Caregivers and Autism Spectrum Disorders: Application of Guidelines for Support

Mandy McKimmy, DNP, FNP-C, APRN

Disclosures

- No conflict of interest
- No endorsements

Objectives

- Recognize common characteristics of autism spectrum disorders (ASDs) in children.
- Describe specific challenges for caregivers & families of children with ASDs.
- Identify evidence-based strategies to improve caregivers & families experiences at the point of care.
Autism Spectrum Disorder (ASD)

- A developmental disability caused by differences in the brain.
- Children with ASD may have differences with:
  - Communication
  - Interactions
  - Behavior
  - Ways of learning (CDC, 2014)

Incidence

- According to the Centers for Disease Control and Prevention (CDC, 2014), 1 in 68 children are now identified as having an autism spectrum disorder (ASD).
- ASDs are 5 times more common among boys (1:42) than girls (1:189).
- ASDs occur in all racial, ethnic, and socioeconomic groups.
- ASD’s often encompass co-morbidities and barriers to access of healthcare.

Identified Prevalence of Autism Spectrum Disorder

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<th>Surveillance Year</th>
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<th>Number of ASD Cases Reporting</th>
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Financial Implications

- Average medical expenditure to care for a child with ASD is $17,000 more than caring for a child without an ASD
- In 2005, the average annual cost for a Medicaid enrolled child with ASD was $10,709
- Behavior interventions costs
  - estimated $40,000 to $60,000 per child per year

Cause and Risk Factors

- The exact cause of autism remains unknown (Strain, Schwartz, & Barton, 2011).
- Risk Factors:
  - Parents with a child diagnosed with an ASD have a greater chance of having a second child with the diagnosis
  - Advanced parental age
  - Among identical twins, if one has an ASD the other will be affected about 36-95% of the time
  - Prematurity
  - Increased incidence with certain genetic/chromosomal conditions (CDC, 2014)

Diagnosis

- Diagnosis at age 2 “reliable, valid and stable” (CDC, 2014)
- Parents often note developmental problems before their child’s first birthday!
- Children are often not diagnosed until or after age 4
  - PDD-NOS (average 4 years, 2 months)
  - Asperger Disorder (6 years, 2 months) (Adams, Guillory, Edmond & Herr, 2010)
In the News

- Mutations in gene linked to brain development
- Treatment in infancy may "prevent further symptoms"
- Possible root in early cerebellum injury
- Children with autism may, "Have too many synapses in their brain"
- Socially-assistive robots, help learn imitative behaviors
- Mother's took less iron supplements in pregnancy

Characteristics of ASDs

Autism Case Training

- ACT Video “Observation: Echolalia”
ASD Umbrella

ASD: Behaviors

- Poor eye contact
- Little, delayed or unusual speech
- Anti-social, asocial, social but awkward
- Normal behavior then changed between 1 and 2 years of age
- Insistence on sameness
- Repetitive behaviors
- Little or no interest in children of same age
ASD: Behaviors

- Under reactive or over reactive to sensory stimuli (sounds, touch, smells, tastes)
- Tantrums
- Picky eater
- Poor or little sleep
- Aggressive or self-aggressive
- Repeat or echo words/phrases
- Appear unaware to others speaking

ASD: Behaviors

- Prefer not to be cuddled
- Not play “pretend” games
- Difficulty adapting to routines
- Loss of skills previously had
- Difficulty understanding others feelings

Challenges for Caregivers and Families
Literature Review

Strategy and Outcome

- OVID, CINAHL, PubMed, PSYCHINFO
- Keywords “autism”, “caregiver”, “burden”
- Google Scholar/Scopus
- > 200 articles identified, 40 considered
  - Limitations: evidence based, peer-reviewed, English language, publication dates between 2006-2013

Behavioral, Financial and Time Strains

+ correlation between parenting stressors and problem behaviors  
  (Estes, Munson, Dawson, Koehler, Zhou & Abbot, 2009)
- Impairments impact caregivers, teachers, family members and community  
  (Karst & VanHecke, 2012)
- Parents may stop working to coordinate care, contributing to financial burden  
  (Wachtel & Carter, 2008)
- Time management poses difficulty for parents
  - Serving as advocates
  - Managing treatment plans
  - Coordinating treatment  
    (Wachtel & Carter, 2008; Koek, 2010)

