Background

Fragile X Syndrome (FXS) is the most common form of inherited intellectual and developmental disability. It offers a genetic model to understanding autism spectrum disorder. It manifests with behavioral problems, anxiety, and sensory processing difficulties.

A battery of standardized, norm-referenced assessments and parent checklists are frequently used as outcome measures in clinical trials. The addition of interview methods will provide family voice and personal stories thus affording:
- An occupation-centered lens to empirically examine living with FXS and the impact on family life.
- A measurement for contextually-based changes as an outcome measure for use in clinical trials.

Methods

Design: Qualitative (interview methods)

Population: Families with children diagnosed with full mutation FXS enrolled in UC Davis MIND Institute sertraline (Zoloft®) clinical trial

Interview sample for this study:
- 12 interviews
- 6 placebo
- 6 treatment

Results

Preliminary trends indicated improvements in the sertraline treatment group compared to the placebo group in the following areas:
- Anxiety
- Maladaptive behaviors
- Expressive & receptive communication
- Sensory (Less)

The sertraline group did not show greater improvements than the placebo group in the following areas:
- Community/social
- Sensory (More)

Research Question

Can qualitative interview methods serve as an outcome measure for use in clinical trials?

Conclusion

This preliminary data did show differences between groups in several areas.

Occupational therapy intervention and clinical research should include parent perspectives, not just standardized assessments.

Families within the FXS community felt a sense of altruism from participating in the study.

Future directions to include a larger sample for analysis.

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