

Mindfulness-based intervention for individuals with Prader-Willi Syndrome and their parents

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Introduction

People with Prader-Willi syndrome can exhibit problem behaviors that pose real challenges to their parents, caregivers and teachers.

Mindfulness-Based Interventions (MBI) represent a valid alternative to programs generally used to help PWS parents and caregivers to more effectively cope with challenging behaviors and manage stress-related disorders affecting caring functions. Infact, studies conducted on parents of people with neurodevelopmental disorders have shown a reduction in stress, anxiety and depression levels (Dykens et al., 2014), a decreased tendency to avoid and identify themselves with suffering (Neece, 2014; Blackledge & Hayes, 2006) as well as positive effects on their own well-being and that of their children (Reid et al., 2016). Furthermore, children have reported a reduction in externalizing symptoms such as aggression and disruptive behaviors.

Aim of our preliminary study is to verify whether mindfulness practices can help parents reduce stress levels as well as increasing emotional and behavioral self-regulation in PWS individuals.

Sample of PWS individuals

10 people with PWS recruited among patients who have been referred to Oasi Research Institute: 2 with Normal Intellectual Functioning; 2 with Borderline Intellectual Functioning; 1 with Mild Intellectual Disability; 5 with Moderate Intellectual Disability.

Mean chronological age = 16.5 years (range 9 - 27 years)

Measures

At the baseline and at the end of the intervention, each participant was administered the following protocol:

1. Child Behavior Checklist (CBCL; Achenbach, 1991a; 1991b) e Adult Behavior Checklist (ABCL; Achenbach, 2003) aimed at assessing social, behavioural and affective problems in children, adolescents and adults. It is used to detect: Anxiety/Depression, Withdrawal, Somatic Complaints, Social Problems, Thinking Problems, Attention Problems, Rule Breaking Behavior, Aggressive Behavior. These areas are organized into three superordinate scales named Internalization Problems, Outsourcing Problems, and Other Issues.
2. Prader-Willi Syndrome Behavior Questionnaire (PWSBQ; Avrahamy et al., 2015) it is based on the classification of typical behavioral and emotional symptoms observed in PWS and organized into 5 domains: Emotional Regulation, Food-Seeking Related Behavior, Lack of Flexibility, Oppositional Behavior and Interpersonal Problems, and Body-Related Behaviors.

Sample of parents

10 parents of PWS individuals (F = 11; M = 3)

Mean age: 49.64; DS = 6.92 (range: 37-60)

Socio-economic status: Medium-High

Education level: (Degree= 5; High school Diploma = 9)

Measures

At the baseline and at the end of the intervention, each participant was administered the following protocol:

1. Interpersonal Mindfulness in Parenting scale (IM-P; Duncan, 2007; 2009) is a measure to investigate the quality of interpersonal mindfulness in parenting;
2. Perceived Stress Scale (PSS; Cohen et al., 1983) is a 14-item measure of the degree to which situations in one's life are appraised as stressful;
3. Psychological General Well Being Index (PGWBI; Dupuy, 1984) is a self-perceived evaluation of psychological well-being expressed by a summary score.

