

# Anxiety in people diagnosed with autism and intellectual disability: Recognition and phenomenology

## Background

Anxiety is reported as occurring frequently in individuals with autism, but varying prevalence estimates indicate uncertainties in identifying anxiety, especially in those with intellectual disability (ID).

## Objectives

The study explores the recognition of anxiety symptoms, and aims to provide suggestions for the assessment of anxiety in individuals with autism and ID.

The main research question is whether physiological arousal, which was the assumption, was more easily recognized than the cognitive aspect of anxiety in these individuals.

## Methods

Two separate samples, a community sample (62 individuals with autism + ID) and a clinical sample (9 individuals with autism + ID + psychiatric disorders) were assessed with anxiety items and general adjustment problems items from a screening checklist, the Psychopathology of Autism Checklist, PAC (Helverschou et al., 2008, 2009).

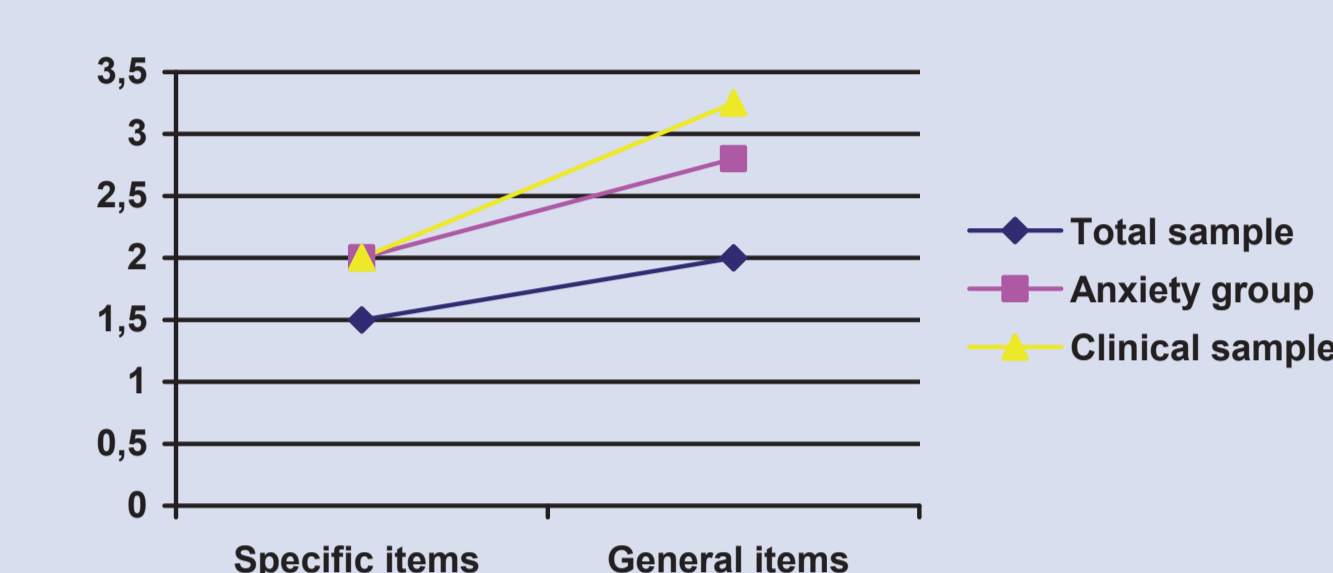
In addition, in the clinical sample checklist results were compared with clinical anxiety assessments.

## Clinical assessment of anxiety

1. The informants (care staff or family members) were provided with general information about anxiety disorders and anxiety symptoms by experienced clinicians.
2. All informants were interviewed as a group about the person's anxiety symptoms, to generate various descriptions of how anxiety could be observed in this particular person.
3. Each informant completed a list describing the signs and symptoms of anxiety in the target person.
4. All the individually obtained information was discussed in the group, supervised by the experienced clinicians. Consensus was established on all regularly observed anxiety symptoms in the target persons. This procedure resulted in a list of symptoms acknowledged by all informants.

