

Assessing mental health transition readiness in youth with medical conditions

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ARTICLE INFO

Keywords:

Mental health
Transfer
Transition readiness
Adolescents

ABSTRACT

Purpose: Many youth with medical conditions also have co-occurring mental health concerns. Limited attention has been given to the mental health transition needs of these youth. We explore bringing transition readiness assessment into the mental health care of youth with co-occurring disorders.

Design and Methods: Mental health transition readiness was assessed in transition-aged youth seen in a hospital-based specialty mental health clinic for youth with co-occurring medical and mental health conditions. Patients and/or parents reported on their awareness of transition policies and experiences. Clinicians formally assessed youth mental health transition readiness using the TR_XANSITION Index.

Results: Only 46.53 % of families knew about the clinic's transition policy. Less than 1/3 reported their provider ever mentioning transition and only 6.93 % knew the deadline for transfer to adult care. Few patients had a transition goal in their treatment plan, even when required by the payor. By assessing transition readiness, clinicians were able to identify deficits in need of remediation in 95 % of patients. Transition readiness was highest in the following domains of the TR_XANSITION Index: Ongoing support (85.15 %), Adherence (78.38 %), and Trade/School (71.29 %). Transition readiness was lowest in New Providers (30.94 %), Rx/Medications (37.99 %), and Insurance (42.57 %). Few knew when their current health insurance coverage would end (10.89 %) or how to get health insurance coverage when they became an adult (11.88 %). Mental health transition readiness and medical condition transition readiness did not differ in a sub-sample of youth with available data, $t(14) = -1.33$, $p = .20$.

Conclusion: Mental health transition readiness is suboptimal in youth with co-occurring mental health and medical conditions. Findings point to specific targets for future intervention to improve patient mental health transition readiness and patient/family awareness of transition practices.

1. Introduction

Approximately 75 % of mental health issues have an onset between childhood and young adulthood.^[1] Youth with chronic medical conditions are at a 51 % greater risk for mental illness compared to youth without medical conditions^[2] and many youth with medical conditions experience mental health problems related to their medical conditions.^[3]

Many children's hospitals offer mental health services specifically tailored to meet the needs of youth with medical conditions. These clinics are commonly staffed with mental health providers, such as pediatric psychologists, who have specialized training in working with

youth with co-occurring medical and mental health conditions.^[4] At our own institution, a contract with the County Department of Mental Health (DMH) allowed us to create the "Co-occurring Clinic". Founded in 2015, the Co-occurring Clinic serves children through young adults (up to age 25) with Medicaid who have co-occurring medical and mental health conditions. The clinic is staffed by pediatric psychologists, marriage and family therapists, social workers, post-doctoral fellows, and psychology practicum students, all of whom provide psychotherapy and case management services. Psychiatric medication management is also provided, if needed, by a pediatric psychiatrist.

While the emergence of such clinics helps to meet the unique mental health needs of youth with co-occurring disorders, less attention has

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<https://doi.org/10.1016/j.hctj.2024.100077>

Received 10 June 2024; Received in revised form 17 October 2024; Accepted 19 October 2024

Available online 4 November 2024

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been given to the mental health transition needs of these youth. Among youth with co-occurring disorders, little is known about their mental health transition. One study found that a mental health diagnosis was associated with increased transition readiness of one's medical condition.^[5] However, all key study variables, including the mental health diagnoses, were self-reported. For increased research rigor and confidence in findings, formal confirmation of one's medical and mental health conditions, along with objective assessment of transition readiness, is needed.

What we know about mental health transition in general (i.e., youth without co-occurring medical concerns) is that it is often poorly planned.^[6] Less than 5 % of youth with mental health needs receive optimal transition services.^[7] In a systematic review of youth transitioning out of the child and adolescent mental health system, which has a firm deadline for the discontinuation of care, only 24 % of youth transitioned to adult mental health services. Nearly half of youth who still needed ongoing mental health care did not receive a referral.^[8] Transition-aged youth disengage from mental health service utilization at a much higher rate than other age groups.^[7,8] Not surprisingly, young adults have the highest prevalence rate of mental illness across all age groups (33.7 %).^[9]

The current study aims to bring transition readiness assessment into the mental health care of youth with co-occurring disorders. This study sought to answer the following questions: 1) To what extent are Co-occurring Clinic patients and parents aware of transition practices and policies governing their mental health care? 2) What is the state of mental health transition readiness in youth with co-occurring disorders? 3) Do clinicians find it helpful to assess mental health transition readiness? and 4) What demographic factors are associated with greater transition readiness? Finally, in a subsample of youth with available data, we conduct an exploratory analysis comparing mental health transition readiness to transition readiness of one's medical condition.

