2014

Family Meanings, Contexts and Hopes Within a Clinical Trial

Laura Greis Hess  
*MIND Institute, University of California, Davis*, laura.hess@dominican.edu

Cynthia Carter Ching  
*MIND Institute, University of California, Davis*

Randi Hagerman  
*MIND Institute, University of California, Davis*

**Survey: Let us know how this paper benefits you.**

**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.  
https://scholar.dominican.edu/all-faculty/104

This Conference Proceeding is brought to you for free and open access by the Faculty and Staff Scholarship at Dominican Scholar. It has been accepted for inclusion in Collected Faculty and Staff Scholarship by an authorized administrator of Dominican Scholar. For more information, please contact michael.pujals@dominican.edu.
Family Meanings, Contexts and Hopes Within a Clinical Trial
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, 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:

- 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 meanings 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

Stress

Family Meanings and Contexts

Child’s Abilities and Special Needs

Social Impact

Behavioral Impact

Family Meanings and Hopes:

STRIKING A BALANCE

AND

Family Meanings

Family Hopes

Fearful / Distressed

Humor

Placebo vs. Medication

Research Rigor

Anything to Help

Tearful / Distressed

Cure

Child’s Special Needs

Altruism – Greater Good

Thankful / Grateful

Cure

Child’s Special Needs

Altruism – Greater Good

Gain

Pleasure

Useful / Helpful

Satisfaction

Family Meanings

Family Hopes

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.

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 this and we could end up getting the freakin’ placebo! (laughing)

I call him the son of a gun. He even 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’m 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 be 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 him calm and help him center and focus. Really hoping and praying that 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 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 sociable 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 eat, 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 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’m 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 be 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 him calm and help him center and focus. Really hoping and praying that it will work.

I call him the son of a gun. He even 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’m 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 be capable of living independently. That is my goal

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 meanings 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?

ACKNOWLEDGEMENTS and CONTACT

- Laura Greiss Hess, PhD, OTR/L (greiss@ucdavis.edu)
- The contents are not copyrighted.转载请注明出处：Laura Greiss Hess, PhD, OTR/L (greiss@ucdavis.edu)
- This study was funded by Health Resources and Services Administration (HRSA, JR-40MC22641).
- Our sincerest thanks to the FXS families who participated in this study and to the FXS community for supporting this research.
- MIND Institute Saratine Team: Lauren Bishop, Salpi Siahyan, Tasleem Chuchi, Jonathan Polussa, Susan Harris, Andrea Schneider, Kerrie Lemons Chitwood, Kylee Cook, Beth Goodlin-Jones, David Hess, Pal Gallego, Louise Gane, Michele Ono and Julie Morello
- Contact: Laura Greiss Hess, PhD, OTR/L (greiss@ucdavis.edu)