



universität
wien

MASTERARBEIT / MASTER'S THESIS

Titel der Masterarbeit / Title of the Master's Thesis

„Quality Of Life Of Adolescents With Autism Spectrum Disorders And Both Their Parents:
Concordances Among Adolescents Self Reports, Parents Proxy Reports And Parents Mutual Reports“

verfasst von / submitted by

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angestrebter akademischer Grad / in partial fulfillment of the requirements for the degree of
Master of Science (MSc)

Wien, 2017 / Vienna 2017

Studienkennzahl lt. Studienblatt /

A 066 840

degree programme code as it appears on
the student record sheet:

Studienrichtung lt. Studienblatt /

Masterstudium Psychologie

degree programme as it appears on
the student record sheet:

Betreut von / Supervisor:

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Abstract

Previous research has barely tested the Quality of Life (QoL) of fathers of adolescents with Autism Spectrum Disorders (ASD). For the first time the QoL of adolescents and both mothers and fathers are tested. This way a model is created out of the three family members which contains self ratings and partly mutual ratings. Data of 15 affected and 24 control group families were collected in Germany. Previous research was confirmed, for example parents of children with disabilities rated their own QoL lower and fathers of children with disabilities rated their QoL higher than mothers. Additionally, among others no difference was found in gender when parents rated the QoL of the adolescents. The difference between mothers and fathers ratings were generally lower than expected. To confirm the findings a repetition of this study with a bigger data size is recommended to avoid assumption violations and increase effect sizes.

Keywords: autism, quality of life, adolescence, fathers

1 Introduction

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder. It is linked with deficits in social interactions and repetitive patterns of behavior, is presented already in the early childhood, causes impairment and is not better explained by intellectual disability (American Psychiatric Association, 2013). Globally 0.6 % of the population could be diagnosed with ASD (Elsabbagh, Divan, Koh, Kim, Kauchali, Marcin & Fombonne, 2012). In the recent years the Quality of Life (QoL) of persons with Autism Spectrum Disorders (ASD) and their parents has been explored (Vasilopoulou & Nisbet, 2015). Out of these studies a model can be constructed which consists of three elements, the child or adolescent with ASD, the mother and the father. First an overview will be given about the research done in this model, concluding with three missing testings - the role of the father, mutual reports between the parents and comparisons between self reports of all three members of the model at once. The model is illustrated in figure 1 while the main research so far is represented by arrows.

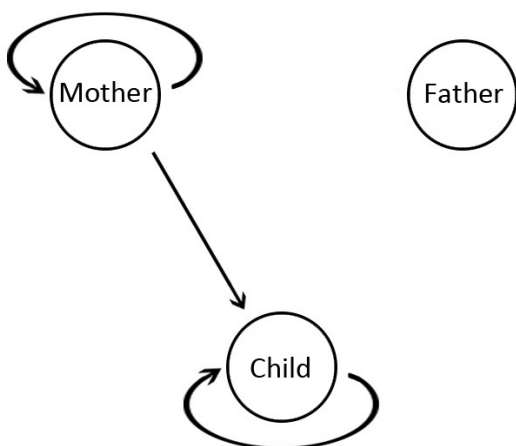


Figure 1. Model of the measurements of the previous QoL research

The QoL of the child can be tested by self report, by standard parent report or by parent proxy report. In standard parent report parents give their own estimation of the QoL of their children, while in parent proxy report they estimate how their children would rate themselves (Sheldrick, Neger, Shipman & Parin, 2012). In general the QoL of people with

ASD was rated lower than the QoL of a control group consisting of persons without ASD (Egilson, Ólafsdóttir, Leósdóttir & Saemundson, 2016) or of a group with chronic somatic diseases like diabetes (Cottenceau, Roux, Blanc, Lenoir, Bonnet-Brilhaut & Barthélémy, 2012). Children rated their QoL higher than parents using proxy reports (Kamp-Becker, Schröder, Muehlan, Remschmidt, Becker & Bachann, 2011; Egilson et al., 2016). General differences between self report and both parental report types can be found (Sheldrick et al, 2012). The Pediatric Quality of Life Inventory's (PedsQL) sub scale Physical Functioning was rated lower by the children, while the subscales Emotional Functioning, Social Functioning and School Functioning were rated higher. Standard parent reports showed a lower correlation with self reports of the children. Therefore, parent proxy reports should be preferred if self reports are not possible. Finally, the authors conclude that the parents are aware that their own view is different from the view of their child.

The QoL of the parents has been tested by self reports. In a meta study lower QoL has been found among parents with ASD compared to control groups or QoL scores of the general population (Vasilopoulou & Nisbet, 2016). Out of 224 parents 114 (51,1 %) experienced moderate or severe problems with anxiety or depression (Khultau, Payakachat, Delahaye, Hurson, Pyne, Kovacs & Tilford, 2014). The research has focused on risk and protection factors in order to find more effective interventions (McStay, Trembath & Dissanayake, 2014). Comparing twelve reviewed studies, stress and parental coping strategies like self-distraction, denial, venting, behavioral disengagement and self blame have been found to be associated with lower QoL (Vasilopoulou & Nisbet, 2016). Also, child characteristics like hyperactivity and inattention, externalizing behavior and low prosocial behavior decreased parental QoL. Four of the twelve studies did not find a correlation between the severity of ASD and parental QoL, while two studies found a correlation. Contextual factors like employment, high household income, family functioning and coherence as well as availability of social and professional support were also increasing the QoL. On the contrary, protection factors are the increase in daily living, communication, object cognition scores and a higher number of siblings (Baghdadli, Pry, Michelon & Rattaz, 2014).

As far as tested, the age of people with ASD does rarely have a significant influence on their QoL. This was checked for the first time when van Heijst & Geurts (2015) collected a small sample (N = 24) of elderly people (age=53-83) with ASD. Additionally, intelligence quotient and symptom severity did not predict the QoL. While young children have often been tested in form of reports from their parents (Hong, Bishop-Fitpatrick, Smith, Greenberg & Mailick, 2016), adolescents have barely been explored. Their QoL was tested for the first time by Cottenceau et al. (2012) who showed that self reports are possible in this age group. The adolescents were able to complete the questionnaire by themselves, requesting help from their parents only when they did not understand the meaning of a question. Generally self reports are more and more considered to be the gold standard for persons with ASD (Sheldrick et al., 2012). This should only be applied to people with an intelligence quotient of at least the average range (Biggs & Carter, 2016).

The impact of the gender of the parents has barely been tested (Baghdadli et al., 2014; Vasilopoulou & Nisbet, 2015). In a meta analysis of chosen studies only 20.6 % of 1529 parents were fathers (Vasilopoulou & Nisbet, 2015). Mothers were found to report a lower QoL. This is consistent with the general finding that mothers of children with disabilities experience lower QoL and wellbeing. The authors add that the small percentage of fathers in the samples makes it difficult to draw significant conclusions. In most studies the percentage of fathers is even lower. Some studies don't differentiate between the parents' gender at all (e.g. Billstedt, Gillberg & Gillberg, 2011; Khultau, Orlich, Hall, Sikora, Kovacs, Delahaye & Clemons, 2010; Kuhltau et al., 2014). Furthermore, the few studies in this field have found three differences. Mothers and fathers have different risk and protection factors, experience of stress and coping styles (McStay et al., 2014). For example, fathers would rather use adaptive and active avoidance coping styles, while mothers would rather use problem-focused coping styles (Pozo, Sarriá & Brioso, 2014).