2. Materials and methods

The current study was approved by the governing institutional review board. Because the study evaluated data collected through clinic procedures being integrated into routine patient care, a waiver of informed consent was granted. The study was conducted at a children's hospital with a large catchment area encompassing three counties in Southern California.

2.1. Co-occurring Clinic

The Co-occurring Clinic sees child, adolescent, and young adult (age 25 and under) patients referred who: 1) have at least one qualified mental health diagnosis (see below), 2) are receiving treatment at the children's hospital for a physical medical condition (e.g., cancer, diabetes), 3) are referred internally by their hospital physician, and 4) have Medicaid health insurance. These eligibility criteria are set forth by the residing county's DMH, which funds the clinic. Regarding qualified mental health diagnoses, patients must have at least one or more mental health conditions listed on the County's approved "ICD Diagnosis List." This list is inclusive, with nearly 250 mental health ICD diagnoses. Patients with mental health diagnoses not on this list (i.e., sleep-wake disorders, sexual dysfunctions) or with diagnoses beyond the expertise of child and adolescent clinicians (i.e., dissociative disorders, neurocognitive disorders, schizophrenia spectrum disorders and other psychotic disorders) are referred out of our system. Patients with neurodevelopmental disorders are seen in the clinic if they also have a separate physical medical condition, a qualified mental health diagnosis (not inclusive of their neurodevelopmental condition) and can verbalize and participate in psychotherapy.

Patients seen in the clinic first undergo a diagnostic evaluation conducted by a licensed clinician. This includes a structured clinical interview in accordance with California DMH guidelines, completion of

county-mandated assessment measures, and formal diagnosis of a qualified mental health disorder (if applicable). Patients in our clinic receive: 1) psychotherapy only, 2) psychiatric medication only, or 3) psychotherapy + psychiatric medication, depending on their specific mental health needs. Most psychotherapy patients participate in weekly or biweekly 50-minute sessions and require long-term support. In accordance with California DMH guidelines governing the clinic, all care is driven by a formalized treatment plan, which clearly describes the patient's problem/diagnosis, functional impairment, treatment goals, and proposed treatment (i.e., interventions used, frequency and duration of treatment). The residing county's DMH also requires that all patients aged 16 and older have a transition goal included in their treatment plan. However, this requirement is not emphasized during annual audits. Further, clinicians do not receive any education or training in transitioning patients to adult care. Prior to this study, there were no programmatic efforts in place targeting transition-aged youth.

2.2. Procedure

The current study was conducted between April 2022 – August 2022. In addition to meeting eligibility criteria for the Co-occurring Clinic, patients included in this study also had to be transition-age (12 years and older). As this was intended to be a clinic-wide implementation, the goal was to include every transition-aged patient seen in the Co-occurring Clinic.

Study involvement consisted of two phases: 1) a web-based questionnaire completed by the patient or parent, and 2) a clinician-administered formal assessment of the patient's mental health transition readiness. Following a one-hour training to orient clinicians to the purpose of the study, study procedures, and assessment tools, each clinician completed a templated Excel spreadsheet containing the names and contact information for patients who were in the study's targeted age range (12 years and older). The study team then generated a unique URL for each patient/parent to complete the web-based questionnaire. All study procedures involving direct patient contact were conducted by clinicians, who are well-versed in integrating assessments and new procedures into patient care. Clinicians distributed the questionnaire URLs and formally assessed the patient's mental health transition readiness during the patient's regularly scheduled appointment.

2.3. Measures & data collection

2.3.1. Sociodemographics

Patient sociodemographics and medical diagnoses were collected via chart review and information provided by clinicians in the templated Excel spreadsheet mentioned above. In addition to patient name and contact information, the sociodemographic form also collected the following variables: medical record number, date of birth, treating clinician name, primary medical subspecialty providing care, number of total subspecialties providing care, presence of transition goal in treatment plan (Y/N), parent primary language, patient primary language, service provision language, and services provided (therapy only, psychiatric medication only, therapy + medication).

