

SHORT REPORT

Changes in Anxiety and Depression from Intake to First Follow-Up Among Transgender Youth in a Pediatric Endocrinology Clinic

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Abstract

Monitoring acute distress in transgender youth initiating gender-affirming care is important given their increased risk for significant mental health symptoms. The current study examined changes in anxiety, depression, and suicidality from initial appointment to first follow-up in 80 youth, ages 11–18. Average time between visits was ~4 months but varied across participants. Results revealed no change in acute distress from intake to follow-up. Neither distance from medical center nor initiation of hormone therapy was associated with symptom changes. While research shows decreased distress with initiation of hormones, study findings suggest changes may actually take longer to occur.

Keywords: transgender, acute distress, mental health, behavioral health screeners, gender dysphoria, access to care

Introduction

The Patient Health Questionnaire-9 (PHQ-9) for depression and anxiety (Generalized Anxiety Disorder-7 [GAD-7]) are brief, easy-to-use, physician-administered screening measures used to identify acute distress among transgender and gender-nonconforming (TGN) youth.¹ Given TGN youth are at higher risk for anxiety, depression, and suicidal ideation than their peers,² identifying youth who endorse high levels of acute distress in the gender clinic setting can highlight those who need access to mental health services and crisis interventions. In our recent study, examining rates of depression, anxiety, and suicidal ideation in TGN youth, 43% of patients 11–18 years of age endorsed clinically significant depression symptoms, 61% of patients endorsed clinically significant anxiety symptoms, and 30% of patients endorsed thoughts of death or self-harm on several days or greater.¹

Medical interventions for pubertal adolescents fall into three general categories: (1) medications to suppress or manage the estrogen or testosterone produced by the body (e.g., hormone blockers), (2) hormone therapy (HT) to masculinize or feminize the body,

and (3) gender-affirming surgeries.³ Some research suggests a positive impact of HT on the mental health of TGN youth and relief of gender dysphoria over time with initiation of surgical interventions.^{2,4} A gap in knowledge exists in how symptoms of acute distress change in the short-term, particularly in youth receiving gender-affirming care who are not undergoing surgery. Gathering these data on how mood changes early in treatment is important for informing both patients and providers on what to expect.

Another gap in the literature is how distance from a medical center may be associated with mood symptomatology. Mental health differences have been found among TGN adults who live in rural versus non-rural areas.⁵ TGN youth and adults also consistently report access to TGN specialists, including mental health providers, as a common barrier to health care.^{6–8} While there are 53 comprehensive clinical care programs for TGN youth in the United States and Canada, the majority are located in large metropolitan cities, making access to services challenging for many families.⁹ To our knowledge, no research has explored whether distance to a comprehensive clinical care program for

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TGN youth might impact the level and persistence of acute distress among these youth.

To fill these gaps in the research, the current study has three aims: (1) Describe changes in anxiety, depression, and suicidality from intake visit to first follow-up appointment using the PHQ-9 and GAD-7 in TGN youth; (2) Examine symptoms of anxiety, depression, and suicidality by distance from medical center (>30 vs. <30 miles) from intake to follow-up; (3) Examine changes in anxiety and depression from intake to first follow-up among the TGN youth who initiate HT.

Methods

Participants and procedure

Participants were TGN youth seeking gender-affirming care at an academic medical center in the Northwestern United States between September 2017 and June 2019. All youth ages 11 and older complete anxiety and depression screeners at every visit regardless of mental health diagnoses or symptom severity. In this clinic, youth do not receive prescriptions for hormone medication management at the initial visit, but many patients initiate medications between their first and second appointments after completing required steps (family receives extensive counseling, signs consent form, completes assessment, and acquires a letter of support from an experienced mental health provider). Initiation of hormone management medications (e.g., hormone blockers) and HT is individualized for each patient and some patients initiate both at the same time. Second visit is recommended 3–4 months after the initial visit.

Youth were included in the current study if they (1) were between the ages of 11 and 18 years, (2) had attended both an initial visit and one follow-up appointment, and (3) completed measures assessing acute distress (PHQ-9 and GAD-7) at both visits. Retrospective chart review was used to extract patient age, affirmed gender, medical interventions, screener results, and distance from clinic. Because chart review was used to collect data, no informed consent procedures were conducted, and data on participant race/ethnicity, socioeconomic status, and education level were not available to include in analyses. It was also infeasible to document the exact time of HT initiation given the variability in how and where individuals received their treatments. The institution's Human Subjects Institutional Review Board approved all study procedures.

Measures

Depression. The PHQ-9¹⁰ is a 9-item screening measure of depression. Items are rated on a 4-point scale for how often each symptom has occurred in the past 2 weeks from 0 (Not at All) to 3 (Nearly Every Day). The final item (item 9) asks about thoughts of death and self-harm. Youth were coded as endorsing suicidal ideation if they responded ≥ 1 on item 9.

Anxiety. The GAD-7¹¹ is a 7-item screening measure of anxiety. Items are rated on a 4-point scale for how often each symptom has occurred in the past 2 weeks from 0 (Not at All) to 3 (Nearly Every Day).

