

Understanding Auditory Aversions in Williams Syndrome A Longitudinal Mixed Methods Approach



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Figure 1: Boy with WS

BACKGROUND

Development of auditory aversions

Aside from auditory fascinations and attractions, auditory aversions (Levitin et al., 2005) are highly probable to occur in Williams Syndrome (Levitin, 2005). In contrast to typical developed control groups, they tend to decrease over time (Klein et al., 1990).

Auditory aversive Symptoms

Levitin et al. (2005) describe two categories of auditory aversions:

- 1) *Odynacusis*, a 'lowered uncomfortable loudness level' (Phillips & Carr, 1998)
- 2) *Auditory allodynia* or *phonophobia*, the aversive experience of sounds not normally found aversive

OBJECTIVE

Further understanding of the individual experience and dynamic development of auditory aversions in order to conclude implications for tailored support.

METHODOLOGY

Explanatory Sequential Mixed Methods Design (Creswell & Plano Clark, 2011)

1) QUANTITATIVE

HOW do 1) the existence and 2) the intensity of auditory aversions change throughout one's lifetime?

STUDY 1

Longitudinal study
N = 98

Parent questionnaire
by Prof. Dr. Pankau

T1 PRE puberty
T2 POST puberty

ANALYSIS

Statistical Data Analysis
via SPSS

Nonparametric comparisons:
PRE versus POST

- 1) Existence: McNemar test
- 2) Intensity: Wilcoxon test

Purposeful Sampling (Schreier, 2010)

Cases with mean values all over
existence: PRE yes POST yes
intensity: PRE medium POST mild

2) QUALITATIVE

How is the EXPERIENCE of auditory aversions described by parents and individuals with WS?
WHY do auditory aversions change throughout lifetime?

STUDY 2

Annelie
Helena
Eva
Jan

Semi-structured
qualitative interviews
(Mey & Mruck, 2010)

Respondents:
parents & individuals with WS

ANALYSIS

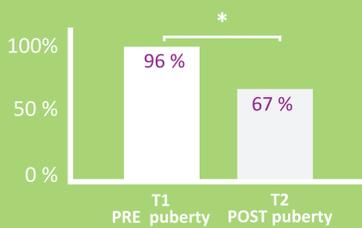
Qualitative Content Analysis
(Schreier, 2012)
Structuring, explanatory

Inductive Coding
via MAXQDA

RESULTS HOW

1) Existence relative frequency

Figure 2: Relative frequency of auditory aversions in T1 and T2. Inferential statistic: McNemar test



2) Intensity (mild, medium, severe)

Mean value (median)
PRE: medium
POST: mild

Difference significant ($p=.00$)

Auditory aversions exist during childhood in **96%** of cases

Incidence in typical developed children: **4%** (Hall, 2016)

Decrease of auditory aversions after puberty:

Decrease of intensity in **87%**
Complete remission in **34%**

RESULTS EXPERIENCE

Inductive Codes

Sounds found aversive

- Squeaking, hissing, whistling sounds
- Poor sound quality (e.g. speakers)
- Metallic sounds (e.g. electric guitar)
- Unexpected onset of sounds
- Noise, loudness itself

Sensory experience during exposure to aversive sounds

- Uncomfortable, but bearable
- Unbearable
- Fear/stress/overarousal
- Somatic pain
- Impulse to cry
- Aversive experience ends with end of exposure
- Being sick the following day

RESULTS WHY

Situative factors that naturally decrease aversions

- Situation is linked to positive memories / interests
- Aversions overlayed by positive, pleasurable stimuli (e.g. favourite food)
- Accordance with overall social situation
- Tolerating the aversion in favour of a trusted person
- Reliance, encouragement by a trusted person

Coping strategies

- Covering ears with hands
- Contacting a trusted person
- Seeking distance to source of sound
- Controlling the source of sound by oneself (e.g. using the vacuum)
- Self-motivated exposure in order to get used to the sound

Changes over time

- 1) Auditory sensitivity itself did not change
- 2) Decrease in aversive experience/behaviour
 - caused by coping strategies to handle aversive emotions related to sounds
 - for individuals with WS in families that empower exposure, overcoming fears, self-advocacy
- 3) Increase in aversive experience/behaviour
 - in times of stress and poor psychosomatic constitution

The typical auditory sensitivity did not change.

Positive social influences and learning strategies to cope with auditory aversive situations and the fears themselves lead to an decrease of aversive behavior.

CONCLUSION

Auditory perception itself was not found to have changed over time. Instead, the subjects **developed strategies to better cope with aversive emotions related to sounds**, thus lowering aversive reactions.

IMPLICATION FOR SUPPORT

Work on **strategies to help lower aversive emotions and anxieties** related to sounds. **Controlled exposure** could be helpful (Ale, McCarthy & Rothschild, 2015)

- 1) **Respect** Take sensitivity seriously, use gradual and sensitive exposure.
- 2) **Relationship** Work on trustful relationship with patient. Create a socially comforting situation.
- 3) **Self-advocacy** Explore the individuals own motivations and strategies to overcome fears. Support self-advocacy instead of solving the situation for the subject.
- 4) **Control** Let patient control the source of sound and exposure itself.

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Figure 1: with kind permission of the Williams Syndrome Association, USA.

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