2.3.2. Awareness of transition policies and expectations

A questionnaire, available in Appendix A, was created for this study to assess awareness of the clinic's transition to adult care policy, education received regarding transition (if any), beliefs about when transfer to adult mental health care would occur and plans to transfer to adult care. This questionnaire was developed by the study authors, who represent a multidisciplinary team of providers that serve on our hospital's Transition Task Force and/or are clinicians in the Co-occurring Clinic, where the study was conducted. The questionnaire was developed based on the team's familiarity with the transition literature and their collective experience of 39 years ($M = 6.5 \text{ years} \pm 4.76 \text{ years}$) conducting research with, and 119 years ($M = 19.83 \pm 8.98 \text{ years}$) of

providing clinical care for, transition-aged youth. Due to institutional policies regarding the completion of online forms by minors, parents completed the questionnaire for all youth under the age of 18 (N = 67) and patients 18 and older completed it themselves. The questionnaire was hosted via REDCap,^[9] an online data collection platform, and was available to families in English, Spanish, and Vietnamese. Spanish and Vietnamese translation were provided by our hospital's in-house language translation service.

2.3.3. Transition readiness assessment

Patient mental health transition readiness was formally assessed using the TR_XANSITION Index (available in several languages).^[10] This clinician-administered 32-item semi-structured interview assesses youth transition readiness skills across the following 10 domains: Type of Condition, R_X/Medications, Adherence, Nutrition, Self-management Skills, Issues of Reproduction, Trade/School, Insurance, Ongoing Support, New Health Care Providers. For additional information on each domain and domain-specific educational handouts, please visit: <https://www.med.unc.edu/transition/transition-tools/starx-questionnaire/>.

The TR_XANSITION Index was designed to be disease-agnostic and has been widely used to assess transition readiness in several chronic illness populations.^[10-12] In our institution, the TR_XANSITION Index is being used by several pediatric subspecialties to assess medical transition readiness. For the purposes of our study, questions were slightly modified. For example, "what is the name of your health condition?" was changed to "what is the name of your mental health condition?" Each patient was assessed by their treating clinician, who scored the patient's answer as either 0 (inadequate/no skill), 0.5 (partial mastery), or 1 (adequate/sufficient mastery) based on their knowledge of the patient's case and information in the patient's medical record. Scores are averaged by domain, then summarized to create a total score (0–10 possible), with higher scores suggesting greater youth transition readiness. The TR_XANSITION Index is among the few well-established, validated instruments to assess transition readiness.^[13] The TR_XANSITION Index has undergone several validation studies,^[10,14] including a longitudinal study spanning nine years.^[12] The TR_XANSITION Index is sensitive to advancing patient age ($\beta = 1.08$, $p < .0001$), has strong inter-rater reliability ($r = .71$), and moderate-to-high item-total correlations scores ($r > .42$).^[10,12,14] Further, higher TR_XANSITION Index scores are associated with fewer emergency room visits and greater adherence to medications.^[15]

2.3.4. Clinician-report of usefulness assessing mental health transition readiness

Following administration of TR_XANSITION Index, clinicians were asked to respond to a Yes/No question to indicate if using the TR_XANSITION Index allowed them to identify a patient knowledge or skill gap in need of remediation. Clinicians were also allowed to enter free text related to their assessment.

2.3.5. Comparison of mental health and medical transition readiness

Chart review identified patients in our sample who had also had their transition readiness assessed for any of their medical conditions using the TR_XANSITION Index. Only those patients with an assessment completed within a year of our assessment of mental health transition readiness were included.

2.4. Data analyses

Descriptive statistics were used to summarize patient demographics and survey responses. Regression analyses examined the link between demographic factors (i.e., age, gender, number of mental health diagnoses, number of subspecialties involved in care) and transition readiness. We expected transition readiness to be positively correlated with age and negatively correlated with number of mental health diagnoses and subspecialties involved in care. A paired sample t-test was

used to compare differences in mental health versus medical condition transition readiness.

3. Results

3.1. Patient demographics

Demographics of the study population are summarized in [Table 1](#). Briefly, participants were 101 transition-aged youth (M = 17.49 ± 2.73 years) ranging from age 12.37–24.24 years. Only three clinic patients within the age range could not be recruited, resulting in a 97.12 % participation rate. Youth were mostly female (60.40 %, N = 61) and of Hispanic ethnicity (79.21 %, N = 80). The sample included youth with a variety of medical diagnoses ([Table 2](#)). Most of the sample (85.14 %, N = 86) received psychotherapy services, as opposed to medication-only treatment (14.85 %, N = 15). Approximately 71 % (N = 71) of the sample had two or more mental health diagnoses (M = 2.01 ± 0.77), with anxiety (64.35 %, N = 65) and depression (62.38 %; N = 63) most common. Over one-fifth of the sample (N = 23) had a co-occurring neurodevelopmental disability (i.e., Autism) in addition to their other mental health and medical diagnoses. Less than one-fifth (17.65 %, N = 12) of patients aged 16 and older had a transition goal listed in their treatment plan.

