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Family Meanings, Contexts and Hopes Within a Clinical Trial

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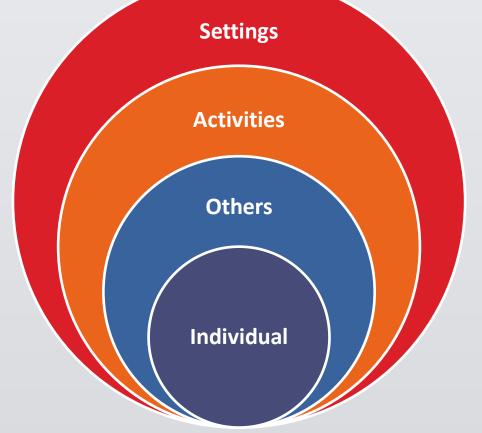
Family Meanings, Contexts and Hopes Within a Clinical Trial School of EDUCATION **MIND INSTITUTE** Laura Greiss Hess, PhD, OTR/L^(1,2), Cynthia Carter Ching, PhD⁽²⁾ and Randi Hagerman, MD⁽¹⁾ (1) Pediatrics, MIND Institute, UC Davis, Sacramento, CA (2) School of Education, UC Davis, Davis, CA

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:

•A dynamic view of development – simultaneous consideration of biological and sociocultural factors (Vygotsky, 1978). •Application of a bioecological 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

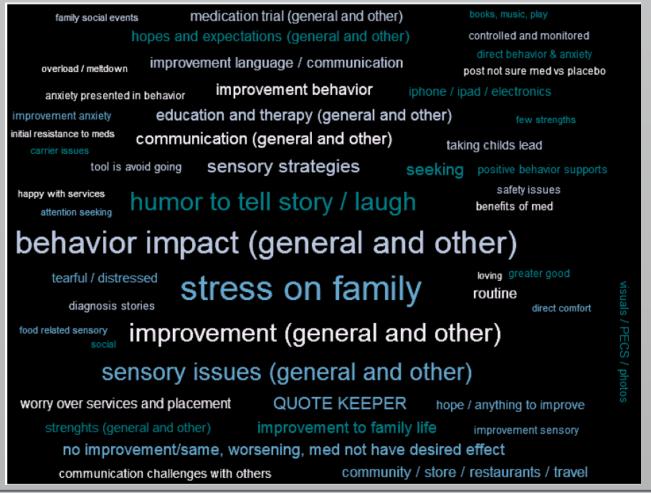
I2 randomly selected interviews (6 baseline and 6 post)

- 4 placebo and 2 sertraline treatment
- Transcription and coding done blind.

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

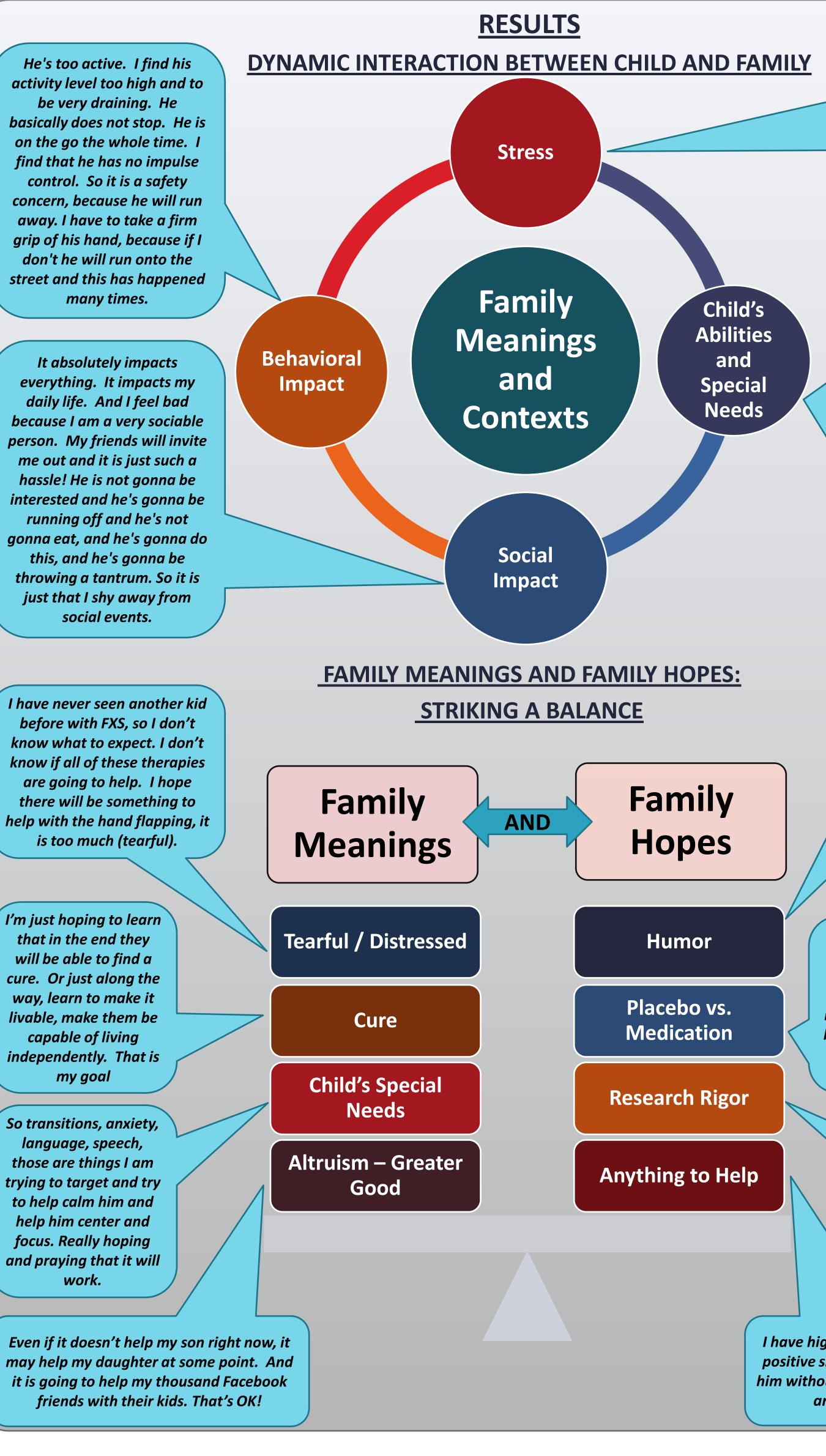
•Families were asked to share their stories and experiences in their own words as a first person account, rather than responding to a set of predetermined response choices.

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



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

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 that it will work.



You just don't want to go out, it is exhausting, 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 everyone 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.

I call him the son of destruction. Oh man! And then he is rearranging the store! Next thing I know he has cottage cheese & other stuff in his arms yelling, "Mine! Mine!" soooo I end up paying for cottage cheese! (laughing).

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 freakin' placebo! (laughing)

> I like the fact that we have the MIND Institute watching him, so if he does have crazy side effects or anything, they know what to look for. We felt better coming here.

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

- \checkmark Nested contexts
- Family hopes for medication often high

•Family perceptions of what constitutes improvement varies

- \checkmark Any improvement is improvement
- \checkmark Searching for something 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

- \checkmark Our interdisciplinary team from the fields of: medicine, occupational therapy, education, and speech pathology
- \checkmark This model is a mirror to what best practices are for intervention for children with FXS

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