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Family Quality of Life when Raising a Child with a Disability - II

Learning objectives

• Identify the primary areas of family quality of life affected when a child has a disability

• Evaluate family quality of life within context of pediatric intervention

• Recognize what to look for when stress is at the level which significantly impacts family quality of life and child outcomes

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Identify the primary areas of family quality of life affected when a child has a disability
We develop, evolve and establish our identity, and find meaning to their lives through participation in occupation (Mee, Sumsion, & Craik, 2004).

Occupation is used as both a treatment/intervention as well as a measure of outcome.

What is the occupation of family life?

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.
Mothers report spending 2.5 hours more per day in caregiving yet feel they have less confidence in their parenting abilities.

7 times more likely to not participate in religious community events.

Significant impact on QoL.

Once we consider the occupations of family life, we can begin to consider the barriers to engagement in these occupations...

Disability disrupts the engagement in occupation, and thus all areas of life. Family quality of life research focuses on both the internal attributes of family life (e.g., interaction, parenting, etc.) and the influence of the environment (e.g., community supports, medical home, school, etc.).
ASD and ADHD as well as SPD have been shown to impact maternal stress and wellbeing, child outcomes and family quality of life (Lee et. al, 2009; Whitney, in press).

Mothers of children with autism and related disorders have higher rates of stress, lower perceived satisfaction in their primary life role of mother, experience higher rates of depression and have less adaptive coping mechanisms than their spouses, mothers of children with physical disabilities or no disabilities (Davis & Carter, 2008; Hastings et al., 2005; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Little, 2002).


Wise Approach

• W = What is the Problem?
• I = Isolate what you know and what you need to know
• S = Start a solution [try something]
• E = Evaluate – did you solve the problem???
Outcome directed at achieving Family quality of life (FQoL) targets the performance patterns of families, the habits, routines and roles with which families tend to their basic daily needs, have a sense of enjoyment of life together as a family as they engage in occupations and activities meaningful to them.

FQoL focuses on both the internal attributes of family life (e.g., interaction, parenting, etc.) and the influence of the environment (e.g., community supports, medical home, etc.) and supports a holistic approach to interventions.

Five factors of family quality of life have been identified when a family is raising a child with ASD/ADHD/SPD (Freedman & Whitney, 2011; Whitney, 2012)

- Family Interaction
- Parenting
- Emotional/Physical Well-being
- Support for Person with Disability
- Material Well-being
Family Interactions (e.g., marital satisfaction, being together at mealtime),
Parenting (e.g., ability to assist the child),
Support for the Person with a Disability (child treatments),
Financial Wellbeing (financial resources), and
Physical and Emotional Wellbeing (coping with parental stress, caring for one's own health and social needs)

Evaluate family quality of life within context of pediatric intervention

Wise Approach
• W = What is the Problem?
• I = Isolate what you know and what you need to know
• S = Start a solution [try something]
• E = Evaluate – did you solve the problem???
• Greatest need in families with a child with ASD appears to be Family Physical Mental Health and Well-being, Caregiver burden, and Disability Support.

• Greatest need in families with a child with ADHD may be Physical Mental Health and Well-being, and Caregiver burden.

• When disability disrupts the engagement in occupation, all areas of life are at risk for impaired performance and quality of life. Pediatric disabilities can create family impairment, isolation, and stigma.

• We must view childhood disabilities as a stressor within an interconnected system within the family and how that can affect health-related quality of life outcomes for the child and members of the family.
Evaluation

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

Evaluate

- Community participation
  - Isolation
  - Stigma
Evaluate

- Stress
- Family Impairment
- Disability support
- Physical and Emotional Wellbeing
- Parenting/ Caregiver burden

Evaluate

- Basic Needs
- Performance Patterns (habits, routines, rituals, roles)
- Enjoyment with family life
- Engagement / participation

Case Example

- Messy house, clutter
- Family gatherings
- All the little tasks I have to do
- All the screaming, fighting and whining in my house
- Child’s meltdowns in public
- Chaos in the house
- Violet tantrums (physical violence, property damage)
- Having to drag a kid to time out
- Banging voices
- Arguments (The sky is blue, no its cerulean, no its turquoise)
- Watching my kids get hurt from one another
- The thought that this will never get any better
### Parenting

