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Family Meanings, Contexts and Hopes Within a Clinical Trial

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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.”

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 blindly.

RESULTS

DYNAMIC INTERACTION BETWEEN CHILD AND FAMILY

Social Impact

Stress

Family Meanings and Contexts

Child's Abilities and Special Needs

Family Meanings and Family Hopes:

STRIKING A BALANCE

AND

Fearful / Distressed

Humor

Placebo vs. Medication

Research Rigor

Altruism – Greater Good

Tearful / Distressed

Cure

Child's Special Needs

Anything to Help

Behavioral Impact

Behavioral Impact

Behavioral Impact

Behavioral Impact

Behavioral Impact

Behavioral Impact

I have never seen another kid before with FXS, so I don’t know what to expect. I don’t know if all of these therapies are going to help. I hope there will be something to help with the hand flapping. It is too much (tearful).

I am just hoping to learn that in the end they will be able to find a cure. Or just along the way, learn to make it livable, make them capable of living independently. That is my goal.

So transitions, anxiety, language, speech, those are things I am trying to target and try to help calm him and help him center and focus. Really hoping and praying it will work.

Even if it doesn’t help my son right now, it may help my daughter at some point. And it is going to help my thousand Facebook friends with their kids. That’s OK!

He’s too active. I find his activity level too high and to be very draining. He basically does not stop. He is on the go the whole time. I find that he has no impulse control. So it is a safety concern, because he will run away. I have to take a firm grip of his hand, because if I don’t he will run onto the street and this has happened many times.

It absolutely impacts everything. It impacts my daily life. And I feel bad because I am a very sociale person. My friends will invite me out and it is just such a hassle! He is not gonna be interested and he’s gonna be running off and he’s not gonna get out, and he’s gonna do this, and he’s gonna be throwing a tantrum. So it is just that I shy away from social events.

I hope he gets the drug. I don’t want him to get the placebo. When we were on that first flight and he was kicking and I had to restrain him the whole time. I was like, oh my god, we are doing all of this and we could end up getting the freaking’ placebo! (laughing)

I call him the son of a gun. He does have crazy side effects or anything, they know what to look for. We felt better coming here.

You just don’t want to go out, it is exhausting. It is the constant people staring. It is hard, because going to a restaurant, you cannot sit quietly. He wants to get out (of his high chair), and he makes a mess around the place.

It’s kind of made us not be able to go to many family functions and things. He would freak out, he would cover his ears and start shaking. He would try and find a way out of the room and if he couldn’t he would just kind of sit there and cry until he was pulled out of there or someone else was moved away. He would just sit there and cry. You feel so bad for him when they are going through this and there is nothing you can do.

His hand flapping. It is hard, I have to try and limit it. I have high hopes, he’s young, he’s showing positive signs, if we can do anything to help him without hurting him then we should do it and that is why we are here.

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 to have a cure 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 the 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 vs. qualitative 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


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