



Autism: An overview of experiences of parents and siblings

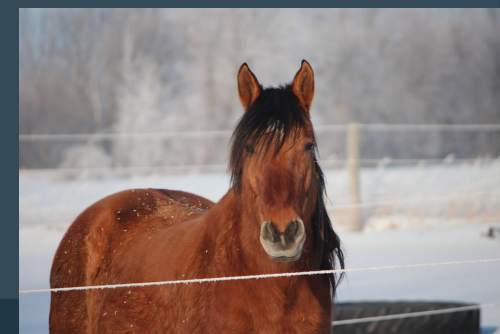
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Quick presentations

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- Horse enthusiast



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.

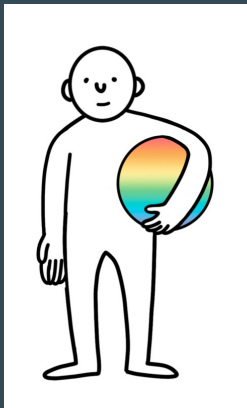
Evolution in representations

- Awareness
- Culture, media
- Social participation, active role in the community
- Participatory research

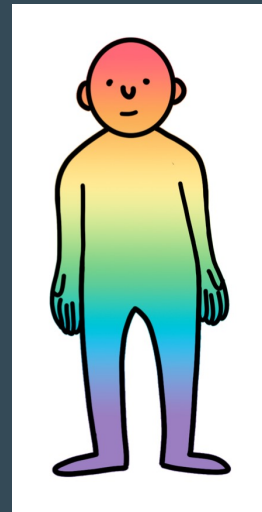
Terminology: then and now

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



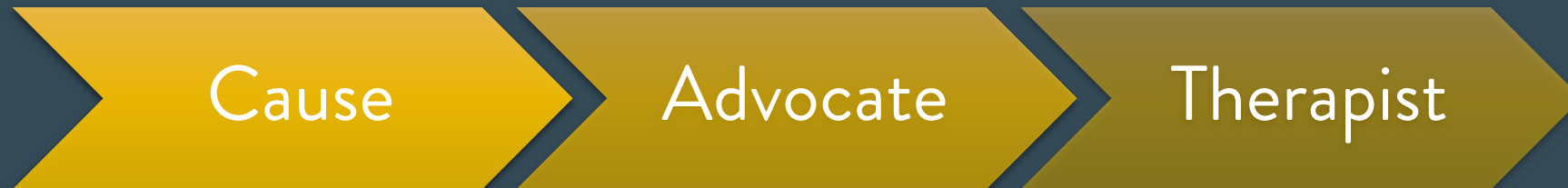
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Role in the evolution of autism representations