3.2. Transition Policies & Practices

Responses to the questionnaire on clinic transition policies and practices were completed either by the patient (if 18 or older) or their parent (if patient was a minor). Patient respondents were significantly more likely than parent respondents to report that their therapist had talked to them about the transition to adult mental health care, $F(2, 99) = 11.00$, $p < .01$; 85.29 % vs. 43.28 %, respectively). There were no significant differences between patient or parent responses to remaining survey questions. Thus, data were collapsed across respondents. Less than half of all respondents (46.53 %, N = 47) reported being aware of the clinic's transition policy. Only seven out of 101 respondents correctly identified the clinic's mandatory age for transfer to adult care (before 26 years of age), with 20.15 years being the average age at which participants believed they would have to transfer. Two respondents expressed the belief that they would continue to receive mental health care at the children's hospital indefinitely and would never transfer

Table 1
Patient demographics.

N = 101	N	M ± SD or %
Age		17.64 ± 2.73
Gender		
Male	34	33.66 %
Female	61	60.40 %
Transgender male	3	2.97 %
Non-binary	3	2.97 %
Race/Ethnicity		
White, Non-Hispanic	3	2.97 %
White, Hispanic	80	79.21 %
Asian	3	2.97 %
Middle Eastern	7	6.93 %
Bi-racial	8	7.92 %
Developmental Disability	23	22.77 %
# of mental health diagnoses		2.01 ± 0.77
Most common mental health diagnoses		
Anxiety Disorder	65	64.35 %
MDD	63	62.38 %
Adjustment disorder	15	14.85 %
Disruptive behavior	18	17.82 %
Eating disorder	12	11.88 %
Mental health services received		
Therapy only	48	47.52 %
Medication only	15	14.85 %
Therapy + Medication	38	37.62 %

Table 2
Primary medical specialties treating study participants.

	N
Neurology (e.g., epilepsy, migraines)	18
Oncology (e.g., leukemias, brain tumors)	18
Endocrinology (e.g., diabetes – Type 1 and 2)	17
Gastroenterology (e.g., inflammatory bowel diseases, irritable bowel disease)	11
Adolescent Medicine (e.g., eating disorders)	11
Pulmonology (e.g., asthma, obstructive sleep apnea)	5
Craniofacial (e.g., cleft lip & palate, oral-facial deformities)	5
Rheumatology (e.g., juvenile idiopathic arthritis, pain syndromes)	4
Cardiology (e.g., Ehlers-Danlos Syndrome, congenital heart disease)	4
Hematology (e.g., Fanconi Anemia, Wiskott-Aldrich Syndrome)	2
Metabolics (i.e., Maple Syrup Urine Disease)	2
Orthopedics (e.g., skeletal deformities)	2
Nephrology (e.g., Hypertension)	1
Plastic Surgery (i.e., Craniosynostosis)	1

care.

Regarding plans for continued mental health care, only two reported they did not plan to continue services in adult care, whereas most intended to transfer (67.33 %, N = 68) or were unsure (29.70 %, N = 30). Reasons for being unsure (free text responses) included: not knowing if mental health services would be needed in the distant future (N = 18), parent would defer to their child to determine their need for continued care once they are of legal age (N = 7), child does not want to start over with a new therapist (N = 3), belief that adult care services will not be needed due to improvements in pediatric mental health care (N = 2), and unsure if they would want to transfer to adult care (N = 1).

3.3. State of mental health transition readiness

For ease of interpretation across measures of transition readiness, scores on the TR_XANSITION Index were transformed into percentages, with higher scores suggesting greater transition readiness. Results are presented in Fig. 1. Patient mental health transition readiness ranged

from 12.08 % to 81.48 % (M = 54.34 % ± 13.53). Mental health transition readiness was highest in the following TR_XANSITION Index domains: Ongoing Support (85.15 %), Adherence (78.38 %), and Trade/School (71.29 %). Regarding Ongoing Support, most patients identified themselves as the primary manager of their mental health care in adulthood and had a plan for their educational/vocational future (Trade/School). Although the overall score for Adherence was high, 66.35 % of youth reported sometimes missing a full day of medication (inclusive of non-psychotropic medications) and 46.15 % reported having trouble taking their medications daily.

