Examining Caregiver Experiences on Telehealth Evaluation of Development of Infants (TEDI) Study

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INTRODUCTION

- Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that may cause difficulties with social, emotional, and communication skills (CDC).
- The average age of ASD diagnosis in the United States is 4 years old despite progress in early evaluation (Juárez et al., 2018).
- Increasing access to early diagnostic services for accurate identification and treatment of ASD in children is crucial (Juárez et al., 2018).
- Systematic evaluation of the potential for telehealth for early identification of ASD is still in need.

OBJECTIVE

To gain an understanding of caregiver opinions on what worked, what didn’t work, and what needs are still unmet for further improvement in the TEDI study.

METHODS

- Participants: 32 caregivers (N = 33 for demographics)
- All open-ended text responses from the TEDI-adapted Telehealth Usability Questionnaire were coded
- Coding was reliability tested
- Themes were generated for three feedback categories
- Themes generated:
  - Likes
  - Dislikes
  - Suggestions
  - Representative of Usual Behavior
  - Less Engaged Behavior
  - Instructions
  - Observing Child Challenges
  - Support
  - Structure
  - Technology
  - Materials
  - Time
  - Clinician Interaction
  - Challenges
  - Technology
  - Support

Descriptive statistics were used to summarize parent demographics of those involved in the study.

RESULTS

| Table 1: Demographic Characteristics of Caregivers Participating in TEDI Study (N = 33) |
|-----------------------------------------|-----------------|
| Education Level                        | Family Income   |
| 36% Bachelors, 36% Masters, 21% Higher | 24% > $200,000, 48% $100,000 - $199,999, 27% < $99,000 |

| Figure 1. Responses for What Worked Well from Telehealth Usability Questionnaire (N = 32) |
|-----------------------------------------|-----------------|
| What did Caregivers Like about the TEDI Study? |
| Convenience                             | 37% |
| Clinician Interaction                    | 41% |
| Materials                               | 53% |

| Figure 2. Responses for What Didn’t Work Well from Telehealth Usability Questionnaire (N = 32) |
|-----------------------------------------|-----------------|
| What did Caregivers Dislike about the TEDI Study? |
| Structure                                | 28% |
| Technology                               | 43% |

| Figure 3. Responses for Suggestions from Telehealth Usability Questionnaire (N = 32) |
|-----------------------------------------|-----------------|
| What did Caregivers Suggest regarding the TEDI Study? |
| Instructions                            | 22% |
| Support                                 | 6% |

SUMMARY

- 31/32 Caregivers reported at least one comment falling into “likes.” These were primarily related to materials (53%), clinician interaction (41%), and convenience (37%).
- 27/32 caregivers reported at least one comment falling into “dislikes.” These were primarily related to technology (43%) and structure (28%).
- 13/32 caregivers reported at least one comment falling into “suggestions.” These were primarily related to instructions (22%) and support (6%).

STRENGTHS & LIMITATIONS

- Strengths
  - Qualitative approach
  - Attempts to address unmet healthcare needs
  - Gain initial understanding of caregivers’ opinions on what worked, what didn’t work, and what needs are still unmet
- Limitations
  - Self-selective sample, not representative
  - High SES families

CONCLUSIONS

- Overall, almost all caregivers reported positive experiences with minor feedback relating to tailoring of individual needs.
- TEDI seems to be a feasible approach to family access to early evaluation for children with ASD characteristics.
- Future studies should examine feasibility of the TEDI by community-based providers in diverse populations.

ACKNOWLEDGEMENTS

I would like to thank Dr. Meagan Talbott, Ph.D., members of the TEDI study lab, and Felipe Avila for their contributions and support throughout this project. I would also like to thank Dr. Janice Enriquez, Ph.D., and Dr. Harolyn Belcher, M.D., M.H.S., and the MCHC RISE-UP program for their mentorship and opportunity.
Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that may cause difficulties with social, emotional, and communication skills (CDC).

The average age of ASD diagnosis in the United States is 4 years old despite progress in early evaluation (Juárez et al., 2018).

Increasing access to early diagnostic services for accurate identification and treatment of ASD in children is crucial (Juárez et al., 2018).

Telehealth has shown to be cost-effective but systematic evaluation of the potential for telehealth for early identification of ASD is still in need.
To gain an understanding of caregiver opinions on what worked, what didn’t work, and what needs are still unmet for further improvement in the TEDI study
- **Participants**: 32 caregivers (N = 33 for demographics)
- All open-ended text responses from the TEDI-adapted Telehealth Usability Questionnaire were coded
- Coding was reliability tested
- Themes were generated for three feedback categories
- Themes generated:

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<th>Likes</th>
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<tbody>
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<td></td>
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“I love that it’s Telehealth. We wouldn’t be able to participate in the study otherwise, since we don’t live nearby.”

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Figure 1. Responses for What Worked Well from Telehealth Usability Questionnaire (N = 32)
“Sometimes following directions on how to perform a task without someone modeling was tricky.”

“I think a video example or link to what the test looks like prior to the first session maybe better for us visual learners.”
CONCLUSIONS

Strengths
■ Qualitative approach
■ Attempts to address unmet healthcare needs

Limitations
■ Self-selective sample
■ High SES families

• Almost all reported positive experiences with minor feedback
• Future studies should examine feasibility of the TEDI by community-based providers in diverse populations