Improving Quality of Life in Individuals with ASD for the Long Run: The Importance of Health Behaviors

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Defining Quality of Life
• What makes us healthy (or unhealthy)?
  • Healthy People 2020
  • Policymaking
  • Social factors
  • Health services
  • Individual behavior
  • Biology and genetics

Quality of Life Issues
• Personal satisfaction with core life conditions:
  o Physical, emotional interpersonal, social, personal growth, material well-being, individuals rights, self-determination.
  o Choice
  o Control
  o Competence: the interplay between choice and control
• Denny Reid: Measuring “Happiness” and changing happiness.

Physical & Psychological Health
• Physical
  o Access to healthcare
    • Participation in routine and non-routine physical exams, ER visits, dental exams, etc.
  o Wellness
    • Participation in recreational activities
    • Participation in exercise programs, sports, etc.
• Psychological
  o Wellness - developing and maintaining relationships

Safety Issues
• Elopement
• Injury
• Aggression
• Victimization
Elopement and ASD

- Prevalence
  - 49% of children with ASD
    - 53% were gone long enough to warrant concern
    - Missing for an average of 41 min.
- Goal-oriented behavior
- One of the most “stressful events” for parents (56%)
  - Half of parents reported “No Training”

(Anderson, et al., 2012)

Elopement: Risk Factors

- **AGE**
  - 46
  - 4x sib
  - 27 coi
- **CHARACTERISTICS**
  - Se
  - Lo
  - Mi
- **SETTING**
  - Home: 76%
  - Stores: 40%
  - School: 29%

Elopement: Treatment Considerations

From AWAARE: Autism Wandering Awareness Alerts Response Education Coalition

**Prevention, Planning, & Responding**

- Secure home
- Tracking device
- ID bracelet
- Teach child how to swim
- Neighbors & First Responders
- Emergency Response Plan

- Parent training
- First responder training
- School personnel training

http://www.autismspeaks.org/wandering-resources/aware

Injury & ASD

- 2-3 times more likely to experience medically attended injuries
- Significantly reduced life expectancy
- Engagement in more risk-taking behaviors than peers

Predictors of Unintentional Injury

- Male
- Over the age of 5 years old
- High impulsivity
- Presence of physical or mental disability
- Impairments in attention, communication, & social interaction
- Low SES
- Exposure to hazardous environments

Causes of Unintentional Injury

(CDC, 2004; McDermott, et al., 2008; WHO, 2008)

<table>
<thead>
<tr>
<th>Rank</th>
<th>ASD</th>
<th>Typical</th>
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<tbody>
<tr>
<td>1</td>
<td>Falls</td>
<td>Falls</td>
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<tr>
<td>2</td>
<td>Struck By/Against</td>
<td>Struck By/Against</td>
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<td>3</td>
<td>Natural Environment</td>
<td>Cut/Pierce</td>
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<td>4</td>
<td>Cut/Pierce</td>
<td>Car Accident</td>
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<td>5</td>
<td>Poisoning</td>
<td>Natural Environment</td>
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<td>6</td>
<td>Car Accident</td>
<td>Bicycle</td>
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<td>7</td>
<td>Burn</td>
<td>Burn</td>
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<tr>
<td>8</td>
<td>Bicycle</td>
<td>Poisoning</td>
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Risk-Taking Behavior

Fear and Injury

- Cognitive and emotional determinants
  o Awareness of impending threat for bodily or emotional harm with expectation of undesirable outcome
  o Fear and accurate appraisals of injury risk
  o Lack of fear associated with elevated injury risk

Participants & Methods

- Children with ASD, primarily autism
  o N = 12 (10 boys, 2 girls)
  o Ages 3-11, Caucasian
- Method
  o Survey
    • PDD Behavior Inventory (PDDBI-Parent Form) (Cohen & Sudhalter, 1999)
    • Child Fear Survey (CFS) (Turner & Romanczyk, 2009)
    • The Child Safety & Injury Questionnaire - Brief Parent Form (BCSIQ-P) (Straub & Romanczyk, 2008)
    • Simplified Injury Behavior Checklist (IBC) (Speltz, Gonzales, Sulzbacher, & Quan, 1990)

Conclusions

- Children with ASD were perceived by caregivers as having no fear to many items
- Being afraid to hurt oneself might be a protective factor against injury in children with ASD
- Caregivers might be intervening when children show no fear to dangerous situations
  o Injury risk could be underestimated due to caregiver intervention for children with no fear

Supervisor Behavior & Injury Risk

- Injuries are more severe
- Supervisors rate children at a lower risk for injury
- Perception of “close” supervision/monitoring

Ongoing Research

- Observations in naturalistic settings
- 99% of the times when “break in monitoring” child is at unsafe distance
  o Not strongly correlated with frequency of injury based on observational data
- Assessing how ASD symptoms and general developmental level might better predict patterns of risk-taking and injury for individuals with ASD
**Injury: Treatment Considerations**

- Parent/supervisor training
  - How to supervise
  - What to “look for”
  - Prevention
- Assessment of fears (or lack thereof)
  - Make others aware of risk taking behavior
  - Choose activities carefully

