

Stress, anxiety, and psychotic experiences in adults with autism spectrum disorder

Citation for published version (APA):

van der Linden, K. F. J. T. (2021). *Stress, anxiety, and psychotic experiences in adults with autism spectrum disorder: an observational study in the context of daily life*. [Doctoral Thesis, Maastricht University]. Gildeprint Drukkerijen. <https://doi.org/10.26481/dis.20211011kl>

Document status and date:

Published: 01/01/2021

DOI:

[10.26481/dis.20211011kl](https://doi.org/10.26481/dis.20211011kl)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
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Impact paragraph

To bridge the gap between science and society, the social impact of the main findings of this thesis will be addressed in this paragraph.

Aims and findings of this thesis

Co-occurring psychiatric symptoms are highly prevalent in adults with autism spectrum disorder (ASD) compared to the general population. Therefore, the present thesis aimed to identify underlying psychological and biological mechanisms and potential risk factors that may contribute to the emergence of these symptoms in adults with ASD.

With daily life electronic self-monitoring studies, based on the experience sampling method (ESM), associations were examined between minor daily stressors and (i) negative mood (emotional stress reactivity), (ii) the stress hormone cortisol (biological stress reactivity), and (iii) psychotic experiences (psychotic stress reactivity) in men and women with ASD and without ASD (i.e., controls). In addition, associations between daily life anxiety and three social contexts (i.e., being alone, with familiar people, or less familiar people) were investigated in adults with ASD and controls. Lastly, the risk factors and psychological mechanisms behind these associations were further studied, by examining self-esteem and negative appraisals of social company in relation to daily life anxiety and by examining neuroticism in relation to emotional stress reactivity.

The self-monitoring was done with a smartphone application which was used by 50 adults with autism and 51 controls. On 10 semi-random occasions per day, when the application signaled to do so, participants not only filled out short questionnaires about their mood, self-esteem, symptoms, appraisals, and experiences but also about (social) activities and other contexts. At the same time, they collected saliva for cortisol measurements.

The main findings were that adults with ASD experienced elevated stress levels, negative mood, and psychotic experiences, but similar cortisol levels, compared to controls. They also experienced increased emotional and psychotic stress reactivity, but no altered cortisol response to stress (biological stress reactivity). Altogether, the results indicate that the basal levels of stress, negative mood, and psychotic experiences in adults with ASD are increased with respect to controls. Besides that, there was evidence that stress is associated with an increased negative mood and psychotic experiences in adults with ASD. This heightened sensitivity to daily life stress highlights the need for stress reduction interventions in this population.

Moreover, adults with ASD reported higher daily life anxiety than controls. The highest anxiety levels in the ASD group were found when being with less familiar people, which was significantly different from being alone or being with familiar people. Although controls had the highest anxiety levels when being alone, there were no significant differences between the three social contexts.

Regarding the risk factors, it was found that a stronger emotional stress reactivity was present in individuals with ASD scoring high on neuroticism relative to those with low neuroticism.

Significant associations between low self-esteem and MA for all three social contexts were shown in both groups, with the strongest association for being with less familiar people in the ASD group and for being alone in the comparison group. Negative appraisals of company was significantly associated with MA in both groups but it did not matter whether participants were in the company of familiar or less familiar people.

These findings on these transdiagnostic factors show the importance of targeting neuroticism, self-esteem, and negative appraisals in the treatment of negative mood and social anxiety in adults with ASD.

In this thesis, both men and women were investigated and, in some studies, we hypothesized sex differences, which was not confirmed for either emotional, psychotic, or biological stress reactivity. However, these results have to be interpreted cautiously since the groups may have been too small to investigate sex differences. Hence, additional research is needed to investigate the effect of sex on stress reactivity in ASD.

The relevance of this thesis

ASD is known to be an (almost always) lifelong complex neurodevelopmental condition, with a significantly lower quality of life compared to non-ASD individuals¹. Currently, one in 54 children is diagnosed with ASD². In the next few years, many of these children will transition into adulthood, a life phase that, overall, has been much less investigated in the field of ASD. Adults with ASD are often confronted with greater health needs than adults without ASD³. The health care costs of adults with ASD are 20% higher compared to adults with attention deficit disorder, and double costs compared to the general population⁴. More specifically, it has been shown that adults with ASD without an intellectual disability cost society approximately €1.15 million during their lifespan⁵. The largest contributors to total costs were medical costs and individual productivity loss⁵. The economic burden is expected to increase in the following years due to the rising prevalence of individuals diagnosed with ASD⁶.