Caregiver’s Quality of Life

- Increased anxiety, depression and stress  
  (Rezendes & Scarpa, 2011)
- Restrictions in social activities & financial strains  
  (Kenny & Corkin, 2011; Wachtel & Wilks, 2009)
- Decreased social connection  
  (Kenny & Corkin, 2011)
- Stress related to sleep dysfunction, self-injurious behaviors, difficulties with toilet training, feeding, lack of social skills & emotional problems  
  (Egge, Wolf, Robert & Adkins, 2011)
**Literature Review**

**Caregiver’s Quality of Life**

- Concerns about the future (Davis & Carter, 2008)
- Lower levels of well-being (Karst & VanHecke, 2012)
- Higher levels of depression (Wachtel & Carter, 2012)

**Literature Review**

**Professional Interactions**

- Parents voiced dissatisfaction with
  - Diagnostic process
  - Lack of professionalism
  - Professional attitudes
  - Communication strategies (Koeck, 2010)
- Time frame to receive a diagnosis is a source of stress (Karst & VanHecke, 2012)
- Stress related to access of care (Koeck, Eikelboom, Doherty, Byrne & Gallagher, 2010)

**Caregiver Burden and Autism Spectrum Disorders: Application of Guidelines for Support: Methods**

- Developed a series of one hour educational sessions based upon New Zealand Autism Spectrum Disorder Guidelines for Support
- Obtained IRB approval and administrative approval
- Conducted education sessions at a local community center
- Evaluated educational sessions
- Recommendations for future
Target Population

- Parents or primary caregivers of children with an established diagnosis of ASD
- Attendees at a local Autism Family and Community Center
- Inclusion criteria:
  - English speaking participants
  - Minimum age of 21
  - Primary caregiver of a child with an existing diagnosis of ASD

Setting/Risks

- Local Autism Community Center
- Minimal risk category
  - Possible discomfort from having lived experiences similar to content covered
  - Participants were allowed to refuse to answer questions or opt out of the project

Benefits

- No direct benefit to participants
- Caregivers had possibility of:
  - Learning ways to manage difficult situations
  - Learning about available resources
  - Learning ways to manage stressors
  - Learning how to advocate for their child
  - Learning how to collaborate with providers
Guidelines: Emotional and Financial Stresses

- Low levels of support from within family
- Raising a child with challenging behavior
- Parental perceptions
- Economic and social impact
- Cost of therapies, medications, interventions, support services, lost earnings (New Zealand Autism Spectrum Disorder Guidelines Summary, 2008)

Literature: Emotional and Financial Stresses

- Behavior problems were strongly associated with stress (Lecavalier, Leone & Hill, 2006)
- Daily mood (of mothers) was found to be more negative (Smith, Greenberg, & Seltzer, 2012)
- Caregivers experienced increased depression, anxiety, strain in marital relationships, and poorer physical health (Shu, 2009)
- Mothers may have higher rates of mental health problems (Mayer, et al., 2011)

- Higher levels of stress than parents of children with other chronic diseases (Yamada, et al., 2012)
- Emotional difficulties have a significant impact on well-being of caregivers (Kenny & Corkin, 2011)
- Children may have excluded from schools due to lack of support (Lambert, 2011)
- Financial burdens associated with payment for services, educational programs and appropriate treatments (Ekas, Lickenbrock & Whitman, 2010)
Guidelines: Support and Respite to Minimize Stress

- Timely and more effective early support needed
- Providing support may save money by avoiding crisis management
- Respite care and a key case management model provides positive outcomes
- Parent-led support groups
- Parent-to-parent support reduces isolation
- Structured interventions for reducing stress

(Literature: Support and Respite to Minimize Stress)

Guidelines: Parent-Professional Collaboration

- Parents take on multiple roles
- Parents and professionals need to agree on roles and responsibilities
- Roles may change over time
- Family values and daily routines need to be accommodated
- Effective outcomes seen with collaboration
- Family participation
- Easy access to information
- Key worker with ASD expertise for coordination
- Care plan developed with family
- Consideration of siblings

