parents/guardians (referred to as parents) of adolescents who received care within KPWA's 700,000-member integrated health system in Washington state. We used electronic health record data to identify a sample of adolescents and parents of adolescents who had a primary care (pediatrics or family medicine) visit within the past year. Potential participants were purposively sampled to achieve a sample of 15 teens and 24 parents for 1:1 interviews and 10 teens for focus groups. Purposive sampling is an intentional selection of participants that allows for understanding variation in participant perspectives that may be attributable to differences in demographic characteristics and/or lived experiences (Bernard & Ryan, 2010). We aimed to engage samples of participants with the following characteristics (1) balanced across age groups (13−14 years and 15−17 years) and include (2) 50% of whom had a mental health or substance use disorder diagnosis in the past 12 months; (3) 40% of whom identified as Black or African American, Indigenous, or a person of color; (4) 15% of whom identified as Hispanic/Latinx; (5) 40% of whom were enrolled in Medicaid; (6) 20% who had a recent virtual (video or telephone) visit; (7) 10% who identified as transgender or nonbinary; and (8) diverse geographic representations across the KPWA region (Palinkas et al., 2015). Adolescents and parents were recruited from separate family units, and no siblings were included. The study programmer randomly selected 800 adolescents that met inclusion criteria across three sampling dates between June and October 2020. Adolescents who met multiple sampling criteria were prioritized for study recruitment, leading to invitations sent to 210 parents and 123 adolescents for interviews. In addition, we sent 100 adolescent focus group invitations to individuals not invited for interviews. Throughout recruitment, adolescents and parents were selected for recruitment calls to ensure fulfillment of sample criteria. Although interviews were underway, we secured additional funding to expand parent interviews to additional respondents from historically underrepresented groups (October 2020 sample), specifically Spanish-speaking parents and parents of adolescents of Asian and East African descent.

Procedures

The project team collaboratively developed interview and focus group guides (see Supplementary Material for interview guides). The adolescent interview guide explored experiences seeking health care in general, answering mental health or substance use screening questions, meeting independently with a primary care physician, and involving parents in health care visits. The parent interview guide explored the above experiences of their child from a parent's perspective. The focus group guide elicited feedback on the

steps in a proposed clinical workflow to screen for depression and substance use and offered opportunities to brainstorm ways to improve the experience.

Three groups of potential participants (adolescent interviewees, parent interviewees, and adolescent focus group participants) were mailed written information about the project and subsequently contacted by phone with an invitation to participate in a virtual interview or focus group. Five study team members (C. L., S. D. B., B. C., L. S., A. J. H.) conducted 1:1 interviews by phone or video, depending on participant preference. A user-centered design researcher (D. M. F.) conducted the focus group discussions by video. A user-centered design researcher applies a methodology that focuses on interactions of a program or intervention with people who are intended to benefit from that program/intervention (Goodman, Kuniavsky, & Moed, 2012). Spanish-speaking parents chose whether their interview was conducted in Spanish or English. Parent recruitment materials and the interview guide were professionally translated into Spanish for Spanish-based interviewees.

Video interviews and focus groups were conducted using the Microsoft Teams (Microsoft Corporation, Redmond, WA) video platform. All interviews were audio-recorded and transcribed. A transcription service translated the Spanish interviews into English, and the bilingual interviewer reviewed them for accuracy. After completing the interviews, each adolescent received a $30 Visa gift card, and each parent received $50 cash to thank them for their time and willingness to provide feedback.

Analysis

We used a thematic analysis approach to identify key challenges and design solutions (Bernard & Ryan, 2010). After each interview or focus group, at least three team members conducted a rapid debrief, during which the interviewer or focus group facilitator shared a summary and key insights. Notes were taken on a shared digital platform (http://www.miro.com) and manually sorted into thematic categories. The focus group discussions were reviewed and summarized by the user-centered design researcher. These summary notes from interviews and focus groups were used to develop an a priori codebook, which was organized using a modification of the socioecological framework to code themes at the individual, parent/family, health system, and community level (Bronfenbrenner, 1979; McLeroy, Bibeau, Steckler, & Glanz, 1988). The coding team reviewed and refined the interview codebook (A. J. H., G. T. L., C. L., S. D. B.). After two coders independently reviewed and coded the first three adolescent and parent interviews using the qualitative analytic software Dedoose (http://www.dedoose.com), the coding team discussed and reconciled codes and revised the code book. The remaining interviews were coded in groups of three by one coder, after which the coding team met to discuss and decide on potential additions and revisions to the code book before coding a subsequent group. After interviews were coded, codes were sorted into challenges and solutions. Solutions included prior positive

