Development of a Transdiagnostic Group Intervention for Pediatric Autonomic Dysfunction

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BACKGROUND

- Autonomic dysfunction (AD), e.g., POTS, affects up to 3 million people in the US. Symptoms include tachycardia, dizziness, fatigue, nausea, head and stomach pain, brain fog [1].
- AD is associated with psychosocial and functional impairment (e.g., school absences, social isolation, frustration) [2].
- Psychological factors can influence illness course (e.g., adherence, catastrophizing, somatic vigilance, depression) [3].
- Acceptance and Commitment Therapy (ACT) has been effective in promoting well-being among youth with chronic pain [4], yet similar interventions have not been developed and tested for pediatric AD.
- A *Transdiagnostic* approach [5] that targets common mechanisms of psychological distress and functional disability (e.g., experiential avoidance, cognitive flexibility) was used in the development of this intervention.

Study aim: Develop a group intervention incorporating ACT principles to target transdiagnostic processes among youth with AD and their parents.

- *Hypotheses: This intervention will be **acceptable** to patients and parents and **feasible** to implement in an outpatient behavior health clinic.*

METHOD

Participants

- 13 female adolescents with diagnoses of AD and their parents participated to completion.
- Functional Disability Inventory (FDI, Walker & Greene, 1991) scores were in the moderate or greater range.

	Group 1 (*n* = 6)	Group 2 (*n* = 7)
Age in years	*M* = 16.2 (range 14.6-18.6)	*M* = 16.1 (range 14.7-17.9)
Median family income	$100,000	$90,000
FDI self report	*M* = 30.7 (range 16-47)	*M* = 33.3 (range 23-43)
CDI self report	*M* = 21.8 (range 6-36)	*M* = 21.4 (range 10-34)
SCARED self report	*M* = 39.8 (range 15-62)	*M* = 38.3 (range 15-56)

CDI = Children's Depression Inventory; SCARED = Screen for Childhood Anxiety Related Emotional Disorders; sum scores shown. FDI scores ≥ 12 are moderate or higher; CDI raw scores ≥ 20 are elevated, ≥ 24 are very elevated; SCARED scores ≥ 25 are clinical.

Group Intervention

- 10-week outpatient group protocol was initially based on research and consultation, revised in response to participant feedback and clinical observation, delivered by Ph.D. level clinicians.

Session	Content of Final Intervention Protocol (Teens)
1	Introductions, group structure and rules, discuss AD, identify values, establish values-based goals.
2	Basic lifestyle modifications using STEPS, i.e., Salt, Taking in fluids, Exercise, Pacing, and Shaping.
3	Review STEPS goals, sleep hygiene, introduction to relaxation with progressive muscle relaxation.
4	Review sleep goals, review relaxation and introduce diaphragmatic breathing and visual imagery.
5	Review relaxation goals; introduce acceptance/willingness vs control/avoidance (i.e., limits of control), introduce mindfulness.
6	Review acceptance vs avoidance ("costs of avoidance" handout), practice mindfulness (body scan).
7	Emotional awareness and CBT model of emotion (i.e., thoughts, behaviors, feelings), automatic thoughts, thinking traps, introduce "detective thinking".
8	Introduce cognitive defusion, practice defusion via metaphors and exercises (e.g., "Milk" exercise, *Leaves on a Stream* exercise), assign defusion practice handout.
9	Mindfulness practice (mindful eating), reducing experiential avoidance, behavioral exposure (i.e., exposure hierarchy)
10	Mindfulness practice (turning pain on and off), review of strategies, relapse prevention, "graduation".

- Additional topics in parent group included parental experiential avoidance, and balance between supporting (e.g., through empathy) and encouraging activity (e.g., through positive reinforcement).

RESULTS

Acceptability

- Satisfaction Questionnaire (adapted from Crawley et al., 2013), 8 items, e.g., "How would you rate the quality of care you have received?" and "Have the services you received helped you deal more effectively with your problems?", overall score ranges from 1 (very dissatisfied) to 4 (very satisfied).

	Teens			Parents		
	Group 1	Group 2	Overall	Group 1	Group 2	Overall
Mean score (1-4)	3.1	3.6	3.4	3.5	3.7	3.6

Selected Participant Comments
"I am satisfied that I now have a support group of people with my same condition and that I no longer feel alone in my illness" (Teen, Group 2).
"Connected me with teens who have/are having similar experiences as I am, gave me coping strategies on pain and related things AND ALSO HELP ME PUT THOSE STRATEGIES INTO PRACTICE" (Teen, Group 2).
"Providing more time to get to know the others in the group at the beginning may help to foster more genuine/intimate conversations between the group" (Teen, Group 1).
"It was very empowering. Helped me to help my teen better. Helped her to help herself better. Helped me to decrease my involvement and increase her independence with self care related to POTS" (Parent, Group 1).
"I had a low bar coming in - more for the moms group. Lame, but I was dreading it. After the first week, I couldn't wait for Mondays to arrive. EVERY week, I went home with a tangible idea to TRY. THANK YOU!!!!" (Parent, Group 2).

Feasibility

- Ease of recruitment, connections with medical providers.
- Drop out (*n* = 3, 1 male) due to lack of connection (*n* = 1), insurance (*n* = 1), and high acuity interfered with attending.
- Attendance: Median sessions missed = 1 (range 0 to 3).

Teen, Parent & Clinician Observations

- Less didactic and more collaborative approach reduced resistance among teens.
- Motivational interviewing promoted readiness to engage in behavioral interventions.
- Parents had difficulty accepting distraction as an avoidance strategy.
- Ongoing discussions about how to improve functioning by setting limits were an important focus for parents.
- Group format provided opportunities for social connections and support, and maximized treatment accessibility (i.e., time- and cost-effectiveness).

CONCLUSIONS

- ACT-based group intervention is ***acceptable*** and ***feasible*** for supporting teens with AD.
- This intervention has the potential to improve adjustment and reduce distress and disability among youth with AD.
- Transdiagnostic approach allows for targeting relevant processes regardless of mental health diagnoses, and provides destigmatized and individualized treatment.
- Future projects examine changes in transdiagnostic mechanisms with intervention, including experiential avoidance, cognitive flexibility, and heart rate variability.

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