FAMILY QUALITY OF LIFE: PART III INTERVENTION

REVIEW

Occupational therapy practitioners view childhood disabilities through a lens that considers the dynamic and interconnected changes within the family.

The Person-Environment-Occupation (PEO) model guides intervention for pediatric disabilities with co-occurring socially disruptive behaviors.

The family is recognized as a system and the community as a powerful environment that influence client outcomes.

Occupations are used as both treatment and outcome measures with which to establish habits and routines that support social participation and engagement.
REVIEW OF PREVALENCE

• Developmental disabilities affect approximately 10 million children in the United States alone (twice as many are males), or about 15% of the school-aged population—a 17% increase over the last decade.

REVIEW

• Two diagnoses with socially disruptive behaviors, attention-deficit/hyperactivity disorder (ADHD; 7% of the population) and autism spectrum disorder (ASD; 1.1% of the population), account for a significant shift in the reported prevalence.

REVIEW

• Additionally—or perhaps co-morbidly—about 16% of children in early elementary years present with symptoms of sensory over-responsivity, a form of sensory modulation disorder (Ben-Sasson, Carter, & Briggs Gowan, 2009), raising the prevalence of children with childhood disorders impacting success to upwards of 30% of the U.S. school-aged population.
REVIEW – STATEMENT OF PROBLEM

By participating in occupation, humans develop, evolve, and establish their identities, and they find meaning in their lives. Yet, disability can disrupt engagement in occupation.

Family quality-of-life (FQoL) research focuses on both the internal attributes of family life (e.g., interaction, parenting) and the influence of the environment (e.g., community supports, medical home).

FQoL

The following are five factors of FQoL that become highlighted when a family is raising a child with a disability:

- Family interactions (i.e., marital satisfaction, being together at mealtime)
- Parenting (i.e., ability to assist the child)
- Support for the person with a disability (i.e., child treatments)
- Financial well-being (i.e., monetary resources)
- Physical and emotional well-being (i.e., coping with parental stress, caring for one’s own health and social needs)

CONSIDERING INTERVENTION

PEO model intervention plan focuses on the following evaluation findings:

- Performance skills of the client
- The areas of occupation, activities, and tasks
- The environmental context as it influences the dynamic transactions
PEO

- Outcomes are assessed according to the client’s progress in occupational performance but interventions are established to reach beyond the child, and multiple options for change can be generated.

There is a dynamic relationship between people, their occupations and roles and the environments in which they live, work and play.

We need to be detectives to identify and solve the right problem(s) and create an onramp to quality of life.

WHAT CONSTITUTES FAMILY QUALITY OF LIFE?

- What does it mean to have QoL within a family?
- What does it mean to have QoL for individuals within a family?
- How do these intersect?
Consideration of co-occupation supports an integrated view of the client's engagement in relationship to significant others within context (AOTA, 2008, p. 269) and is an essential role of the occupational therapy intervention.

Families who are able to participate in meaningful occupations with friends and one another within their community have higher states of well-being (Lee et al., 2008).

FQoL

- Engagement in occupations...
  - Going to the store
  - Attending church or meeting
  - Going to a movie or out to dinner
  - Having a sleepover
  - Having a meal together
  - Going to school, doing homework
  - Getting dressed, taking a bath, helping carry in groceries
  - Others?

Family Interaction

FQoL

Parenting

Support for Person with Disability

Emotional/Physical Well-being

Material Well-being
CASE 1: BOBBY

- Primary problem –
  - Family meals
  - Parents report child ‘wolfs down food and leaves table’, child picky eater
  - Child reports family meals are too loud, food stinks, makes him nauseous to hear food in people’s mouths...

WISER APPROACH

- What is the problem?
- Isolate what we know and seek to understand what we don’t know
- Try a solution
- Evaluate
- Reflect

CASE 1: BOBBY

- Primary problem –
  - W = Family meals
  - Parents report child ‘wolfs down food and leaves table’, child picky eater
  - I = problem identified as family interaction
  - Child reports family meals are too loud, food stinks, makes him nauseous to hear food in people’s mouths...
  - I = I need to know about auditory and other sensory processing
  - S = I will try a solution aimed to reduce auditory and olfactory hypersensitivity
  - E = I will assess family meal/interaction after
  - R = I will reflect with the family on strategies
WHAT IS THE PROBLEM?