Aims and research questions

Overall three aspects are still missing in this research field. First, fathers have barely been tested, as in many studies only a small percentage of the parents were fathers. Some studies did not even mention the gender of the tested parents at all (Baghdadli et al., 2014;

Vasilopoulou & Nisbet, 2015). Differentiating gender could help to find gender differences in the support strategies. Second, no study has tested how parents rated each other's QoL, neither in form of a standard report nor in form of a proxy report. Mutual reports of the parents could give more insight about the role of the father. For example, if fathers were aware of the mother's QoL this could be an important mediator for their ability to adapt their role in the family. It could also mediate changes in risk and protective factors. Third and finally, no study has tested the child, its mother and its father at the same time using self reports. One study used proxy reports instead of child reports due to the low age of the children (McStay et al., 2014). Comparing the three self reports, or comparing the self reports with both mothers' and fathers' parental reports, could also give more insight about the role of the father in the model.

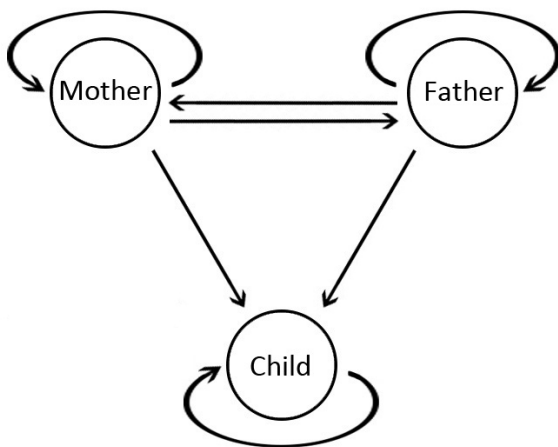


Figure 2. Model of the QoL research of this study

Kamp-Becker et al. (2011) found that parents rated the QoL of their children lower than the children rated themselves. In their study they did not distinguish between the ratings of fathers and mothers. They see three possible reasons for parents rating the QoL of their children lower than their children did. First, parents of children with health issues generally report a lower QoL than the children themselves. Second, people with autism might have difficulties reporting their own QoL. Third, children may perceive their limited functioning as a less sincere problem. Kamp-Becker et al. (2011) conclude the discrepancy would derive from a perceptual difference and not from a lack of parental knowledge. But

since firstly mothers typically assume a larger part of the responsibility of taking care of their family's needs in these families, fathers are often hard to reach and mothers are the ones who are involved in the decision-making process related to their children with disabilities (Meadan, Stoner & Angell, 2015). Secondly, fathers use more active avoiding strategies including self-blame, distraction and denial (Pozo et al., 2014). One could conclude that mothers have more knowledge about their child than the fathers. Therefore, fathers should rate the QoL of their child lower than the mothers. Additionally, it is of importance if this rating is based on ASD, and so it is tested if there is a difference to the general population.

H0₁: Fathers rate the QoL of their child with ASD lower than mothers do in comparison to the control group.

H1₁: Mothers rate the QoL of their child with ASD lower than fathers do in comparison to the control group.

In the study of McStay et al. (2014) fathers reported significantly higher levels of QoL than mothers. This has also been found for mothers of children with other disabilities (Vasilopoulou & Nisbet, 2016). This hypothesis will be checked, but also compared to the control group.

H0₂: Fathers rate their own QoL higher than mothers rate their own QoL in comparison to the control group.

H1₂: Mothers rate their own QoL higher than fathers rate their own QoL in comparison to the control group.

Both mothers and fathers of children with ASD show higher levels of parenting stress and psychological distress than parents of typically developing children (Burrell, Ives & Unwin, 2017). Furthermore, it has never been tested if both parents notice that each other's QoL might differ. Foody, James and Leader (2015) found that parent responsibility, distress, anxiety and depression is higher for mothers than for fathers. So fathers could rate the QoL of the mothers lower than the other way around.

H0₃: Fathers rate the QoL of the mothers lower than mothers rate the QoL of the fathers in comparison to the control group.

H1₃: Mothers rate the QoL of the mothers lower than fathers rate the QoL of the mothers in comparison to the control group.

Parents will be asked to rate the QoL of their children. Finally, it is of interest if the QoL of the parents is higher if parents and their children rate the QoL of the adolescents more similarly.

H0₄: The QoL of the parents is higher if the self reports and the proxy reports of the adolescents' QoL are more similar.

H1₄: The QoL of the parents is lower if the self reports and the proxy reports of the adolescents' QoL are more similar.

3 Methods

3.1 Participants

In this study families the participants were 15 families with adolescents with ASD and 24 families with typically developing adolescents. To be included in our sample both parents or legal guardians of the adolescent had to be available. The abbreviated nine item form of the Raven's Standard Progressive Matrices Test (RSPM) test was made to make sure adolescents were able to fill out the questionnaire by themselves. One family of the control group was excluded due to not reaching the needed IQ level of ≥ 80 . Between ASD group and control group age, gender and predicted RSPM score of the adolescents were matched naturally, as education of the parents and income of the father. The income of the mother was the only remarkable difference. Since the education of the parents is similar, it was deducted the income difference is not related to social class but having to care for a child with special needs. Thus, there was no need to exclude further families to match the ASD group and the control group.

Nine families with an adolescent with ASD were recruited through two German institutes who support pupils with disabilities. Two of these institutions were recommended by the German Federal Association For Autism. Six further families with adolescents with

ASD were recruited through a German coordination center for autism. Because the recruitment was made by the employees of the institutions on site, the percentage of returned questionnaires is unknown. The control group was chosen by hand. Here 24 out of 26 questionnaires (92.3%) were returned.

Demographic characteristics of all families are presented in table 1. The average age of the adolescents in the ASD group was 14.73 (SD = 2.09, range = 11-18) and 80.0% (N = 12) of the children were male. The average age of the adolescents in the control group was 14.25 (2.38, range = 11-19) and 70.8% (N = 17) of the adolescents were male. At the end of the questionnaire adolescents were asked if they their parents helped them with filling out the questionnaire. N = 2 (13.3%) of the adolescents with ASD were helped, none of the adolescents without ASD were helped. The average age of mothers of an adolescent with ASD was 46.40 years, compared to 46.50 years for mothers in the control group. The average age of fathers of an adolescent with ASD was 50.87 years, compared to 49.08 years for fathers in the control group. 93.3 % (N = 14) of the fathers in the ASD group were the biological fathers, while 95.8% (N = 23) of the fathers in the control group were the biological fathers.

Table 1
Demographic characteristics of the participants

	<u>ASD group</u> (n = 15)	<u>control group</u> (n=24)
<u>Adolescents</u>		
age		
M (SD)	14.73 (2.09)	14.25 (2.38)
range	11-18	11-19
sex		
male	12 (80.0%)	17 (70.8%)
female	3 (20.0%)	7 (29.2%)
German nationality	15 (100%)	24 (100.0%)
filled out questionnaire		
without parents' help	13 (86.7%)	24 (100%)

Mothers

age		
M (SD)	46.40 (4.09)	46.50 (5.16)
range	39-55	38-55
German nationality	15 (100%)	23 (95.8%)
education		
no graduation	0 (0%)	0 (0%)
Hauptschule	1 (6.7%)	1 (4.2%)
Realschule	5 (33.3%)	5 (20.8%)
Gymnasium	1 (6.7%)	6 (25.0%)
university degree	8 (53.3%)	12 (50.0%)
net income		
0-1000 €	10 (66.7%)	8 (33.3%)
1000-2000 €	4 (26.7%)	9 (37.5%)
2000-3000 €	1 (6.7%)	4 (16.7%)
4000-5000 €	0 (0%)	1 (4.2%)
5000€ or more	0 (0%)	1 (4.2%)
missing	0 (0%)	1 (4.2%)

Fathers

age		
M (SD)	50.87 (4.09)	49.08 (6.88)
range	42-66	40-72
German nationality	15 (100%)	24 (100%)
education		
no graduation	0 (0%)	1 (4.2%)
Hauptschule	3 (20.0%)	2 (8.3%)
Realschule	1 (6.7%)	5 (20.8%)
Gymnasium	1 (6.7%)	3 (12.5%)
university degree	10 (66.7%)	13 (54.2%)
net income of father		
0-1000 €	1 (6.7%)	2 (8.3%)
1000-2000 €	2 (13.3%)	0 (0%)
2000-3000 €	3 (20.0%)	7 (29.2%)
4000-5000 €	4 (26.7%)	7 (29.2%)
5000€ or more	4 (26.7%)	8 (33.3%)
missing	1 (6.7%)	0 (0%)
biological father	14 (93.3%)	23 (95.8%)

3.2 Procedure

The data were collected between January and July 2017. Printed questionnaires were used instead of online surveys because the target group was very specific and three people of the same family were needed. Packages of questionnaires were given to the institutions along with a self-addressed and stamped envelope for their return. The participants were given sealable envelopes. It was pointed out to all three family members that participation is voluntary and anonymous. The participants were given a paper with a password and an internet link where they could inform themselves about the verbalized results of the study after the analysis. Additionally, an expense allowance of 30 euros was given to each family who filled out their questionnaires completely. The money was partly funded by the University of Vienna.

