7-2014

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

Follow this and additional works at: https://scholar.dominican.edu/all-faculty

Part of the Occupational Therapy Commons

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.
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 bioecological framework and consideration of ever changing nested settings and contexts over time (Bronfenbrenner, 2005).

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 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 empirically explored the following questions:

- Through interview methods and qualitative analysis we empirically explored the following questions:
  - Application of a bioecological framework and consideration of ever changing nested settings and contexts over time (Bronfenbrenner, 2005).

DYNAMIC INTERACTION BETWEEN CHILD AND FAMILY

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 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 gotta do this, and he’s gotta be throwing a tantrum. So it is just that I shy away from social events.

Family Meanings and Contexts

There was a 12 randomly selected interviews (6 baseline and 6 post) at a set of predetermined response choices.

- Baseline and post testing.
- 12 randomly selected interviews (6 baseline and 6 post)
- To a set of predetermined response choices.

RESULTS

DYNAMIC INTERACTION BETWEEN CHILD AND FAMILY

Stress

Family Meanings and Contexts

Child’s Abilities and Special Needs

Social Impact

Behavioral Impact

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.

FAMILY MEANINGS AND FAMILY HOPES:

STRIKING A BALANCE

Family Meanings

AND

Family Hopes

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: medication, occupational therapy, education, and speech pathology

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

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
- Searches for 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 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

SELECTED REFERENCES