The Experience & Alteration of Ritual Events for Families with Children with Special Needs

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INTRODUCTION

22% of families in the U.S. include a child with special needs.¹ Family rituals are important in fostering a sense of belonging, bonding and identity for family members. Family rituals are believed to be important to supporting family quality of life.² They are “codified” ways of doing things together; meaning is generated by their sameness. However, these must often be reshaped to accommodate children with special needs. Few studies have examined how caregivers construct rituals to include family members with special needs.³⁴⁵ This qualitative study describes the phenomenon of ritual events with children with special needs.

RESEARCH DESIGN & METHODS

Participants:
19 mothers of children with special needs from diverse ethnicities (Caucasian, Hispanic, Native American, and dual ethnicity) and spiritual backgrounds

Interview questions:
1. How does your family celebrate special events such as holidays, birthdays?
2. Are there any special routines or rituals that you do?
3. Do you make any special accommodations for your child?

Procedures:
• ²nd data analysis of the Cross-cultural Study of Mother’s Well-being and Daily Occupations when Parenting a Child with a Disability
• Interviews were read in their entirety for a holistic perspective of the families’ experiences. Answers to the interview questions above were then coded line by line, and these codes were grouped by emergent themes.

RESULTS

Major Themes:

1. Altering the ritual
84% of mothers reported modifying how rituals occurred or reduced or ended participation in ritual events altogether.

“Holidays were going to be at my house, and if you wanted to see us, then you have to come by my house.”

“[At Easter we’ll still go to church once [my son] decides he’s not going to be a terror in church. Right now we’re going through a time where sitting is not exactly a wonderful thing.”

Because ritual participation influences familial and cultural identity, this can greatly impact the entire family.

2. Inclusion/exclusion of child
Many mothers discussed their decision to include (63%) or exclude (25%) their children from ritual events.

“…there’s just no doubt but that you’re going to the Seder, you know. That’s just it and [my son] knows that.”

“So [Christmas shopping] is not a fun thing …[my son] runs around, he hides under …the displays of clothes and he knocks the thing when he gets out, so… he stays home. And I go by myself, you know.”

“I mean, [my son] didn’t eat with us. That’s the thing. He didn’t really eat with us. I fed him ahead of time. He slept through dinner … I mean, people celebrate a lot at meals. People eat together. That’s a big way of celebration here in the States. And in Brazil, everywhere I think. Feasting and just gathering to eat together.”

The sense of belonging that comes from participation in ritual events is likely impacted by this decision. The decision to exclude may have been a practical strategy to avoid escalations of the child’s behavior that would disrupt everyone’s holiday.

3. Stress management
58% of mothers discussed increased stress surrounding ritual events; 42% expressed difficulty managing this stress and only 16% noted their abilities to effectively manage it.

“When I try to keep up with everyone else’s way of celebrating holidays, I feel completely overwhelmed.”

“I feel so much like I want to do something for the grandmas or I want to do something for [my husband] and it never seems like enough.”

“I look forward to [the holidays]. They’re special times. And I finish my Christmas shopping by November, by Thanksgiving. That’s my rule so that I get to enjoy the whole holiday season while everybody’s running around stressed, I’m done.”

Ritual celebrations have been identified as a way of improving family quality of life. Ineffective stress management, however, may detract from the health promoting qualities of these events.

CONCLUSIONS

Mothers with children with special needs may perceive that they celebrate holidays in a manner that is similar to typical families. Depending on the individual child’s needs and preferences, the environment, and the expectations, however, special accommodations are often necessary. These accommodations include staying home to celebrate, altering the ritual, deciding whether or not to include the child, or refraining from celebrating at all. The degree of impact these modifications have on the celebration varies widely depending on the context in which they occur.

Implications for Practice
Ritual events such as holiday celebrations hold special meaning to individual families. Occupational therapists can assist in preparing children and families for major events, make suggestions for environmental adaptations to meet the child’s needs, and practice skills that will help enable the child to fully participate in these events. Increased understanding into how families celebrate ritual events also adds to practitioners’ cultural competency, enhancing the quality of treatment.

REFERENCES


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