3.3 Measures

Parents and adolescents received different questionnaires. The adolescents' questionnaire consisted of a demographic questionnaire, the RSPM and the PedsQL. The parents' questionnaire consisted of a demographic questionnaire, the WHOQOL-BREF in self and in proxy version, and the PedsQL proxy version. The questionnaires for mothers and fathers were identical, except that fathers had to state if they were the biological parent or not.

The PedsQL is for rating the QoL of the adolescents since it is a validated and widely used measure (Biggs & Carter, 2015) and it has been used in seven studies with adolescents with ASD (Heijst and Geurts, 2015). It consists of 15 items and 4 subscales which are Physical Functioning, Emotional Functioning, Social Functioning and School Functioning. Both S. Both reliability and validity were sufficient. The Cronbach α ranged from .70 to .89 (Varni, Seid & Rode, 1999). Since the PedsQL is originally a self rating instrument, it was additionally transformed into a proxy version. This way the parents were able to rate the QoL of their child.

The WHO Quality of Life Assessment Instrument (WHOQOL-BREF) is used for rating the QoL of the parents because it has been used in previous studies, too (Heijst & Geurts, 2015). It consists of 26 Items and 4 subscales which are Physical Health, Psychological, Social Relationships and Environment. The subscales of both scales, WHOQOL-BREF and PedsQL,

are similar (Physical Functioning vs. Physical Health, Emotional Functioning vs. Psychological, Social Functioning vs. Social Relationships, School Functioning vs. Environment). International checks found acceptable values for Cronbach's α ($> .68$) in all four domains (Skevington, Lotfy & Connell, 2004). The test-retest reliabilities for all domains were $> .68$ and the ability in discriminating between ill and well respondents is excellent (Harper & Power, 1998). As the PedsQL the WHOQOL-BREF was additionally transformed into a proxy version for this study.

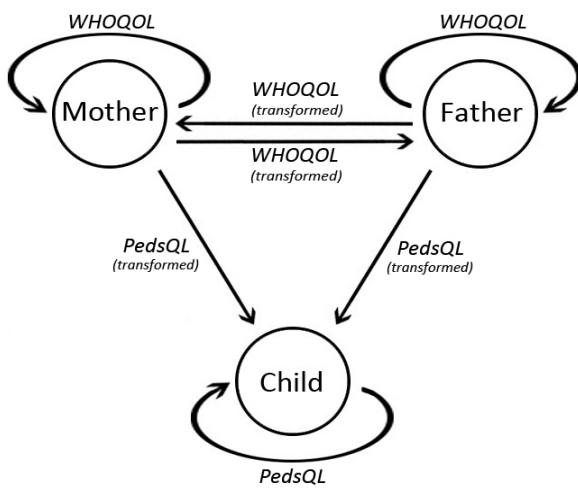


Figure 3. Model of the QoL research in this study with QoL scales

The RSPM is used to test for fluid intelligence (Bilkers, Hansen, Brensinger, Richard, Gur & Gur, 2012). The original 60 items of the RSPM were reduced to 9 with $r = .98$ (Bilker et al., 2012). Out of the two existing and equal forms Form A was used. The test has little dependency on language abilities. The 9-item RSPM (form A) showed good internal consistency (Cronbach's $\alpha = .80$) in the validation study (Bilker et al., 2012). On the one hand the RSPM's purpose was to match the intelligence quotient of adolescents with and without ASD. On the other hand it should guarantee that adolescents were able to fill out the test by themselves as they are highly functioning by having an $IQ \geq 80$ (Egilson, Ólafsdóttir, Lleósdóttir & Saemundson, 2017).

3.4 Analyses

The data were analyzed using SPSS 19. The requirements for the general linear model (GLM) are metric scale, independence of measurements, normal distribution and homogeneity of variances. Sphericity had not to be considered since there are only two repeated-measures conditions and therefore sphericity is fulfilled. Cronbach's α was used to assess the internal reliability of the scales. All alphas were .79 or higher, except fathers rating adolescents in the ASD group (Cronbach's α = .74) and mothers rating themselves in the control group (Cronbach's α = .76).

Table 2

Internal consistencies (cronbach's α)

	<u>ASD group</u> (n = 15)	<u>control group</u> (n=24)
<u>PedsQL</u>		
adolescents rating themselves	.84	.79
mothers rating adolescents	.87	.83
fathers rating adolescents	.74	.85
<u>WHOQOL-BREF</u>		
mothers rating themselves	.94	.76
fathers rating themselves	.91	.86
mothers rating fathers	.91	.86
fathers rating mothers	.94	.91

Note: PedsQL = Pediatric Quality of Life Inventory; WHOQOL-BREF = WHO Quality of Life Assessment Instrument.

The IQ of the adolescents was tested with RSPM. Adolescents with ASD scored 6.01 (SD = 2.12, range = 2-9) out of 9 questions while adolescents of the control group scored 6.00 (SD = 1.89, range = 2-9) out of 9 questions. Transforming the SPM score into the RSPM score adolescents with ASD scored 46.86 (SD = 9.43, range = 26.8-56.3) out of 60 questions while adolescents of the control group scored 47.51 (SD = 7.80, range = 26.3-56.3). Therefore, on the one hand the IQ is matched between the groups. On the other hand since the oldest participant is 11 years old and scored 26.3 questions, the IQ of all participants is ≥ 76.3 (Horn, 2009). The criteria of an IQ of 80 was lowered down to ≥ 76.3 due to the already small sample size. Despite this it was assumed still all adolescents were theoretically able to

fill out the questionnaire by themselves (Cottenceau et al., 2012). Two adolescents (N = 13.3%) of the ASD group stated their parents helped them with filling out the questionnaire.

4 Results

The first three hypotheses were tested with general linear model (GLM) with repeated measurement. Gender was used as within-subject-factor. Group was used as between-subject-factor.

Table 3

Results of the first three hypotheses and their assumptions (for $\alpha = .05$)

	Hypothesis 1	Hypothesis 2	Hypothesis 3
Difference in group	$p = .00^{**}$ (d = 2.39)	$p = .02^{*}$ (d = .84)	$p = .22$ (d = .42)
Difference in gender	$p = .40$ (d = .28)	$p = .48$ (d = .24)	$p = .30$ (d = .35)
Interaction between group and gender	$p = .43$ (d = .22)	$p = .04^{*}$ (d = .70)	$p = .36$ (d = .31)
Levene-Test			
mothers	$p = .20$	$p = .06$	$p = .05$
fathers	$p = .85$	$p = .06$	$p = .36$
Kolmogorov-Smirnov-test			
ASD group: mothers	$p \geq .20$	$p = .00$	$p \geq .20$
ASD group: fathers	$p \geq .20$	$p \geq .20$	$p = .12$
control group: mothers	$p \geq .20$	$p = .06$	$p = .01$
control group: fathers	$p \geq .20$	$p \geq .20$	$p \geq .20$
mean (SD)			
ASD group: mothers	3.18 (.66)	3.89 (.68)	4.01 (.50)
ASD group: fathers	3.06 (.55)	4.14 (.47)	3.91 (.57)
control group: mothers	4.16 (.37)	4.34 (.24)	4.15 (.34)
control group: fathers	4.14 (.47)	4.22 (.31)	4.14 (.37)

Note: Hypothesis 1 = Do fathers rate the QoL of their child with ASD lower than mothers do in comparison to the control group?; Hypothesis 2 = Do fathers rate their own QoL higher than mothers rate their own QoL in comparison to the control group?; Do fathers rate the QoL of the mothers lower than mothers rate the QoL of the fathers in comparison to the control group?; * = $p \leq .05$; ** = $p \leq .01$.