Mental health transition readiness was lowest in the following domains: New Health Care Providers (30.94 %), R_x/Medications (37.99 %), and Insurance (42.57 %). Regarding New Health Care Providers, only 21.78 % (N = 22) of youth knew how they would find an adult mental health provider and only 8.91 % (N = 9) knew what was required to transfer their mental health record. Nearly two-thirds (63.46 %, N = 64) of patients could not correctly identify the names, and 40.48 % (N = 41) could not identify the purpose of their prescribed psychotropic medications (R_x/Medications). For the Insurance domain, only 46.53 % (N = 47) correctly identified their current health insurance provider. Few knew when their current health insurance coverage would end (10.89 %, N = 11) or how to get health insurance coverage when they became an adult (11.88 %, N = 12).

3.3.1. Clinician perceptions of utility of mental health transition readiness assessment

Clinicians reported that utilizing the transition readiness assessment helped them identify a knowledge gap in need of remediation for 95.10 % (N = 96) of their patients. Many noted in their free text responses that their patients knew very little about insurance or how to find an adult mental health provider.

3.4. Factors associated with greater mental health transition readiness

Mental health transition readiness did not significantly differ

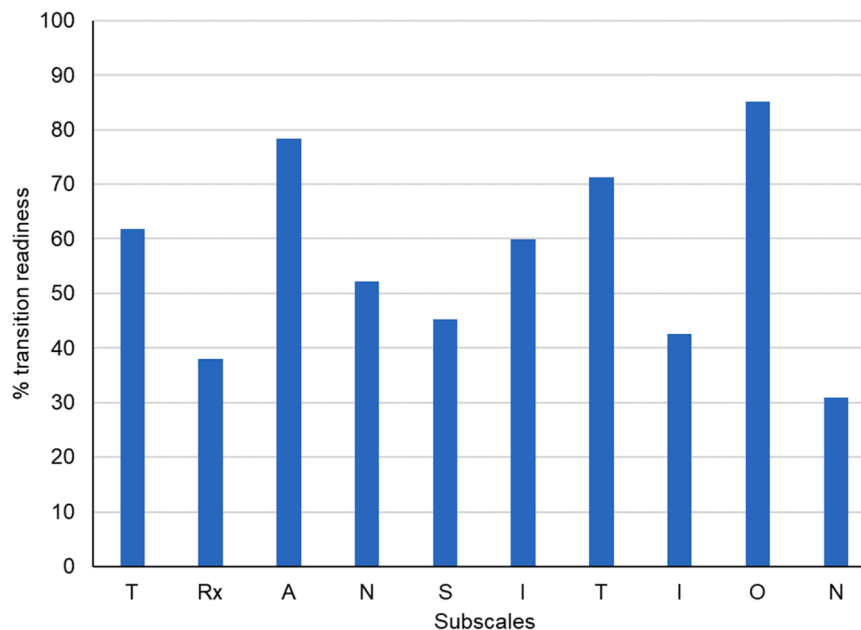


Fig. 1. Transition readiness scores by subscale. Higher scores indicate greater transition readiness. Subscale scores are as follows: Type of condition (knowledge of medical condition, symptoms, and future disease course), R_x/Medications (names, purpose, and dosing frequency of prescribed medication, awareness of consequences of non-adherence), Adherence (remembering and taking medications as prescribed, attending scheduled doctor appointments), Nutrition (awareness of healthy food choices and special diets, if recommended), Self-management skills (independence in disease management tasks), Issues of reproduction (awareness of interplay between illness and fertility/pregnancy and safe sex practices), Trade/School (presence of a plan for future schooling or work), Insurance (knowledge of what insurance is, their current plan name, when current coverage will end, and how to get insurance in adulthood), Ongoing support (plan for management of health care needs in adulthood), New health care providers (knowledge of how to find an adult provider and transfer medical records).

between males ($M = 5.14 \pm 1.29$) and females ($M = 5.29 \pm 1.23$), $R^2 = .03$. $F(1100) = 2.69$, $p > .05$. Age was positively associated with transition readiness, with each year of a patient's age equating to an approximate 10.3 percentage point increase in a patient's overall transition readiness score, $R^2 = .26$, $F(1, 100) = 34.55$, $p < .001$. There was no correlation between a patient's number of mental health diagnoses and transition readiness, $R^2 = .004$. $F(1, 99) = 0.43$, $p > .05$. However, there was a small relationship between the number of medical specialties (excluding mental health) involved in the patient's care (a proxy for medical complexity) and transition readiness, $R^2 = .04$. $F(1, 99) = 4.54$, $p < .05$. Each additional medical specialty involved in a patient's care equated to a 2.5 percentage point decrease in the patient's overall transition readiness.