(Literature: Support and Respite to Minimize Stress)

Guidelines: Support and Respite to Minimize Stress

- Evaluation of parental stress to identify parents at risk
- Addressing parental needs and stressors is key to enable provision of appropriate support
- Familial and relationship stress is highest at time of diagnosis, providing adequate support during this time for caregivers is crucial
- Educating parents with coping mechanisms is key
- Higher levels of social support are associated with lower levels of negative impact

(Literature: Support and Respite to Minimize Stress)

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(Literature: Support and Respite to Minimize Stress)
Literature: Parent-Professional Collaboration

- Parent and family outcomes as well as child outcomes should be evaluated (Karst & Hecke, 2012)
- Group-based parent training interventions may be beneficial (Fink, et al., 2010)
- Public policy and public funding should provide access to services for children with ASD (Strain, Schwartz, & Barton, 2011)
- Early recognition and diagnosis of ASD and referral for early intervention results in better outcomes for families (Twoy, Calvin, & Novak, 2007)
- Clinical services should aim to support parents (Iannaccone, et al., 2006)

Guidelines: Advocacy

- Information should be made available to parents
- Conflict resolution skills
- Access to quality advocacy services for parents who may not feel confident to advocate
- Specialists and teachers can support parents
  - Understanding of vocabulary
  - Systems of education

Literature: Advocacy

- Parents of children with ASD may have to be teachers, advocates, researchers and caregivers. Formal and informal support should be provided for families (Strain, Schwartz, & Barton, 2011)
- Family members manage many aspects of caregiving (Habib, Johnson, & Zauszniewski, 2012)
- Families need to be equipped with all available resources (Elder & Alessandro, 2009)
- Parents must cope with diagnosis, search for treatment and intervention, change parenting practices, and manage financial burdens (Koblenz, Hsu, & Meltzer, 2009)
Guidelines: Health Needs & Health Promotion

- Healthcare needs of people with ASD can be complex
- Level of social skills development will affect understanding of roles of health care practitioners
- Communication difficulties can limit information provided to healthcare professionals
- Some individuals with ASD experience perceptual sensitivities to a range of experiences such as light, sound, touch, taste, and pain
- Unpredictable reactions to medications, sleep disturbances, diet issues and harmful behaviors

(New Zealand Autism Spectrum Disorder Guideline Summary, 2008)

Guidelines: Health Needs & Health Promotion

- Comprehensive medical assessments should be done
- Routine health care screening
- Close surveillance for the development of mental health problems
- Age-related prompts for screening
- Dietary and exercise guidelines to prevent secondary health issues
- Education in ASD for health care practitioners
- Educating families to attend to their own health care

(New Zealand Autism Spectrum Disorder Guideline Summary, 2008)

Guidelines: Health Needs & Health Promotion

- National campaigns on smoking, obesity, driving, alcohol and drug abuse, sexual health and safety and occupational safety exist
- No research has been found to assess the effectiveness of these campaigns on people with ASD
- Adapting national health campaigns to effectively engage people with ASD and their families and development of ASD-specific campaigns on health issues is recommended

(New Zealand Autism Spectrum Disorder Guideline Summary, 2008)
Literature: Health Needs & Health Promotion

- Children with ASD may have trouble expressing their needs and adapting to changes in routine (CDC, 2011)
- Parents like “evidence-based” care (Lenne & Waldby, 2011)
- Multidisciplinary team with a range of expertise is needed (Kenny & Corkin, 2011)
- Plans of care do not always include full parental participation (Kenny & Kelly, 2011)
- Some people with autism live independent lives while others need specialist support throughout life (Lambert, 2011)
- More research is needed to discover how to support people with ASD through adulthood (Strain, Schwartz, & Rarick, 2011)

Outcomes: Discussion & Themes

- Avoidance of clinic visits due to non-supportive staff
- “Demeaning” staff and non-supportive environment
- Medical records missing or unavailable (older records)
- All participants reported that health care providers often feel parents don’t have an adequate understanding of their child’s condition and clinical staff are not supportive
- Social isolation
- Difficulty maintaining friendships