- 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

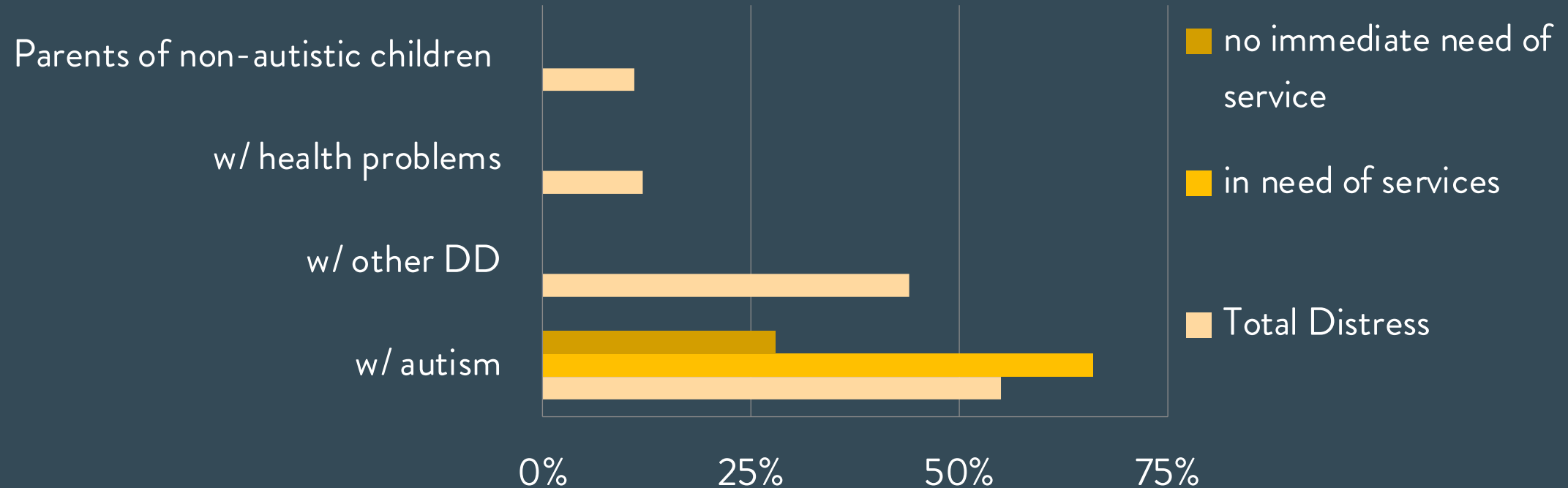


Parenting demands

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

Parental stress: a unique parenting experience



- 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)

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

	Experimental group		Waitlist control group	
	I	II	I	II
Cortisol activity	moderate	low	highest	lowest
Perception of parenting stress	low	high	moderate	clinical levels

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

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)

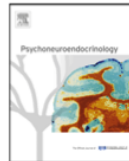
Psychoneuroendocrinology (2010) 35, 1187–1193



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Effect of service dogs on salivary cortisol secretion in autistic children

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KEYWORDS

Salivary cortisol;
Autism;
Cortisol Awakening
Response;
Service dogs

Summary Children with Autism Syndrome Disorders (ASDs) exhibit social, communicative, and behavioral deficits. We know that human interaction with dogs, which is thought to serve as a social catalyst, results in a decrease of cortisol levels in healthy adults. Introducing service dogs to children with ASD is an attractive idea that has received growing attention in recent decades. However, no study has measured the physiological impact of service dogs on these children. Therefore, the goal of our study was to assess the effects of service dogs on the basal salivary cortisol secretion of children with ASD. We measured the salivary cortisol levels of 42 children with ASD in three experimental conditions; *prior to and during* the introduction of a service dog to their family, and *after* a short period during which the dog was removed from their family. We

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Parenting stress and salivary cortisol in parents of children with autism spectrum disorder: Longitudinal variations in the context of a service dog's presence in the family



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In memoriam of Robert Viau.

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ABSTRACT

A significant portion of parents of children with autism spectrum disorder report high levels of stress related to parenting responsibilities, which have been linked to abnormal cortisol patterns. This study seeks to better understand the parents' adaptation to caregiving demands and use of a service dog, by taking into account longitudinal variations in salivary cortisol and perception of parental stress. Salivary cortisol was collected one day per week for 15 weeks by 98 primary caregivers of children with ASD. Overall, parents perceived high levels of stress at baseline. Mean morning cortisol increase was below expected levels for healthy adults, and perception of stress predicted morning cortisol activity. Hypocortisolism related to chronic stress may be present in parents of children with ASD. Longitudinal analysis revealed that the presence of a service dog in the family had an effect on parenting stress, wakening and morning cortisol levels.

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1. Introduction

a daily basis to meet their child's needs (Dykens & Lambert, 2013;