4.1 Do fathers rate the QoL of their child with ASD lower than mothers do in comparison to the control group?

There was a difference in group ($p = .00$, $d = 2.39$, $\alpha = .05$) but no difference in gender ($p = .40$, $d = .28$, $\alpha = .05$). The interaction between gender and group was not significant ($p = .43$, $d = .22$, $\alpha = .05$). Variances were tested by Levene test. They were equal for mothers rating adolescents, $F(1, 37) = 1.73$, ns ($p = .20$), and for fathers rating adolescents $F(1, 37) = .04$, ns ($p = .85$). Normal distribution was tested by Kolmogorov-Smirnov-test. For the ASD group, the mothers rating adolescents, $D(15) = .15$, $p \geq .20$, and the fathers rating adolescents, $D(15) = .17$, $p \geq .20$, were both significantly non-normal. For the control group, the mothers rating adolescents, $D(24) = .12$, $p \geq .20$, and the fathers rating adolescents, $D(24) = .12$, ns ($p \geq .20$), were both significantly non-normal.

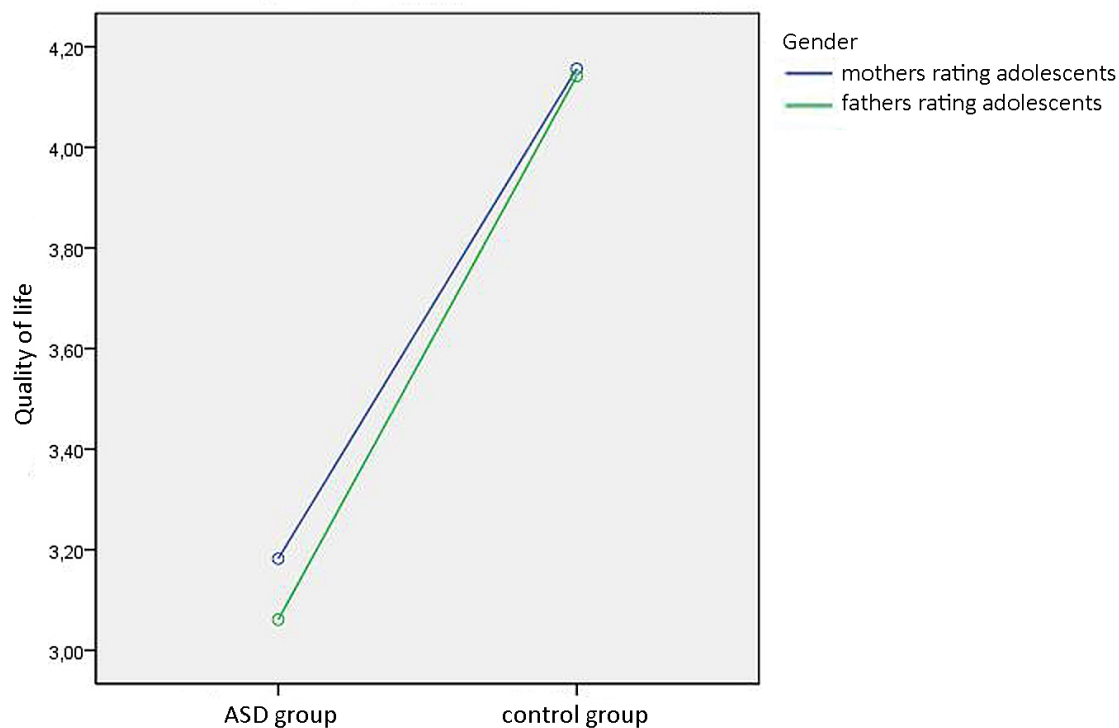


Figure 4. Difference in means of hypothesis 1

4.2 Do fathers rate their own QoL higher than mothers rate their own QoL in comparison to the control group?

There was a difference in group ($p = .03$, $d = .84$, $\alpha = .05$) but no difference in gender ($p = .29$, $d = .24$, $\alpha = .05$). The interaction between gender and group was significant ($p = .04$, $d = .70$, $\alpha = .05$). Variances were tested by Levene test. Variances were significantly different for mothers rating themselves, $F(1, 37) = 3.80$, $p = .06$, but equal for fathers rating themselves, $F(1, 37) = 3.98$, ns ($p = .06$). Normal distribution was tested by Kolmogorov-Smirnov-test. For the ASD group, the mothers rating themselves, $D(15) = .31$, $p = .00$ was significantly normal, and the fathers rating themselves, $D(15) = .16$, $p \geq .20$, was significantly non-normal. For the control group, the mothers rating themselves, $D(24) = .18$, $p = .06$, and the fathers rating themselves, $D(24) = .13$, $p \geq .20$, were both significantly non-normal.

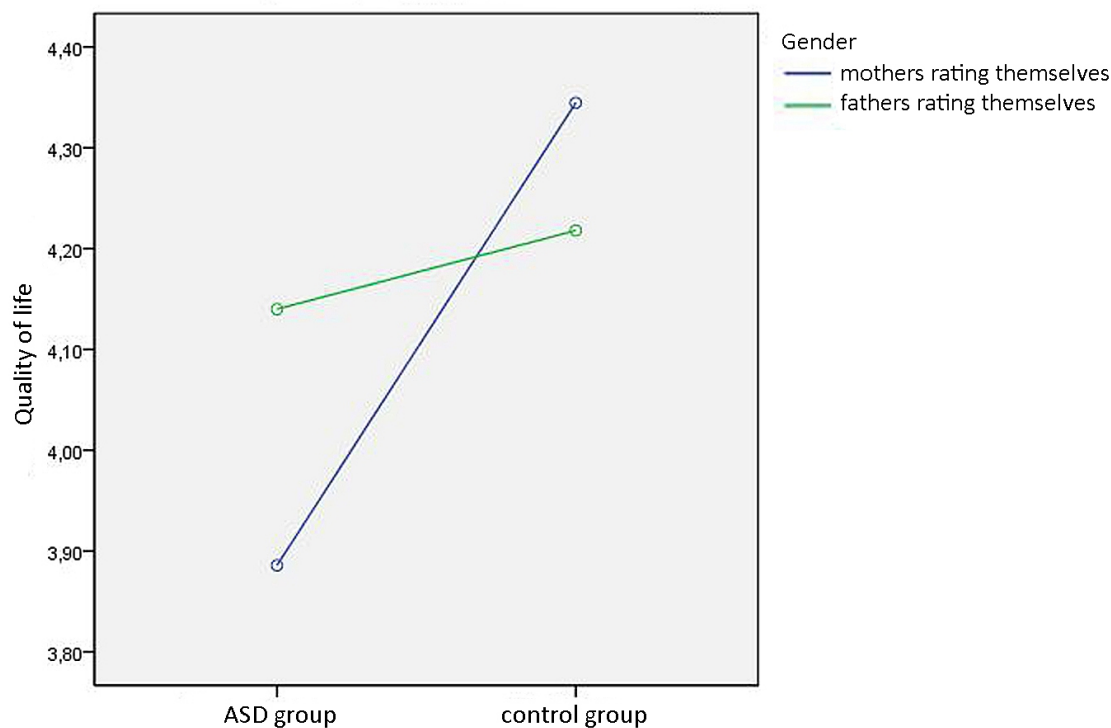


Figure 5. Difference in means of hypothesis 2

4.3 Do fathers rate the QoL of the mothers lower than mothers rate the QoL of the fathers in comparison to the control group?

