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“Caring for Yourself”
Integrating Wellness and Self-Care for Parents of Children with Special Needs

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Terminology

- Note the term “parent/caregiver” or “parent” in this course will be used to refer to a caregiver of children with special needs in the home.
- Can refer to a biological parent, a step-parent, a grandparent, aunt, uncle or other relative as well as a foster parent or court-appointed guardian.
- Does not refer to paid childcare providers or caregivers, although they are often an important part of the client system.
Learner Outcomes

- 1) Identify three occupations that parents of children with special needs report having difficulties with.
- 2) Describe a family-based intervention that targets occupational needs of parents.
- 3) Recognize three effective strategies for conducting an OT-led workshop or group addressing parent/caregiver self-care.

Case Study: The Overwhelmed Parent

- You can use inflated balloons for demonstration at a staff meeting or presentation.
- Give one balloon to the volunteer “parent/caregiver” each time he or she has had a stressor happen in the day.
- Case study is included in the course materials, or create your own depending on the unique ages and demographics of your workplace.
Case Study: The Overwhelmed Parent

Prevalence of CSHCN’s

- Approximately 15% of children under age 18 have a special healthcare need
- 23% of all U.S. households have a child with a special healthcare need, including disability or chronic medical condition.
- Of those, 25% of parents of CSHCN’s said they had to quit work or cut back on hours to provide additional care.

Source: National Survey of Children with Special Healthcare Needs, 2009-10
OT Practice Framework

- 3 concepts in OT domain and process that can be affected by caring for a child with special needs:
  - 1) Health- more than the absence of disease or infirmity
  - 2) Well-being- physical, mental, and social aspects of human life domains
  - 3) Participation- involvement in a life situation


Parent/Caregiver Occupations: IADL’s

- Care of others
- Child rearing
- Financial management
- Health management and maintenance incl. physical fitness and nutrition
- Home establishment and management
- Meal prep and cleanup, incl. nutritious meals

Parent/Caregiver Occupations: Other

- Rest (rest & sleep)
- Sleep preparation (rest & sleep)
- Sleep participation (rest & sleep)
- Leisure exploration (leisure)
- Leisure participation (leisure)
- Social participation through community, family, and friends (social participation)


Video #1: Needs Identified by Parents
Designing Interventions

Dawn is a 48 year-old grandmother who is the primary caregiver of her two grandsons, Robby and Jonathan due to an unstable living environment with their parents. She is single and is on disability due to her own Type II diabetes and chronic pain issues. Her grandsons both have effects of fetal alcohol syndrome and other developmental concerns. Robby is 11 and has mild cerebral palsy and fetal alcohol syndrome, which is supported with an inclusive classroom at school.

Designing Interventions

Jonathan is 6 years old and has a non-specified developmental delay. He has just started kindergarten this year and is being seen for multiple medical evaluations to get a clearer diagnosis. He was referred outpatient speech services for speech delay as well as occupational therapy for sensory-related issues including aggression when other children touch him.
Designing Interventions

- Assume you are the OT practitioner at Jonathan’s second treatment session after his initial evaluation.
- Treatment goals have been set for Jonathan and include self-regulation, increased tolerance of light touch, and family adoption of a sensory diet.
- Although your job is to work on Jonathan’s goals, you notice his grandmother seems overwhelmed and distant when you review home strategies with her.

Designing Interventions

- What questions would you ask to get a better picture of Jonathan’s mom’s needs?
- What are some caregiver occupations that could be worked on during an outpatient OT session focused on Jonathan (assume payor source expects session to include Jonathan)?
- What are some treatment ideas that could be integrated into the session?
- Early intervention or school-based settings?
Designing Interventions, 1:1 settings

- Listen to parent needs and concerns before, during and after the treatment session with the child.
- Ask questions regarding parent occupations in IADL’s, leisure, sleep and social participation.
- Create family-based interventions that are meaningful to the parent/caregiver.

Designing Interventions

- Keep in mind parent needs for sleep, socialization, and self-care
- Meal and feeding interventions can involve healthy foods and habits for the parents/caregivers as well as the child
- Can help with parent sleep preparation by encouraging calming rituals and decreased screens for the whole family before bedtime.
Potential Tools to Draw From

- American Medical Association’s Caregiver Self-Assessment Questionnaire, although it was designed for caregivers of older adults
- Coping Health Inventory for Parents (CHIP) (McCubbin et al., 1996), asks parents questions about their own self-efficacy
- Observations of parent occupations

Group Interventions
OT-Led Parent Groups: Tips

- Provide childcare
- Provide food, or include healthy meal prep as an intervention
- Focus on doing rather than too much discussion or dialogue: group case studies, physical activity, yoga, relaxation/breathing
- Include community resources and time to socialize (allow at least an hour per group)
- Work with your organization for creative funding sources

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OT-Led Parent Groups

- 5:30-5:45: Brief parent intros and balloon activity
- 5:45-6:05: Group cardiovascular activity
- 6:05-6:15: 10-minutes active yoga
- 6:15-6:45: Dinner and family eating activity (handout from Marino, et al.) or simple meal prep
- 6:45-7:10 Interactive activity or worksheet surrounding stressors and coping and/or sleep hygiene (handout from Clark, et al.)
- 7:10-7:30 Breathing/mindfulness meditation activity and introduce mindfulness apps (Bazzano et al., 2013)
- 7:30-7:45: Group case study re: social supports
- 7:45-8:00: Post workshop assessment
OT-Led Parent Groups--Evaluation

- Post test or course evaluation asking about specific occupations covered in the group, and what group activities were most meaningful
- Ask what activities or routines they will enhance or change in the home as a result of participation in this program
- Potential for use of standardized adult occupation-based assessments if this is a research project or billable group series

Healthy Living Skills
Video #2: Impact of the Caring for Yourself Program

Summary

- Parents of CSHCN’s have their own occupations that are affected by raising children with special needs.
- OT’s can help support and engage parents in healthy occupations as part of a treatment plan that includes listening to their needs and including them in the plan.
- OT’s can run groups for parents of CSHCN’s to help them more fully participate and engage in various occupations surrounding self-care.
References


Video #3: Advice for OT Practitioners Working with Parents and Caregivers of Children with Special Needs
Q&A

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