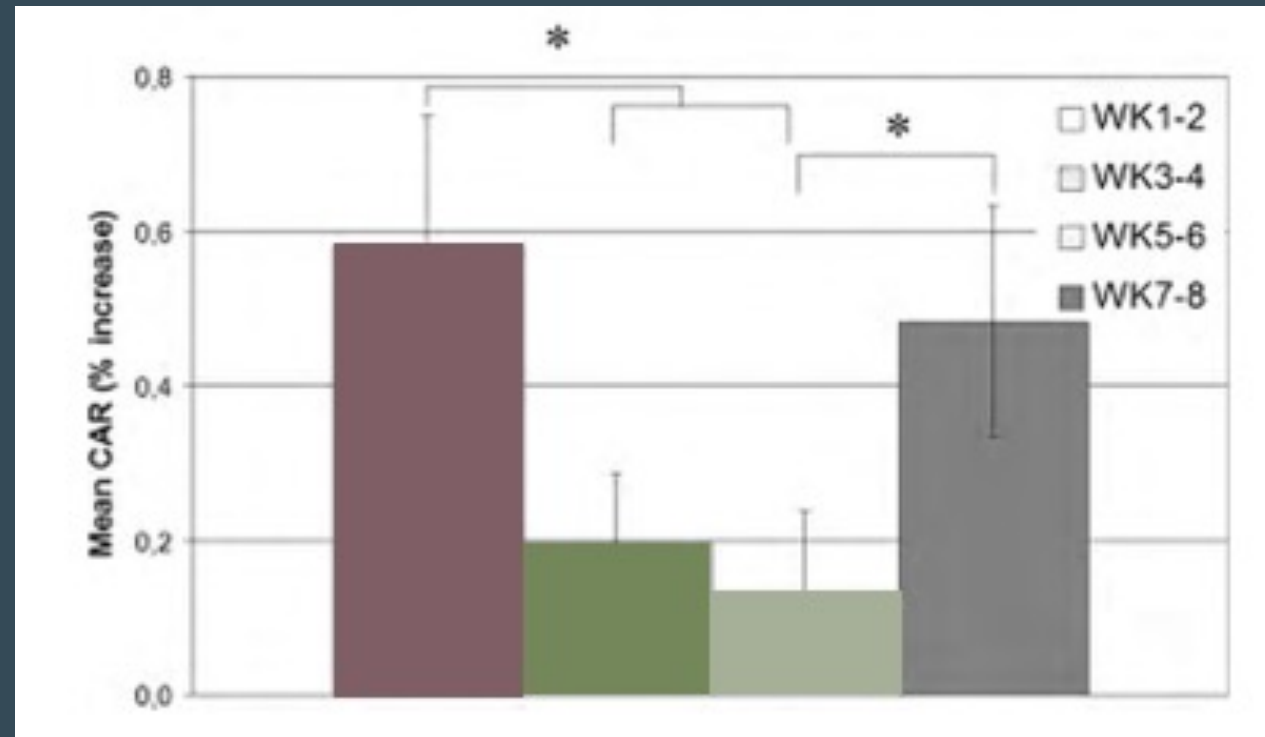
The dogs



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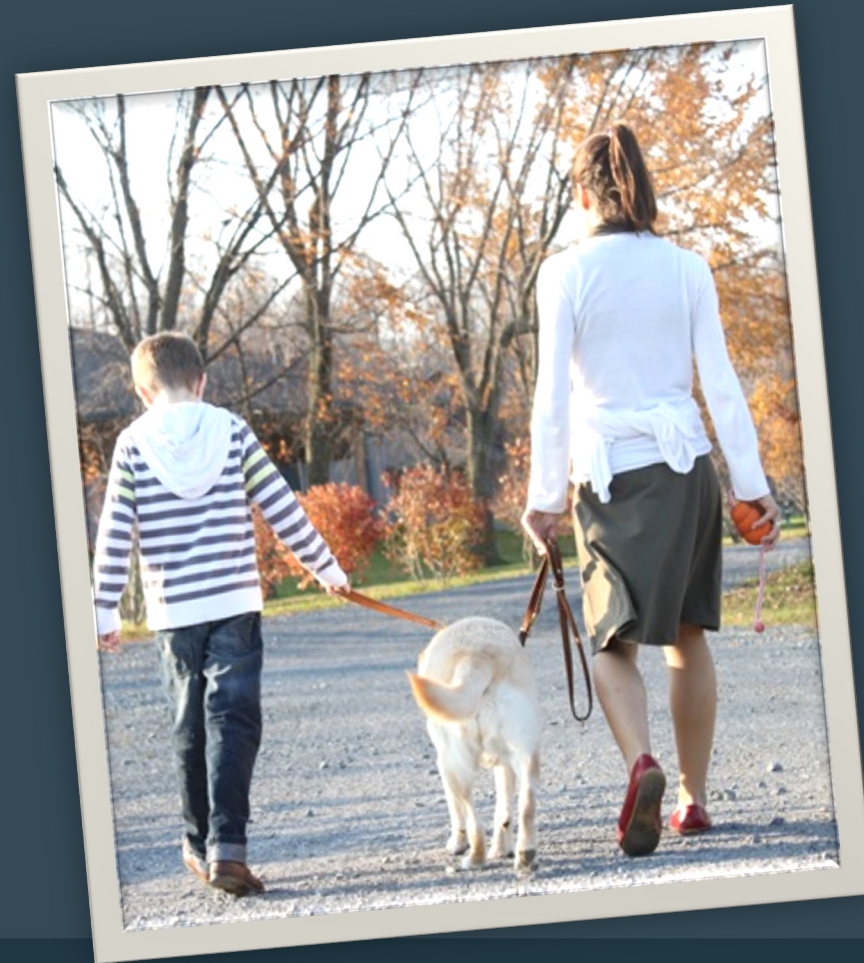
Effects on children's stress system

