Facing Your Fears: Collaborating with Autistic Young Adults and Parents to Adapt an Evidence-Based Anxiety Intervention

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A Note on Language

To be inclusive to those who prefer identity-first or person-first language, we choose to use both types of language. In this poster you will see "autistic students" as well as "students with autism."

Introduction

College students in the United States have been presenting to counseling centers in increasing numbers for stress-related psychological health issues over the past decade (Center for Collegiate Mental Health, 2020). Most students who seek help at college counseling centers report anxiety as both the top and most frequent complaint affecting their functioning. At the same time, students with autism are increasingly entering and attending college (White et al., 2011). While it is known that rates of clinical anxiety in the adult autistic population are significantly higher than rates in the general adult population and that youth with autism respond to cognitive behavioral treatment, **little is known about how autistic college students experience anxiety or how evidence-based interventions may be appropriately adapted for autistic college student populations.** Given the need for information on how anxiety manifests in and impacts college students with autism, *this study sought to gather firsthand input from autistic college students and their parents on students' anxiety-related experiences as well as their treatment needs and preferences.*
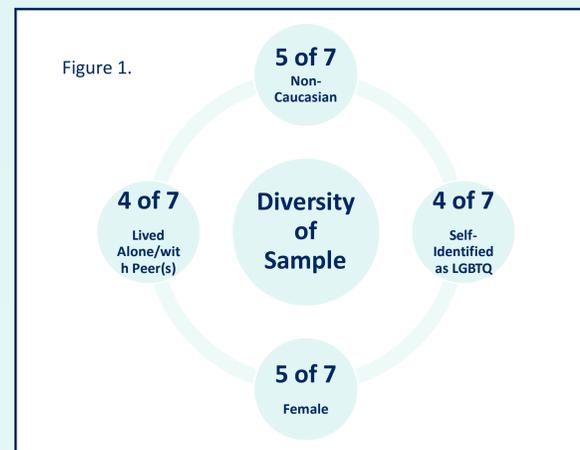
Methods & Analysis

Participant Recruitment

Our main sample for this study was **five university students** recruited through the disability office of a large public university who all self-identified as being autistic. Our secondary sample was **three parents** of autistic undergraduate or graduate students who were recruited through personal email communications. Demographics of the student sample are represented in Figure 1. In addition, **survey data was requested from twelve other eligible students** who expressed interest in study participation. Student participants were recruited for study participation via email invitations through the university's disability support services office.

Methods & Analysis

This study used a **focus group format** to collect data from five participants. A pre-written protocol containing 14 different questions was utilized by the lead focus group meeting facilitator as a guide for the meeting. The focus group was completed within one, 1.5-hour session **held virtually over Zoom**. Focus group data was collected via the built-in Zoom audio recording feature. The twelve **additional, interested and eligible participants were sent a Qualtrics survey** containing the same open-ended guiding questions that were asked to the focus group. **Two of the twelve additional participants responded to the survey.** The focus group audio recording data was deidentified and transcribed into a tabular script and then the Qualtrics survey responses were incorporated into the script under each corresponding guiding question. A team of four researchers independently **coded the resulting data using the Rigorous and Accelerated Data Reduction (RADaR) technique** (Watkins, 2017).

Figure 1.

Diversity of Sample

- 5 of 7 Non-Caucasian
- 4 of 7 Self-Identified as LGBTQ
- 5 of 7 Female
- 4 of 7 Lived Alone/with Peer(s)

Results

Five student themes were identified amongst student participants' responses, with subthemes listed in order of greatest to least popularity:

Table 1.

Theme & Subthemes	Theme Definition
Causes *Student:* Environmental, Academic, Career, Family, Global/Political, Social *Parent:* Academic, Change/Uncertainty, COVID, Social	Factors that participants identified as causing them either to start experiencing, continue experiencing, or experience greater anxiety.
Markers *Student:* Psychological, Behavior, Somatic, Health *Parent:* Behavior, Change, Psychological	Factors that participants clearly identified as acting as signals that their anxiety is present, in circumstances where they have experienced anxiety.
Alleviate *Student:* Coping Behaviors, Avoidance, Support-Seeking, Medication/Supplements	Actions, thoughts, experiences, resources, or other means which participants reported they either have used or currently use to prevent, decrease, or eliminate their anxiety.
Daily Living *(no subthemes)*	Any undesired changes or alterations that participants reported as interfering with one or more daily life routines due to their experiencing anxiety.
Recommendations for FYF* *Student:* Curriculum, Delivery, Benefit/Positive *Parent:* Delivery, Curriculum, Measures, Valuations	Recommendations, critiques, reactions, or other thoughts offered by participants in regard to the designing, scheduling, participant recruitment strategy, or implementation of an adapted group-based anxiety treatment program for autistic college students that was described by the facilitators.

