PRO-Parenting: Incorporating a Monolingual Spanish-Speaking Cohort into a Parent Training RCT

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International Society for Autism Research (INSAR) Cultural Diversity Committee Summer Research Internship 2019
Introduction

Parents of children with Autism Spectrum Disorder (ASD) or other developmental disabilities/ delays (DD) typically experience higher level of stress than other parents (e.g. Baker et al., 2003)

Parent stress is often higher when the child has challenging behaviors (Matson & Nebel-Schwalm, 2007)

Interventions in these areas have rarely been examined with diverse populations (West et al., 2016)

Spanish-speaking Latinx/Hispanic families of children with ASD/DD experience even greater service disparities (Zuckerman et al., 2017)
Part of PRO-Parenting study: larger Randomized Controlled Trial (RCT) comparing the efficacy of two 16-week interventions

Parents randomly assigned to six weeks of:
- Mindfulness-Based Stress Reduction (MBSR) OR
- Psychoeducation and support group

Followed by 10 weeks of Behavioral Parent Training (BPT) adapted for children with developmental disabilities
Present study

Two sites: Portland, OR, and Loma Linda, CA

Spanish-speaking cohort is the 2\textsuperscript{nd} cohort in Loma Linda

Recruitment procedure:
1. Informational fliers distributed to regional service centers, clinics, doctor’s offices, etc.
2. Initial phone calls to evaluate interest and eligibility
3. Home visit to go over consent and complete evaluations
2019 INSAR Summer Internship

Traveled to Loma Linda for summer of 2019
Made calls to over 200 interested Spanish-speaking participants; conducted screenings with 158 of those
Led first 17 home assessment visits
Worked on developing and translating assessment and intervention materials
Figure 1. CONSORT diagram of participant inclusion.

- Assessed for eligibility and inclusionary criteria \((n = 158)\)
  - Excluded based on child’s age \((n = 40)\)
  - Excluded for not having diagnosis of ASD or DD \((n = 3)\)
  - Excluded for already enrolled in other class or therapy \((n = 3)\)
  - Withdrew due to lack of interest \((n = 52)\)

- Enrolled and randomized \((n = 60)\)

- Allocated to BPT-E \((n = 30)\)
  - Attended at least one session \((n = 23)\)

- Allocated to BPT-M \((n = 30)\)
  - Attended at least one session \((n = 24)\)
Participants

60 Spanish-speaking caregivers of 3-5 year old children with ASD or other DD
- 34 with official ASD diagnosis, 22 other DD, 4 other DD on ASD waitlist

Mean household income: $29,038 (SD: $16,285)
Education: 28.3% greater than HS education
Mean stress score: 115.2 on PSI, or just about “clinically significant”
Mean distance from LLU: 25 miles (maximum of 75 miles!)
Intervention groups

Starting in February, 2020:

• Six sessions in-person (MBSR or psychoeducation)

• **PAUSE** of 4 weeks due to COVID-19

• Weekly calls to check on: participants’ stress, interest/capacity to switch to telehealth, Zoom practice calls

• 10 BPT sessions online via Zoom
MBSR

Evidence-based stress reduction intervention (Kabat-Zinn, 2009)
Combination of mindfulness, body awareness, and exploration of thoughts and actions
Goal of increasing consciousness that comes from paying attention, on purpose, to the present moment without judgment
Delivered in a group format including didactic training, practice exercises, and discussions
Psychoeducation and support

Intervention to provide information and social support to parents

Broader content base (i.e. what defines different disorders) than specific skills training

Combined with support group elements, such as sharing experiences among parents

Discussions around relevant supports related to education, therapies, and other services
Adaptation of the “Incredible Years” for parents of children with ASD and other DD (McIntyre, 2008a)

Topics include:
• Appropriate play
• Use of praise and rewards
• Understanding and managing challenging behaviors
• Limit setting
• Ignoring/ consequences
Telehealth

BPT sessions were delivered via Zoom

Advantages:
• Did not have to drive to groups
• Easier and cheaper to do

Disadvantages:
• No child care or food provided
• Some parents struggled with technology
• Less communication/support between parents (convivencia)
Group reactions

Generally positive reactions to the various aspects of interventions

Some attendance drop off, but not huge, following switch to telehealth

“Gracias por ayudarme a entender los comportamientos de mi hija y hacerme ver que soy humana y que soy capaz de aprender de cualquier forma cuando hay una educación de calidad como la que ustedes me han brindado ya sea en persona o virtual.”
Implications and future directions

One of the first times any of these interventions (MBSR, psychoeducation, BPT) or delivery modality (telehealth) have been used with this population.

Working on completing virtual post-intervention assessments and focus groups to gather more information on acceptability/ feasibility/ alignment with values of different components.

Goal of using feedback to culturally adapt interventions in future iterations.
Implications of Jonathan’s Internship

Jonathan has remained closely involved in our lab:
- Weekly lab meetings
- Continued to serve as a PEI therapist for 20 families
- Led the virtual BPT groups
- Conducting focus groups
- Co-authored publication currently under review

Jonathan continues to be an integral part of our lab and I hope to be able to mentor him for many years to come.
Acknowledgements

Funding:

INSAR Summer Research Internship in Autism Spectrum Disorder and Cultural Diversity

R01 HD093661; MPIs LL McIntyre & C. Neece

Special thanks to:

Cameron Neece, Laura Lee McIntyre, Alan Garcia, Marbella Serna Rodriguez,

Geovanna Rodriguez, Jaime Napan, Ann Marie Martin

And the rest of the Loma Linda University Child and Family Lab!
References