OTs collaborate with the parent to promote a PEO fit.

If the family doesn’t eat meals together because of parent fatigue, the therapist might provide energy conservation and work simplification strategies.

If family meals don’t occur because of child behaviors, that becomes the problem to focus on.

PERSON/ENVIRONMENT/OCCUPATION

- Remediate/rehabilitate – focus on changing the underlying area of deficit
- Accommodate – provide a support that enables function
- Modify – change the expectations of the task
- Compensate – table intervention on the problem until a future time

AREA AFFECTED:

FAMILY INTERACTION

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<td>Assistive technology</td>
<td>Change the task</td>
<td>Family Planning</td>
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<tr>
<td>Improve</td>
<td>Such a work arduous</td>
<td>Provide</td>
<td>Adapt / modify</td>
<td>Adjust / compensate</td>
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Example
- Reduce hypersensitivities
  - Consider meals, consider all meals and the flow of the meals

Example
- Modify phenomena foods
  - Consider existing stimuli and sensory needs

Example
- Compensate
  - Consider eating quietly and family activity

Example
- Modify
  - Consider eating quietly and sharing time

Example
- Compensate
  - Consider eating quietly and family activity

Example
- Reinforce
  - Children/siblings, review meal protocols

Example
- Compensate
  - Provide family education regarding meal training and meal-related tasks

Problem: Child Sensitivity

Example
1. Reduce hypersensitivities
   - Consider music, consider quiet meals
   - Audit the noise level of the family

Example
1. Modify
   - Consider
   - Headphones/ear buds

Example
1. Compensate
   - Consider
   - Eating quietly and sharing time

Example
1. Provide
   - Family education regarding sensory sensitivities and ways to balance the scales.

Problem: Parent Fatigue

Example
1. Improve
   - Endurance through exercise and de-stressing activities

Example
1. Compensate
   - Consider
   - Ready-made meals to reduce caregiver burden

Example
1. Modify
   - Home delivery of groceries

Example
1. Compensate
   - Review meal protocols

Example
1. Provide
   - Family education regarding meal training and meal-related tasks.
Understanding what is required by the activity and the skills required to execute it is a critical element within occupational therapy evaluation and practice.

PROBLEMS

- Community participation
- Isolation
- Stigma
- Stress
- Family Impairment
- Disability support
- Physical and Emotional Wellbeing
- Parenting/ Caregiver burden
- Basic Needs
- Performance Patterns (habits, routines, rituals, roles)
- Enjoyment with family life
- Engagement / participation

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Community participation
Stress
Basic Needs
Performance Patterns (habits, routines, rituals, roles)
Enjoyment with family life
### SUPPORT FOR PERSON

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<td>Example:</td>
<td>Sample: Reduce work and create child care by involving family in work schedule</td>
<td>Example: Provide additional supports to reduce stress and improve mood</td>
<td>Example: Identify stressors and develop coping strategies</td>
<td>Sample: Identify and support family with strategies to promote successful outcomes</td>
</tr>
<tr>
<td>Problems:</td>
<td>Child care concerns due to disruptive behaviors</td>
<td>Worry about the future</td>
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### PARENTING

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<td>Example:</td>
<td>Complete SQ1 or PDI to see where area of need is greatest</td>
<td>Sample: Complete quality of time questionnaire</td>
<td>Sample: Use FlyLady to promote small changes</td>
<td>Sample: Complete daily schedule and work to decrease stress levels through intervention</td>
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<td>Problems:</td>
<td>Not getting help with chores</td>
<td>Limited time for parents to have 'adult time'</td>
<td>Unsupportive spouse, not on same page</td>
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### EMOTIONAL AND PHYSICAL WELLBEING