There was no difference in group ($p = .22$, $d = .42$, $\alpha = .05$) but a difference in gender ($p = .30$, $d = .35$, $\alpha = .05$). The interaction between gender and group was not significant ($p = .36$, $d = .31$, $\alpha = .05$). Variances were tested by Levene test. Variances were significantly different for mothers rating fathers, $F(1, 37) = 4.21$, $p = .05$, but equal for fathers rating mothers $F(1, 37) = .84$, ns ($p = .36$). Normal distribution was tested by Kolmogorov-Smirnov-test. For the ASD group, the mothers rating fathers, $D(15) = .12$, $p \geq .20$, and the fathers rating mothers, $D(15) = .00$, $p = .12$, were significantly non-normal. For the control group, the mothers rating fathers, $D(24) = .21$, $p = .01$, was significantly normal, and the fathers rating mothers, $D(24) = .12$, $p \geq .20$, was significantly non-normal.

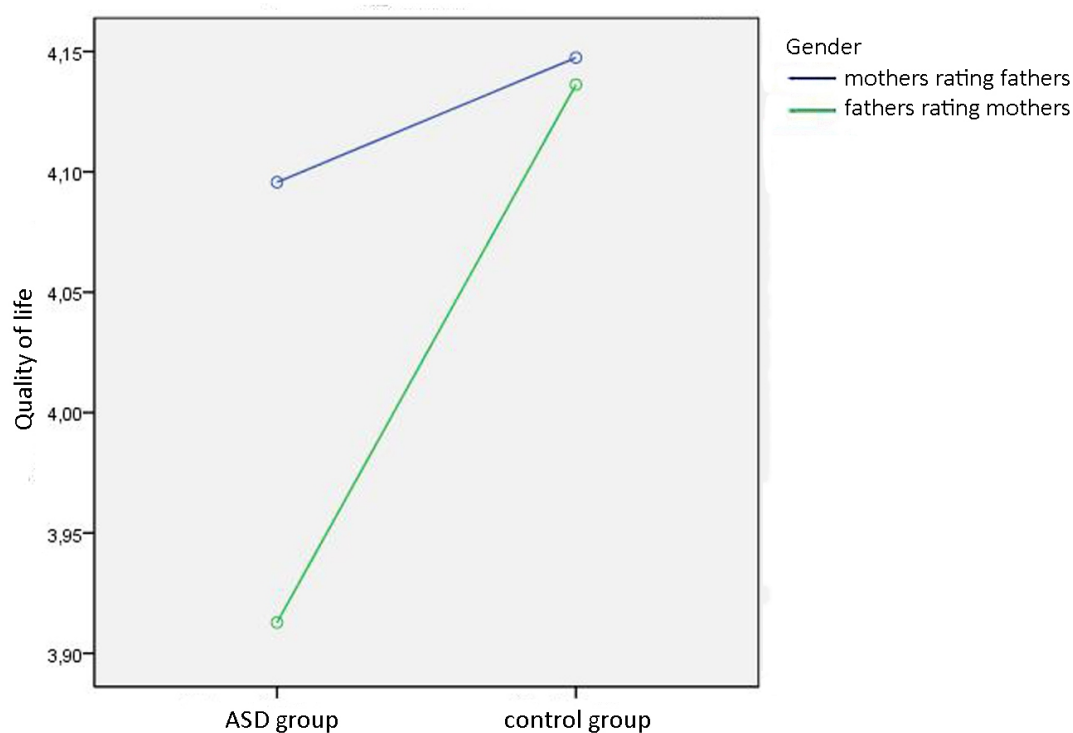


Figure 6. Difference in means of hypothesis 3

4.4 Is the QoL of the parents higher if the self reports and the proxy reports of the adolescents' QoL are more similar?

For this hypothesis the difference between the self reports and the average proxy report of both parents was calculated. Then a linear regression was made from this variable as to the average QoL of both parents. There was no significance in the ASD group ($p = .15$, $R = .41$, $R^2 = .17$, $B = -.53$, $\beta = -.41$, $\alpha = .05$) and no significance in the control group ($p = .063$, $R = .39$, $R^2 = .15$, $B = .40$, $\beta = .39$, $\alpha = .05$). Assumptions were only partly given. For the ASD group there is a sign for linearity in the scatter diagram. Normal distribution was not given for the average QoL of both parents, $D(15) = .21$, $p = .01$, but given for the difference between the self reports and the average proxy report, $D(15) = .18$, $p \geq .20$. For the control group there is a sign for linearity in the scatter diagram. Normal distribution was given for the average QoL of both parents, $D(24) = .01$, $p \geq .20$, and given for the difference between the self reports and the average proxy report, $D(24) = .12$, $p \geq .20$.

4 Discussion

This study aimed on the hand to create a more complete model about the QoL of families with adolescents with ASD and on the other hand to explore the role of the father. The first hypothesis asked if fathers rate the QoL of their child with ASD lower than mothers do in comparison to the control group. All statistical requirements were fulfilled. Using GLM parents of adolescents with ASD rated the QoL of their children lower than parents of children without ASD. First, this result is consistent with the previous research showing that parents of children with disabilities rate their QoL lower (Kamp-Becker et al., 2011; Egilson et al., 2017). The effect size is extremely strong. Second, fathers and mothers compared their children similarly in both groups. In contrast to conjectures, taking less often care of family's needs, using more active avoiding strategies and having less knowledge about the child, fathers do not rate their adolescents differently than mothers. Third, there is no interaction between group and gender. For example, having a child with ASD does not influence how fathers rate the QoL of their children compared to the mothers.

The second hypothesis asked if fathers rate their own QoL higher than mothers rate their own QoL in comparison to the control group. The validity of results is restricted on the

one hand because of having no homogeneity of variances in the group of mothers with adolescents with ASD, and on the other hand because of a significant interaction effect. First, parents of adolescents with ASD rated their own QoL lower than parents of children without ASD. Fathers with ASD rating their QoL higher is consistent with previous research (McStay et al., 2014). The effect size is strong. Second, no difference in gender was found, but this is influenced by interaction. Surprisingly fathers of the ASD group rated their QoL higher than mothers while fathers of the control group rated their QoL lower comparing the means. A strong effect in this study suggests that having a child with ASD has less effect on the QoL of fathers, independent of having a child with ASD or not.

The third hypothesis asked for the first time if fathers rate the QoL of the mothers lower than mothers rate the QoL of the fathers in comparison to the control group. All assumptions were fulfilled, except the homogeneity of variances was not given for mothers of the control group. First, the GLM suggests parents of adolescents with ASD did not rate the other legal guardian differently compared to parents without adolescents with ASD. Second, according to the GLM there is no significant difference in gender. Fathers seem to rate the QoL of mothers insignificantly, but little lower than mothers rating the QoL of fathers in the ASD group. This could go back to fathers seeing mothers more influenced and bounded if having a child with ASD. Third, there was no interaction between gender and group.

The fourth hypothesis asked if the QoL of the parents is higher if the self reports and the proxy reports of the adolescents' QoL are more similar. This is the not case in the ASD group and in the control group. In the control group the significance is almost given. So if parents and adolescents rate the QoL more similarly the QoL of the parents is higher.

Overall on the one hand this study confirms the previous research in this field. Parents of children with disabilities rated their QoL lower (Kamp-Becker et al., 2011; Begeer, Yujie, Koot, Wierda, van Beijsterveldt & Boomsma, 2017) and fathers of children with disabilities rated their QoL higher than mothers (McStay et al., 2014). On the other hand additional results were found. Since partly assumptions were violated, the most reliable new finding is that there is no difference in gender when parents rate the QoL of their adolescents.