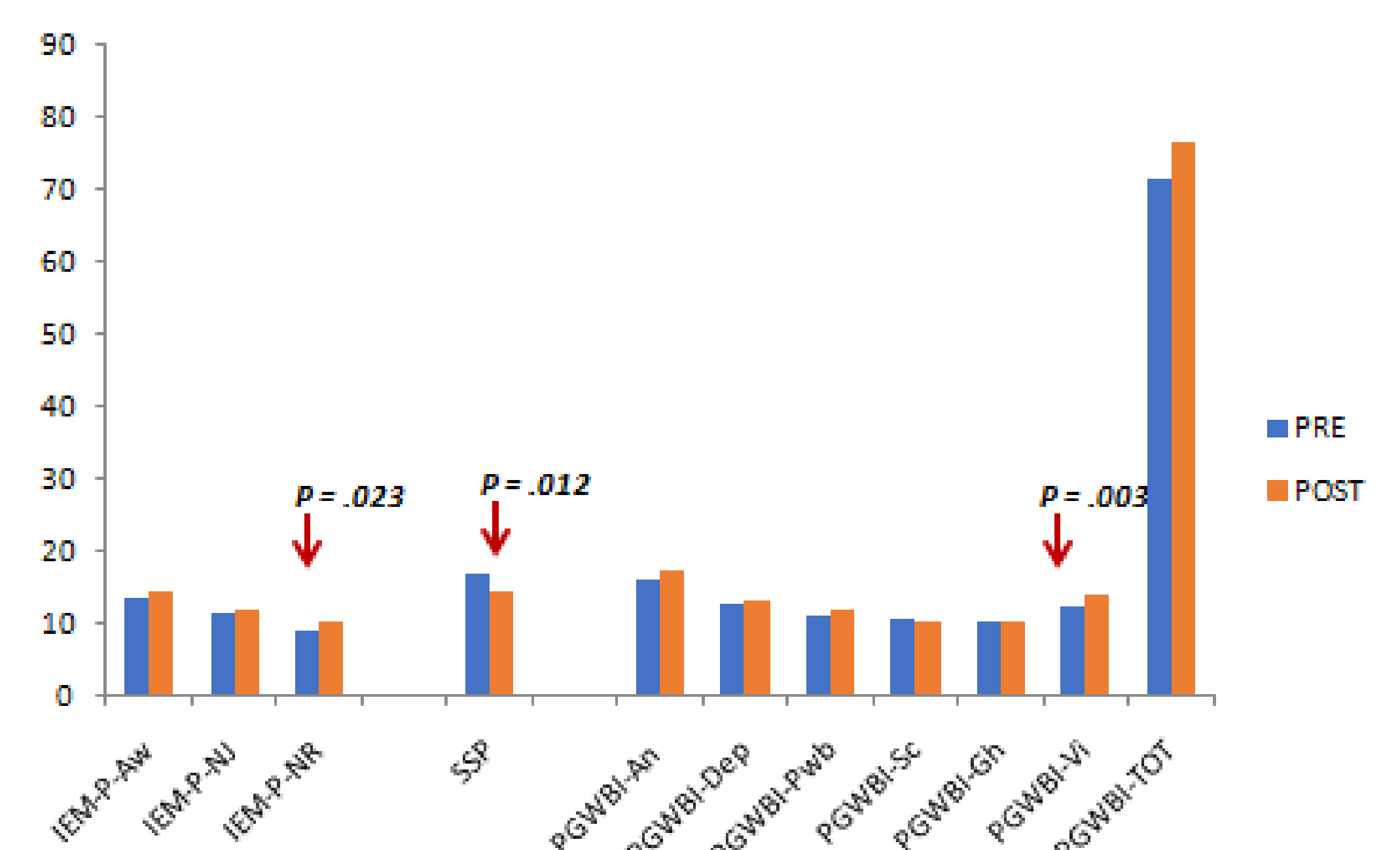
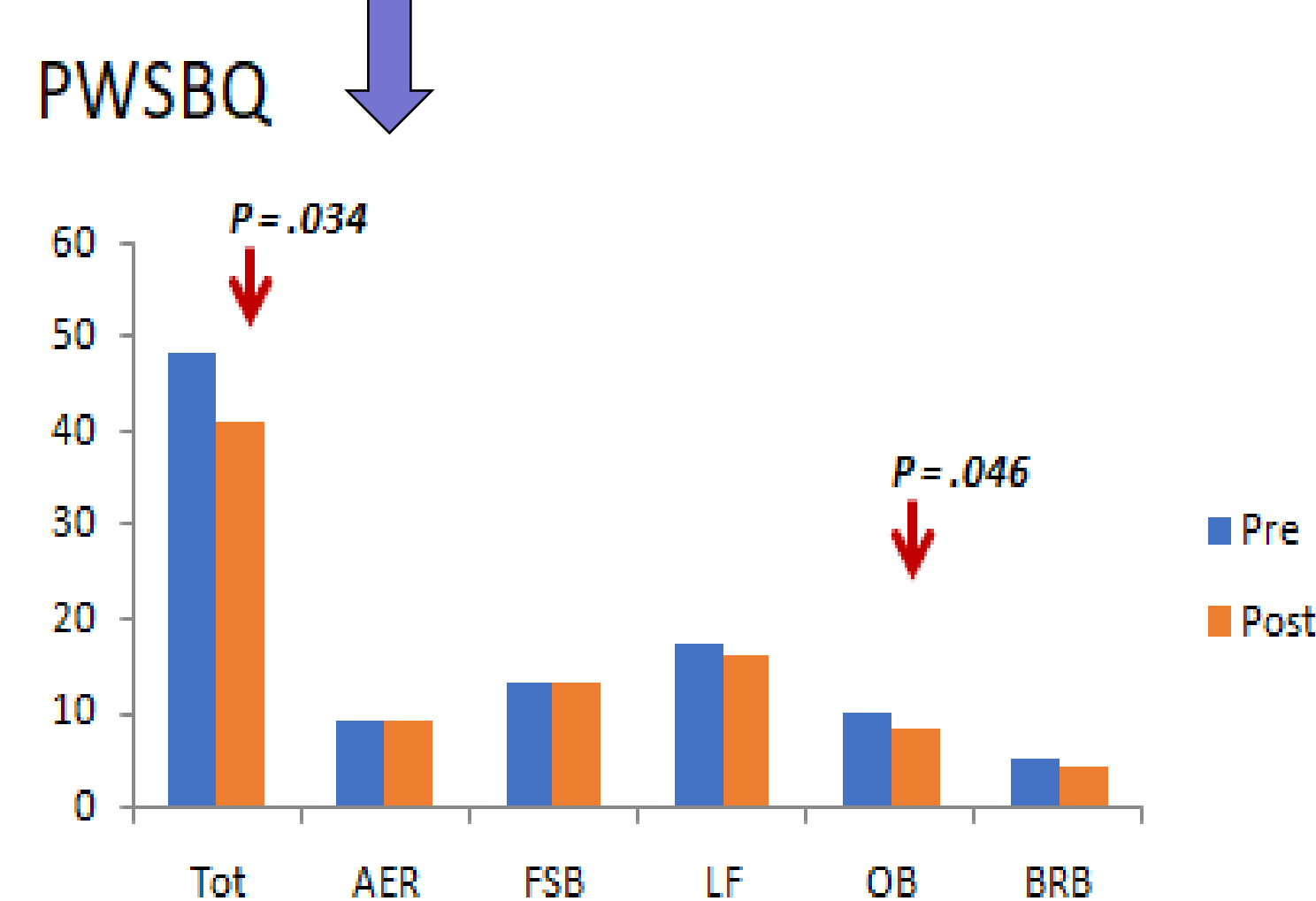