experiences and new ideas from participants. Codes were sorted into overarching design principles and refined by the user-centered design researcher on the basis of focus group findings. Representative quotations from interviews were chosen to reflect the central insights of the codes and design principles. The final code summary was iteratively refined by the coding team until consensus was reached.

RESULTS

Of 223 youth and 210 parents invited, 17 adolescents and 24 parents participated in one-on-one interviews. Ten additional adolescents participated in two focus group sessions (five each). Participants were diverse in terms of adolescent age and gender identity, history of mental health or substance use disorder diagnosis, adolescent race and ethnicity listed in the electronic health record, and geographic location across the region served by the health system (Table 1). Compared with the demographic characteristics of all KPWA members, our sample (as intended) included a greater proportion of teens who identified as Black, Indigenous, people of color and/or Hispanic, transgender, or gender expansive and who had public insurance (data not shown).

Five overarching design principles were identified from the coding and analysis process, capturing challenges and design solutions from the perspectives of both adolescents and Parents: Engagement, Privacy, Communication, Choice, and Ease. Each principle is summarized in brief below. Tables 2 and 3 present the key challenges identified for each

design principle, proposed solutions, and representative quotations within each design principle for adolescents and parents, respectively. We provide a supplemental table with additional representative quotations from the challenges and solutions codes.

Engagement

The design principle of engagement describes the need of adolescents—and parents' need for their adolescents—to experience authentic rapport building with their health care providers. It describes their need to feel respected, cared for, and safe with all persons involved in their health care experiences, with attention to a diverse range of experiences and cultural perspectives normalized. For parents, engagement also means being a partner in their adolescent's care, supporting emerging adolescent autonomy, and navigating confidential services. Both parents and adolescents shared many positive experiences about their interactions with providers regarding mental health and substance use concerns, reinforcing the benefits of provider continuity during adolescence and having systems in place to support youth in crisis.

Respondents emphasized that engagement must be inclusive, acknowledging the diversity of family structures and cultural contexts that impact adolescents' and parents' care experiences. Adolescent interviewees prioritized a desire for providers who model curiosity about what drives their risk behaviors rather than making assumptions or passing judgment. Parents shared the challenges of experiencing bias from providers because of their cultural beliefs or family

TABLE 1. Demographic information of adolescent and parent participants		
Demographics	Adolescent participants (n = 27)	Parent participants[a] (n = 24)
Age range (mean), years	13−17 (14.7)	13−17 (15.1)
Race		
Asian	4 (14.8)	4 (16.7)
Black/African American	4 (14.8)	3 (12.5)
Native Hawaiian/pacific islander	0 (0.0)	2 (8.3)
Native American/indigenous	0 (0.0)	1 (4.1)
Multiple races/other	1 (3.7)	1 (4.1)
White	13 (48.1)	10 (41.6)
Unknown	5 (18.5)	3 (12.5)
Ethnicity		
Hispanic/Latinx	4 (14.8)	5 (20.8)
Non-Hispanic/Latinx	18 (66.7)	17 (70.8)
Unknown	5 (18.5)	2 (8.3)
Gender		
Cisgender female	15 (55.6)	9 (37.5)
Cisgender male	9 (33.3)	12 (50.0)
Transgender or gender expansive	3 (11.1)	3 (12.5)
Insurance status		
Medicaid	7 (25.9)	12 (50.0)
Private insurance	20 (74.1)	12 (50.0)
Mental health and/or substance use disorder diagnosis in the past year	13 (48.1)	11 (45.8)