3.5. Comparison of mental health vs. chronic medical condition transition readiness

An exploratory analysis was conducted to compare mental health transition readiness to medical condition transition readiness in a subset of youth who had both assessments (within one year of each other) in the medical record ($N = 15$). Although the number of medical specialties involved in care ranged from 1 to 4 ($M = 1.99 \pm 1.22$), no youth in the sample had more than one medical transition readiness assessment on file. There was no significant difference in mental health ($M = 6.28 \pm 1.32$) vs. medical condition ($M = 6.94 \pm 1.68$) transition readiness, $t(14) = -1.33$, $p = .20$.

4. Discussion

This study presents data on the formal assessment of mental health transition readiness in a sample of transition-aged youth with co-occurring mental health and medical conditions. Previous research has examined transition readiness of one's medical condition in youth with co-occurring mental health conditions.^[5] We examined mental health transition readiness in youth with co-occurring medical conditions. In our small sample, there were no significant differences in youth's mental health vs. medical condition transition readiness. Our exploratory findings suggest youth lack the readiness skills necessary to transition to adult care, whether it be for their mental health or medical condition.

The intersection between mental health and medical condition management is nuanced, with mental health sometimes serving as a facilitator, and sometimes a barrier to transition.^[16] Some research suggests that learning how to manage/overcome a mental health condition can build resilience. Through therapy, patients develop positive coping and self-management skills, which may facilitate their ability to transition to adult care.^[5,16] For example, interactions with mental health providers can provide patients with the practice of explaining their medical conditions to others. Repeated contacts with such providers can function as "mini exposure exercises" that can help extinguish anxiety about interacting with new providers.^[5] At the same time, uncontrolled mental health symptoms can serve as a barrier.^[16] Those with anxiety may become overwhelmed by managing multiple appointments and navigating a new healthcare system, ultimately avoiding, or delaying care. Patients with depression may struggle with self-management skills^[17] and lack the motivation and skills to navigate a new healthcare system and keep track of their appointments.^[5]

Youth with co-occurring mental health and medical conditions face many challenges as they transition to adult care. As they are assuming responsibility for managing not just one, but two or more conditions, they are also figuring out how to navigate new health care systems.^[18] Such systems (i.e., mental health and medical) are often independent of one another and may be fragmented within themselves. Additional research in youth with co-occurring disorders is needed to understand their experiences when transitioning to numerous adult care systems.

Over 97 % of our participants were ethnic minorities (almost 80 % of Hispanic ethnicity). Sociodemographics and culture influence

transition,^[16] with access issues particularly affecting Hispanic and Black young adults.^[19] The unique impact of culture on transition readiness is hard to determine due to its overlap with factors such as socioeconomic status, immigration status, acculturation, and insurance.^[16] Additionally, the high heterogeneity within our Hispanic/Latino sample complicates culture-specific conclusions and remains an important area for further research.

A quarter of our sample had a developmental disability co-occurring with their mental health and medical diagnoses. Regarding this sample, only youth who were verbal and could participate in therapy were seen in our clinic. As such, our sample was higher functioning and not representative of the wide spectrum of abilities observed in those with developmental disabilities. We know that youth with developmental disabilities also experience struggles with transitioning to adult care and adulthood in general.^[20-22] They also have higher rates of comorbidity.^[23,24] Our population of youth are at the intersection of three risk factors for poor transition outcomes: developmental disability, mental health, and physical health.^[16] How these complex health care needs interact to impact transition readiness is unknown. Research on transition in individuals with developmental disabilities is siloed from transition research in individuals with mental illness, which in turn is siloed from transition research among those with medical conditions. Such youth would likely benefit from the services provided by complex care programs,^[25-28] which provide additional assistance in caring for and transitioning youth with complex medical and psychosocial needs.

5. Strengths and limitations

Our findings should be considered in the context of our study's strengths and weaknesses. Regarding strengths, this is the first known study to specifically examine mental health transition readiness in a large and diverse sample of youth with co-occurring medical conditions. We had a high participation rate (97.12 % of clinic patients) and used a formalized and validated clinician-administered assessment of transition readiness. Many transition readiness assessments rely solely on patient self-report, which captures what patients say they know without verifying their true knowledge and skills. Clinician administered assessments, such as the TR_XANSITION Index, allow one to measure what patients truly know.^[10] For example, a self-report instrument might ask a patient if they know how their medical condition may impact their future. This is susceptible to a socially desirable response (i.e., Yes) and such questionnaires provide no avenue to confirm the accuracy of such responses. The TR_XANSITION Index asks patients to explain how their medical condition will impact their future, which allows for direct assessment of the patient's true knowledge. By using the TR_XANSITION Index, our clinicians determined that over 95 % of patients had a knowledge or skill gap in need of remediation.