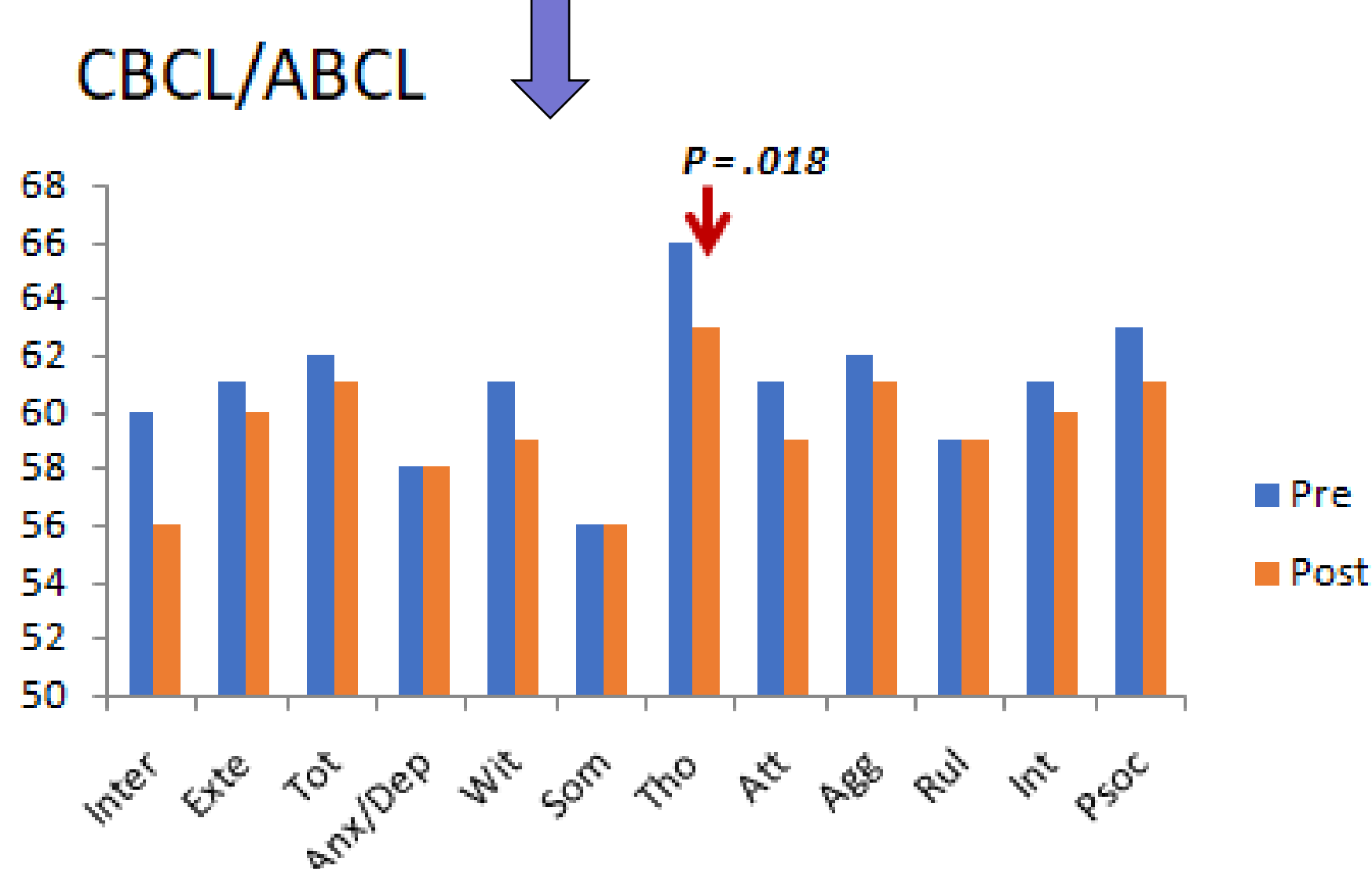
Procedure