Note. *Presented values are n (%) unless otherwise specified.*
[a]*Demographic characteristics listed for parent participants are those of their adolescent, obtained from the adolescent electronic health record.*

TABLE 2. Adolescent perspectives: Five design principles with representative quotations, key challenges, and solutions

Design principle	Adolescent challenges	Adolescent solutions
Engagement "I see the same [provider] there. And so I just like a familiar face. And she just always reassures me, every time I go there, that it's confidential and it's just between me and her and stuff" (No. 70070)	Screening forms can feel "invasive" and sometimes like "checking the boxes" or a "standardized test" with concerns about being judged for one's responses Discussing mental health and substance use with providers can be embarrassing or "awkward" Adolescents dislike being surprised in the health care setting by unexpected input from parents or disclosure of information from provider to parent Virtual visits create unique difficulties to authentic expression and connection for adolescents	Reinforce trust, safe spaces, and listening to adolescents to create patient satisfaction with a care experience Prioritize continuity with the same provider to establish rapport and trust Establish rapport by sharing personal information, showing concern and curiosity, and learning more about adolescent's life (overlaps with communication) Offer specific information about substance use (even if the adolescent has no experience), mental health diagnoses, and how confidentiality is maintained Explore preferences in advance about screening and 1:1 time via e-mail or electronic patient portal
Privacy "Mental health and substance use questions are) just easier to answer without parents around. . . .It's just that certain—that ride home is terrifying if you answer them with them there. It's like so—it's terrifying" (No. 60065)	Some adolescents have inadequate privacy from parents in the clinic and household during virtual visits Adolescents fear getting in trouble or other consequence for honest responses to mental health and substance use screening (overlaps with engagement)	Standardize 1:1 time to ask "embarrassing" questions and respond to provider questions honestly without fear of consequences Outreach to adolescents via the patient portal or phone before the visit to complete screening forms and assess preferences for 1:1 time during a visit Communicate rationale for 1:1 time to parents and remove the burden from adolescent to request this of a parent Reassure adolescents of confidentiality protections and practices with frequent verbal reminders of privacy to help young patients communicate honestly with the provider about mental health and substance use. Explicitly communicate limitations of privacy and mandated reporting requirements (overlaps with engagement)
Communication "I remember (my clinician) not asking what I am interested in, and sometimes that can be kind of boring. . . I want to be able to talk about something with them. [Clinicians should] be able to understand how [teens are] feeling or what they're doing. Or just be able to talk about some kind of subject with whoever their client is" (No. 60093)	Adolescents dislike when a provider interacts directly with parents or allows parents to answer for them as it limits a provider's full understanding of adolescent experience Adolescents may downplay concerns to avoid judgment, consequences like hospitalizations, or needing to involve parents or may "shut down" if the provider alerts them that information will be disclosed to parents, without collaborating with the adolescent in how the information is disclosed Some adolescents feel "uncomfortable" or "nervous" without a parent present, depending on the maturity of the patient and the skill level of the provider	Give adolescents an active role in deciding how to involve parents in their care and may appreciate role-plays to help prepare for this (overlaps with choice) Be "friendly," empathize and normalize the mental health and substance use screening experience; use an informal tone when asking about mental health and substance use. Offer safer alternatives and promote harm reduction to risky behaviors Support adolescent communication with a provider before or after the visit via the patient portal
Choice "[My clinician] gave me a choice on whether or not I wanted to take medicine. . . like take some pills. And so that was nice to have an option whether or	Adolescents feel rushed or overwhelmed to commit to a treatment plan, sometimes without being given information about various options (overlaps with engagement) Adolescents often feel that they have no choice in the treatment plan or	Present adolescents with options about screening question format (paper vs. electronic), treatment plans, follow-up and how parental communication is handled to help adolescents feel safe, more in control, and reduce pressure (overlaps with privacy and choice)