**Aggression & ASD**

- Not a diagnostic feature of ASD, but co-occurs often
- Prevalence ranges from 20% to 70%
  - Recent study 53%
- Topography

*Hartley et al., 2008; Lecavalier et al., 2006; Mazurek, Kanne, & Wodka, 2013*

**Aggression: Risk Factors**

- Young children > older children, adolescents (5%)
- Presence of Self-injury
- Sleep problems
- Limited IQ
- Limited or delayed language
- Poor social skills
- Sensory problems
- Gender is NOT a predictor

**Aggression: Treatment Considerations**

- Functional (behavioral) assessment
- Parent training with behavioral intervention
- Behavioral sleep interventions
- Functional communication training
- Social skills
- Coping Skills

**Victimization & ASD**

- Bullying
  - Cyber-bullying
  - Victim vs. Bully
- Abuse & Offending
  - Sexual, Physical
- Safety concerns at school by children with ASD
- 70% reported being bullied
- Emotional injuries > Physical injuries
- Approximately 1/5 children will “fight back”; 40% “meltdown” resulting in disciplinary action
- Perception of emotions of others
- Literal interpretation of language

**Victimization: Risk Factors**

- School-age children through adolescence*
- ASD & ADHD or depression are at increased risk of being bullied
- ASD and conduct disorder/oppositional defiant disorder more likely to be bullies
- *Cyber-bullying can last through adulthood. Stigmatization is also problematic for the lifespan of individuals with ASD.*
Victimization: Treatment Considerations

- Bullying - specific
- School-wide, classroom-wide interventions
- Teaching coping strategies to child with ASD
- Teach social skills to child with ASD
  - in peer context

http://www.autismspeaks.org/family-services/bullying

ASD & Violence

- Case Studies (e.g., Baron-Cohen, 1988; Haskis & Silvia, 2006; Mawson et al., 1985; Muntie et al., 2002)
- Ghazaluddin, Tsal, and Ghazaluddin (1991)
- Review of cases 1944-1990
- 132 cases only 2.35 demonstrated violent behavior
- Mouridsen et al. (2007)
- Arson/AS relationship, “significant” ($p = .07$) relationship between AS and sexual offending
- Langstrom et al. (2009): criminal registry
- Violent crime 20%
- Sexual offense 2.42%
- Sipromma et al. (2001): juveniles
- 13% of offenders met criteria for ASD (3% AS)
- No information about sexual offenses

Sexuality

- Individuals with ID and ASD are sexual beings!
- Education is important
  - Early childhood:
    - Privacy, boundaries (self and others)
  - Adolescence:
    - Often do not learn and experience sexual behaviors (kissing, dating, etc)
    - 36-53% adolescents with physical disabilities have had sex.
- Barriers to education: Parents’ anxieties; schools’ anxieties.

Adult Years: 21-55 Years Old

- Sexuality and freedom of expression of sexuality, is becoming increasingly important and recognized as such.
- Staff often not trained in sex education practices.
- Older adults: 55+
  - “We are sexual until our death” (Cole & Cole, 1993, pg. 202, as cited in Richards et al. 2006)

Issues

- Sexual orientation
- Birth control
- Masturbation
- Sexual offending
- Sexual abuse
- Reproduction/Menstruation
- Marriage
- Long-term relationships

Risk Factors | Protective Factors
---|---
Experience of sexual abuse | Infrequent social contact
Lack of empathy | Limited ability to deceive others
Sexual frustration | Highly rule governed behavior
Obsessional interests of a sexual nature | Supervision
Difficulty discriminating between public and private |
**Sex Education for ASD**

- Include the following elements:
  - Interpersonal skills
  - Gender and sexual identity
  - Masturbation
  - Contraceptives

- “Programme for the Development of Sociosexual Skills” (Henault, 2006)
  - Role-playing, rehearsal, repetition, and visuals
  - Includes module on homosexuality
  - Debunks myths related to sexual orientation
  - Delivered directly by a professional; different from other programs that have parents do sex education training.

- Lack of evidence of best educational program.

**Challenges of Teaching Sexuality**

- How do you define it?
- Societal norms
- Public misperceptions
- Social nature of sexual behavior

**Aging in ASD & ID**

- Individuals with ID and ASD have similar average life expectancies as the general population.

**Aging means behavioral decline and loss…**

- Self-care (adaptive behaviors)
- Opportunities for Leisure skills/activities
- Opportunities to engage in social interactions
  - Social support and relationships lost
- Response latency, fluency, & accuracy

**How do we support aging for those with ASD/ID?**

- Often cannot choose where to live; what support will be available to them
- Experience disruption during mid-life (when parent dies)
- Might be placed in group home or residential setting that is not a good match for their needs.
- Need advocacy groups for older adults with ID to coordinate with group homes/residential care for aging settings.

**Take Home Messages**

- Establishing a positive quality of life is a consideration across the lifespan
- The challenges individuals face will vary with age
- As providers and caregivers, we need to:
  - Focus on what is functional “now”
  - Plan to integrate skills that will be important 5, 10, 15, and more years from now – don’t wait until its needed to teach it
  - Provide both environmental supports and skill instruction to promote independence and success
  - Ensure that we are sensitive to the values, views, and life choices made by those we support
References


Thank you!
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