Engagement in Acceptance and Commitment Training Predicts Outcomes in Individuals with Neurofibromatosis 1 (NF1), Plexiform Neurofibroma tumor (PNs), and Chronic Pain

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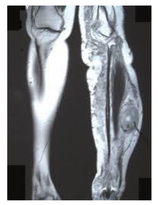
Background

- Neurofibromatosis Type 1 (NF1) is a genetic disorder that affects multiple systems of the human body.
- Individuals with NF1 are at risk for developing plexiform neurofibromas (PNs) which are tumors that grow on nerves and can cause pain and disfigurement.



- Chronic pain is common in individuals with NF1 and PNs and associated with diminished quality of life and interference in everyday activities (Wolters et al., 2015).
- Research supports the efficacy of ACT across pain populations (Vowles et al., 2014) yet very little is known about how adherence to ACT interventions relates to outcomes.
- There are studies that suggest that participation and adherence to treatment modalities, such as Cognitive Behavior Therapy, in chronic pain are associated with better coping (Kerns et al., 2014).
- We are presenting data from a sub-study from an ongoing randomized controlled trial investigating the effectiveness of ACT in helping adolescents and adults with NF1, PNs, and chronic pain.

Objective

- We examined how home-based engagement in an ACT intervention related to post-intervention pain-related outcomes among individuals with NF1, PNs, and chronic pain.

Methods

Eligibility

Adolescents and adults with NF1 were recruited from an electronic NF registry and NF1 clinics nationally. At least one PN and chronic pain for more than 3 months were required to be eligible for the study.

Procedures

- Study participants completed questionnaires assessing pain interference and pain-related inflexibility prior to the intervention.

In Clinic

- Each participant took part in a 2-day (4-hour) in-person ACT training and learned about key concepts of ACT (eg, mindfulness, defusion, values).

At Home

- Participants were instructed to practice newly-learned ACT skills at home for the next 8 weeks.
- The at-home part of the intervention was supplemented by biweekly video-chats with the ACT therapist and weekly email assignments that focused on mindfulness exercises, noticing thoughts and feelings, and taking valued-actions to achieve goals.
- Participants completed the same questionnaires at 8 weeks and a third measure reporting how often they practiced ACT skills (engagement).

Methods (continued)

Measures

- PROMIS Pain Interference Scale: Assesses how pain interferes with daily life in the past week (e.g., "*How much did pain interfere with your day to day activities?")*
- Psychological Inflexibility in Pain Scale (PIPS): Assesses the extent to which a person avoids activities or exhibits inflexible thoughts about pain (e.g., *"It's not me that controls my life, it's my pain."*).
- ACT Engagement Inventory: Assesses the frequency with which participants used ACT strategies (e.g., mindfulness, defusion, value-driven behaviors) in the past month. Uses single items for each skill and a composite score (mean of all three skills).

Statistical Analyses

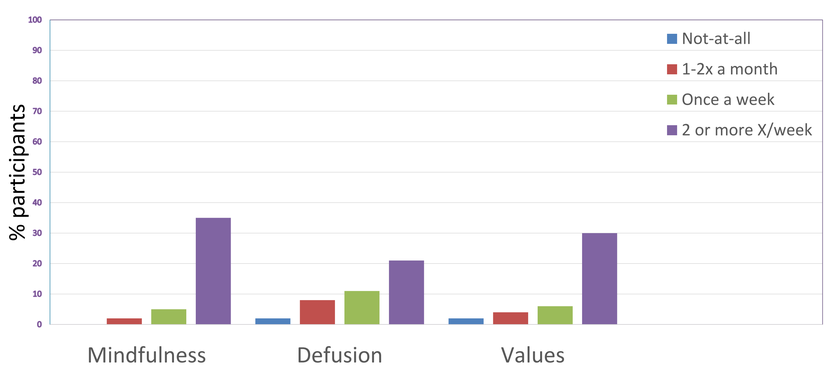
- Pearson correlations examined the post-intervention associations between engagement in ACT strategies and changes in pain inflexibility.
- Using longitudinal data, a mediation model tested the indirect effects of engagement with the different ACT strategies on reductions of pain interference.

Results

Table 1.Participant Characteristics (N=42)

	M±SD	N (%)
Mean Age in Years (SD)	27.4 (±10.64)	
Mean Years of Education (SD)	13.2 (±2.3)	
Gender: Male		19 (45)
Female		25 (55)
Race: Caucasian		33 (78)
African American		5 (12)
Other		4 (10)

Figure 1. Frequency of Engagement in ACT strategies at Home (%)



- A majority of participants reported using ACT strategies at least once a week during the 8-week at-home intervention period.

Results (continued)

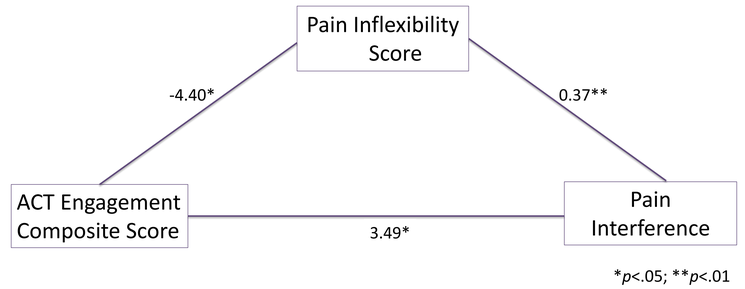
Table 2. Post-intervention Correlations

	Mindfulness Practice	Defusion Practice	Values Practice
Change in Pain Inflexibility	**-.31***	**-.38***	-.01
Change in Pain Interference	-.07	.18	.21

*p<.05

- Greater engagement in mindfulness exercises and defusion strategies, though not values-consistent activity, were associated with less psychological inflexibility post intervention.

Figure 2. Mediation Model of Pain Interference



*p<.05; **p<.01

- Engagement in home-based ACT practice has a significant indirect effect on change in pain interference at follow-up, which is mediated by adaptive changes in pain inflexibility post intervention (Path *ab*; *F*(2,38)=5.60, *p*<.01; 95% CI:-3.90 to -0.47).

Summary

- Engagement in ACT practices at home had a direct and adaptive effect on pain inflexibility, which indirectly reduced pain interference.
- Weekly emails and biweekly video chats may have helped to keep participants engaged at home.
- This study also provides support to the feasibility of telehealth (emails and video chats) as a supplement to face-to-face counseling, in providing mental health services to patients.
- Future directions include analyzing data 6 months post-intervention to see if engagement in ACT practices is sustained over time and exploring patient characteristics that may relate to better engagement.

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