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



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

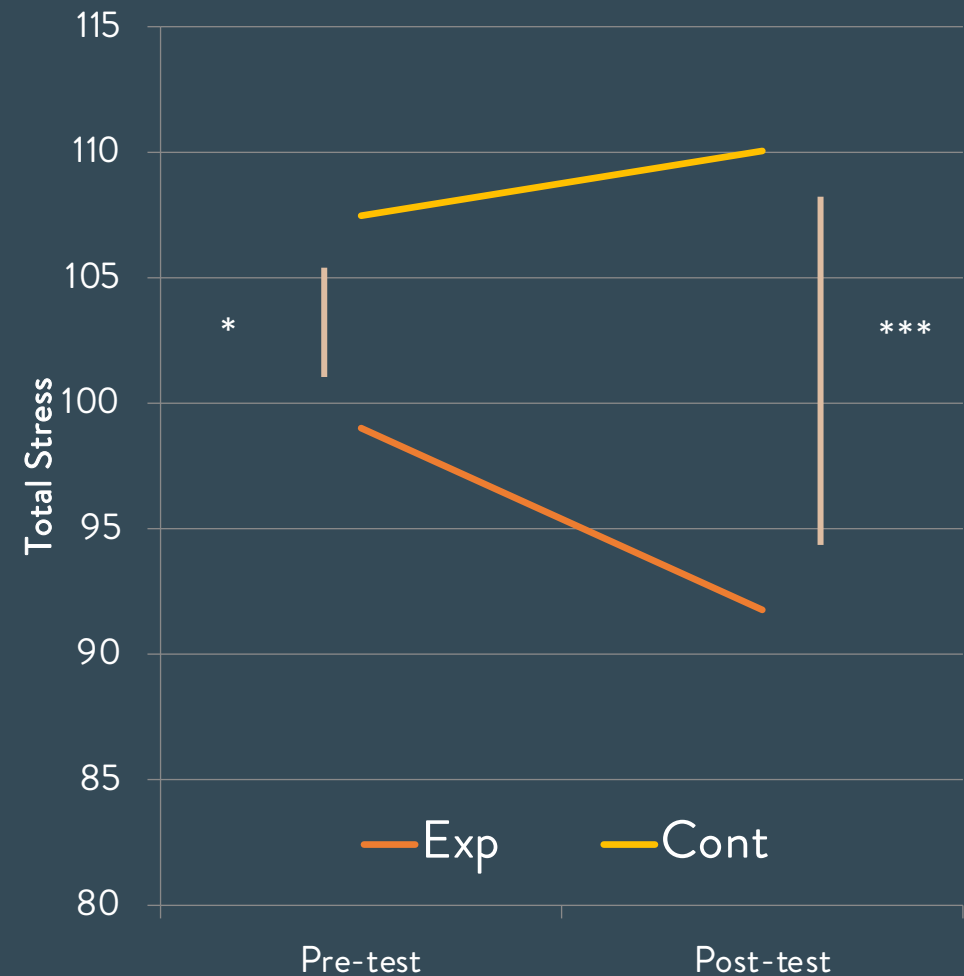




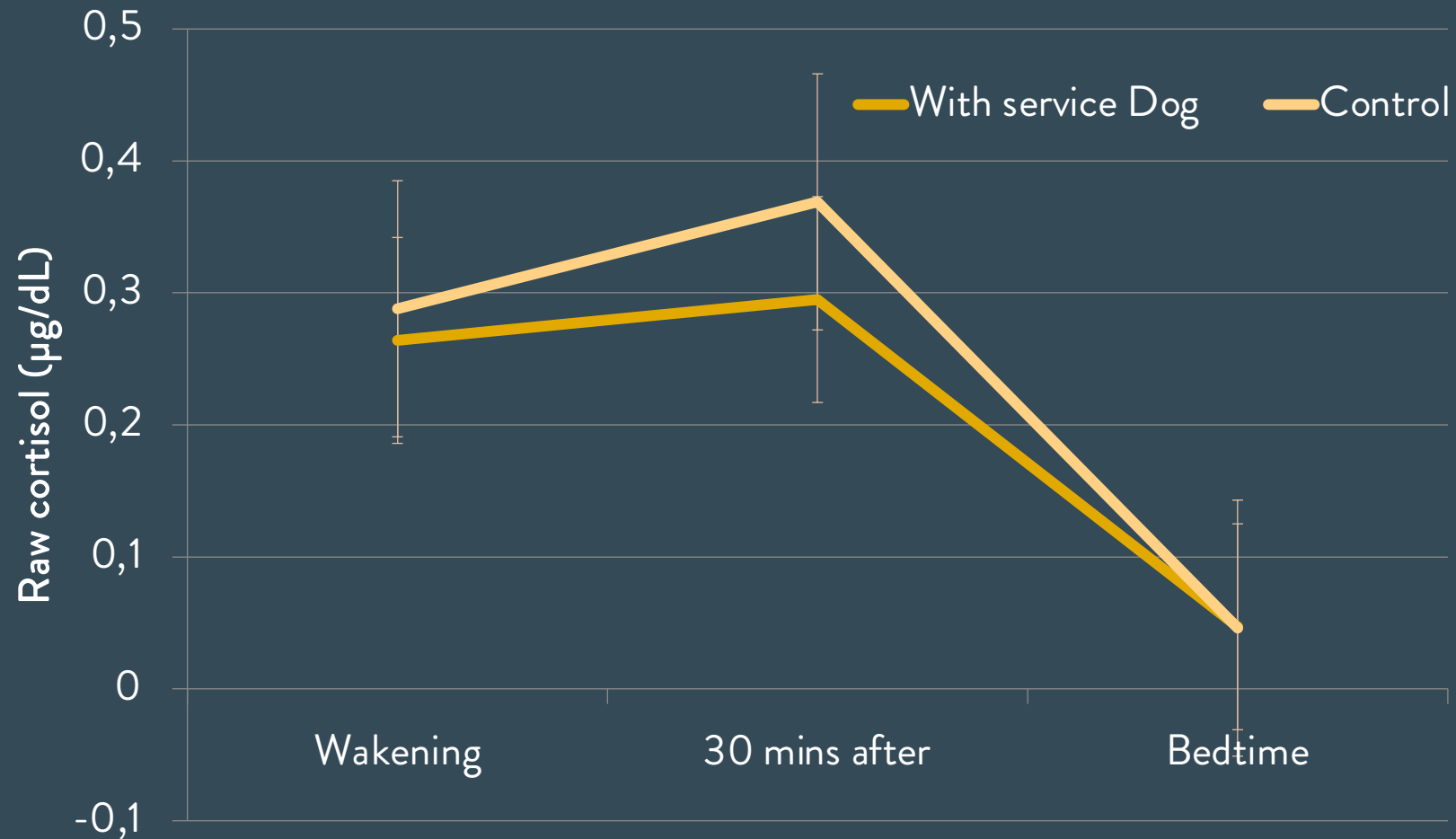
Results

Perception of parental stress

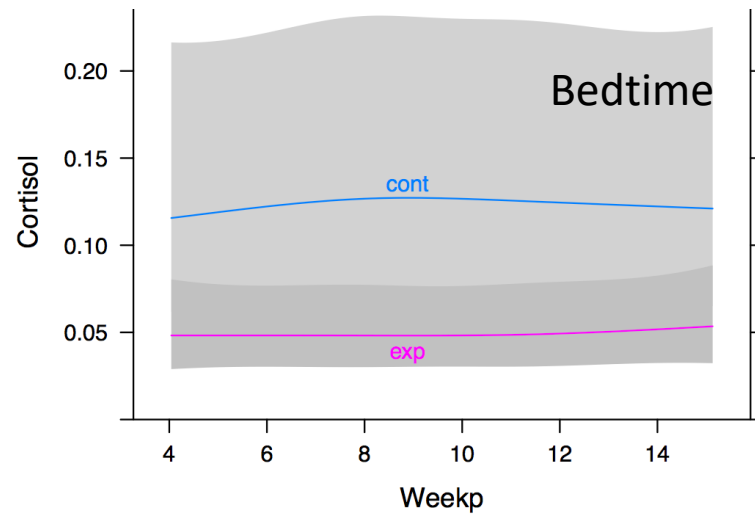