To make the best use of societal resources, suitable interventions are needed⁵. However, mental health problems are still poorly understood and understudied in adults with ASD⁷. Besides, it has recently been shown that adults with ASD reported that mental health professionals had too little understanding and knowledge of co-occurring psychiatric symptoms⁸. Therefore, by investigating subclinical psychiatric symptoms (i.e., symptoms that are not yet clinically visible) and underlying mechanisms in everyday life, the present thesis contributes to a better understanding of mental health problems in this population. This may add to the development of person-tailored and cost-effective prevention strategies. To date, preventive strategies for adults with ASD are mainly centered around ASD symptoms and delivered via psychoeducation, social skills training, and employment and study support⁹. This demonstrates the need for more attention toward preventive strategies related to psychiatric comorbidity. The present thesis, showed the usefulness of the ESM to detect subclinical psychiatric symptoms in adults with ASD. The ESM may have great potential for clinical usage in this population to develop self-insight in previous implicit patterns of thought and behavior. Due to the high rates of depression and (social) anxiety in

adults with ASD¹⁰, it may be relevant to screen for negative mood and anxiety in the daily life of adults with ASD. Screening for psychotic experiences, however, may not be necessary for everyone since these experiences are often transient¹¹. However, it might be beneficial to screen for psychotic experiences in specific subgroups; those displaying high levels of stress, or those who experienced a psychosis previously. If necessary, it can be decided to treat elevated subclinical symptoms with cognitive-behavioral therapy. Nonetheless, increased self-insight, may lead to small adjustments in daily life (e.g., asking for support when meeting with less familiar people) or may lessen distress related to these symptoms because of increased awareness and acceptance.

Target audience

First, the results of this thesis are relevant for adults with ASD and their caregivers. Psychoeducation nowadays plays an important role in the treatment of adults with ASD but is quite focused on the core ASD features. Learning more about their psychological vulnerabilities and resilience beyond the autism spectrum may play an important role in self-awareness, self-acceptance, self-compassion, and resilience-strengthening techniques. For the same reasons, these findings are equally relevant to younger people with ASD. Based on the present results, it may be beneficial for people with ASD to pay extra attention to stress reduction by using stress management techniques that can be easily applied at home via a wide range of smartphone applications, such as relaxation techniques, yoga, or mediation. Also, the present results have shown that anxiety may lessen when being with familiar people. Therefore, people with ASD who experience high anxiety levels during the day could benefit from social support from a family member, partner, or close friend. And if possible, it is recommended to ask for social support when meeting someone for the first time, e.g., a new mental health professional.

Additionally, the current findings may help caregivers and important others to enhance insight into how to support adults with ASD in daily life. For example, this thesis has shown the impact of minor daily stressors (especially unpleasant events) on negative mood and psychotic experiences. Unpleasant events may not always be preventable, but caregivers could help people with ASD to cope better with these hassles. It might help to talk the event through step by step, providing help restructuring the day, or by applying a stress management technique, e.g., a mindfulness exercise. With respect to daily life anxiety, caregivers are advised to accompany people with ASD who experience high levels of anxiety when meeting with less familiar people. This may reduce anxiety and give some extra comfort. Afterward, it may be helpful to talk things through and especially point out what went well to improve their self-esteem. More research is needed to understand the findings on negative appraisals of others but it is recommended to take notice that people with ASD may be more vulnerable to experience negative appraisals during social interactions compared to those without ASD.

The findings of this thesis are also beneficial for mental health professionals and researchers. Regarding the latter, we demonstrated the relevance to investigate everyday experiences and symptoms by using a self-monitoring application. However, there is still much to learn about the role of stress sensitivity in psychiatric comorbidity in ASD and

longitudinal research may be needed. Also, there is a need for studies investigating larger samples to further explore the effect of sex and (personality) traits on co-occurring symptoms in adults with ASD. Additional research implications have been described in **chapter 7**. For mental health professionals, the results address the importance of a more transdiagnostic approach regarding mental health issues in adults with ASD. By identifying underlying mechanisms of transdiagnostic factors in ASD such as self-esteem and neuroticism, transdiagnostic interventions acting upon these factors may have a simultaneous effect on multiple symptom domains. The effectiveness of such interventions needs to be further investigated in the near future. At this moment, mental health professionals may want to consider screening for a variety of traits, symptoms, and their causative and maintaining factors as described in this thesis. Both traditional questionnaires and self-monitoring apps can be used to do so, and the results of this thesis show that the combination of both instruments, because of their complementary, is clearly relevant in terms of diagnostic approaches. Also, the importance of stress reduction in adults with ASD has been demonstrated. Although the literature on treatment interventions in this group is limited, there is some evidence that cognitive-behavioral therapy¹² and acceptance and commitment therapy¹³ may lead to a significant stress reduction. See for more details the paragraph on clinical implications in **chapter 7**.

Knowledge dissemination

The current results were or will be shared via (open-access) scientific publications in peer-reviewed journals and a link to these studies will be shared with the autism community via social media. Additionally, results were (and will be) presented to mental health professionals and researchers on different occasions (conferences, symposia, or online presentations), which made it possible to discuss the findings. This led to both interesting new research ideas and ideas on how to implement these results in clinical practice. Besides, I work as a psychologist in an outpatient center for adults with ASD and we will be discussing how to implement the results into clinical practice. As it is common in this center, adults with ASD will participate in these discussions. The outcomes will also be shared with the members of 'Stichting CASS18+', a broad network for mental health professionals working with adults with ASD throughout the Netherlands.

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