OAR Applied Research Grant Summary – Christina McDonnell (December 2023)

Why is this topic important?

Autistic youth experience very high rates of many forms of traumatic events. Autistic youth also experience higher symptoms of posttraumatic stress disorder (PTSD). PTSD symptoms occur after experiencing a traumatic event and include (1) changes in mood and thinking (depressed feelings, self-blame), (2) increased hypervigilance (alertness for danger, difficulty sleeping), (3) avoidance (staying away from reminders of trauma, difficulty remembering or communicating about trauma), and (4) intrusions (unwanted memories of the trauma). Traumatic stress symptoms also include broader changes in mental health that can occur after trauma, such as depression, anxiety, and other behavioral changes. PTSD and traumatic stress symptoms can prevent an individual from achieving their goals and lower quality of life.

Fortunately, many support programs work very well at reducing PTSD and traumatic stress symptoms for children and adolescents. One program that has a very high level of research support (many strong studies show that it is effective for youth) is called Trauma-Focused Cognitive Behavioral Therapy (TF-CBT; Cohen et al., 2016). TF-CBT involves about 12 weeks of individual meetings with youth and their caregivers. Youth learn about trauma and coping skills, before proceeding to learn how to communicate about their traumatic and/or stressful experiences in safe and supported ways. One of the central goals of the program is to help youth and their caregivers communicate together about the child's experiences, and plan for the future.

Despite many years of research studies showing that TF-CBT is a highly effective program, little research has previously included Autistic youth. Therefore, we had little knowledge about whether this program is helpful for and valued by Autistic children/adolescents and their caregivers. Therefore, the goal of this project was to study whether TF-CBT is effective at reducing PTSD and traumatic stress symptoms, and obtain feedback on the program from Autistic youth and their caregivers. There are many barriers to accessing therapeutic programs, including needing to travel far distances to access mental health care. Telehealth options can make mental health programs more accessible, and also became essential during the COVID-19 pandemic. Therefore, because prior studies have shown that TF-CBT can be delivered via telehealth, we examined whether telehealth-based TF-CBT is also helpful for Autistic youth.

What did we do?

First, we conducted study screening followed by telehealth-based assessments over Zoom. In order to participate, youth had to be Autistic, between the ages of 10-17 years, have experienced a traumatic event, and be experiencing traumatic stress symptoms that they desired support for. Research staff asked both youth and their caregivers about child trauma symptoms using validated measures of PTSD symptoms, including interview (Anxiety Disorders Interview Schedule) and questionnaire tools (Child and Adolescent Trauma Screen). We also used a range of tasks and questionnaires to assess other aspects of youth and caregiver mental health.

Out of 30 families who completed screening, 17 families fully received and completed telehealth-based TF-CBT. Of these 17 families, the average child age was 13.76 years (ranged from 10-17 years). Around one third of youth were identified as having a minoritized racial or ethnic identity. Around thirty percent of youth were girls or had a gender diverse/expansive identity (e.g., non-binary). Participants completed 12 weekly sessions that lasted between 60-90 minutes. Each session happened on Zoom and involved brief assessment of how youth were doing that week (outcome monitoring), individual time for the child, individual time for the

parent/caregiver to review skills, and conjoint time for both the child and parent/caregiver together. After completing the program, youth and their caregivers repeated the same set of measures we had used at the beginning of the study, in order to look at changes over time.

See the table below for a summary of the components that were taught in the program, which follows the PRACTICE acronym. The second column shows examples of different adaptations and flexibility techniques that were used to creatively teach the program content. Other general flexibility strategies included decreasing the length of sessions if needed (providing the content in a shorter amount of time each week), encouraging movement and attention breaks, having caregivers attend for a longer duration of each session if helpful, learning about a child's interests and hobbies, and answering questions/providing more background information about PTSD and autism as relevant. We were grateful to incorporate strategies from many useful resources, including from the TF-CBT website and the Medical University of South Carolina's telehealth trauma program.