4.1 Strengths and limitations

The strengths of this study are as follows. First, for the first time both parents were tested at once, and both parents rated each other. Second, by focusing on both parents fathers were equally tested as mothers. Third, the hypotheses focused strongly on comparisons to the control group. Fourth, it was significantly found out that there is no difference in gender when parents rate the QoL of their adolescents. Fifth, for the first time parents rated each other's QoL.

This study has several limitations. First, families with adolescents with ASD were not representative. They were chosen intentionally by employees of organizations who support people with ASD. Families who were willing to participate could be more social than the average family. Additionally, both two legal guardians had to be available and willing to participate. Adolescents had to be high functioning to fill out the questionnaire by themselves. The nationality of almost all family members was German. Second, the control group also was not representative. Families were chosen by hand and not randomly. In both groups 116 out of 117 persons (99.1%) were German and therefore the sample lacked diversity in ethnicity. 40 out of 78 parents (51.3%) had an university degree, and therefore the sample also overrepresents academic families. Third, the number of families of the ASD group (N=15) could only partly not sufficiently guarantee homogeneity of variances. Fourth, the response rate of the ASD group is unknown. Fifth, only teenagers were tested and not non-adults of any age. Sixth, to have an even more broad model, more persons could be added, e.g. other children of the parents. Seventh, the used scales focus more on negative implications of ASD instead of possible strengths of the concerned person. Egilson et al. (2017) point out that children with ASD, despite lower QoL scores, revealed their overall positive emotions and satisfaction with life, as well as satisfaction with their relationships, autonomy and schools. Eighth and finally, quantitative research alone is not able to give a full picture of the effect of ASD on QoL and its impact on families, and has to be complemented with qualitative methods.

4.2 Conclusions

Generally fathers' ratings were not as different from mothers' as expected. The question of gender differences was as contrary as in previous studies (Begeer et al., 2017). Therefore, differentiating between mothers and fathers seems possibly mostly unnecessary concerning QoL. When parents were asked to rate each other, there was also no significant difference in gender and group. As a consequence fathers are comparable to mothers not only in self but in proxy ratings, even though they have a higher income and are less often depressed than mothers. For future research the study could be expanded to higher amounts of participants, even more family members or persons with more severe forms of ASD who are unable to fill out the questionnaires by themselves.

5 Acknowledgments

The author declares no conflict of interest. The data for this study was collected in cooperation with Nils Bukowski (in print). The data collection was partly financially supported by a research scholarship from the University of Vienna.

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9 List of abbreviations

ASD	Autism Spectrum Disorder
WHOQOL-BREF	WHO Quality of Life Assessment Instrument
PedsQL	Pediatric Quality of Life Inventory
SPM	Raven's Standard Progressive Matrices Test
RSPM	Abbreviated 9 item form of the SPM
GLM	General linear model

10 Appendix

A. German abstract

Die bisherige Forschung hat kaum die Lebensqualität (QoL) von Vätern von Jugendlichen mit Autismus-Spektrum-Störung (ASD) getestet. Zum ersten Mal wird die Lebensqualität von Jugendlichen und sowohl Müttern als auch Vätern geprüft. Auf diese Weise wird ein Modell geschaffen, das aus drei Familienmitgliedern besteht und Selbsteinschätzungen als auch teilweise gegenseitige Bewertungen beinhaltet. Daten von 15 betroffenen und 24 Kontrollfamilien wurden in Deutschland gesammelt. Bisherige Forschung wurde bestätigt, beispielsweise dass Eltern von Kindern mit Behinderungen ihre eigene Lebensqualität niedriger schätzen und Väter von Kindern mit Behinderungen ihre Lebensqualität höher als Mütter einschätzen. Zusätzlich wurde unter Anderem kein Unterschied im Geschlecht gefunden wenn Eltern die Lebensqualität der Jugendlichen einschätzen sollten. Der Unterschied zwischen Bewertungen von Müttern und Vätern war allgemein niedriger als erwartet. Um die Ergebnisse zu bestätigen wird eine Wiederholung dieser Studie mit einer größeren Datenmenge empfohlen, um Voraussetzungsfehler zu vermeiden und Effektstärken zu erhöhen.

Schlüsselbegriffe: Autismus, Lebensqualität, Jugend, Väter

B1. Consent form (parents)

Sehr geehrte Studienteilnehmer/in,

im Rahmen der Abschlussarbeit unseres Studiums versuchen wir mehr über das Leben der Familien von Jugendlichen mit Autismus-Spektrum-Störungen herauszufinden. Forschung dieser Art soll langfristig helfen, das Leben von allen betroffenen Familien zu verbessern.

Neu an unserer Studie ist, dass wir gleichzeitig Ihr Kind und beide Eltern des Kindes befragen wollen. Deshalb ist uns wichtig, dass alle drei Personen den Fragebogen vollständig ausfüllen (Ihr Kind mit Autismus-Spektrum-Störung, der Vater und die Mutter des Kindes).

Uns ist bewusst, dass dieser Fragebogen für Sie drei interessant sein, aber auch Mühe bedeuten kann. Er wird etwa 30 Minuten Ihrer Zeit in Anspruch nehmen. Wir danken Ihnen persönlich für die Zeit, die Sie investieren!

Das Ausfüllen des Bogens ist dabei vollkommen anonym. Ihre Daten werden vertraulich und nur für diese Studie verwendet. Die Teilnahme erfolgt vollkommen freiwillig. Sie können daher jederzeit entscheiden, aus der Studie auszusteigen.

Bitte suchen Sie für das Ausfüllen des Fragebogens einen Ort auf, wo Sie nicht gestört werden. Falls Sie dies wünschen, bitte reden Sie mit dem Vater/ der Mutter des Jugendlichen erst über den Inhalt des Fragebogens, nachdem Sie ihn ausgefüllt haben, damit Sie sich nicht gegenseitig beeinflussen.

Sollte Ihr Kind Hilfe benötigen beim Ausfüllen, können Sie es gerne unterstützen. Einzige Ausnahme sind die Muster, die Ihr Kind zuordnen soll. Falls Ihr Kind hier keine "Lösung" findet, bitte helfen Sie dem Kind nicht, die aus Ihrer Sicht "richtige" Lösung zu finden.

Wichtig ist, dass es keine "falschen" und "richtigen" Antworten gibt - bitte antworten Sie einfach so, wie es Ihnen am Zutreffendsten erscheint.

Bitte geben Sie die ausgefüllten Bögen in den vorgefertigten Umschlag. Sie können diesen Umschlag entweder 1. an Ihre Kontaktperson zurückgeben.

Falls es Fragen, Probleme oder Anmerkungen Ihrerseits gibt, können Sie uns gerne jederzeit unter der Emailadresse studie2016@gmx.net oder der Telefonnummer 0043/6506614183 erreichen (Anruf, SMS, Whatsapp, Telegramm).

Anbei finden Sie zudem einen Zettel, den Sie behalten dürfen und aufbewahren sollen. Über diesen Zettel können Sie etwa im Sommer des kommenden Jahres alle Ergebnisse dieser Studie erfahren.

Wir danken Ihnen nochmals sehr herzlich!

B2. Consent form (adolescents)

Lieber Studienteilnehmer/ liebe Studienteilnehmerin,

wir sind Studenten von der Universität Wien. Für unsere Abschlussarbeit wollen wir mehr über Familien wie deine herausfinden. Auf lange Sicht soll das helfen, dass sie noch besser unterstützt werden.

Auf den folgenden Seiten wirst du verschiedene Fragen finden. Zu jeder Frage gibt es verschiedene Antwortmöglichkeiten zum Ankreuzen. Bitte kreuze jeweils eine der Antwortmöglichkeiten pro Frage an. Manchmal sollst du auch einfach nur eine Zahl eintragen. Bitte lass keine der Fragen aus, sondern beantworte alle.

Wir vermuten, dass du etwa 30 Minuten brauchen wirst. Wir danken dir sehr, dass du teilnimmst!