- Poopy pants, stains in pants, poop on the floor, lying about poopy pants, poop smell, the older boys complaining about poop smell
- Worrying the bed
- Scheduling soccer
- Saying no and being afraid to set [child] off
- Fighting with my spouse
- Worrying my husband will lose his temper if I leave the kids with him
- People interrupting me in the shower or nap to ask for me to turn the computer on (when dad is right there?)
- Sex with an unfeeling partner
- Being in the same house with an angry, uncommunicative partner
- Agencies messing around with funding

### Financial Wellbeing

- I've lost 20 years of full time employment and that affects me financially
- Worry about having a job flexible enough for my child
- Having the right clothes for my child's dress code
- Having adequate transportation
- I might lose my job
- I have a leaky roof and no money to fix it

### Support for Child with Disability

- Being my son's 'frontal lobe'
- I have no social life
- I eat more because I'm stressed, I'm stressed because I've gained weight and I can't find time to exercise
- Fights with the school
- I worry about my son's future
- Finding good reliable childcare
- Remembering to call about the kid's appointments
- [Child's] afterschool problems
- Worry about [child's] future
- Afraid of what [child] will do in school today
<table>
<thead>
<tr>
<th>Physical and Emotional Health and Wellbeing</th>
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<tbody>
<tr>
<td>Never having enough time to do all the things I want/need to do never get enough sleep I’m always tired I have no social life I’m lonely eat more because I’m stressed I’m stressed because I’ve gained weight and I can’t find time to exercise I live in a mess house People interrupting me in the shower or nap to ask me to turn the computer on when dad is right there Eating too much weight Poor relationship with my selfish [sister mother mother-in-law friend] who never makes time for [child] Not feeling well and health as I would like trying to figure out menus for everyone when I have my own issues with food Not meeting commitments to MYSELF when I seem to be able to fit in meeting the needs of everyone around me My inability to lose weight especially as it is impacting my overall health</td>
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**Evaluate**

- Time and motion patterns

- Sense of Cohesion (meaning, manage and understanding)

Consider:
- FQoL Survey
- SOC scale
- QoL Inventory
- Parenting Stress Index
- Adult Sensory Profile
Stress

The mental and physical response of our bodies to the changes and challenges in our lives.

The situation triggering the response = stressor

The body’s reaction = stress response
Stress tells the body to gear up to either fight or flee a perceived danger. We are SUPPOSE to attend to the threat, get away and then RELAX.

The stress response is an ancient survival mechanism.

The sympathetic nervous system gets the body ready for action:
- heart rate increases, blood pressure rises, breathing rate increases, blood routed to brain and muscles, pupils dilate to increase vision, muscles tense up, sweating, GI tract slows, endorphins released.


Recognize the Behavioral Signs of Stress...

The sympathetic nervous system gets the body ready for action:
- heart rate increases, blood pressure rises, breathing rate increases, blood routed to brain and muscles, pupils dilate to increase vision, muscles tense up, sweating, GI tract slows, endorphins released.
Think about it ....

- How does this show up in the clinic?
- School?
- Families?
- Positive coping and less optimal coping

Stress and anxiety

- SOR and Anxiety
- SUR and Depression
  (both stressors)

- Suppression of social support is a powerful predictor of depression and anxiety in mothers parenting children with challenging behaviors (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009); yet informal support offers a buffer against maternal stress, interrupting the downward trajectory toward depression and anxiety (Boyd, 2002).
- Understanding how a child with socially disruptive behavior experiences daily life is a component of evidence-based intervention.
Problems from stress:

- Depression
- Anxiety
- Headaches
- Fatigue
- Susceptibility to infection, illness
- Immune disorders
- Gastrointestinal problems
- Eating problems
- Sleep problems
- Sexual and reproductive problems

- The long term wear and tear of the stress response on the body

- High allostatic loads are linked with hypertension, obesity, heart disease, and reduced brain and immune system functioning. Is it an accident many mothers complain of weight gain???
### Family Interaction

- Establish social activities families can attend together
- Support family to have meals together
- Provide suggestions re games and activities to promote sharing (two truths & a lie, kid in the blank, bedtime routines, talking books, etc)

### Parenting *Support for person w/ DA*

- Support exploration and participation in leisure interests
- Provide family education as part of your service (offer childcare)

### Material wellbeing

- Provide resources for long term planning
- Facilitate religious/spiritual activities
- "we’re best at this as a society"

### Emotional/Physical wellbeing

- Work simplification/energy conservation for parents
- Stress activities
- Education re importance of time for self
- Support smoking cessation
- Support self regulation of sleep (child and parents)
- Support understanding at schools

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**Questions?**

Thank you!
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References provided separately