## **Autism Spectrum Disorder and Ioneliness**

## Differences between mild and severe symptoms

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#### **Abstract**

Numerous studies have shown that children or adolescents with Autism Spectrum Disorder (ASD) are more lonely than children or adolescents without Autism Spectrum Disorder. A possible explanation for this increased loneliness is that children with ASD have fewer friends in comparison to children without ASD. Also, children with severe ASD symptoms have fewer friends compared to those with mild ASD symptoms. This study examined the difference in loneliness of children and adolescents with mild ASD symptoms and severe ASD symptoms. It was hypothesized that children and adolescents with more severe ASD symptoms are lonelier in comparison to children and adolescents with milder ASD symptoms. Participants included 37 children and adolescents with a clinical ASD diagnosis (aged 8-20 years), of which 3 were girls and 34 were boys. The participants were divided into three groups, depending on the level of their social responsiveness as measured by the Social Responsiveness Scale (SRS): (1) normal social responsiveness (n=8), (2) mild deficits in social responsiveness (n=16), and (3) severe deficits in social responsiveness (n=13). Loneliness was measured using a questionnaire called the Loneliness Rating Scale (LRS). Results show no difference in loneliness between the three groups. Results do therefore not confirm the hypothesis. This suggest that there is no overall difference in loneliness between children diagnosed with ASD.

*Keywords:* Autism Spectrum Disorder, loneliness, symptom severity, friendship, Loneliness Rating Scale, Social Responsiveness Scale

In his landmark paper from 1943, Leo Kanner identified a phenomenon he named 'autistic aloneness' and described as follows:

"There is from the start an *extreme autistic aloneness* that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. . . . The children's *relation to people* is altogether different. Every one of the children, upon entering the office, immediately went after blocks, toys or other objects, without paying attention to the persons present. But the people, so long as they left the child alone, figured in about the same manner as did the desk, the bookshelf, or the filing cabinet." (pp. 242, 246)

Even though years of research have passed since these first remarks on what we nowadays would call Autism Spectrum Disorder (ASD), deficits in social communication and social interaction are still core criteria in the diagnostic process (American Psychiatric, 2013; Kerig, Ludlow, & Wenar, 2012). Kanner however suggests in his quote that children with ASD are not interested in relationships with people or social contact (Kanner, 1995). This is in contrast with a phenomenon that we nowadays find when comparing children with and without ASD: Children with ASD are lonelier than their typically developing counterparts (Bossaert, Colpin, Pijl, & Petry, 2012).

#### Loneliness

Numerous studies have shown this to be true for both children and adolescents with ASD. When concerning children, one study showed that children with ASD report a higher level of loneliness compared to those without ASD (Bossaert et al., 2012). Other studies showed that loneliness was experienced more intensely and more frequently by children with

ASD than it was by typically developing children (Bauminger & Kasari, 2000; Bauminger, Shulman, & Agam, 2003, 2004; Storch et al., 2012; Zeedyk, Cohen, Eisenhower, & Blacher, 2016). Another study stated children with special educational needs in primary and secondary schools felt lonely more often than children without such needs (Schwab, 2015). This difference in loneliness is not only reported by children, but remains prominent in adolescence (Deckers, Muris, & Roelofs, 2017; Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Locke, Ishijima, Kasari, & London, 2010; Whitehouse, Durkin, Jaquet, & Ziatas, 2009)

This high level of loneliness in children and adolescents with ASD might be a serious concern, since loneliness is known to be linked to a range of negative consequences. For example, one study showed that lonely people feel more anxious and threatened and that the quality of their sleep was worse than that of non-lonely people (Cacioppo et al., 2002). Another one of their studies showed that loneliness and feelings of depression are positively correlated and also that loneliness is associated with anxiety, anger and low social support (Cacioppo et al., 2006).

## Friendship

A possible explanation for the increased loneliness in youth with ASD might be their trouble to make friends (Zeedyk et al., 2016) as they have difficulties with the skill of cooperation (Macintosh & Dissanayake, 2006). In one study youth with ASD showed lower levels of social competence and social skills in comparison with a control group (Deckers et al., 2017). Social competence and social skills correlated negatively with loneliness. Another study found a similar difficulty with making friends in boys with ASD (Lasgaard et al., 2010).

