Autism: An overview of experiences of parents and siblings

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Quick presentations

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Objectives and outline

Objectives:
• To initiate to the realities of parents of individuals on the autism spectrum
• To cross experiential and scientific knowledge related to the care of a person on the autism spectrum
• Discuss conditions facilitating the use of a service dog by parents

Outline
• Autism terminology
• Parental experiences
• Fraternal relationship
• Service dogs for families of children on the autism spectrum
Evolution of terminology
Terminology: then and now

Past marked by eugenics and the psychoanalytical approach

Medical Model:
• Traditional model used to describe autism
• 2 domains described as Deficits, atypical, intensive, repetitive, etc.

Evolution in representations
• Awareness
• Culture, media
• Social participation, active role in the community
• Participatory research
Terminology: then and now

Evolution in terminology:
- Autism spectrum disorder, has Autism, is Autistic, Autistic person, Aspergers, condition, disorder, neurodiversity
- Person-first <-> Identity-first
  - Stigma
  - Sense of belonging
  - No consensus in a unique preference
Role in the evolution of autism representations

- History of advocacy
- Mobilization
  - Long contributed to changes in social representations of autism

- "Development Disability Act" of 1975 conceptualized autism as a disability and no longer a disease.
Parental experiences
Parenthood

Potential stressors:
• Changes in the marital relationship
• Carrying numerous tasks related to the care of the child
• Financial difficulties
• Management of minor misbehaviour in children
• Work-family balance
• Added mental load
• Care of a child with special needs

Available resources

Parenting demands
Paths to acceptance and action

• Diversity of reactions to the diagnosis
• One theory: Five stages of grief model (Kubler-Ross, 1969)
  • Denial, Anger, Bargaining, Depression, Acceptance
    • Faced with the powerlessness to change the situation:
      • Appearance of feelings of sadness, despair, depression…
      • Look for the causes, to understand and justify how the child is,
      • Search for a culprit and meaning;
      • Ambivalent feelings: Recognition of the child's difficulties but a refusal of the diagnosis.
    • Refusal of treatment, but hope for progress
• Acceptance of the child as he/she is (strengths and challenges)
• Parental involvement in the interventions
• Better use of the proposed strategies

Detraux, Di Duca, & Van Cutsem, (2001)
Parents of non-autistic children

w/ health problems

w/ other DD

w/ autism

Parents of adult children with ASD expressed higher stress, manifested more physical symptoms, hypoactivation of salivary cortisol (Baker et al., 2012; Foody et al., 2014; Seltzer et al., 2009; 2010)

(Baker-Ericzén, Brookman-Frazee & Stahmer, 2005; Dumas, 1991; Hastings et Johnson, 2001; Schieve et al., 2006)
Alternative from a group-mean conception

- If 5 stages, imply that all participants be at the same stage?
- Positive experiences
- Alternative to a group-mean conception of parental adaptation
  - Clusters
  - 72 mothers of children on the autism spectrum (5-10 years old) waitlist for a service dog
    - Perception of parenting stress + cortisol activity = 4 groups of mothers

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<thead>
<tr>
<th>Cortisol activity</th>
<th>Perception of parenting stress</th>
<th>Experimental group</th>
<th>Waitlist control group</th>
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Sibling relationship
The sibling relationship

Acceptance and tolerance
  • Knowledge related to autism

Involvement
  • Language
  • Technological skills
  • Emotion regulation

Opportunities
  • Acceptance, respect, patience, tolerance, empathy, compassion, sense of responsibility

(Angell et al., 2012; Claudel-Valentin et al., 2021; Osmond, 2018; Schmeer et al., 2021; Viswanathan et al., 2022)
The autistic siblings point of view

Interview with 15 autistic adults: (mean age: 22.2 years old; 8 women, 1 non-binary) in Quebec, Canada

The SR is characterized by:
• Showing interest in each other’s every day life and interest
• Attentiveness during conversations
• Acceptance
• Appreciation
• Affection
• Conflicts
• Reassurance
• Mutual aid
Service dogs
A bit of research

Viau et al. (2010): 42 autistic children (7.1 ± 3.1 years old, 5 girls)

Fecteau et al. (2017): 98 Parents of autistic children (6.7 years old, 19 girls)
The dogs
Effects on children’s stress system

The introduction of service dogs into the homes translated into a reduction of CAR.

Viau et al., 2010
What about the parental experience?

- Principal caregiver
- Main handler
- 5 to 7 days of training
- Added responsibilities
Effects on parental stress

• Saliva cortisol Collected at home by the parents
• 3 weeks before the dog’s arrival: Parental Stress Index-SF, Childhood Autism Rating Scale
• 12 consecutive weeks after the dog’s arrival
  • On the same day of every week
  • Wakening, 30-45 minutes later and bedtime

Baseline 12 first weeks when dog is present 9 months
Results
63.8% of the total sample reported significantly high levels of parental stress on the Parental Stress Index.

Parents from the control group perceived more parental stress related to their child’s characteristics ($t = -2.36$, $p \leq 0.05$) and more dysfunctional parent-child interactions ($t = -1.98$, $p \leq 0.05$).
Salivary cortisol regulation before the dog’s arrival

- **Raw cortisol (μg/dL)**

- **With service Dog**
- **Control**

- **Dimensions:** 960.0x540.0

- **Graph:**
  - X-axis: Wakening, 30 mins after, Bedtime
  - Y-axis: Raw cortisol (μg/dL)
  - Comparison between With service Dog and Control
  - Data points show cortisol levels at different times.

- **Legend:**
  - Orange: With service Dog
  - Light orange: Control
Longitudinal analysis
Scientific contributions

• Confirmed group low cortisol activity

• Severity of the child’s behaviour difficulties has no impact on stress

• Service dog in the family brings change in cortisol activity and reduces perception of stress

Limits

• Precise time of saliva collection were not known;

• The daily collection of three saliva samples = a minimum to estimate the diurnal rhythm;

• Mean group based approach
A parental testimony
Conclusion
Service dog’s

The handler = the beneficiary.
At school; At work; In the community

Success Factor:
• Extensive training in handling and caring for the dog
• Self-identity related to autism
• Support and acceptance from the environment
• Follow-up and support from the trainer
Key points

• No consensus in terminology, but a preference for Identity-first language (e.g. autistic adult). Be mindful that some terms may be offensive to members of the autism community
• Stress experienced by adults on the autism spectrum causes important challenges to daily adaptation
• Stress reduction is a proposed mechanism to AAT
• Public awareness of the use of service dogs and the rights of the beneficiary
• Autism is evolving: keep up, question and be inclusive
References