Regarding limitations, this was an exploratory use of the TR_XANSITION Index to assess mental health transition readiness. Although the TR_XANSITION Index was designed to be disease-agnostic and has undergone several validation studies, which have included youth with co-occurring mental health conditions,^[29] to our knowledge there are no studies specifically examining its psychometric properties in a mental health population. Our sample size, although large for the unique population we assessed, is insufficient for the conduct of formal validation of this measure in a mental health population. However, multi-site collaboration may provide a venue for formal validation. Only one transition readiness measure, the Transition Readiness Assessment Questionnaire,^[30,31] has been validated for use in mental health populations.^[29] However, this instrument is based on self-report, which has its own previously mentioned limitations. Additionally, mixed-method research has raised concerns about this measure's sensitivity to measuring transition readiness in youth with co-occurring mental health conditions.^[5] Additional limitations include the single-site nature of our study and the small number of patients included in our exploratory comparison of mental health and medical condition transition readiness.

Few patients had an available transition assessment in their medical record, as only a small number of medical teams have fully integrated transition readiness assessment into their clinic workflow. Finally, it is possible that clinicians may have rated their patient’s responses to transition readiness questions more favorably to reflect more positively on their own clinical skills. However, this is unlikely as results were not shared with management and were not tied to any performance-based incentives.

6. Practice implications

Our findings suggest that although mental health transition readiness is suboptimal in youth with co-occurring medical conditions, implementing formalized assessments with patients can help to identify gaps in need of remediation. Youth in our study scored lowest in the areas of knowledge of their prescription medications, insurance, and finding a new health care provider. Recommendations for addressing key study findings are summarized in Table 3.

A recent Delphi survey identified 26 core components to guide the transition from child/adolescent to adult mental health services.^[32] These core components are grouped thematically under GotTransition’s Six Core Elements^[33] and provide concrete steps providers can take to improve transition to adult mental health. While the 26 core elements were developed with the Canadian mental health system in mind, readers in other countries can find much helpful guidance within the recommendations provided to structure their own approach to transitioning patients to adult mental health care.

7. Future directions

Additional study of youth with mental health conditions is needed. Population-level research is needed to help us learn the extent to which youth with mental health conditions “fall through the cracks” in the American healthcare system, and the barriers they encounter. This information may help to inform educational efforts and interventions to improve transition. Longitudinal research examining the trajectories of youth who leave the pediatric mental health care system may also shed light on the long-term costs of poorly managed mental health transition. Given the large percentage of youth with mental health conditions, it is imperative that greater attention be given to this growing, and vulnerable, population.

8. Conclusion

Youth co-occurring mental health and medical conditions have limited awareness about transition practices governing their mental health care. They also demonstrate gaps in their transition readiness skills and knowledge related to transferring from pediatric to adult mental health care. Youth with co-occurring mental health and medical conditions likely face multiple challenges transitioning to adult care due to the fragmented and siloed nature of mental health and medical care in the adult setting. Further, poorly managed mental health may undermine the ability of youth to persist and overcome challenges they may encounter. Additional support is needed to help these youth navigate the complex care systems they will encounter, with education and preparation focusing on both their mental health and medical transition needs.

Funding/Financial Statement

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethical Statement

The current study did not require institutional board approach as it

Table 3
Summary of Key Findings, Their Importance, and Recommendations.