## Results

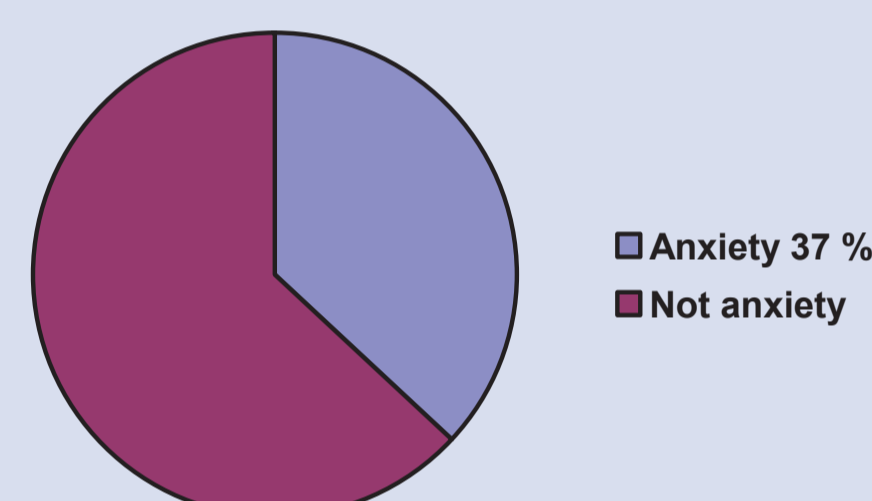
Figure 1: Average scores on the anxiety items in different groups



Rating scale 1 = no problem, 4 = severe problem  
Anxiety group: Participants with scores above cut-off ( $\geq 1.8$ ) on the anxiety disorder subscale + severe general adjustment problems (scores above cut-off  $\geq 2.0$ ) on the general adjustment subscale of the PAC.

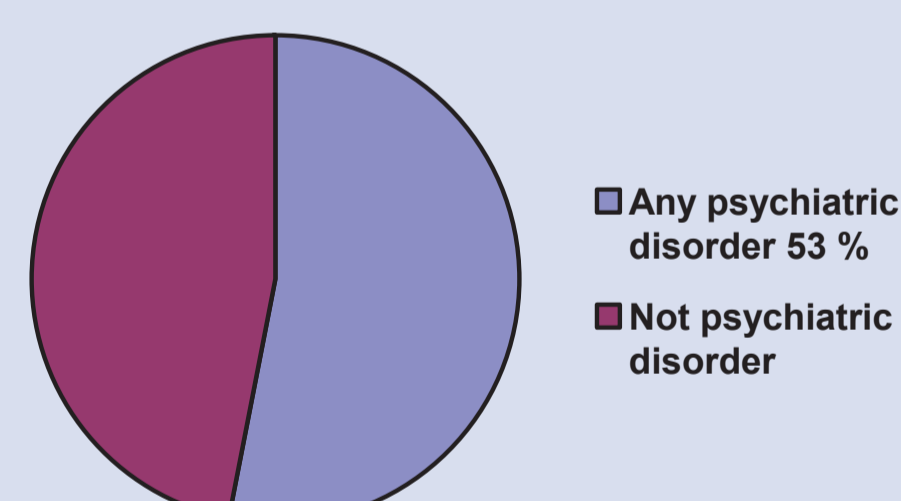
All three groups demonstrated a similar pattern, with highest scores on the two general items, Fear in unusual situations and Seems to be nervous, and lowest scores on the items assessing physiological arousal, Sweats Hyperventilates, Shivering and Distended pupils.

Figure 2: Anxiety problems in the community sample



Twenty-three participants (37.1%) in the community sample met criteria for anxiety problems i.e. scoring above cut-off ( $\geq 1.8$ ) on the anxiety disorder subscale and above cut-off ( $\geq 2.0$ ) on the general adjustment subscale in the PAC.

Figure 3: Psychiatric disorder in the community sample



Over half (53%) of participants in the community sample were identified as having at least one psychiatric disorder (i.e., >cut-off on any disorder-specific subscale and > cut-off on the general adjustment subscale of the PAC, Bakken et al., 2010).

## Comparing checklist and clinical anxiety assessment

Broad descriptions of anxiety symptoms were obtained for all 9 participants in the clinical sample. Descriptions similar to the items in the checklist were also used in the clinically obtained information. This made it possible to compare the two assessment approaches.