Content	Goals	Sample Adaptations
Psychoeducation and **P**arenting	Learn about trauma and its effects (e.g., role of avoidance, fight/flight/freeze reactions); Review parenting strategies for supporting youth who have experienced trauma	Use multiple ways of teaching (visuals, videos, manipulatives), and provide repeated opportunities to learn
Relaxation	Learn skills for relaxation (e.g., deep breathing, progressive muscle relaxation, imagery, etc)	Provide opportunities to directly practice and demonstrate skills; use "teach-back" method to reinforce content and collaborate with caregiver; brainstorm unique mindfulness activities
Affective Modulation	Learn to identify and talk about emotions, and how to regulate them	Use a child's interests and hobbies to make skills relevant; practice skills using real world examples personalized to an individual's enjoyed activities
Cognitive Coping	Learn about what thoughts are, and how they relate to our feelings and what we do	
Trauma Narrative	Communicate about traumatic and stressful experiences in context of one's life	Use creative approaches that match language and communication style (don't rely on verbal speech, use images/songs/etc; promote child's self-determination; create life story)
In Vivo Desensitization	Additional practice coping with feared situations	
Conjoint Sessions	Practice sharing about traumatic and stressful experiences with caregivers	Provide structure in advance for both youth and caregiver to know what to expect; present information in multiple ways
Enhancing Future Safety	Planning for the future	Use child's values and goals to make content meaningful

What did we find?

We found that this program was helpful for reducing PTSD symptoms among Autistic youth. From the beginning to end of the program, Autistic youth were reporting significantly

fewer PTSD symptoms. Caregivers agreed; they were also reporting significantly lowered PTSD symptoms for their children. These significant improvements in PTSD symptoms were also seen at 1 month after the program ended, suggesting that they lasted after the weekly program was over.

We also saw that there were improvements in many co-occurring mental health symptoms that commonly occur after trauma. For example, children were reporting significantly improved anxiety at the end of the program and 1 month after. Caregivers were also reporting significantly improved anxiety, depression, and resilience, and lower behavioral concerns for their children. See the table below for examples of some of these key child outcomes.

Mental Health Symptom	Examples of Key Findings
Child PTSD Symptoms	Both youth and their caregivers reported significantly improved PTSD symptoms at the end of the program and 1 month later.
Child Anxiety	Both youth and their caregivers reported significantly lower anxiety symptoms at the end of the program and 1 month later.
Child Depression	Caregivers reported significantly lower depression symptoms for their child at the end of the program and 1 month later.
Child Externalizing	Caregivers reported significantly lower externalizing concerns for their children at the end of the program and 1 month later.
Child Resilience	Caregivers reported significantly higher resilience for their children at the end of the program and 1 month later.

What did Autistic youth and their caregivers think of the program?

Overall/on average, Autistic youth and their caregivers were satisfied with this program. For example, we asked how much they enjoyed, understood, felt helped by, would recommend, agreed with the message, and felt involved in the program on a scale from 1 (not at all), 2 (slightly), 3 (moderately), 4 (very much), to 5 (greatly). All youth-reported values averaged above a 3.5 out of 5 (between moderately to very much), with average scores above a 4 (very much) for feeling involved, understanding, and agreeing with the program's message. All parent/caregiver reported values averaged above a 4.4 out of 5 (between very much to greatly). We also asked about how satisfied they were with using telehealth on a 1-4 scale, with 4 indicating the highest possible satisfaction. All parent-reported values were above a 3.6 out of 4, and all child-reported values were above a 3.1 out of 4.

What does this study teach us, and what is next?

This study shows that TF-CBT can be a helpful program for Autistic youth and their caregivers. We need more research to continue to improve this program and make it easy to access for more Autistic youth. We are very grateful to the participants, graduate students and collaborators who were part of this study, and to the Organization for Autism Research who supported this work. We are planning to continue to analyze the data from this study to further understand changes in other outcomes at the parent and family level, how this program works, for whom the program is most versus least helpful, and how to enhance the program moving forward. We also want to evaluate this program more intensely in a larger research study, specifically by comparing this program to other types of support strategies. Lastly, we hope to further increase the accessibility and reach of this program in partnership with Autistic individuals and clinicians.

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