Despite the difficulties children and adolescents with ASD face, their desire to be involved in relationships with others seems no different from typically developing children

(Bauminger & Kasari, 2000). Even though this desire might be present, a difference in friendship between youth with and without ASD is present. Children with ASD have indeed a lower number of friends (Bauminger & Shulman, 2003; Koning & Magill-Evans, 2001; Rowley et al., 2012) as well as a smaller social network compared to typical developing classmates (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011). Several studies did reported though that children or adolescents with ASD have at least one friend (Bauminger & Shulman, 2003; Daniel & Billingsley, 2010; Kuo, Orsmond, Cohn, & Coster, 2013; Rowley et al., 2012) and that children with ASD in generally are satisfied with their friendship (Calder, Hill, & Pellicano, 2013); However, the self-reported quality of their friendship is poorer in comparison to typically developing children (Kasari et al., 2011).

Furthermore, not only are the positive dimensions of friendship negatively associated with loneliness (Bauminger et al., 2004), but friendship also seems a protective factor against loneliness. For example one study indicated that perceived social support from a close friend was protective factor of loneliness (Lasgaard et al., 2010). In another study by Bauminger et al. (2003) children with ASD understood just as well as children without ASD that having a close friend could protect them from feeling lonely. Both these studies emphasize once more the importance of friendship when trying to understand loneliness.

One very important study regarding the relationship between ASD and friends comes from Mazurek and Kanne (2010). In this study the severity of symptoms is associated with the amount of friends one has: the more severe the ASD symptoms are, the fewer friends a child has. The severity of social difficulties is also negatively associated with peer acceptance (Laws, Bates, Feuerstein, Mason-Apps, & White, 2012). In both these studies the severity of the autistic symptoms has an influence on the friendships of a child with ASD, and could therefore also have an effect on their feelings of loneliness.

#### DSM-5

A recent development gives reason for more research. The change referred to is the development of a new edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM). The transition from DSM-4 to DSM-5 brought upon many changes, the biggest difference concerning developmental disorders being the change on how people are differentiated. All subtypes of ASD, as they existed in DSM-4 (American Psychiatric, 2013; Kerig & Ludlow, 2015) are now bundled up in one umbrella term: Autism Spectrum Disorder. As the term suggests, the differentiation between people is now made on a spectrum. To make this differentiation, DSM-5 has introduces a 'severity' marker that is based on the level of support one needs (Kerig & Ludlow, 2015). This transition can be considered a good thing because of considerations concerning these subtypes: Different subtypes of the DSM-4 are too similar to make a distinction between (Macintosh & Dissanayake, 2004; Witwer & Lecavalier, 2008) and the big amount of comorbidity between pervasive developmental disorders (Rutter, 2011).

Since severity of ASD symptoms is now a big part of the diagnosis of ASD, it is important to realize what kind of influence this severity has on different construct that are closely linked to ASD, such as loneliness. As mentioned before, the severity of ASD symptoms has an influence on the amount of friends one has and could therefore also have a major impact on the feelings of loneliness a child or adolescent with ASD has.

### The present study

The purpose of the present study is to contribute to the existing knowledge of loneliness in children and adolescents with ASD by investigating the association between loneliness and severity of ASD symptoms. Exploring this relationship could give us more knowledge and

understanding of the feelings of loneliness in this particular group of youths. Moreover, this knowledge could help shape or change existing interventions on loneliness. Accordingly, this study has not only relevance for our theoretical understanding of ASD, but might as well have a practical relevance. Based on the review of literature as mentioned above, it is hypothesized that children and adolescents with more severe ASD symptoms are lonelier in comparison to children and adolescents with milder ASD symptoms.

#### Method

## **Participants**

Participants of the present study included 57 children and adolescents diagnosed with ASD between the ages of 8 and 20 years old. All participants followed education on a special education school in the Netherlands. The participant group existed of 54 boys and 3 girls. Inclusion criteria for the statistical analysis were (1) clinical ASD diagnosis and (2) completion of the Social Responsiveness Scale (SRS) by the parents. Since the parents of 17 participants did not complete the SRS, those 17 participants are considered missing in this study and are therefore excluded from the analyses. Consequently, 37 children and adolescents (34 boys; 3 girls) are included in the analyses. These 37 participants will be divided into three groups, depending on their ASD symptoms.