Design principle	Adolescent challenges	Adolescent solutions
not I was ready to try therapy or medication or both. I guess that was nice knowing that I had options" (No. 60016)	how or what information is conveyed to parents	offer adequate time to prepare for follow-up mental health and substance use conversations is important (overlaps with privacy) Assess for an adolescent's developmental maturity and comfort involving parents in the visit
Ease "It might be smart to get you an appointment with a therapist while you're with the doctor so that you can't just like say, oh, yeah, I'll think about it and then never think about it again" (No. 60082)	Proactively notifying a provider in advance about their desire for 1:1 time is difficult and time-consuming Delays in scheduling referrals to mental health care are distressing for adolescents Reliance on parents for transportation may limit access to visits	Health care teams should offer creative solutions for adolescents to communicate with providers and develop treatment plans that are efficient and accessible to adolescents (overlaps with privacy)

TABLE 2. (Continued)

structures. Parents from multilingual families also underscored the value of language-concordant providers when possible and a diverse health care workforce that welcomes parents as partners in their teens' care. Parents also desired culturally inclusive educational materials to empower parents whose primary language and cultural context may differ from their teens to discuss mental health and substance use with teens and providers.

Privacy

The design principle of privacy is focused on the adolescent need for standardized privacy protection practices while discussing mental health and substance use issues with providers. Some interviewed adolescents voiced concerns about the potential negative of sharing substance use or mental health behaviors with behaviors, such as getting in trouble with parents or law enforcement. The privacy principle also spotlights the frequently mentioned parental need to address concerns and challenges regarding adolescent confidentiality in the health care setting. Some parents viewed adolescent confidentiality as in conflict with parental engagement and safety, whereas others saw it as aligned with adolescents' developmental needs. Parents expressed an overarching desire to keep their teens safe and avoid harm related to care when parents are not involved in decision-making (such as adverse medication side effects or lapsed prescriptions).

We observed a broad range of adolescent and parental comfort with independence during health care encounters, with younger adolescents more likely to forgo privacy and involve their parents in all aspects of their care and older adolescents tending to strongly desire private time with their providers. Some parents adamantly endorsed their adolescents taking the lead role in their care, whereas others feared their adolescent's needs would fall through the cracks if their parents were not completely informed of an assessment and/or treatment plan. This privacy principle emphasizes a tension that sometimes exists between teen, parent, and health system perspectives, requiring design solutions that span different user needs.

Communication

The design principle of communication emphasizes optimizing interactions between adolescents, parents, and providers during and outside health care visits regarding adolescent mental health and substance use. Adolescents desired communication strategies centered on their perspectives and needs, whereas many parents desired support and skills to talk with their adolescents about mental health and substance use. Many parents also yearned for more direct interactions with providers to convey their concerns about their adolescent's well-being and care. Parents whose primary language was not English noted specific challenges communicating with providers and their teens about mental health and substance use concerns if they did not have a shared language and cultural context to support this.

TABLE 3. Parent perspectives: Five design principles with representative quotations, key challenges, and solutions

