

ASSESSMENT OF THE FEMALE ASD PHENOTYPE: THE M-ASD QUESTIONNAIRE

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Background

ASD diagnostics are based mainly on the male ASD phenotype. People with a **female ASD phenotype** are often under- or misdiagnosed. This phenotype seems more subtle due to better camouflaging techniques (Lai et al., 2011), a higher social motivation and gender specific preoccupations (Hiller et al., 2014). However, an ASD diagnosis is indisputably present.

A questionnaire taking into account the female ASD phenotype could aid in a faster identification of these women, but also of men with this more subtle phenotype. This could lead to a better prognosis, prevent secondary problems, reduce family stress and societal costs (García-Primo et al., 2014).

In 2016, we developed the **Miss-ASD questionnaire (M-ASD)** (Dutch). It consists of 120 items derived from literature search on female ASD expressions, clinical impressions of the authors, and data analysis of sex differences in adults with ASD on other questionnaires. The M-ASD **covers 6 domains**: Social interaction and communication, Rigidity, Coping and camouflaging, Sensory issues, Information processing, and Miscellaneous.

In pilot testing, the M-ASD already seemed to be **suitable for measuring ASD characteristics** in general; the correlation with the AQ was high. Also, differences between men and women with ASD were higher for the M-ASD domains, than for AQ scales (INSAR, Grondhuis et al., 2018). Women with ASD reported higher scores on all domains, and most profoundly on better camouflaging techniques and more sensory issues.

Objectives

Our goal is to **ameliorate the case identification of patients with more subtle ASD**. Since the findings from the pilot testing were promising, we wanted to **shorten the M-ASD**, for clinical use. In doing so, we wanted to (1) include the opinions on the items of both ASD patients and practitioners, and (2) update some M-ASD items, since this is a highly evolving research field.

Methods

Items were judged based on statistical and qualitative analyses.

For the **statistical analyses**, the data of adults suspected for ASD were analyzed. They all underwent an extensive ASD diagnostic assessment, including the completion of the M-ASD. The research group consisted of **183 patients** (age: $M = 35.07$, $SD = 12.54$), of which ultimately 83% received an ASD diagnosis. There were 88 women with ASD, 63 men with ASD; 25 women and 7 men received other psychiatric diagnoses (non-ASD group).

There were **different subgroups** (see Table 1); differences between women with ASD and women without ASD (pink group) were marked as the most informative for the use of this instrument in clinical practice.

Qualitative analyses were based on two focus groups: (1) 3 women and 1 men with ASD, and (2) 4 psychologists with elaborate ASD expertise. All gave feedback on content, wording and layout of the questionnaire. Also, new literature (2016-2018) was reviewed and a test theorist was consulted.

For both statistical and qualitative results, **M-ASD items were categorized as 'keep', 'reject' or 'doubt'**. Items were there was full agreement for 'keep' and 'reject', were judged accordingly. When there was no full agreement, judgement was based on consensus after discussion between all researchers (for some examples, see Table 2). Thereby, statistics were considered as more decisive (based on individual item analyses, including discriminant indices and Fisher-Z exact tests).

Table 1: Number of participants

Group	ASD	Non-ASD	Total
Women	88	25	113
Men	63	7	70
Total	151	32	183

Table 2: Judgment of M-ASD items

Item	Judgement statistical analyses	Judgement qualitative analyses	Decision
I'm very tense in social situations (2)	Keep	Keep	Accepted, no changes
I find it difficult to take into account social hierarchy (11)	Keep	Reject	Accepted, no changes
I am (or people say I am) too harsh or direct (23)	Keep	Doubt	Accepted, reformulation
There is little variation in my eating patterns (53)	Reject	Keep	Rejected
I find it hard to throw away things (59)	Reject	Reject	Rejected
I don't like visits (going or receiving) (3)	Doubt	Doubt	Rejected

Results

ASD patients scored higher than non-ASD patients on every M-ASD item. Based on the combination of statistical and qualitative analyses, the **best 47 items were retained**. Among them are the items that differentiated the most clearly between the ASD and non-ASD group, and more specifically between ASD and non-ASD women (DI = 0.3-0.7, significant Fisher test). But also, items that could discriminate best between ASD women and ASD men; the latter concern mostly sensory and camouflaging issues.

Based on the focus groups and new literature, 15 items of the 47 items were rephrased and **7 novel items**, mostly on camouflaging, were added.

The **shortened M-ASD consists of 54 items**.

Conclusions

The new, abbreviated version of the M-ASD is considered to be more appropriate for clinical use than the pilot version.

Most ASD screening instruments are developed and validated in the general population. Those instruments perform less well in clinical practice, in terms of sensitivity and specificity (Bezemer et al., submitted). This is not the case for the M-ASD. Follow-up research will focus on the **further validation and standardization** of this promising new screening tool in a larger clinical sample, also including non-ASD groups.

Note: Since there are also men with a more subtle 'female' ASD phenotype, we changed the name of the Miss ASD questionnaire in the M-ASD, which stands for not only Mrs. but also Mr.

References

Bezemer, M.L., & Blijd-Hoogewys, E.M.A. (2016). *Miss ASD*. Groningen: INTER-PSY.



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