### Measurements

Social Responsiveness Scale

The Social Responsiveness Scale is a parent or teacher questionnaire which measures autistic traits/symptoms and consists of five sub-scales: social awareness, social cognition,

social communication, social motivation, and autistic mannerisms (Roeyers & Thys, 2010). The SRS takes approximately 15-20 minutes to complete. It consists of 65 statements about a child's behavior, which can be answered on a four-point Likert-scale. Answer possibilities range from 0 (never true) to 3 (almost always true). An example of a statement is "Expressions on his or her face don't match what he or she is saying", "Plays appropriately with children his/her own age" and "Seems to react to people as if they are objects". The higher a child scores in total, the more autistic traits it is believed to show. The SRS manual divides t-scores into four different groups: (0) High level of social responsiveness (T-scores of below 40), (1) normal level of social responsiveness (T-score between 40 and 60), (2) mild to moderate deficits in social responsiveness (T-scores between 61 and 75) and (3) severe deficits in social responsiveness (T-scores above 75). When children score within group 0 or 1, so they score below 60, it suggests that their social responsiveness does not show any deficits, which is slightly unexpected when a child is diagnosed with ASD. When a child scores within group 2 or 3 however, their social responsiveness does show deficits. The SRS has a Cronbach's Alpha for girls of 0,95 and for boys of 0,93 (Roeyers, Thys, Druart, Schryver, & Schittekatte, 2011). The SRS is also reported to have good reliability, validity and good sensitivity (Aldridge, Gibbs, Schmidhofer, & Williams, 2012).

In order to test the hypothesis, first the scores on the five subscales of the SRS (social awareness, social cognition, social communication, social motivation, and autistic mannerisms) were combined into one total raw-score. This raw-score was then made into a t-score, as explained in the SRS manual (Roeyers et al., 2011). There are different scoring ways for boys and girls. Third, the different groups of ASD severity were then differentiated, using the interpretation of the SRS. Since none of the children scored below 40, this group will not be taken into account any further. The demographics can be found below in table 1.

## Loneliness Rating Scale

The LRS was used to measure the children's feelings of loneliness. The LRS is a questionnaire consisting of 24 statements, such as "I feel lonely" or "I have no one to talk to" (reverse coding is used for both these particular statements). Eight of those 24 statements are filler items: These eight statements concern hobby's and do therefore not measure loneliness. Each statement can be answered by indicating how true a statement is for themselves. This is indicated on a five-point scale ranging from 1 (always true) to 5 (not true at all). Each statement is either read aloud by the experimenter (when the participants attended primary school) or read by themselves (when the participants attended high school), after which the child scores it 1 to 5. A higher total score indicated more feelings of loneliness. Possible total scores range from 16 (low level of loneliness) to 80 (high level of loneliness). The LRS has reported to have good validity and good test-retest reliability for both four week test-retest reliability and six week test-retest reliability (Scalise, Ginter, & Gerstein, 1984). The LRS has also reported to correlate with the UCLA Loneliness Scale with moderate degree (correlations of .25 to .46) (Corcoran & Fischer, 2013).

## **Procedure**

The present study is part of a bigger study about Autism Spectrum Disorder called "Autism, everyone different" and studies constructs such as Theory of Mind, loneliness, empathy, (pro)social behavior, study-teacher relationships and ASD symptoms. The test battery in this bigger study takes between 30 and 45 minutes to finish, depending on the age of the child or adolescent. The present study however will only use the information of loneliness and ASD symptoms. The participants were recruited by convenience sampling by contacting special education schools in the area of Noord-Brabant. The participating schools

were asked to send out letters to all parents of ASD children. These letters informed parents and children about the study and asked for consent. The children of whom the schools received a consent letter from their parents (children above the age of 12 had to give informed consent as well) participated in the study. The study itself was conducted at the schools of the children and was always individual. All participants were taken to a separate room where they made the test individually on a laptop, while the experimenter was in the room. The LRS took about 10 minutes to fill in. The experimenter read the questions out loud for primary school children (high school children read the questions for themselves) and participants were then asked to answer every question on a laptop. After this, participants were informed that a vvv-bon with a value of 10 euros was to be raffled among all participants and the younger children (12 years and younger) participating in the study were also given a small presents as a thank you. There was a debriefing if the children asked for it.