Design principle	Parent challenges	Parent solutions
Engagement "I'm honestly glad with [my son's confidence in his doctor] because the more he's becoming a man, the more closed off he is, and he doesn't want to talk to me" (No. 70466 translated from Spanish)	Parents feel "in the dark" regarding what their teen is struggling with, especially if a teen is not open with them, they do not share a primary language with their teen, or the teen does not allow parents to participate in protected health care encounters Parents worry that screening questions about mental health and substance use may feel out of scope for a reason for visit, cause a teen to feel self-conscious or even "triggered" and escalate current concerns, and may not be adequately followed up on during the visit Parents are concerned that receiving a mental health diagnosis or treatment recommendation can feel stigmatizing or "wrong," and some parents struggle with a teen being "labeled" or needing to be "fixed" Parents feel that getting a teen to use the patient portal is challenging and requires much parental encouragement. Parent proxy portal access is limited in functionality (overlaps with ease) Virtual care communication may limit parent access to important treatment plan recommendations if they are not present (overlaps with communication) Parents feel that their teen meeting with a social-work provider same day could cause concern or frustration parent because of additional time for a visit, and they are not being informed about the process at the moment	Optimize cultural humility and culturally inclusive practices among clinical staff through diversifying and training the workforce. Ensure that concordant language providers are available whenever possible Teach adolescents how to navigate the health care system (including the patient portal) with growing independence and create tools that help parents support this as well Build more time during visits for an adolescent to form an authentic and trusting connection with the provider Outline detailed steps of any treatment plan to allow for successful follow-through, including referrals, prescriptions, and care coordination with other providers Develop a range of culturally inclusive educational materials about adolescent mental health and substance use (video, coaching, printed materials, workshop). Partner with historically marginalized community members when developing educational materials (overlaps with communication)
Privacy "How can we be part of the team if we don't know anything?" (No. 60129)	Current confidentiality practices cause parents to feel excluded, helpless, or uncomfortable (overlaps with engagement) Some parents strongly dislike or oppose confidentiality laws, particularly when in conflict with a family's cultural or faith values	Provide parents with information and support to understand confidentiality practices that ensure adolescents' privacy and limit parental access to certain information, using a variety of communication methods Articulate what information is and is not protected and explain in which circumstances confidentiality would be broken to ensure an adolescent's safety
Communication "So really trying to bridge the gap, communication gap between where the parents are and where the kids are, I think that would go a long, long way" (No. 70060)	The burden is on parents (or adolescents) to communicate across providers at different organizations, which is "overwhelming" and fragmented Education resources sent by mail or electronically may be missed or not include desired information about minor consent for services and financial responsibilities of parents. No single communication mode about adolescent care issues meets the needs of all parents and adolescents (overlaps with engagement and choice) Many parents struggle to communicate their concerns to their teen's provider because of logistical and time limitations, privacy restrictions, or discomfort sharing concerns in front of their child (overlaps with engagement)	Offer multiple avenues of communication between parents and providers (mail, electronic, phone, in person) and translation/interpretation support when needed Help parents more effectively communicate with their teens about mental health and substance use through coaching and resources Prepare and reassure parents that any potentially life-threatening circumstance will be managed with the adolescent's safety as the highest priority

TABLE 3. (*Continued*)

Design principle	Parent challenges	Parent solutions
	If an adolescent lacks maturity, experience, or has communication challenges, the provider may not clearly understand the patient's needs without parent input Parents whose primary language is not English face additional barriers to communicating about mental health and substance use to their teens and providers	
Choice "I know making decisions, especially important decisions as far as your health, mental, physical, however the case may be, I know it can be very intimidating to [teens]" (No. 60223)	Parents often feel that adolescents do not have the skills to navigate health care decisions independently (overlaps with engagement)	Parents and providers should create opportunities and structure for adolescents to build skills in making decisions about their health care Parents expressed diverse perspectives about the acceptable format of screening forms (paper, verbal, electronic) as well as content (checklist vs. flexible conversation) (overlaps with engagement)
Ease "I think that more access to mental health professionals would circumvent a lot of problems. . . I think that we have such little access in our country to mental providers and it's such a low priority" (No. 70450)	Families experience long delays, lack of continuity, and unmet need for urgent mental health evaluation/services, sometimes going outside the delivery system or paying out of pocket to get timelier services. Delays and inconsistencies in care occur with external providers as well Getting an appointment with the right provider with adequate time for 1:1 time is challenging Gaps in mental health and substance use care resources and limitations on what schools can offer to leave youth at risk of entering the juvenile detention system Clinical spaces are often orientated toward younger children and less acceptable to adolescents (overlaps with engagement)	Improve appointing process to ensure timely, appropriate care and prepare the adolescent patient and parent for what will occur during the visit Expand mental health service capacity to meet the surging need for timely and appropriate care Modify physical spaces in clinics to be more welcoming and customized to adolescents

Choice

The design principle of choice highlights emerging adolescent autonomy and frequent desire to engage in shared decision-making about mental health and substance use screening and treatment planning. Multiple parents and adolescents expressed an interest in integrating expertise from their lived experiences with a provider's clinical expertise to reach a consensus on a plan. Some adolescents voiced a desire to be offered various mental health and substance use treatment options, grappling with if and how to involve their parents. Parents emphasized the need to help adolescents learn how to navigate health care choices, communicate via the electronic patient portal, and participate in their health care management, generally feeling that this is an adulting skill that is developed gradually over time with the support of parents and providers.