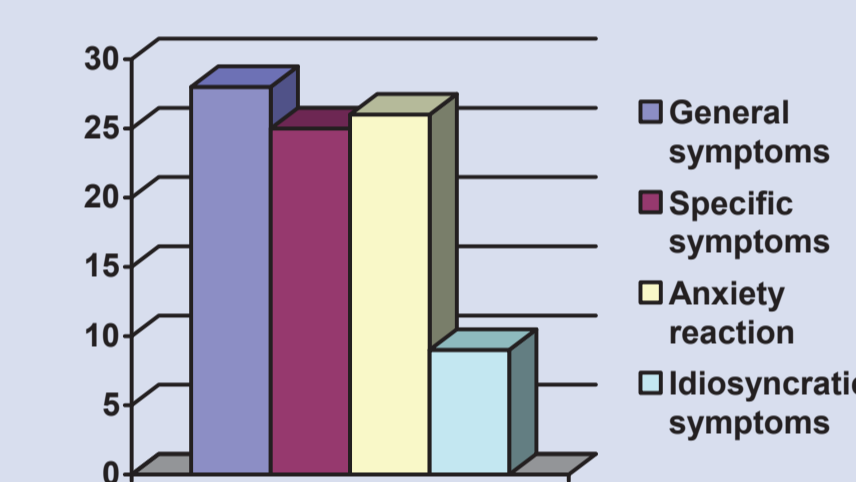
Table 1: PAC vs. Clinical Assessment, N=9

- PAC: All 9 participants obtained GAP scores above cut-off
- PAC: Only 7 participants obtained anxiety scores above cut-off
- Diverging reports between the PAC and clinical assessment in 4 participants; i.e. PAC items with a score of 1.00, but the same symptom described as a sign of anxiety in the clinical assessment
- In all cases diverging reports were related to specific items assessing physiological arousal: Shivering, Hyperventilating, Distended pupils, and Sweats.

GAP: general adjustment problems

All clinically obtained anxiety symptoms occurred regularly in the participants, which may correspond to checklist ratings of 2 or higher (a minor, moderate or severe problem).

Figure 4: Distribution of anxiety symptoms identified by clinical assessment



The anxiety symptoms reported in the clinical assessment included 36 different symptoms.

### The symptoms were arranged in four categories:

1. General symptoms: descriptions of the informants' general impression of the probands' distress, worries and well-being
2. Specific items: descriptions of physiological arousal
3. Anxiety reactions: descriptions of actions indicating physiological arousal
4. Idiosyncratic symptoms: descriptions of atypical actions, indicating physiological arousal

Most of the symptoms described were typical anxiety symptoms, i.e. anxiety symptoms often described in individuals without autism. Only nine idiosyncratic symptoms were reported, i.e. unusual expressions of anxiety. The total number of idiosyncratic symptoms is significantly lower than in the other categories (Robust Rank Order Test,  $\alpha = 4.27 p < .01$ )

## References

- Bakken, T. L., Helverschou, S. B., Eilertsen, D. E., Heggglund, T., Myrbakk, E., & Martinsen, H. (2010). Psychiatric disorders in adolescents and adults with autism and intellectual disability: A representative study in one county in Norway. *Research in Developmental Disabilities, 31*, 1669-1677.
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- Helverschou, S.B., Bakken, T.L., & Martinsen, H. (2009). The Psychopathology in Autism Checklist (PAC): a pilot study. *Research in Autism Spectrum Disorders, 3*, 179-195.
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## Conclusions

- Physiological arousal may not be as readily observable as assumed in individuals with autism and intellectual disability.
- Anxiety occurs frequently in this population.
- This support previous findings that the close association between anxiety and other psychiatric disorders also applies to individuals with autism and ID.

## Clinical implications

Anxiety may be recognized in this group by similar symptoms as in individuals without autism, but the difficulties in recognizing signs of physiological arousal indicate the importance of increased clinical awareness of such symptoms.

When using screening checklists to identify individuals in need of further psychiatric assessment, anxiety signs as well as signs of general adjustment problems should be included. However, for diagnostic purposes and for monitoring treatment, individual anxiety assessment conducted in cooperation with clinicians, care staff and family members who know the individual well is indicated.

## Contact:

Sissel Berge Helverschou  
The National Autism Unit, Oslo University Hospital  
Box. 4950 Nydalen, NO-0424 Oslo, Norway.  
E-mail: shelvers@ous-hf.no