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<td>Reduce stress by contacting friends and family and sharing ideas and solutions</td>
<td>Sample: Promote understanding of good sleep and insomnia</td>
<td>Sample: Download apps for mindfulness and meditation</td>
<td>Sample: Identify stressors and develop coping strategies</td>
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<td>Problems:</td>
<td>No time for de-stressing</td>
<td>No time for friends</td>
<td>No time for self</td>
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R Whitney/OccupationalTherapy.com
Stress busters

FINANCIAL WELLBEING

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<td>Work with financial planner to create budget</td>
<td>Example: Use app to log spending</td>
<td>Example: Take advantage of online tools</td>
<td>Example: Check with insurer / providers to identify reimbursement options</td>
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<tr>
<td>Problem:</td>
<td>Cost of therapies</td>
<td>Example:</td>
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<td>Example:</td>
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FAMILY INTERACTION

- Identify social activities families wish to attend together and remove barriers to participation, such as taking walks or hikes, organizing family potlucks, going to the local pool, attending church, and participating in community meetings.

- Help families establish routines for having meals together at least three times a week.

- Recommend games and activities that will promote sharing and family cohesion, such as establishing bedtime routines, making and using a traditional “talking stick,” and playing two truths and a lie (Whitney & Gibbs, 2013).
**PARENTING**

- Understand (and don’t underestimate) caregiver burden.
- Make parent education part of your intervention plan, and provide education in parenting strategies.
- For example, add 15 minutes to a therapeutic social skills group that is supervised by a student intern and use this time to work with parents to problem solve various barriers to achieving higher quality of life.

**EMOTIONAL AND PHYSICAL WELL-BEING**

- Provide strategies that help parents conserve their energy. For example, create a website or handout of cook-once, use-twice meals.
- Suggest de-stress activities families can do at home, such as after-dinner walks.
- Provide tips for supporting better sleep habits.

**SUPPORT FOR THE PERSON WITH A DISABILITY**

- Identify and share resources for respite in the community with families, such as Friday “Parents Night Out” drop off to bowl or play Laser Tag, or host a parents’ night out at your facility.
- Create a webinar or blog or use social media that families can readily access to inform their community about their needs as a family as well as the unique, positive contributions they can make to communities.
FINANCIAL WELL-BEING

• Create a webinar or blog or use social media to share tips on establishing financial resilience (e.g., creating living wills, sharing purchases at shoppers' clubs).

• Teach parents how to optimize your therapeutic intervention through community resources (e.g., karate, rock climbing, scouts, gaming tournament drop-in events).

• Encourage and facilitate sharing of resources (e.g., create a bulletin board at your facility for swapping resources, materials).

CASE 2: SAM

Sam is 10 but won’t leave me alone – we were recently at the grocery store and Sam began to scream for no apparent reason and dig his nails into my bare leg, drawing blood. As I wrestled with Sam to calm him down, everyone stared at me. I had a cart full of groceries and nothing at home for dinner – I had to get through the check out! I began to cry which made everything worse but I wasn’t going to surrender my spot in the line. I guess I wasn’t moving forward fast enough because the manager came over and rudely asked me to move forward in the line. I was humiliated and angry and my leg was throbbing.

When we finally got to the car with the food, I could hardly see to buckle Sam into the car – no wonder I’m exhausted all the time.

WISER APPROACH

• What is the problem?

• Isolate what you know and need to know

• Try a solution

• Evaluate your outcome

• Reflect on what you learned
IN CONCLUSION

- Social isolation and stress in families is of critical concern. Childhood disability can interrupt all areas of occupation.

- We need to focus on the family rather than just the child if we want to achieve optimal outcomes.

- Conceptualizing outcomes as the fit between the PEO transactions can foster quality of life in the family.

- Since families live and grow within a community, the capacity for the community to welcome and support these families is an area for further consideration and intervention.

IN CONCLUSION

If the profession is to assume responsibility for helping to develop children who can thrive and live life to its fullest, we must focus our interventions on interactivity between the child, the family, and the community in which these developing occupational beings live.