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Short Report



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A co-designed psychoeducation for older autistic adults-a multiple case study

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#### **Abstract**

There are currently no old-age specific interventions for autistic adults. Therefore, in this explorative study, we examined the possible effects of a co-designed psychoeducation program for older autistic adults (55+years), with a multiple case study design (N=9, age 56-73 years; Netherlands Trial Register (code Trial NL5670)). For each participant, also a person close to them (a proxy) participated. This allowed us to calculate a discrepancy score regarding autistic traits and cognitive challenges. The main hypothesis was that our program, delivered after general psychoeducation, would result in a discrepancy reduction between self and proxy reports. However, contrary to our hypothesis, we observed neither intervention effects on our primary outcome measures (discrepancy scores) nor the secondary outcome measures (mastery, self-efficacy, self-esteem, self-stigmatization, quality of life, and hope and future perspectives). Thus, despite co-designing the current intervention, the results were not promising. However, the positive feedback and suggestions of the participants make developing an improved version of a specific psychoeducation program for older autistic adults still a worthwhile pursuit.

#### Lay abstract

After receiving an autism diagnosis by a clinician, psychoeducation (i.e. information regarding autism) is often offered. However, older autistic adults (55+years) may need specific information about the challenges they face in daily life as they are in a specific life phase. A psychoeducation program for this specific age group does not exist yet. We first developed such a program together with autistic adults and clinicians working with autistic people, after which we tested the program with nine autistic adults (56–73 years) and someone close to them (so-called proxy). Before testing the program, we determined together with autistic older adults what they thought should be the outcome of this intervention in order to state whether it was, indeed, a useful intervention. Earlier studies found that autistic people often think differently about their own autistic characteristics than their proxy. A reduction of this difference could increase mutual understanding. Therefore, the main hypothesis was that the program would decrease this difference with respect to autistic characteristics and cognitive challenges (e.g. memory problems). Another hypothesis was that the program would have a positive impact on a series of other factors, such as self-esteem. The results showed that the program did neither decrease the difference in insight nor the other tested factors. Nonetheless, we believe it is important to keep on working on a psychoeducation program for older autistic adults, because participants informed us the program had still helped them in certain ways and they gave helpful feedback for improvements of the program.

## **Keywords**

autism, co-design, intervention, old age, psychoeducation

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Worldwide, approximately 1% of the people meet criteria for an autism spectrum disorder (ASD) diagnosis by the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013), irrespective of age (Lai & Baron-Cohen, 2015). In 2019, about 703 million people in the world were over 65 years old (United Nations, 2020), which indicates that there are roughly 7 million older autistic adults globally. This indicates that a substantial group of older autistic adults could benefit from research regarding the challenges they may encounter in their daily lives. However, research benefiting older autistic adults is scarce. Therefore, we tested whether a co-designed psychoeducation program directed at autistic adults over 55 years is beneficial.

Before specific personalized interventions start, people who are recently diagnosed receive information within a formalized psychoeducation program to explore how a specific diagnosis is related to someone's past, present, and future experiences. Psychoeducation related to, for example, schizophrenia and attention-deficit/hyperactivity disorder (AD/HD), is shown to improve quality of life (QoL; Hoxhaj et al., 2018; Xia et al., 2011), and to decrease self-stigmatization (Karidi et al., 2010). Unfortunately, there is only little research including psychoeducation for autistic adults and findings seem inconsistent (e.g. Backman et al., 2018; Spek & Boxhoorn, 2014).

An additional psychoeducation might, however, be beneficial for older autistic adults as there is a large discrepancy between self- and other-reported ratings of autism characteristics (Lever & Geurts, 2018). This observed discrepancy could reflect that people close to the autistic adults (i.e. their proxy) misunderstand the specific needs of autistic adults when trying to offer support. Moreover, according to the autistic adults and clinicians who co-designed this study, such a difference in perspective may even lead to misunderstandings or friction between them. Our co-designed psychoeducation program "Older and Wiser" (van Heijst & Geurts, 2016) is, therefore, aimed at improving knowledge for older autistic adults themselves as well as for their proxies. Thus, a reduction in the discrepancy between autistic adults themselves and their proxies is considered to be an important aspect of determining whether or not the psychoeducation program was successful.