Ease

We define the final design principle of ease as the importance of reducing barriers to adolescents receiving timely and appropriate mental health and substance use care. Both adolescents and parents cited delays and limited access to mental health counselors as key hurdles, including, but not exclusively, those resulting from the deleterious impact of the COVID-19 pandemic on access to mental health and substance use care. Some adolescents noted transportation limitations as an additional challenge, and parents highlighted the cost or time required to take adolescents to appointments. Parents also cited the burden of paying for an out-of-network provider when care needs were urgent and unable to be met in-network, as well as geographic barriers related to in which care was available.

DISCUSSION

This initiative used rigorous qualitative methods to explore the perspectives of adolescents and parents about adolescent mental health and substance use screening and care, ultimately informing our health system's design of a quality improvement road map. We identified five overarching design principles to consider when expanding IMH services for patients aged 13−17 years within a health system: Engagement, Privacy, Communication, Choice, and Ease. Some challenges and solutions that were raised were beyond the scope of our project but warrant future consideration, such as addressing regional gaps in mental health access, liberalizing the constraints of confidentiality laws in Washington state, or improving cultural competence within the health system. This feedback spotlighted support needs among parents and adolescents in navigating the mental health and substance use screening with their family and cultural values regarding adolescent health and development.

Engaging youth and families in the design of preventive health interventions has been shown to improve acceptability and effectiveness; however, substantial variability exists in how engagement is defined—from patients acting as informants to patients serving as core-searchers (Bate & Robert, 2007; Larsson, Staland-Nyman, Svedberg, Nygren, & Carlsson, 2018; Moore et al., 2019; Orlowski et al., 2015). In our project, adolescents and parents played a critical role as key informants at the outset of our program development and allowed us to bring their insights directly to the local clinical teams designing and implementing the pilot screening program. Many of our findings are aligned with the tenets of adolescent-friendly health services, such as the importance of clear communication, active listening, a friendly and nonjudgmental tone, and an age-appropriate environment with adolescent-orientated processes (Ambresin, Bennett, Patton, Sanci, & Sawyer, 2013). We also noted alignment with Bright Futures guidance for adolescent visits published by the American Academy of Pediatrics, specifically with guidance for providers to emphasize and assess the emotional well-being of adolescent patients (American Academy of Pediatrics, 2017) alongside physical growth, development, social determinants of health, and risk reduction and safety. The continued importance of provider continuity was underscored by parents and adolescents, aligned with other studies of adolescent-friendly care (Coker et al., 2010; Dixon, Hoopes, Benkeser, Grigg, & Grow, 2016).

Parent respondents in our study desired proactive communication from the health system about age-related changes to privacy and confidentiality practices that occur as children transition into adolescents in various formats with culturally inclusive messaging. This was a recurrent theme that had not been explicitly described elsewhere. In addition, the need to actively teach skills to independently seek health care, particularly in adolescent confidentiality, virtual care, and patient portals, was an emergent theme from our interviews not described elsewhere.

We have integrated the feedback from these conversations into the design of KPWA's pilot adolescent IMH program, currently fielded in three primary care clinics, with the opportunity to iterate in partnership with local implementation teams. We outline specific program goals and operational features on the basis of our design principles (Table 4). Future directions include evaluation of the pilot program, including assessment of implementation barriers and facilitators, as well as adaptations to the adolescent IMH program as they relate to integrating the design principles. We hope to amplify within and beyond our health system the importance of standardizing 1:1 time with adolescents at least once a year, offering clear, adolescent- and parent-centered messaging in a variety of formats about confidentiality laws and privacy practices, and creating opportunities for adolescents to build skills to make independent health care decisions over time. Ensuring that IMH workflows occur opportunistically, beyond the traditional preventive health visit context, will help address screening, assessment, and treatment disparities. We also highlight systemic factors such as lack of language-concordant providers, limited community support resources, and stigma related to mental health and substance use that play a role in the experiences of adolescents and parents.