## Statistical analyses

In order to test the hypothesis, the mild ASD symptoms group will be compared to the severe ASD symptoms group on how they score on loneliness (respectively groups 2 and 3). The mild ASD group is the group of children that scored between 60 and 74, while the severe group scored above 75. Since some of the participants within the ASD group also scored outside the social responsiveness deficits range, but still were diagnosed with ASD, they have to be taken into account as well (group 1). All three groups will therefore be compared on their loneliness using a one-way between subjects ANOVA. Second, the difference between feelings of loneliness in these children or adolescents will also be measured as continuous data by performing a linear regression analyses to predict loneliness using the participants SRS scores.

#### **Results**

As stated before, the hypothesis of this study is that children and adolescents with severe ASD symptoms are more lonely than children and adolescents with mild ASD symptoms. To answer this hypothesis, a one-way between subjects ANOVA was conducted to compare the effect of SRS score on Loneliness, using the three groups. The assumption of homogeneity of variances, as measured by the Levene's test, was violated (p= .038). But because the largest group was no more than 1,5 times the size of the smallest group, the test was robust. No significant difference between the groups was found (F(2, 34) = .621, p = .543, R Squared= .035).

Since the ANOVA showed no significant differences between the groups and to prevent that any information would be lost by differentiating the participants into groups, a regression analyses was also executed (p = .980, B = -,005, Std. Error = .183). No significant link between the SRS scores and loneliness was found. See table 2. There was no difference in feelings of loneliness found between children and adolescents with mild ASD symptoms and children or adolescents with severe symptoms.

#### Discussion

The present study examined the relationship between loneliness and autistic symptoms within children diagnosed with ASD. The aim was to find possible existing differences in feelings of loneliness between children with mild ASD symptoms and those with severe ASD symptoms. No such difference was found. This result is not in line with the expectation that was based on previous studies, since a study by Mazurek and Kanne (2010) showed that severity of ASD symptoms was negatively associated with the amount of friends one has and

therefore positively associated with loneliness. Based on these studies the expectation was that severity of ASD symptoms would have an effect on friends and therefore on loneliness. However the results show that there is no difference in loneliness between the children with mild symptoms and severe symptoms.

A possible explanation for the result of this study might be that the results of previous studies concerning loneliness and friendship do not apply to children with ASD. The studies from Bauminger et al. (2004) and Lasgaard et al. (2010), for example, both studied children with normal development. These outcomes might be different when studied on children or adolescents with ASD, since children with autism seem to have a different understanding of friends (Calder et al., 2013). Or perhaps children with ASD have a different perspective on loneliness, since they claim to be satisfied with their friendship in generally (Calder et al., 2013). One study found evidence that children with ASD do indeed have a different understanding of loneliness: they do not regard emotional feelings, such as sadness, as being caused by loneliness (Bauminger & Kasari, 2000). They do however understand, just as well as children without ASD, that having a close friend could protect them from feeling lonely (Bauminger et al., 2003). Several studies do show that children and adolescents with ASD have at least one friend (Bauminger & Shulman, 2003; Daniel & Billingsley, 2010; Kuo et al., 2013; Rowley et al., 2012). So perhaps this means that having just one friend is enough for both children with mild and severe ASD symptoms to have the same amount of loneliness.

Second, it might be the case that that children with severe ASD symptoms overestimate the number of friends they have. One study found that the more severe a child's ASD symptoms were, the bigger the difference was between their number of reported friends and the number their parents reported (Kuo et al., 2013). If it indeed is the case that children with more severe ASD symptoms have in fact fewer friends than they estimate, this might be

a reason why no difference is found between their feelings of loneliness and those with mild ASD symptoms.

Finally, another possible explanation for the fact that no significant difference was found in this study is that the result from the study of Mazurek and Kanne (2010), one of the major studies on which the hypothesis of the present study was based, might not be as straightforward as it seemed. That specific study found that children with more severe ASD symptoms had a lower number of friends than those with milder ASD symptoms. This outcome was measured using a parent report on number of friends. However, parents underestimated the number of friends their child has more when the ASD symptoms of that child are severe in comparison with parent reports of children with mild ASD symptoms (Kuo et al., 2013). This might suggest that parent reports are not the best measurement of number of friends, especially when ASD symptoms of the child are severe.

A limitation of the present study is that it failed to look at the number of friends the children and adolescents with ASD had, since friendship has shown to be somehow linked to loneliness as suggested by previous studies. For instance, positive dimensions of friendship associate negatively with loneliness (Bauminger et al., 2004) and friendship seems to be a protective factor against loneliness (Lasgaard et al., 2010). It might be interesting to look once more at the relationship between symptom severity and number of friends, as long as no parent reports are used (Kuo et al., 2013), and to see how both these constructs are linked to loneliness.

