

7-2014

Family Meanings, Contexts and Hopes Within a Clinical Trial

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Recommended Citation

Hess, Laura Greis; Ching, Cynthia Carter; and Hagerman, Randi, "Family Meanings, Contexts and Hopes Within a Clinical Trial" (2014). *Collected Faculty and Staff Scholarship*. 104.

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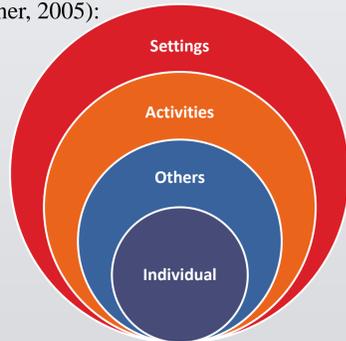
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INTRODUCTION

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:

- 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):



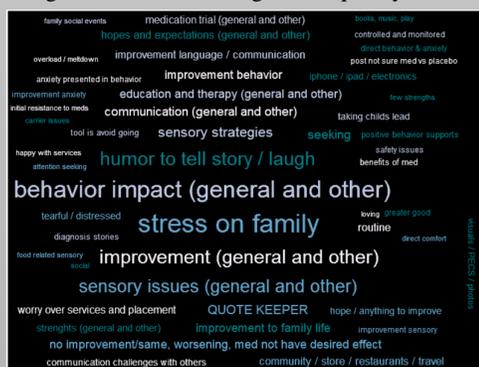
RESEARCH QUESTIONS

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?

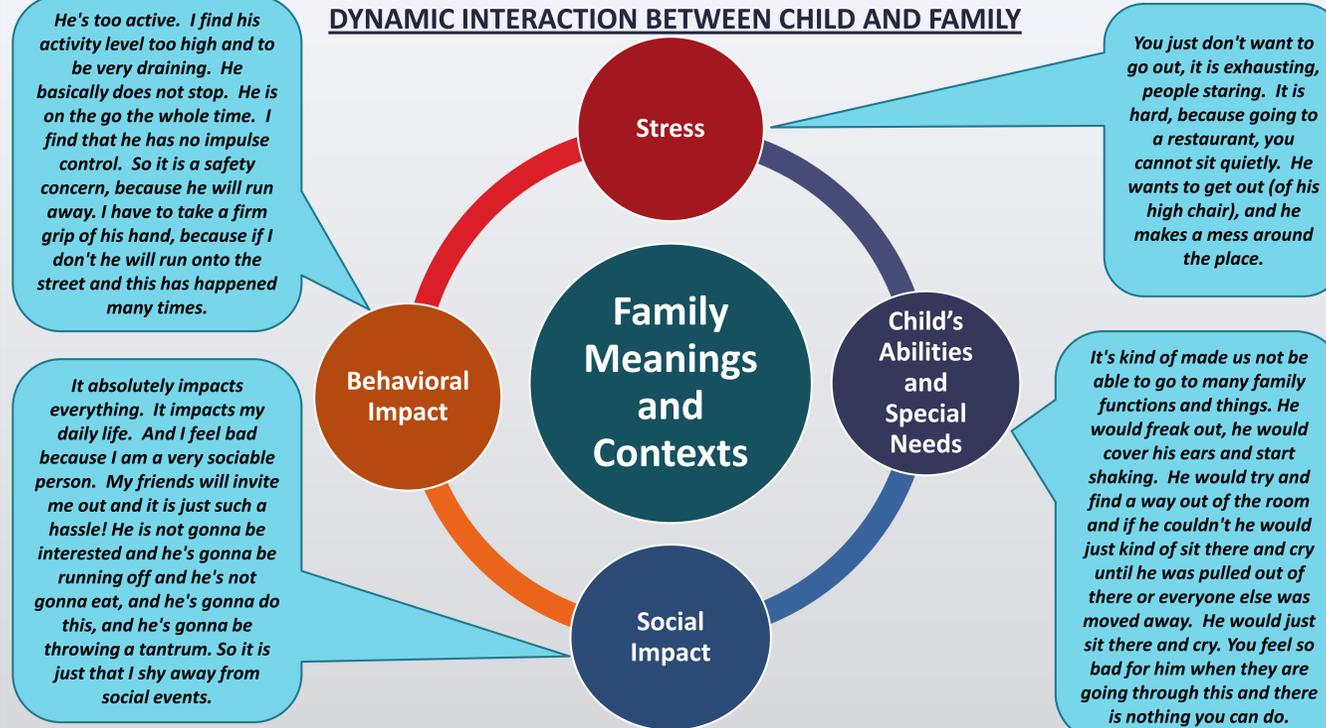
SAMPLE and METHODOLOGY

- 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.