We hypothesize that this co-designed psychoeducation program will primarily lead to improvement on primary outcome measures (i.e. an improved insight in the autistic characteristics and the potential cognitive challenges, for participants and their proxy). Furthermore, we hypothesize that secondary effects of the program include improved mastery, and increased self-efficacy, self-esteem, QoL, and hope and future perspectives. Finally, we hypothesize that self-stigmatization decreases. We will test these hypotheses by means of a multiple case study, as this

design can provide both more qualitative as well as more in-depth information regarding the understudied and complex research field of autism in older adults.

# **Method**

## **Participants**

Participants were nine autistic older (aged 56–73 years, mean (M)=65.00, standard deviation (SD)=5.59) adults (eight males, one female), recruited through two locations of the Mental Health Care institute "Dr. Leo Kannerhuis," in Amsterdam and Doorwerth. Proxies were nine people chosen by the participants: seven were participants' partners, one was a participants' daughter, and one was a caretaker. The time that the participants knew their proxies ranged from 7 months to 47 years.

Participants received a clinical ASD diagnosis from a specialized multidisciplinary autism assessment team, had no known co-occurring conditions which were a contraindication to follow psychoeducation, were fluent in Dutch, and had already received general psychoeducation.

#### Materials

Psychoeducation program "Older and Wiser" (van Heijst & Geurts, 2016): based on regular aging psychoeducation program-, aging-, and autism research plus brainstorm sessions with autistic adults, clinicians, and scientists, we determined (a) the program (including guidelines for the number of participants, number of sessions, duration of sessions, and subjects to include in the program) and (b) the primary and secondary outcome measures. Based on a pilot study (N=3) to test the provided manual, the feasibility of the assignments, and the measures used, the psychoeducation program and outcome measures were fine-tuned and finalized (van Heijst & Geurts, 2016). An overview of themes covered by the program can be found in Table 1.

The program consisted of six weekly meetings of 2h each, designed for four to six participants per group and with two trainers per group. The program was developed as an additional psychoeducation program, specifically dealing with aging when autistic. The topics were tailored to the age group. Participants had to read background information in an appendix and needed to complete assignments in a workbook before each meeting. In order to increase consolidation, transfer of knowledge, and mutual understanding, a proxy was not just receiving assignments and questionnaires but was also invited to one of the meetings. This was restricted to one meeting to ensure that the autistic adults were in the majority in most of the meetings which enhances the likelihood that they feel comfortable, speak freely, and learn from one another. Every meeting started with reviewing the past week, after which current topics

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**Table 1.** Information regarding the content of the weekly meetings of the psychoeducation program "Older and Wiser" (van Heijst & Geurts, 2016), the set-up of the study, and participants' feedback.

Study phase	Week	Primary OM	Secondary OM	Theme	Content
Baseline	I			Informed consent, inclusion check	Inclusion check: 55+ years old. Confirmation of autism diagnosis: ADOS. <sup>a</sup> IQ > 80: DART <sup>b</sup> or MoCA <sup>c</sup> score above cut-off.
	2	X	X		
	3		X		
	4		X		
	5		X		
	6	X	X		
Intervention	7		X	Autism cognitive theories	DSM classification, cognitive theories, prevalence, gender differences
	8		×	Cognitive aging part I: memory	Cognitive aging, differences in aging processes between autistic and non-autistic people, aging and memory, memory in autistic people, compensation techniques.
	9		X	Cognitive aging part II: autism-specific theories	Aging when autistic with regards to ToM, double empathy, central coherence, executive functions.
	10		X	Daily life	Health, daytime activities, living situation.
	П		X	Social network	Characteristics of the social network, changes in the social network when one ages, social resilience.
	12	X	X	Future	Coping strategies, life purpose, reviewing and looking ahead.
After intervention				Feedback	For example: useful contact with other participants, improved self-confidence.