Distance from the medical center. Distance from the participants' home to the medical center was calculated using the zip code of the youth's home address documented in the medical record. This variable was then dichotomized into two groups: youth who lived <30 miles and youth who lived >30 miles to the medical center.

Analyses

Descriptive statistics were used to examine sample characteristics and differences in endorsements of suicidal ideation. Paired sample *t*-tests were used to examine overall changes from initial visit to follow-up, and independent sample *t*-tests were used to examine simple differences across groups. Repeated measures factorial analysis of variance (ANOVA) was used to examine the role of potential moderators (i.e., initiation of HT and distance from clinic) in the changes in distress over time. All analyses were completed using SPSS, with the exception of power analyses, which were completed using G*Power.

Results

Subject demographics are depicted in Table 1. Participants were 80 youth 11–18 years of age (80 youth completed PHQ-9 screeners at both time points and 78 youth completed GAD-7 screeners at both time points). Average time between initial visit and follow-up appointment was 4.7 months. However, there was significant variability ranging from <1 month to 11 months, with 80% of follow-up visits occurring between 2 and 7 months.

Only 1 individual initiated HT before the initial visit, and 28 youth initiated HT between initial visit and first follow-up. Of those 28 youth, 6 were started on feminizing hormones and 22 were started on masculinizing

Table 1. Summary of Sample Characteristics (n = 80)

Age in years, mean (SD), range	15.1 (1.8)	
Distance in miles, mean (SD), range	36.2 (39.9)	
Within 30 miles, n (%)	46 (57.5)	
Beyond 30 miles, n (%)	34 (42.5)	
Affirmed gender, n (%)		
Female	15 (18.8)	
Male	58 (72.5)	
Nonbinary	7 (8.8)	
Follow-up time in weeks, mean (SD)	20.4 (10.2)	
Interventions, n (%)	Initial visit	Follow-up
Hormone blockers only	2 (2.5)	13 (16.2)
HT only	1 (1.3)	25 (31.2)
Both hormone blockers and HT	0 (0.0)	4 (5.0)
Neither hormone blockers or HT	77 (96.2)	38 (47.5)

Interventions represent treatment initiated before current visit.
HT, hormone therapy.

hormones. A total of 17 youth initiated hormone blockers between their initial visit and first follow-up, 4 of which also initiated HT. No analyses were conducted to examine differences between which hormone was started or for those that also initiated puberty blockers due to small and skewed samples.

Aim 1 examined changes in anxiety, depression, and suicidality from initial visit to first follow-up appointment. At initial visit, 37 (46%) youth met the cutoff for depression (PHQ-9 score ≥ 11). Of those 37 youth, 28 (76%) continued to meet the cutoff at follow-up and 9 (24%) no longer met the cutoff for clinically significant depression. At initial visit, 49 (61%) youth met the cutoff for anxiety (GAD-7 ≥ 6). Of those 49 youth, 41 (84%) continued to meet the cutoff at follow-up and 8 (16%) no longer met the cutoff for clinically significant anxiety. For the total sample, mean values for anxiety and depression were lower at first follow-up compared with initial appointment, but these changes were not statistically significant (Table 2). Changes in suicidality from initial visit to follow-up were also examined. Of the 27 (34%) youth who endorsed suicidality at intake, 22 (81%) continued to endorse suicidality at their follow-up visit, and only 4 (4%) no longer endorsed suicidality at follow-up.

Aim 2 examined changes in acute distress symptoms for those living within 30 miles of the medical center compared with those living beyond 30 miles (Table 2). A repeated measures factorial ANOVA did not reveal any significant differences in anxiety or depression by proximity to the clinic. Mean changes were examined qualitatively for potential trends, and a similar pattern of interaction effects was observed

Table 2. Change in Depression and Anxiety from Initial Visit to First Follow-Up

	Initial visit Mean (SD)	Follow-up Mean (SD)	t	p
Total sample				
PHQ-9 (n = 80)	10.5 (6.5)	10.0 (6.4)	0.87	0.385
GAD-7 (n = 78)	9.1 (6.1)	8.8 (5.7)	0.58	0.561
	Initial visit Mean (SD)	Follow-up Mean (SD)	F	p
PHQ-9 distance			1.33	0.253
Within 30 miles (n = 46)	10.5 (6.9)	10.6 (6.7)		
Beyond 30 miles (n = 34)	10.5 (6.2)	9.3 (6.1)		
GAD-7 distance			2.44	0.123
Within 30 miles (n = 44)	8.7 (6.3)	9.1 (5.6)		
Beyond 30 miles (n = 34)	9.6 (5.8)	8.4 (5.9)		
PHQ-9 HT			1.44	0.235
HT initiated (n = 28)	9.8 (7.1)	10.3 (7.3)		
No HT (n = 51)	11.1 (6.3)	10.1 (5.9)		
GAD-7 HT			0.24	0.624
HT initiated (n = 27)	8.4 (6.4)	8.5 (5.5)		
No HT (n = 50)	9.6 (5.9)	9.1 (5.8)		

GAD-7, Generalized Anxiety Disorder-7; HT, hormone therapy; PHQ-9, Patient Health Questionnaire-9.

across depression and anxiety scores. Specifically, small decreases in mean scores on anxiety and depression were observed from initial visit to follow-up, but only for the youth living beyond 30 miles. There were no differences in the number of youth who endorsed suicidal ideation at intake or follow-up visit by proximity from clinic.