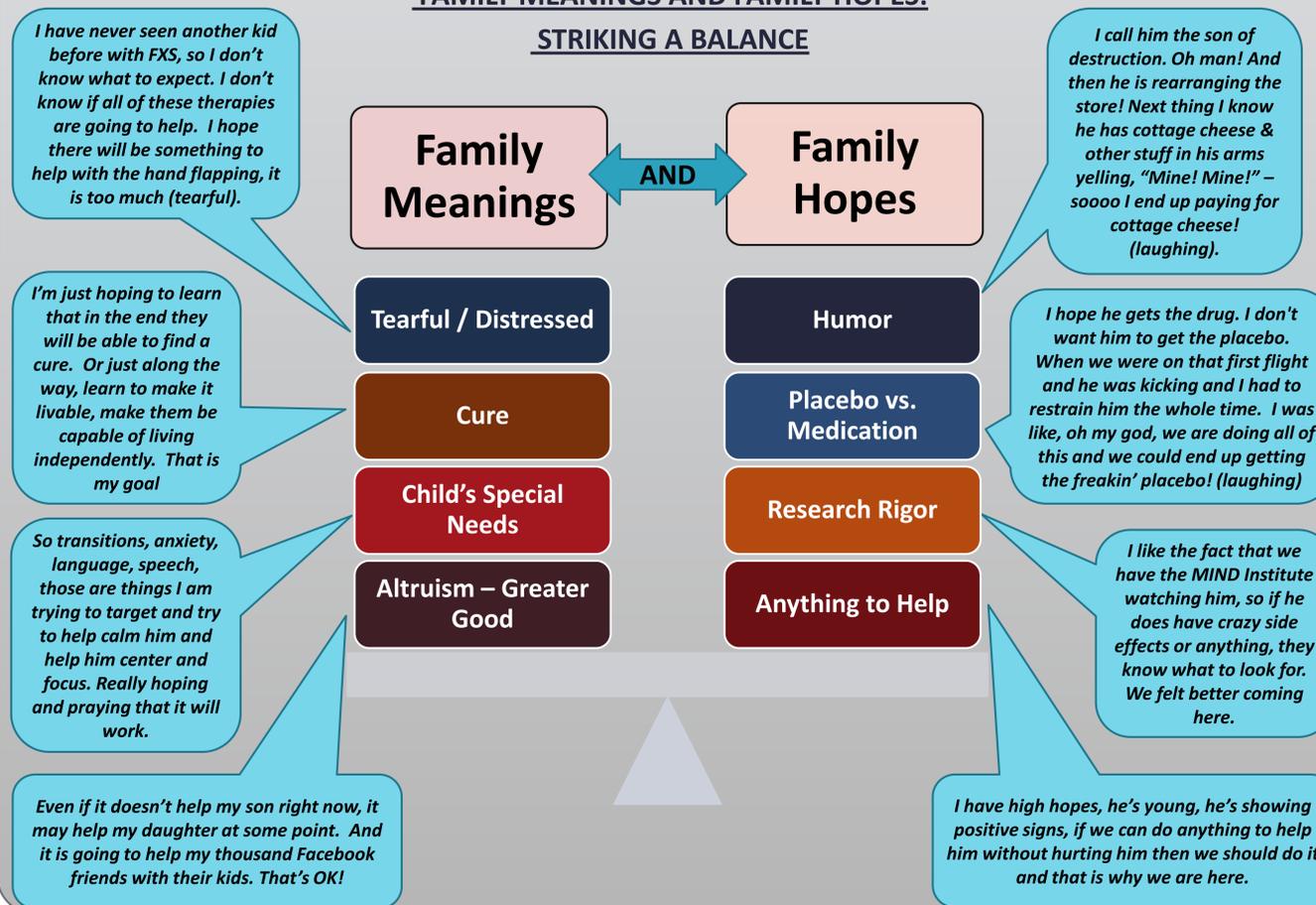


RESULTS

DYNAMIC INTERACTION BETWEEN CHILD AND FAMILY



FAMILY MEANINGS AND FAMILY HOPES: STRIKING A BALANCE



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

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ACKNOWLEDGEMENTS and CONTACT

- This study was funded by Health Resources and Services Administration (HRSA, #R40MC22641).
- Our sincerest thanks to the FXS families who participated in this study and to the FXS community for supporting this research.
- MIND Institute Sertraline Team: Lauren Bishop, Salpi Siyahian, Tasleem Chechi, Jonathan Polussa, Susan Harris, Andrea Schneider, Kerrie Lemons Chitwood, Kylee Cook, Beth Goodlin-Jones, David Hessl, Pam Gallego, Louise Gane, Michele Ono and Julie Morcillo
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