Wichtig ist, dass es keine "falschen" und "richtigen" Antworten gibt. Bitte antworte einfach so, wie es sich für dich richtig anfühlt.

Deine Antworten sind dabei völlig anonym. Sie werden nur für diese Studie verwendet. Außerdem ist die Teilnahme vollkommen freiwillig. Du kannst also jederzeit entscheiden, nicht an der Studie teilzunehmen.

Bitte suche für das Ausfüllen des Fragebogens einen Ort auf, wo du nicht gestört wirst. Versuche erst einmal, den Fragebogen alleine auszufüllen. Falls es dir schwer fällt, kannst du aber gerne deine Eltern um Unterstützung fragen.

Bitte gib den Bogen in den vorgesehen Umschlag. Deine Eltern werden sich kümmern, dass er uns erreicht.

Falls du Fragen, Problemen oder Anmerkungen hast kannst du entweder deine Eltern fragen oder uns jederzeit gerne unter der Emailadresse studie2016@gmx.net oder der Telefonnummer 0043/6506614183 erreichen (Anruf, SMS, Whatsapp, Telegramm).

Anbei findest du einen Zettel, den du behalten darfst. Über diesen Zettel kannst du im Sommer alle Ergebnisse dieser Studie erfahren.

Wir danken dir nochmal sehr herzlich, dass du mitmachst!

C. Basic data questionnaires (parents)

Ihr Alter	_____ Jahre
Ihr Geschlecht	☐ weiblich ☐ männlich
Ihre Staatszugehörigkeit	☐ deutsch ☐ andere: _____
Ihr höchster akademischer Abschluss	☐ ohne Abschluss ☐ Hauptschule ☐ Realschule ☐ Abitur ☐ Studium
Ihr monatliches Einkommen	☐ unter 1000 € ☐ 1000-2000 € ☐ 2000-3000 € ☐ 4000-5000€ ☐ mehr als 5000 €
Ihr Beziehungsstatus	☐ ledig ☐ verheiratet ☐ geschieden ☐ verwitwet ☐ _____
Befinden Sie sich mit dem Vater des Kindes noch in einer Partnerschaft?	☐ ja ☐ nein

Angaben zu Ihrem Kind:

Alter des Kindes	_____ Jahre
Geschlecht des Kindes	☐ weiblich ☐ männlich
Aktuelle Schulklasse	_____te Klasse
Staatszugehörigkeit	☐ deutsch ☐ andere: _____
Ihre Beziehung zum Kind	☐ Mutter

D. Basic data questionnaires (adolescents)

Ein paar Angaben zu dir:

Dein Alter	Ich bin _____ Jahre alt.
Dein Geschlecht	☐ weiblich ☐ männlich
Aktuelle Schulklasse	Ich gehe in die _____te Klasse.
Staatsangehörigkeit	☐ deutsch ☐ andere: _____

D. Scales

D.1 WHOQOL-BREF

In diesem Teil des Fragebogens werden Sie danach gefragt, wie Sie Ihre Lebensqualität, Ihre Gesundheit und andere Bereiche Ihres Lebens beurteilen. **Bitte beantworten Sie alle Fragen.** Wenn Sie sich bei der Beantwortung einer Frage nicht sicher sind, wählen Sie bitte die Antwortkategorie, die Ihrer Meinung nach am ehesten zutrifft. Oft ist dies die Kategorie, die Ihnen als erstes in den Sinn kommt.

Bitte beantworten Sie alle Fragen auf der Grundlage Ihrer eigenen Beurteilungskriterien, Hoffnungen, Vorlieben und Interessen. Bitte denken Sie bei der Beantwortung der folgenden Fragen an Ihr Leben **während der vergangenen zwei Wochen.**

	Sehr gering	Gering	Weder gering noch gut	Gut	Sehr gut
Wie würden Sie Ihre Lebensqualität einschätzen?	☐	☐	☐	☐	☐

	Sehr unzufrieden	Unzufrieden	Weder zufrieden noch unzufrieden	Zufrieden	Sehr zufrieden
Wie zufrieden sind Sie mit Ihrer Gesundheit?	☐	☐	☐	☐	☐

	Überhaupt nicht	Ein wenig	Mittelmäßig	Ziemlich	Äußerst
Wie stark werden Sie durch Schmerzen daran gehindert, notwendige Dinge zu tun?	☐	☐	☐	☐	☐
Wie sehr sind Sie auf medizinische Behandlung angewiesen, um das tägliche Leben meistern zu können?	☐	☐	☐	☐	☐
Wie gut können Sie Ihr Leben genießen?	☐	☐	☐	☐	☐
Betrachten Sie Ihr Leben als sinnvoll?	☐	☐	☐	☐	☐

	Überhaupt nicht	Ein wenig	Mittelmäßig	Ziemlich	Äußerst
Wie gut können Sie sich konzentrieren?	☐	☐	☐	☐	☐
Wie sicher fühlen Sie sich in Ihrem täglichen Leben?	☐	☐	☐	☐	☐
Wie gesund sind die Lebensbedingungen in Ihrem Wohngebiet?	☐	☐	☐	☐	☐

*In den folgenden Fragen geht es darum, im welchem Umfang Sie während der **vergangenen zwei Wochen** bestimmte Dinge erlebt haben oder in der Lage waren, bestimmte Dinge zu tun.*

	Überhaupt nicht	Eher nicht	Halbwegs	Überwiegend	Völlig
Haben Sie genug Energie für das tägliche Leben?	☐	☐	☐	☐	☐
Können Sie Ihr Aussehen akzeptieren?	☐	☐	☐	☐	☐
Haben Sie genug Geld, um Ihre Bedürfnisse erfüllen zu können?	☐	☐	☐	☐	☐
Haben Sie Zugang zu Informationen, die Sie für das tägliche Leben brauchen?	☐	☐	☐	☐	☐
Haben Sie ausreichend Möglichkeiten zu Freizeitaktivitäten?	☐	☐	☐	☐	☐

	Sehr schlecht	Schlecht	Mittelmäßig	Gut	Sehr gut
Wie gut können Sie sich fortbewegen?	☐	☐	☐	☐	☐

In den folgenden Fragen geht es darum, wie **zufrieden, glücklich oder gut** Sie sich während der vergangenen zwei Wochen hinsichtlich verschiedener Aspekte Ihres Lebens gefühlt haben.

	Sehr unzufrieden	Unzufrieden	Weder zufrieden noch unzufrieden	Zufrieden	Sehr zufrieden
Wie zufrieden sind Sie mit Ihrem Schlaf?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit Ihrer Fähigkeit, alltägliche Dinge erledigen zu können?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit Ihrer Arbeitsfähigkeit?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit sich selbst?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit Ihren persönlichen Beziehungen?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit Ihrem Sexualleben?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit der Unterstützung durch Ihre Freunde?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit Ihren Wohnbedingungen?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit Ihren Möglichkeiten, Gesundheitsdienste in Anspruch nehmen zu können?	☐	☐	☐	☐	☐
Wie zufrieden sind Sie mit den Beförderungsmitteln, die Ihnen zu Verfügung stehen?	☐	☐	☐	☐	☐

	Niemals	Nicht oft	Ab und zu	Oft	Immer
Wie häufig haben Sie negative Gefühle wie Traurigkeit, Verzweiflung, Angst oder Depression?	☐	☐	☐	☐	☐

D.2 WHOQOL-BREF (transformed version for fathers)

Im Folgenden sollen Sie die **Lebensqualität der Mutter des Kindes** einschätzen. Bitte denken Sie bei der Beantwortung der Fragen an ihr Leben **während der vergangenen zwei Wochen**. Ihre eigene, persönliche Einschätzung der Lebensqualität der Mutter des Kindes ist hier für uns wichtig. Bitte fragen Sie sie daher nicht direkt.

