Family Meanings, Contexts and Hopes Within a Clinical Trial

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INTRODUCTION

These qualitative analyses are a component of the clinical trial: “Effects of Sertraline Treatment for Young Children with FXS: Examination of Developmental Outcomes and Family Contexts.”

We argue that inclusion of a sociocultural perspective within the context of a clinical trial affords consideration of:

- Application of a biocultural framework and consideration of ever changing nested settings and contexts over time (Bronfenbrenner, 2005).

RESEARCH QUESTIONS

Through interview methods and qualitative analysis we empirically explored the following questions:

(1) What are the complexities of daily life, experiences and family meaning associated with various phenotypic manifestations of FXS? (e.g. language / communication, behavior, sensory processing, and anxiety)

(2) What are family hopes and meanings for participation in this clinical trial?

SAMPLE and METHODOLOGY

- 12 randomly selected interviews (6 baseline and 6 post)

- 4 placebo and 2 sertraline treatment

- Transcription and coding done blind.

- We used a directed, narrative, conversational interview at baseline and post testing.

- Families were asked to share their stories and experiences in their own words as a first person account, rather than responding to a set of predetermined response choices.

- Interviews were audio recorded, transcribed verbatim and coded using the Constant Comparison Method. Code cloud below – largest codes indicate highest frequency.

RESULT

FAMILY MEANINGS AND FAMILY HOPE: STRIKING A BALANCE

Family Meanings

- Family

    - Meanings

    - Contexts

    - Other

Family Hopes

- Family

    - Hopes

    - AND

    - Family Meanings

    - Family Hopes

    - Humor

    - Placebo vs. Medication

    - Research Rigor

    - Anything to Help

CONCLUSIONS

- Overall family functioning strongly enmeshed with child’s functioning including family participation in social events and in the community

- Nested contexts

- Family hopes for medication often high

- Family perceptions of what constitutes improvement varies

- Any improvement is improvement

- Seeking improvement more pronounced (e.g. going from non-verbal to verbal in a 6 month trial)

- Inclusion of qualitative narrative interviews within the context of a clinical trial provides:

  - Insights into complexities of family life in context
  - An outcome measure that can be applied to compare placebo vs. medication groups beyond the scope of developmental measures or questionnaires
  - An outcome measure that can be examined quantitatively in future analyses

- This study represents a mixed methods (both quantitative and qualitative) model for a collaborative and interdisciplinary clinical trial research

- Our interdisciplinary team from the fields of: medical, occupational therapy, education, and speech pathology

- This model is a mirror to what best practices are for intervention for children with FXS

SELECTED REFERENCES


- Vygotsky’ s educational theory in cultural context

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