ADOS: Autism Diagnostic Observation Schedule; IQ: intelligence quotient; OM: outcome measures; DSM: Diagnostic and Statistical Manual of Mental Disorders; MoCA: Montreal Cognitive Assessment; ToM: theory of mind; DART: Dutch Adult Reading Test.

Specific data on ethnicity and socioeconomic status were not recorded.

\*Lord et al. (1989).

were discussed, and at the end of each meeting, participants were asked to (a) answer content-related questions, (b) discuss what goes well in daily life and what could improve, and (c) evaluate the program of that specific meeting and the trainers.

Primary outcome measures. Two questionnaires, namely, shortened Autism Spectrum Quotient (AQ) (AQ-28, 28 questions on a 4-point Likert-type scale) and the Cognitive Failures Questionnaire (CFQ, 25 questions on a 5-point Likert-type scale) were administered both to the participants and their proxy. Higher total scores reflect, respectively, more autism traits or more cognitive failures. The difference scores between the proxy and the self for the AQ-28 and CFQ were the dependent measures. The rational is that a smaller difference between self and proxy reflects better mutual understanding of the challenges the autistic person might experience.

Secondary outcome and additional measures. With six self-report questionnaires, we measured mastery, self-efficacy,

self-esteem, internalized stigma, hope and future perspectives, and QoL.<sup>2</sup> In order to provide context for the interpretation and discussion of the intervention findings on both the primary and secondary outcome measures, participants were asked to indicate any (major) life changes they had experienced during the study, to what extent the psychoeducation had (not) helped them (7-point Likerttype scale), and if they had any recommendations.

# **Procedure**

This exploratory study was carried out according to a multiple case study design. All questionnaires were sent through emails. We aimed to minimize missing data by calling or emailing participants who did not fill out questionnaires on the designated day. During the intervention phase, the older autistic adults participated in the psychoeducation program "Older and Wiser" (van Heijst & Geurts, 2016), provided by experienced trainers from the participating mental health institutions. Information for the trainers on how to run the groups was provided in a trainer's

bSchmand et al. (1992)

<sup>&</sup>lt;sup>c</sup>Nasreddine et al. (2005).

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#	ISMI	RS	SE	Phy QoL	Psy QoL	Social	Environment	RSE	PMS	Satisfaction (1–7)	Life events (yes/no)
ī	=	+	=	=	=	_	+	+	+	4	No
2	=	=	=	=	=	_	+	=	+	3	No
3	=	=	=	=	=	=	_	=	=	5	Yes
4	=	=	=	=	=	=	=	=	=	4	Yes
5	=	-	=	_	+	+	_	=	=	6	No
6	=	=	=	_	=	_	+	=	=	6	No
7	=	=	=	=	=	+	=	=	=	5	Yes
8	=	=	=	=	=	+	+	=	+	?	?
9	=	=	=	=	+	=	+	=	+	7	7

**Table 2.** An overview of RCI changes of the secondary outcome measures for every participant, and their satisfaction rating of the psychoeducation program, and self-reported negative life events.

ISMI: Internalized Stigmatization Scale of Mental Illness; RS: Remoralization Scale; SE: Generalized Self-Efficacy Scale; Phy QoL: World Health Organization Quality of Life Domain I Physical Health; Psy QoL: World Health Organization Quality of Life Domain 2 Psychological Health; Social: World Health Organization Quality of Life Domain 3 Social Relationships; Environment: World Health Organization Quality of Life Domain 4 Environment; RSE: Rosenberg Self-Esteem Scale; PMS: Pearlin Mastery Scale; Satisfaction: subjective Likert-type score that indicates if the psychoeducation had helped the participant; Life events: participants could state whether they had experienced any other (major) life events study period, besides participating in the study.

# means participant number; = means no RCI difference; + means RCI improvement; - means RCI decline; ? means missing score.

manual. Treatment fidelity was not assessed in this study. All participants gave informed consent, and the study was approved by the ethics committee of the University of Amsterdam (reference code: 2015-BC-4464). An earlier set-up of this study was registered at the Netherlands Trial Register (code: NTR 5907) but could not be carried out due to practical issues. Based on that randomized controlled failed trial, design adjustments were made and this adapted study was again registered (code Trial NL5670).