Aim 3 examined changes in acute distress symptoms for those who initiated HT between initial visit and first follow-up compared with those who did not begin treatment (Table 2). Participants started on hormone blockers only were not included in this analysis. The analysis *included* the four youth who were started on both HT and hormone blockers and *excluded* the participant who had started HT before the initial visit. A repeated measures factorial ANOVA did not reveal any significant differences in depression and anxiety scores among youth who did versus did not initiate HT following their intake visit. Similarly, there were no differences in the endorsement of suicidal ideation between initial and follow-up visit for youth who did versus did not initiate gender-affirming hormones.

Conclusion

The present study explored acute changes in depression, anxiety, and suicidal ideation from initial visit in a pediatric gender clinic to first follow-up visit among TGN youth, with attention to differences

between those living within and beyond 30 miles of the clinic and between those who did versus did not initiate HT between visits. Depression and anxiety were assessed using the PHQ-9 and GAD-7, which are completed by all youth 11 years and older at every clinic visit. These screening measures were chosen due to their ease of use, sensitivity to change, and scoring that can be used clinically and for research.¹⁰ Previously published data from this clinic has demonstrated that these screeners capture rates of anxiety and depression similar to the broader literature.¹

Overall, the results of this study suggest that no clinically significant changes in mood symptoms occur during this initial time frame, with the majority of youth maintaining similar levels of symptomatology at their first follow-up as they did at their initial visit. While some evidence to date lends strong support for symptom improvement over time^{4,12–16} the current study suggests changes likely occur gradually and may not begin to occur until several months into treatment. This may be related to the fact that masculinizing and feminizing physical changes occur slowly after initiation of HT.¹⁷ While most previous research has used more in-depth psychological assessments and interviews rather than screeners, the PHQ-9 and GAD-7 are sensitive to change¹⁰ and have been shown in this clinic to capture similar rates of anxiety and depression as broader literature,¹ lending further support to the strength of these results.

These results lend support for educating providers, youth, and their families about setting appropriate expectations for change. The results of this study suggest that this overall pattern of symptom maintenance in the early stages of treatment did not differ between those who initiated HT before their first follow-up and those who did not. This suggests that improvements in mood symptoms with HT may take longer to occur or that other factors not assessed in the current study (e.g., level of family support, access to mental health services) play a more significant role in early improvements.

The present study also examined the role of proximity to clinic in changes in distress. There were no significant differences in distress at either time point, or changes over time by distance suggesting that this particular measurement of clinic access did not impact early changes in distress. With larger samples it will be important to look at differences in youth who live in urban versus rural areas and also use more robust measures to assess access to clinical care and resources.

It will be important in future studies to assess distance as a potential proxy for community support as well as access to services.

There are important limitations to take into account when interpreting these results. Data collected were limited to one clinic, with a relatively small sample size and only two time points examined. Power analyses revealed that the current sample would have been well powered to detect large effects, but not small-to-moderate effects, which are more likely when looking at shorter time frames. Due to sample size, we could not examine how age, affirmed gender, or initiation of hormone blockers were associated with changes in symptoms of distress. Sample size also limits the ability to examine differences among those with genderqueer and nonbinary identities.

Another important limitation includes the variability with regard to exactly when HT was initiated and the variability in time between initial visit and first follow-up. The recommended follow-up time between first and second visits is typically 3–4 months, and most participants in this study actually attended a second appointment 2 to 7 months after the initial visit. While variability may impact the results of this study, these data reflect what is typical for this clinic, which likely generalizes to other real-world situations. Given that patients may not experience the physical effects of HT until 3–6 months following initiation,¹⁷ depression and anxiety may not be impacted until visible effects begin to occur.

Further research is required to determine the trajectory of mood during the course of HT over multiple time points as well as how symptoms change with variable factors (e.g., mental health treatment, etc.). Data continues to be collected within this clinic and analyses with larger samples and additional time points are planned which will help increase our understanding of mental health changes during treatment in this population.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

No funding was received for this article.

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Cite this article as: Cantu AL, Moyer DN, Connelly KJ, Holley AL (2020) Changes in anxiety and depression from intake to first follow-up among transgender youth in a pediatric endocrinology clinic, *Transgender Health* 5:3, 196–200, DOI: 10.1089/trgh.2019.0077.

Abbreviations Used

ANOVA = analysis of variance
 GAD-7 = Generalized Anxiety Disorder-7
 HT = hormone therapy
 PHQ-9 = Patient Health Questionnaire-9
 SD = standard deviation
 TGN = transgender and gender nonconforming