Outcomes: Discussion & Themes

- Fears, worry
- Need for support systems in place for families
- Mentorship among families with “match” to ASD
- Need for humor in life “humor and love get you through”
- Neurodiversity, “ableism”, wording
Outcomes: Literature

- Overall, literature supports the guidelines in all aspects
- Literature aligns with project findings in relation to parent-professional collaboration and advocacy
- Literature supports need for a multidisciplinary team with a wide range of expertise

Strategies for best care

- Development of mentorship programs among caregivers
- Education for healthcare providers and staff in conjunction with caregiver input
- Further investigation of verbiage related to ASDs
- Multidisciplinary approach
- APRN’s can be key members of care teams/advocates
Screening

- Early intervention has proven to be a key factor with diagnosis and treatment of ASDs (CDC, 2011)
  - CDC recommends all children be screened at 9 months, 18 months, 24 or 30 months.
- Screening for ASD’s should begin at an early age.
  - Step One: Developmental Screening
  - Step Two: Comprehensive Diagnostic Evaluation
- Screening for developmental disabilities including, but not limited to:
  - Learning Disabilities
  - Speech/language difficulties
  - Gross motor/fine motor skill delays

Screening: Oregon

- Oregon Assuring Better Child Health and Development Early Childhood Screening Initiative (ABCD Screening Initiative)
  - Guidelines for improving early childhood screening, surveillance and referral practice in the state of Oregon
  - Public-private partnership including the Oregon Pediatric Society, the Oregon Department of Human Services, the Oregon Center for Children and Youth with Special Health Needs at OHSU

Screening: Oregon ABCD Initiative

- Integrate structured screening and surveillance during well-child examinations
  - ASQ (Ages & Stages Questionnaire)
  - PEDs (Parents Evaluation of Developmental Status)
  - MCHAT (Modified Checklist for Autism in Toddlers)
  - Bright Futures Pediatric Intake Form and Parent Point of Care Screening Tool
- Continued, longitudinal management of care
  - Enables identification of children with developmental or behavioral problems
  - Referral
    - Early Childhood Intervention/Special Education
Screening: Additional tools
- Communication and Symbolic Behavior Scales (CSBS)
- Australian Scale for Asperger’s Syndrome
- Childhood Asperger Syndrome Test (CAST)
- Autism Spectrum Screening Questionnaire (ASSQ)
  - 27 item parent/teacher completed checklist (Asperger and other high functioning ASD in children/adolescents)

Interdisciplinary Plan
- Referrals may include:
  - Speech and Language Therapy
  - Occupational and Physical Therapy
  - Music and Play Therapy
  - Social Services
- Psychiatry or Psychology services
  - Behavioral problems associated with ASD’s have been linked to increased parental depression, stress, and relationship difficulties (George & Brack, 2011)

Disciplines involved in planning and implementation of plan
- Speech Pathology
- Primary Care provider
- Social Services
- Medical, Behavioral, & other
  - Psychiatry and Psychology
  - Diet
Learn the Signs. Act Early.

- CDC Campaign
  - Watch Me! Training
  - ACT (Autism Case Training)
  - Milestones Checklists (English/Spanish)

http://www.cdc.gov/ncbddd/actearly/index.html

Resources/Support

- Early Intervention Programs
- IEP (Individualized Educational Plan)
  - IDEA-Individuals with Disabilities Education Act
    - Children under 3 years at risk of having developmental delays may be eligible for services (state services)
- Dietary changes
- Therapeutic interventions
- Applied Behavior Analysis (ABA)
  - Encourages positive behaviors and discourages negative behaviors; progress is tracked and measured
  - http://www.youtube.com/watch?v=iyCx-OLzgJw
- TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children)
  - http://www.youtube.com/watch?v=ddGLJ2r4rcw
- Support groups
- Autism Treatment Network: medical treatment

Summary

- The rise in prevalence of autism, health risks and barriers to care are all considerations when addressing this population.
- Research has indicated that early diagnosis and early intervention are key in the treatment and success of these children.
- A multidisciplinary approach is necessary to meet the needs of children with ASD’s and their families, in order to provide optimal care with best health outcomes.
- Consideration of literature/guidelines for care
Final note

http://www.youtube.com/watch?v=6SGucf-B3O4

Questions?

References


References


References


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