*Note: FYF stands for Facing Your Fears (Drmic et al., 2017), an evidence-based anxiety intervention for autistic adolescents that is currently being adapted by this study's research team for use in college populations.

Within parents' responses, **three identical parent themes** emerged: Causes, Markers, and Recommendations for FYF. **Two unique parent themes** were found:

Table 2.

Theme & Subthemes	Theme Definition
Community Support *Parent:* College, Mental Health Providers	Available community-based experiences, resources, or social interactions which have supported the prevention, decreasing, or elimination of anxiety in autistic college students according to participants.
Barriers to Treatment *(no subthemes)*	Reported factors that participants observed to negatively affect, or that would presumably negatively affect, their student's ability or tendency to access on-campus intervention treatment for their anxiety symptoms based upon participants' observations of a factor's affects on their student accessing support. Excluded from this subtheme were recommendations that participants mentioned in specific relation to the program described by the researchers.

The **example quotes provided represent comments from the top three or four most popular subthemes** amongst both groups. Parent quotes are listed in brown.

What types of things make autistic students worried, nervous, or anxious?

"events with a lot of people...and not just people, but a lot of sensory stimulation" *(Environmental)*

"exams" ... "being behind in classes" ... "knowing what to do, like passing my classes" ... "dealing with professors" *(Academic)*

"the 'what if's'" ... "change in schedule"... "something unexpected" ... "fear of the unknown" *(Change/Uncertainty)*

"not knowing anyone" ... "I don't like being judged" ... "disappointing professors, or anyone" *(Social)*

When students are worried, nervous, or anxious, how do they know?

"repeating a sentence over and over in my head" ... "can't talk or reason" ... "twitching [or] feeling the urge to pace" ... "uncompleted work" *(Behavior)*

"issues noticing how I'm feeling internally" ... "feels guilt" *(Psychological)*

"knot in my stomach" ... "my ears hurt" ... "hard to swallow" ..."feel like I'm gonna throw up" *(Somatic)*

Where (or how) do students find support to help with their anxiety?

"I meditate a lot" ... "I will aggressively pace" ... "I like to hike" ... "I throw things away" *(Coping Behaviors)*

"I don't spend a lot of time on campus. I try to get down there right before class and leave right after class." *(Avoidance)*

"I usually talk to people to see if I can find solutions" ... "works weekly with a psychologist" *(Support Seeking and Mental Health Providers)*

How does anxiety impact autistic students' daily life at college?

"birding's an interest of mine, and I have trouble going on some of [the birding club's] outings and events"

"with me avoiding more crowded places, I'm not going to make as many friends"

"taking a medical leave for eating disorders...anxiety was a factor"

"I kind of waste a lot of time [using coping strategies]"

"I wasn't able to go to the cafeterias to eat food, so I would be hungry a lot"

How can Facing Your Fears be modified in a way that fosters maximum growth?

"maybe [meet] once a week" ... "[consider] time or an economic incentive"... "have some leftover time so that nothing's ever rushed" ... "concern would be that [facilitators] have the experience working with autistic students" *(Delivery)*

"I would not prefer parent involvement" ... "[include] dealing with some kind of their own social issues" ... "preface meetings with statements on inclusiveness" ... "structure it so that it [is] more of a supportive community where the students [are] kind of brainstorming with each other" *(Curriculum)*

"anything where I would be able to visualize the stages of anxiety... seems incredibly helpful" ... "main benefit that I see is just bringing students who have those challenges together...That I think would have incredible value" *(Benefits/Positives and Valuations)*

Why can't students with autism access supports?

"that [treatment provider] was only available like once every two months...and [the student] didn't even want to try"

"[student] has to seek this [treatment] out and just isn't"

"As soon as anxiety pops up, isn't able to advocate for [themselves]"

"structural barriers that would keep those diverse students from participating?"

"'I don't know' is a common response to [me] offering help."

Conclusions & Future Research

Below are several main takeaways from this study:

- Academic-, sensory-, and environmental change-type stressors (not social stressors) seemed to cause the most anxiety in our participants
- While our participants reported using a variety of coping skills and supports typically used for general stress management, these strategies did not seem to prevent anxiety effects
- In adapting youth interventions for autistic college students, consider the population's preferences (e.g., independence from parents, convenient and considerate timeframes, group diversity)
- For groups looking to design interventions for other college environments, parents may serve as key informants for understanding prevalent treatment barriers and supports

We recommend that future research explore the following:

- Replicating this research in different autistic college student and family populations to gather a full sense of this population's needs and preferences
- Applying this study's results to a participatory action research study on the design and efficacy of an evidence-based, adapted anxiety intervention for college students with autism

References/Contact Information: Contact the lead author at klbaldw@udel.edu for a complete list of citation references for this poster or with questions related to this study.