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Family Quality of Life when Raising a Child with a Disability

Learning objectives

- Identify the primary areas of family quality of life affected when a child has a disability
- Identify how to evaluate family quality of life
- Recognize how family stress impact family quality of life and child outcomes

Abstract

There is a dynamic relationship between people, their occupations and roles and the environments in which they live, work and play. 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.
Put on your oxygen mask first

Introduction

Family quality of life (FQoL) is a term of recent coinage and reflects the manner with which families tend to their basic daily needs, enjoyment of life together as a family as they engage in occupations and activities meaningful to them.

FQoL takes an ecological approach to wellbeing and 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, etc.)

• Researchers estimate 5% to 15% of children, within the general population, show signs of sensory modulation difficulties. (Ahn, Miller, Milberger, & McIntosh, 2004) impacting social participation, academic success, activities of daily living and family quality of life (Whitney, 2011).

• There is a much higher prevalence of atypical sensory processing in clinical populations.

• In addition to core features of ASD, 95% of children with ASD also report atypical sensory processing (Tomchek & Dunn, 2007).

• Sensory overresponsivity and ADHD are estimated at 69% (Parush, Sohmer, Steinbert, & Kaitz (2007))

Each of these children live within and impact a family.
ADHD MORBIDITY

- Number of children 3-17 years of age ever diagnosed with ADHD: 5.2 million
- Percent of children 3-17 years of age ever diagnosed with ADHD: 8.4% (About 3% of all school-aged children)
- Percent of boys 3-17 years of age ever diagnosed with ADHD: 12.0%
- Percent of girls 3-17 years of age ever diagnosed with ADHD 4.7%
- Criteria: DIRECTLY IMPACTS SOCIAL, ACADEMIC/OCCUPATIONAL ACTIVITIES

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Through participation in occupation, humans develop, evolve and establish their identity, and find meaning to their lives (Mee, Sumsun, & Craik, 2004).

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.).
Brown examined FQoL in families with a child with ASD (Brown, et.al 2007).

Using the FQoL-2006 Survey, Brown et al. (2007) found families with a child with ASD (n=18) have lower FQoL than those with a child with Downs (n=27) and the control group.

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).


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)
• 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.

✓ 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)
How do these behaviors affect FQoL?

- Sensory Over-responsivity
- Sensory Under-responsivity
- Sensory Seeking-Craving

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**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

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**Not all stress is bad...**

- **Eustress** is positive stress because it stimulates, motivates, helps us channel our energy into performance and achievements

- **Distress** is negative stress and causes anxiety, tension, feeling “burnt out”
Fight/Flight/Freeze

• The body gears up to either fight or flee a perceived danger. It 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.
  - How to know someone is ‘into you’ with pupil dilation

Cortisol levels, a biomarker of toxic stress, found in mothers with children exhibiting externalizing behaviors were at high levels, paralleled only by individuals with post traumatic stress disorder (PTSD), combat soldiers, and Holocaust survivors (Seltzer, 2009).
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).


Consequences of unmitigated stress span generations (Liu, et al., 1997), suggesting that maternal stress can create changes that affect offspring genetically, as cortisol crosses the placenta and affects prenatal development (Anderson, 2000).

Van den Bergh & Marcoen's work suggests antenatal stress was a significant independent predictor of hyperactivity disorder symptoms, externalizing problems, and self-reported anxiety in offspring (2004).

Even when controlling for other demographic variables, "stress was the only psychosocial variable that significantly predicted the physical health-related quality of life (HR-QoL) of parents raising children with high-functioning autism or HFASD" (Lee et al. 2010, p. 235).

Rapid Licked Rat Pups

High stress during gestation in rat populations not only produces offspring who grow to be hyper-anxious adult rats but the next generation of rat pups retain this heightened arousal levels even when environmental factors are controlled for (Liu et al 1997).

This transferring of the negative effects of distress genetically to future generations, hippocampal atrophy and prolonged exposure to neurochemical consequences of stress, has important ramifications for human populations.

This suggests interactions between maternal stress and parenting one child with socially disruptive behaviors may have important influences on prenatal and lifelong health consequences to later born siblings.
• 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???

Why Zebras Don’t Get Ulcers

by Dr. Robert Sapolsky

Why Zebras Don’t Get Ulcers

by Dr. Robert Sapolsky is a Professor of Neurology at Stanford University

Sapolsky quotes.....

“Stress is anything in the external world that knocks you out of homeostatic balance. For a zebra, stress had an extremely short if potentially deadly span; it was “three minutes of screaming terror” after which the animal was either dead or once again roaming the Savannah and feeling safe. Human beings, on the other hand, had an “anticipatory stress response” that spun easily out of control, like a car losing traction on an icy slope.”
The most essential factor in dealing with stress—"having a shoulder to cry on."

The biggest predictor of mortality across the board for all infectious disease is the degree of social isolation versus social affiliation.

Think about it -- People who live alone don't have someone to remind them to take their medicine every day and don't have healthy dinners. Social isolation is a major health-risk factor.

http://www.youtube.com/watch?v=TtjU0-dOTLM

Protections

Do you have friends? How many? Are they casserole friends?