- 10 sessions lasting about 2 hours, with weekly frequency, for parents. Each session consisted of awareness practices, psycho-educational treatment, discussion on the practices and weekly homework.
- 9 sessions lasting 1 hour, with weekly frequency were implemented for PWS individuals.
- The intervention was conducted remotely by a psychologist/psychotherapist, a certified mindfulness instructor, flanked by another psychologist and a pedagogue with experience in meditation practices.
- An experimental study design was used. At the baseline and at the end of the intervention, each parent was administered the following protocol: IM-P; PSS; PGWBI; CBCL or ABCL; PWSBQ.
- Data were entered in a database and analyzed in SPSS.

Results

With regard to the parents pre-and post data comparison showed statistically significant differences *Non-reactivity scale* of IM-P ($p = 0.023$), in the *Total score* of PSS ($p = 0.012$) and in the *Vitality scale* of PGWBI ($p = 0.035$).

Regarding the **PWS individuals**, the results showed a statistically significant change in the dimensions referred to Thought Disorders of CBCL/ABCL ($p = .018$), in the Total Score ($p = .034$), and in the area of Oppositional Behaviors and Interpersonal Problems ($p = .046$) of the PWSBQ.



Conclusions

Based on the data obtained, we believe that mindfulness-based parenting intervention can help to reduce parenting stress and improve well-being.

Preliminary results confirm the effectiveness of mindfulness practices in improving emotional and behavioral self-regulation skills by reducing oppositional behaviors with consequent improvement of the interpersonal environment.

The continuation of the study includes the expansion of the sample, the identification of a control group, the analysis by levels of severity of the ID and the detection over time of the stability of the changes.