#### Community involvement

Autistic adults and clinicians working in the autism field contributed to the study through their participation in a think tank, in which they gave input on various detailed decisions that were made throughout the research project.

#### Results

### Primary outcome measures

First, we observed no significant difference in the AQ discrepancy scores for the baseline phase (M=7.11, SD=6.25) and the intervention phase (M=6.78, SD=4.79), t(8)=0.165, p=0.873. This implies that the psychoeducation program did not significantly improve mutual insight in autistic traits. Moreover, the Bayes factor (null/alternative; BF<sub>01</sub>) suggested that it was 3.07 times more likely to observe the data under the null hypothesis (i.e. no intervention effect) than under the alternative hypothesis (i.e. an intervention effect). This result is in line with the aforementioned paired samples t-test.

Second, there was also no significant difference in the CFQ discrepancy scores on the baseline phase (M=9.56, SD=8.49) and the intervention phase (M=6.89, SD=6.05),

t(8)=1.91, p=0.092. This implies that the psychoeducation program did not significantly improve mutual insight in cognitive challenges. However, as BF<sub>01</sub>=0.86, it is only 0.86 times more likely to observe the data under the null hypothesis than under the alternative hypothesis. The Bayes factors between 0.33 and 3 are considered as indicating "data insensitivity." Therefore, this result is undecided.

#### Secondary outcome measures

Following Maric et al. (2015), estimated phase end points were used to assess reliable change, where a reliable change index (RCI) > +1.96 or < -1.96 indicated reliable change. We found that one participant showed significant improvement on three of the outcome measures (i.e. at least half of the outcome measures), namely, hope and future perspectives, QoL, and mastery.

The other eight participants showed improvement on only two or less of the outcome measures. The improvement was mostly on one or more of the QoL domains.

The results of the quantitative questionnaire that participants filled out after the study showed, among others, to what extent participants did feel like the psychoeducation program had helped them (7-point Likert-type scale satisfaction score, M=4.7, SD=1.1).

Table 2 shows an overview of the RCI scores for each participant and the satisfaction scores. Please note that two participants did not answer the satisfaction question after the study. For the seven remaining participants, there is no clear relation between improvement on the secondary outcome measures and subjective treatment satisfaction. The last column shows whether participants indicated if they experienced any (major) life events besides participating in the study.

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#### Discussion

Contrary to our expectation, the co-designed psychoeducation program for autistic adults did not reduce the discrepancy of insight between participants and their respective proxy in neither one's autistic traits nor their experienced cognitive failures. Moreover, less than half of the participants improved on at least half of the secondary outcome measures. We argue that it would be premature to conclude that a psychoeducation program in itself cannot be useful, since participants gave positive feedback afterwards and seemed satisfied with the intervention itself. But before going back to the drawing board, we will critically reflect upon the current null findings.

First, some participants and clinicians mentioned that they experienced a rather heavy workload from filling out the weekly questionnaires and assignments. This could have caused time-pressure and might have left too little time for (self)reflection. A way to avoid this could be to plan one session every 2 weeks instead of every week.

Second, it might be helpful to use the outcome of the (bi-)weekly questionnaires in the intervention. Such an integration might help people in reflecting and making the translation from what is learned in the intervention to daily life. We expected that this translation to daily life was strengthened through the inclusion of a proxy. However, according to the exit questionnaire, this was not sufficient. An alternative explanation is that translation to daily life might also just need some more time. For example, in an AD/HD psychoeducation study (Ferrin et al., 2020), it was shown that effects only emerged 6 months after the program. Therefore, we recommend including follow-ups with large time scales in future studies.

Third, even though we also used the Bayesian statistics, this was a small explorative study with low power, potentially leading to a risk for type II errors. This may have led to a false negative result. Future studies, with larger groups of participants, are therefore needed. Moreover, only one of the participants that was referred by clinicians was female. There should be a better gender balance in future studies.