TABLE 4. Key adolescent integrated mental health (IMH) program goals and specific features incorporated into the adolescent IMH program

Design principle	Program goals	Program feature incorporated into adolescent IMH program
Engagement	Ensure both adolescents and parents know what to expect from IMH services and feel their unique needs are addressed	The standardized expectation of adolescent and provider 1:1 time during opportunistic adolescent IMH visit with longer visit lengths available A limited number of written assessments administered after a positive mental health or substance use screen to encourage further assessment through adolescent and provider discussion Developed specific training resources for provider teams, prioritizing cultural humility and inclusive language and practices
Communication	Develop care teams' ability to skillfully engage in adolescent-centered interactions with adolescents and parents and avoid judgment or shaming	Designed an adolescent- and parent-facing handout with information about adolescent mental health and substance use screening and adolescent confidentiality to offer both adolescents and parents at the time of adolescent IMH visit Trained provider teams on skills for communicating about adolescent mental health and substance use Worked to improve standardized communication by the health system to ensure consistent, proactive messaging of adolescent health care best practices
Privacy	Standardize processes to ensure adolescent privacy of health information, when indicated, and confidentiality of services; ensure clinical teams understand the rationale for these processes	Developed standard workflows to: • Collect screening form in a confidential folder • Limit cascading assessments before a visit • Document screening responses in a confidential encounter in which the provider can also enter additional documentation related to the assessment and treatment plan Created parent handout and provider training materials on minor consent and confidentiality and 1:1 time with adolescents and providers
Choice	Provide adolescents and parents with care options that allow for shared decision-making and emerging adolescent health care autonomy	Implemented digital questionnaires that can be completed before the visit with the option to use paper forms if desired Developed process for "opting out" of screening reminders if a patient had cognitive disabilities that made mental health and substance use questions inappropriate Trained provider teams on the standard expectation of engaging adolescents in discussions about when and how to share information with parent
Ease	Minimize delays and complexity in connecting adolescents to mental health and substance use services when indicated	Curated on-demand, real-time resources for additional assessment and treatment recommendations based on screening results Developed standard workflow for warm handoffs to clinical social workers, referrals, and/or appointing to further mental health or substance use care

Strengths and Limitations

Our sample of adolescents and parents was small, as is typical in qualitative research, yet included individuals from a variety of backgrounds, historically and unjustly marginalized populations, such as those of Latinx, Asian, and African racial/ethnic identities, and youth who identify as Lesbian, Gay, Bisexual, Transgender, Queer, Two-Spirit, and beyond. Participants were diverse in terms of gender, family size and structure, and experience with adolescent mental health and substance use issues. Qualitative interviews allowed for exploring nuanced perspectives and a deeper understanding of patients' and families' lived experiences. Our adolescent demographic information is derived from the electronic health record and was not confirmed with participants during interviews and may impact the accuracy and completeness of those data. The participant sample may have been impacted by selection bias, and less engaged or satisfied adolescents and/or parents may have chosen not to participate in an interview or focus group.

Furthermore, adolescent recruitment necessitated calling the parent to request contact information for the adolescent, which could have further limited the perspectives shared in our sample. This project occurred during the early phases of the COVID-19 pandemic, necessitating all interviews and focus groups to be conducted virtually. Although this approach may have reduced certain participation barriers, it may have limited rapport building and the depth of perspectives shared in person. Furthermore, in the pandemic, adolescents have experienced increased mental health challenges, which may have influenced the salience with which parents and adolescents perceive mental health-related care (Rogers, Ha, & Ockey, 2021).

CONCLUSIONS

Pediatric providers and health systems who serve adolescents in the primary care setting may consider applying our findings to the development of similar adolescent IMH and substance use screening, assessment, and treatment programs, with a focus on inclusive practices, the cultural context of each family, and addressing the developmental continuum of adolescent health care needs. Future studies we are planning will explore the patient, family, and health system impacts of implementing an IMH program that incorporates these design features in the identification and treatment of adolescent mental health and substance use disorders.

SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at https://doi.org/10.1016/j.pedhc.2022.06.006.

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