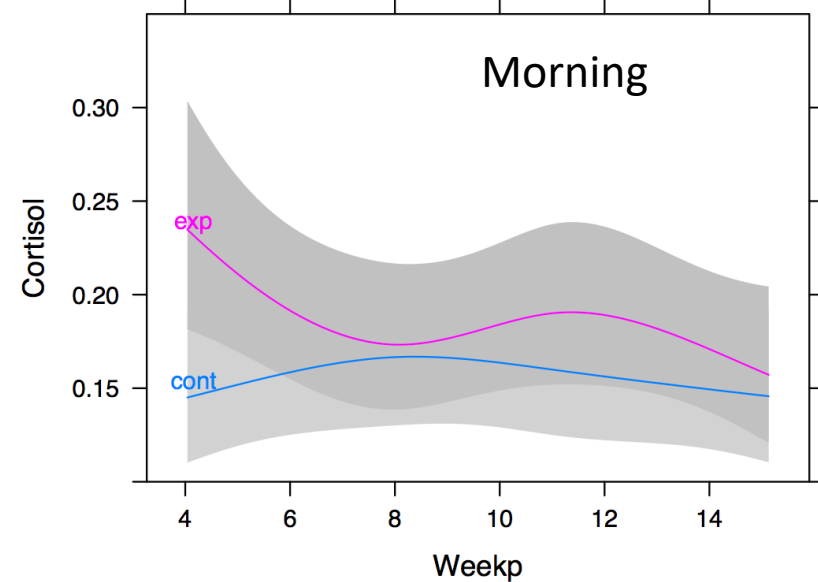
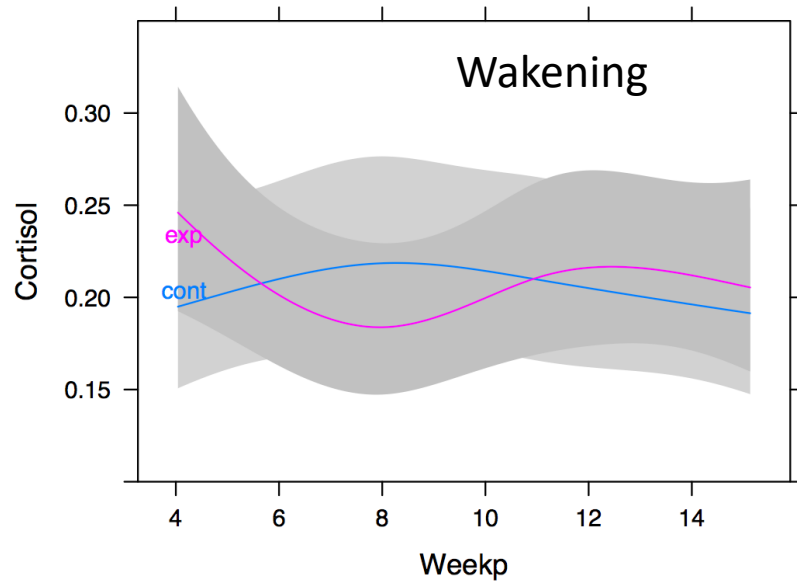
- 63.8% of the total sample reported significantly high levels of parental stress on the Parental Stress Index
- Parents from the control group perceived more parental stress related to their child's characteristics ($t = -2.36, p \leq 0.05$) and more dysfunctional parent-child interactions ($t = -1.98, p \leq 0.05$)



Salivary cortisol regulation before the dog's arrival



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



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