Fourth, treatment fidelity was not assessed in this study. In order to test whether the set protocol can be followed, fidelity ratings should be incorporated in future studies.

A fifth, more speculative, possibility is that participants actually did improve, but not on the outcome measures that were used in this study. Even though participants and their proxy may still feel different about the (amount of) autism traits and cognitive failures a participant experiences and shows, there may be an increased sense of a mutual understanding and connection after finishing the psychoeducation program. Participants and their proxy may not agree on certain points, but this does not have to cause problems in daily life, as long as they "agree to disagree." Another option is that both participants and proxies gained more insight in the autistic person's autism traits, leading to a change in understanding but not in a reduced

discrepancy score. The aforementioned speculative possibilities would be in line with the results shown in Table 2, where no clear relation is shown between improvement on the secondary outcome measures and subjective treatment satisfaction: some participants with few to no improvement on the secondary outcome measures were still relatively satisfied (i.e. a score of 5 or 6 on the 1–7 Likert-type scale) with the psychoeducation program. Moreover, (major) life events during the time of the study did not seem to have a clear effect on the subjective effectiveness of the program. Perhaps autistic adults and their proxy benefit from an improvement in insight in different ways than we measured, or the chosen measures were not sufficiently sensitive to change. Therefore, in future studies, a more appropriate outcome measure, next to treatment satisfaction and acceptability, might be the degree to which participants and their proxy agree on the autistic adults' values and/or goals in life.

Finally, the current program is intended to be used after the more traditional psychoeducation programs currently used. In these traditional programs, one focuses on recognizing how being autistic is impacting yourself and your environment, and information is provided on classical autism theories. An intervention effect over and above such a first intervention by focusing on age-related topics might be only a small additive effect.

While the current program was co-designed, we could still improve the intervention by involving autistic adults even better. For example, the psychoeducation program could be delivered by both a non-autistic and an autistic trainer, to have a better representation of lived experiences. Moreover, even though autistic adults read and commented on the previous version of the provided program, scientific language could still be too prominent. Our autistic codesigners were all highly educated; including a broader group of autistic adults co-writing and proofreading the text might increase the accessibility of the information provided.

Concluding, this first exploratory study of a co-designed psychoeducation program for older autistic adults did yield practical suggestions for improvement of this and future programs and showed that the program as it currently stands should not be implemented yet. The positive feedback of the participants suggests that co-designing a specific psychoeducation program for older autistic adults is still a worth-while pursuit. Such a psychoeducation program should probably be regularly updated as knowledge regarding this often-neglected group is currently accumulating. Therefore, a more blended (face-to-face group sessions combined with online content) form might be more future proof.

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topics to include, through group size, to outcome measures. The authors also thank the participants and clinicians who were willing to be part of this study.

#### **Declaration of conflicting interests**

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Two of the authors (B.F.C.V.H. and H.M.G.) developed the psychoeducation program.

#### **Ethical approval**

The study was approved by the ethics committee of the University of Amsterdam (reference code: 2015-BC-4464). An earlier set-up of this study was registered at the Netherlands Trial Register (code: NTR 5907) but could not be carried out due to practical issues. Based on that randomized controlled failed trial, design adjustments were made, and this adapted study was again registered (code Trial NL5670).

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# Notes

- 1. The AQ (Hoekstra et al., 2011) was chosen based upon its earlier use in a study researching the discrepancy between self and other reports (Lever & Geurts, 2018) and the CFQ (Broadbent et al., 1982) based upon the fact that cognitive failures are often reported by older autistic people (Lever et al., 2015; van Heijst & Geurts, 2014).
- Pearlin Mastery Scale (Pearlin & Schooler, 1978), Generalized Self-Efficacy Scale (Jerusalem & Schwarzer, 1992), Rosenberg Self-Esteem Scale (Rosenberg, 1965), brief version of the Internalized Stigma of Mental Illness (ISMI; Boyd et al., 2014), WHOQol-BREF (Skevington et al., 2004), and Remoralization Scale (Vissers et al., 2010).
- 3. Verhage (1964) M=6.1, SD=0.08.

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