Another limitation concerning this study is the limited amount of participants. The study consisted of a total amount of participants of 37. These 37 were then differentiated into three groups. Such small participant groups make comparing between those groups difficult and less reliable. Also, the participant group consisted mainly of males, and even though ASD is more common in males than in females (Kerig et al., 2012), the differentiation of boys and

girls within the present study was not corresponding to that of the overall ASD population. Within the population, ASD is three to four times more common in men than it is in women (American Psychiatric, 2013). In the present study however there are about 12 times more male participants than female participant. A distribution of three to four times more male participants than female participants would be better to make generalizations about the population. Future studies should therefore be conducted with a larger number of participants and with a closer distribution of boys and girls to the overall ASD population.

An implication of the present study might be that severe ASD symptoms are not a risk factor for loneliness, since no difference between mild and severe ASD symptoms was found. The fact that children with more severe ASD symptoms do not feel more lonely than those with mild symptoms could therefore be regarded a positive outcome. Loneliness is for instance positively linked to feelings of anxiousness and is also associated with anxiety, anger and low social support (Cacioppo et al., 2002; 2006). However, since no difference was found in the amount of loneliness between mild and severe symptoms, this could also suggest that being on the mild side off the ASD spectrum is not a protective factor against loneliness.

Whether severe ASD symptoms are not a risk factor for loneliness or mild ASD symptoms are neither a protective factor, the fact remains that there is a difference in loneliness between typically developing children in comparison to children diagnosed with ASD (Bauminger et al., 2003, 2004; Bossaert et al., 2012; Schwab, 2015; Storch et al., 2012; Zeedyk et al., 2016), but no difference in loneliness within ASD children. As said, children with ASD score significantly higher on loneliness than those without ASD, but even then their scores on loneliness are not that high. The mean score on the Loneliness Rating Scale (LRS) in this study for children with ASD is 34,05. The total scores on the LRS range from 16 (low level of loneliness) to 80 (high level of loneliness). The 16 items about loneliness are scored from 1 (always true) to 5 (not true at all), with a score of 5 as an indication of greater

loneliness. Since the standard deviation of the ASD group was 10,95 on the LRS, a score of 34,05 probably means that ASD children scored each statement a score of 2 or 3. This low standard deviation suggests that there are not a lot of differences between the scores on each statement. A score of 2 would suggest that a child feels hardly ever lonely and a score of 3 would suggest that they sometimes feel lonely. These mean scores could be considered relatively low scores. Even when compared to the typically developing participants from the bigger study 'Autism everyone different', of whom this study was part, the difference is not that big, although it is significant: the group of typically developing participants has a mean score of 25,31. This could suggest that they too score each statement between 2 and 3. So even though children with ASD score higher on loneliness that their typically developing counterparts, this difference might not be that large. Why this difference between children with ASD and children without ASD exists, is still not entirely clear. Hopefully, the present study expanded our insight into loneliness and AUSD remains necessary.

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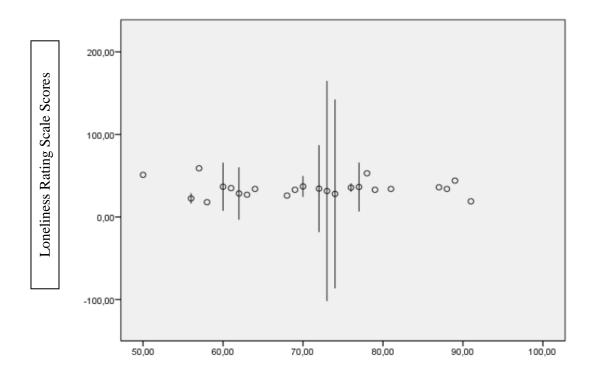
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68,69	80,92
4,71	15,66
61-74	76-91
31,75	36,08
	8,91
	61-74

Three groups: 1 (normal social responsiveness), group 2 (mild deficits in social responsiveness) and group 3 (severe deficits in social responsiveness).

<sup>\*</sup>Social Responsiveness Scale (T-scores)

<sup>\*\*</sup>Loneliness Rating Scale

Table 2



Regression plot showing the amount of loneliness for each score on the Social-Responsiveness Scale

Social Responsiveness Scale Scores