Key Findings	Why is this important?	Recommendations
<p>Limited knowledge regarding transition</p> <ul style="list-style-type: none"> • Less than half (46.53 %) aware of clinic transition policy • Less than 1 % correctly identified clinic’s mandatory age for transfer • Two respondents expressed belief that mental health care at the children’s hospital would be provided indefinitely • Fewer than 1 in 5 youth aged 16 or older had a transition goal in their treatment plan despite this being a requirement <p>Clinicians found mental health transition readiness assessment helpful</p> <ul style="list-style-type: none"> • Assessment helped clinicians identify knowledge gap in need of remediation in 95.10 % of their patients 	<p>Lack of communication about transition expectations can lead youth and parents to feel that the timing of transition is arbitrary^[34]</p> <p>Transition communication is positively associated with overall transition readiness^[35]</p> <p>Patient lack of knowledge about their diagnoses and treatment is a major barrier to the transition to adult health care^[38]</p> <p>Health literacy and knowledge associated with greater transition readiness^[35]</p>	<ul style="list-style-type: none"> • Ensure all staff are knowledgeable and trained to support youth transition to adult care^[36] • Develop a transition policy^[37] • Make policy visible in the clinic space • Communicate policy to families^[37] beginning at age 12–14^[37] • Review policy regularly with patients and parents^[37] • Make youth active collaborators in their transition planning^[34,36]
<p>Low transition readiness related to Psychotropic Medications</p> <ul style="list-style-type: none"> • two-thirds of patients could not correctly identify the names of their medications • 40.48 % could not identify the purpose of their psychotropic medications • 66.35 % of youth reported sometimes missing a full day of medication <p>Low transition readiness related to knowledge of insurance/finding a new provider</p> <ul style="list-style-type: none"> • Only 46.53 % correctly identified their current health insurance provider • Only 10.89 % knew when their current health insurance 	<p>Patient lack of knowledge about their treatment is a major barrier to the transition to adult health care^[38]</p> <p>Poor understanding/knowledge of psychotropic medications is associated with non-adherence^[40]</p> <p>Non-adherence to psychotropic medication is associated with worsened mental health, increased risk for substance abuse, violence, and suicide, reduced treatment effectiveness, reduced response to future treatment, poorer quality of life, increased risk of work absenteeism and disability, and increased risk for re-hospitalization^[41-43]</p> <p>Insurance/access issues are major barriers to transition^[38]</p> <p>Patients may struggle to find and afford a new mental health provider due to:</p> <ul style="list-style-type: none"> • Increased demand for mental health services^[46] • Nationwide shortages in mental health providers^[47] • A large percentage of therapists do not take insurance.^[48,49] • Insurance impacts mental health accessibility via low provider reimbursement 	<ul style="list-style-type: none"> • Assess transition readiness annually^[39] • Exercise caution when relying on self-report alone to assess transition readiness^[5] • Utilize evidence-based approaches to improve adherence to psychiatric medication^[44] • Educate patients about their psychotropic medications^[45] • Monitor adherence to medications^[17,41]
<p>Low transition readiness related to knowledge of insurance/finding a new provider</p> <ul style="list-style-type: none"> • Only 46.53 % correctly identified their current health insurance provider • Only 10.89 % knew when their current health insurance 	<p>Insurance/access issues are major barriers to transition^[38]</p> <p>Patients may struggle to find and afford a new mental health provider due to:</p> <ul style="list-style-type: none"> • Have a financial coordinator on board that can help patients understand and navigate insurance^[32] • Begin planning transfer at least 6 months in advance of the intended date^[32] • Create a transfer packet containing clinical records and confirm packet is received by the new 	<ul style="list-style-type: none"> • Have a financial coordinator on board that can help patients understand and navigate insurance^[32] • Begin planning transfer at least 6 months in advance of the intended date^[32] • Create a transfer packet containing clinical records and confirm packet is received by the new

(continued on next page)

Table 3 (continued)

Key Findings	Why is this important?	Recommendations
coverage would end • Only 11.88 % knew how to get health insurance coverage when they became an adult • Only 21.78 % of youth knew how they would find an adult mental health provider • Only 8.91 % knew what was required to transfer their mental health record	rates, restrictive health plan approval processes, coverage limitations for mental health services, and limitations on the types of in-network providers allowed ^[50]	provider before the date of transfer ^[32]

was an examination of internal clinic operations for the purpose of program development.

ORCID authorship contribution statement

Michael Weiss: Writing – review & editing, Conceptualization. **Adrienne Alpern:** Writing – review & editing, Data curation, Conceptualization. **Carlos Konishi:** Writing – review & editing, Data curation, Conceptualization. **Erin Benekos:** Writing – review & editing, Data curation, Conceptualization. **Lauren Partain:** Writing – review & editing, Project administration, Data curation, Conceptualization. **Wendy N Gray:** Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors would like to thank the following individuals for their assistance in implementing transition readiness into clinical care: Dr. Elisa Corrales, Dr. Tiffany Torigoe-Lai, Isela Aguirre Verdugo, Michelle Lopez, Karina Martinez, Dr. Anita Saavedra, Dr. Julieta Aguilera Rice, Dr. Courtney Kwan, Dr. Bhakti Agrawal, Dr. Elizabeth Gramillo, Dr. Earaj Afzal, Baleska Alfaro, and Carolina Viera.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2024.100077](https://doi.org/10.1016/j.hctj.2024.100077).

Data availability

The authors do not have permission to share data.

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