You need 4 others with whom you can rely upon in times of need and speak with about meaningful and intimate concerns for health and will help you even if they have to go out of their way...*


Activity...

Take out two pieces of paper

• On the first one, spend one minute writing out all your blessings

• On the second one, write out a list of friends with whom you can share and who will help you even if they have to go out of their way....
Evaluation

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

We all cope - here are some less than positive Coping

Using alcohol, tobacco, over-eating/coffee or drugs leave the body in a MORE stressed state and prevent it from returning to homeostasis, causing more problems in the long run.

Tantrums, withdrawal from social opportunities....
[others?]
Activity..

- Write something on a piece of paper that you are worried about.

Crumble the paper and throw it in your trashcan....

**FAMILY QUALITY OF LIFE (cont.)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family values spending time together</td>
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<td>2. My family sometimes help the children learn to be independent</td>
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<td>3. My family has time for me to relax outside</td>
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<td>4. My family sometimes have friends or other family members together</td>
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<tr>
<td>5. My family sometimes help the children with school and activities</td>
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<td>6. My family sometimes have transportation to get to places we need to go</td>
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<td>7. My family sometimes seek help with work</td>
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<tr>
<td>8. My family sometimes teach the children how to get along with others</td>
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<tr>
<td>9. My family sometimes have more time to spend time together</td>
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<tr>
<td>10. Our family routines are special</td>
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<tr>
<td>11. My family sometimes suggest each other to accomplish goals</td>
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<tr>
<td>12. My family sometimes plan the day/week</td>
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</tbody>
</table>
What does this suggest to us for intervention?

1. Effective tx for child must address the family as the context in which the child develop

2. Supporting families to develop greater ability to engage in meaningful occupations and employing treatment strategies targeted at family wellness may be critical to optimal child

3. An ecological approach to treating children with ASD and ADHD is critical

Environment

- Interventions aimed at the environmental level create the context for performance and occupational engagement. For example, supporting family interaction provides the context for children to experience a sense of belonging, acceptance and support. Creating a context... Emotional/Physical wellbeing... Parenting...
Occupations

Goals at the occupational level support developing the habits, routines and rituals that enable the performance of occupations: activities of daily living, social participation, and are conceptualized within the occupational role (student, parent, friend, family member).

Provide a handout, webquest or workshop for families with suggestions....

- Practice mindfulness
- Deep breathing exercises
- Yoga, stretching
- Progressive muscular relaxation
- Meditation
- Imagery
- Watch your self-talk
- Exercise
- Feng shui your space
- Write in a journal

Person

- Remediate
- Accommodate
- Modify
- Compensate
Lets think of some examples!

Some examples of intervention strategies might include:

**Family Interaction**
- Identify social activities families wish to attend together and remove barriers to participation, such as walks or hikes, family potlucks, going to the local pool, church or meeting participation.
- Help family establish routine of having meals together at least 3 times a week.
- Recommend games and activities that will promote sharing and family cohesion such as bedtime story times and routines; make and use a talking stick, 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, adding 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 quality of life.
- When gathering data for the occupational profile, listen for key sensory words that give emphasis to the caregiver's lived experience

**Emotional / Physical wellbeing**
- Provide strategies that help parents conserve their energy. For example: create a website of cook once use twice meals.
- Provide de-stress activities families can do at home.
- Support smoking cessation.
- Support self-regulation of sleep (child and parents).
- Encourage and enable participation ...
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 at Laser Tag or host a parents night out at
your facility
Create a webinar, blog or use social media that families can readily access to
inform their community about their experiences as a family

Financial Wellbeing
Create a webinar, blog or social media on tips for financial resilience (living wills,
etc)
Teach parents how to optimize your therapeutic intervention through community
resources (karate, rock climbing, scouts, Magic the Gathering drop-in events)
Encourage and facilitate sharing of resources (create a bulletin board for
swapping resources, materials, etc).

<table>
<thead>
<tr>
<th>Family Interaction</th>
<th>Parenting</th>
<th>Material wellbeing</th>
<th>Emotional/ spiritual wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish social activities families can attend together</td>
<td>Consistent, organizing routines for care</td>
<td>Provide resources for long term planning</td>
<td>Work simplification/ energy conserv for parents</td>
</tr>
<tr>
<td>Support family to have meals together</td>
<td>Understand caregiver burden</td>
<td>Identify and share community resources</td>
<td>De-stress activities</td>
</tr>
<tr>
<td>Provide suggestions on games and activities to promote sharing (two truths &amp; a lie; fill in the blank; bedtime routines; talking stones, etc)</td>
<td>Support exploration and participation in leisure interests</td>
<td>Help families maximize therapies (more is not always better)</td>
<td>Education re: impact of time for self</td>
</tr>
<tr>
<td>Sample ideas to consider for assessment...</td>
<td>Facilitate successful attendance of religious/spiritual activities</td>
<td>Support self-regulation of sleep (child and parents)</td>
<td>Support understanding at school</td>
</tr>
</tbody>
</table>

Translation of all this research into practical family strategies...
Thank you!

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Questions?

References provided separately