	Sehr gering	Gering	Weder gering noch gut	Gut	Sehr gut
Wie würden Sie die Lebensqualität der Mutter einschätzen?	☐	☐	☐	☐	☐

	Sehr unzufrieden	Unzufrieden	Weder zufrieden noch unzufrieden	Zufrieden	Sehr zufrieden
Wie zufrieden ist die Mutter mit seiner Gesundheit?	☐	☐	☐	☐	☐

	Überhaupt nicht	Ein wenig	Mittelmäßig	Ziemlich	Äußerst
Wie stark wird die Mutter durch Schmerzen daran gehindert, notwendige Dinge zu tun?	☐	☐	☐	☐	☐
Wie sehr ist die Mutter auf medizinische Behandlung angewiesen, um das tägliche Leben meistern zu können?	☐	☐	☐	☐	☐
Wie gut kann die Mutter ihr Leben genießen?	☐	☐	☐	☐	☐
Betrachtet die Mutter ihr Leben als sinnvoll?	☐	☐	☐	☐	☐

	Überhaupt nicht	Ein wenig	Mittelmäßig	Ziemlich	Äußerst
Wie gut kann die Mutter sich konzentrieren?	☐	☐	☐	☐	☐
Wie sicher fühlt die Mutter sich in ihrem täglichen Leben?	☐	☐	☐	☐	☐
Wie gesund sind die Lebensbedingungen im Wohngebiet der Mutter?	☐	☐	☐	☐	☐

*In den folgenden Fragen geht es darum, im welchem Umfang der Vater des Kindes während der **vergangenen zwei Wochen** bestimmte Dinge erlebt hat oder in der Lage war, bestimmte Dinge zu tun.*

	Überhaupt nicht	Eher nicht	Halbwegs	Überwiegend	Völlig
Hat die Mutter genug Energie für das tägliche Leben?	☐	☐	☐	☐	☐
Konnte die Mutter ihr Aussehen akzeptieren?	☐	☐	☐	☐	☐
Hat die Mutter genug Geld, um ihre Bedürfnisse erfüllen zu können?	☐	☐	☐	☐	☐
Hat die Mutter Zugang zu Informationen, die sie für das tägliche Leben braucht?	☐	☐	☐	☐	☐
Hat die Mutter ausreichend Möglichkeiten zu Freizeitaktivitäten?	☐	☐	☐	☐	☐

	Sehr schlecht	Schlecht	Mittelmäßig	Gut	Sehr gut
Wie gut kann die Mutter sich fortbewegen?	☐	☐	☐	☐	☐

In den folgenden Fragen geht es darum, wie **zufrieden, glücklich oder gut die Mutter des Kindes** sich während der vergangenen zwei Wochen hinsichtlich verschiedener Aspekte Ihres Lebens gefühlt hat. Bitte geben Sie auch hier ihre eigene Einschätzung.

	Sehr unzu- frieden	Unzufrieden	Weder zu- frieden noch unzu- frieden	Zufrieden	Sehr zu- frieden
Wie zufrieden ist die Mutter mit ihrem Schlaf?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit ihrer Fähigkeit, alltägliche Dinge erledigen zu können?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit ihrer Arbeitsfähigkeit?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit sich selbst?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit ihren persönlichen Beziehungen?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit ihrem Sexualleben?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit der Unterstützung durch Ihre Freunde?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit ihren Wohnbedingungen?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit seinen Möglichkeiten, Gesundheitsdienste in Anspruch nehmen zu können?	☐	☐	☐	☐	☐
Wie zufrieden ist die Mutter mit den Beförderungsmitteln, die ihr zu Verfügung stehen?	☐	☐	☐	☐	☐

	Niemals	Nicht oft	Ab und zu	Oft	Immer
Wie häufig hat die Mutter negative Gefühle wie Traurigkeit, Verzweiflung, Angst oder Depression?	☐	☐	☐	☐	☐

D.3 PedsQL (parents' version)

Im Folgenden sollen Sie die **Lebensqualität des Kindes** einschätzen. Bitte denken Sie bei der Beantwortung der Fragen an das Leben des Kindes **während der vergangenen vier Wochen**. Ihre eigene, persönliche Einschätzung der Lebensqualität Ihres Kindes ist hier für uns wichtig. Bitte fragen Sie Ihr Kind daher nicht direkt.

	nie	fast nie	manchmal	häufig	fast immer
Es fiel meinem Kind schwer mehr als 100 Meter zu Fuß zu gehen.	☐	☐	☐	☐	☐
Es fiel meinem Kind schwer zu rennen.	☐	☐	☐	☐	☐
Es fiel meinem Kind schwer an sportlichen Aktivitäten teilzunehmen.	☐	☐	☐	☐	☐
Es fiel meinem Kind schwer etwas Schweres aufzuheben.	☐	☐	☐	☐	☐
Es fiel meinem Kind schwer Aufgaben im Haushalt zu erledigen.	☐	☐	☐	☐	☐
Mein Kind hatte Angst.	☐	☐	☐	☐	☐
Mein Kind war traurig.	☐	☐	☐	☐	☐
Mein Kind war sauer.	☐	☐	☐	☐	☐
Mein Kind machte sich sorgen, dass ihm/ ihr etwas passieren wird.	☐	☐	☐	☐	☐
Mein Kind hatte Schwierigkeiten mit anderen Jugendlichen gut auszukommen.	☐	☐	☐	☐	☐
Andere Jugendliche wollten mit meinem Kind nicht befreundet sein.	☐	☐	☐	☐	☐
Andere Jugendliche hänselten mein Kind.	☐	☐	☐	☐	☐
Es fiel meinem Kind schwer im Unterricht aufzupassen.	☐	☐	☐	☐	☐
Mein Kind vergaß Dinge.	☐	☐	☐	☐	☐
Meinem Kind fiel es schwer, das zu erledigen, was es in der Schule und für die Schule tun sollte.	☐	☐	☐	☐	☐

D.4 PedsQL (adolescents' version)

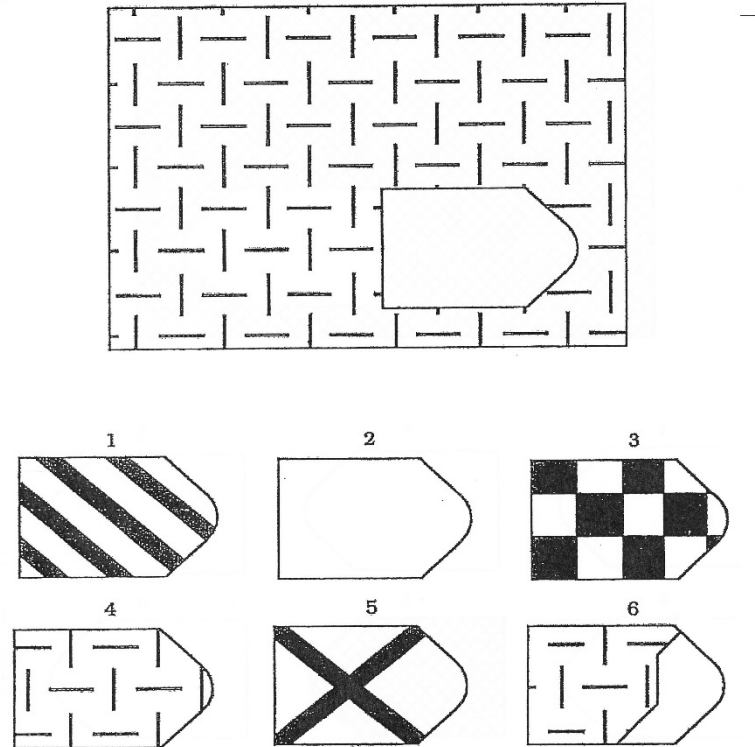
Hattest du in den **vergangenen 4 Wochen** folgende **Probleme oder Schwierigkeiten**?

	nie	fast nie	manch- mal	häufig	fast im- mer
Es fiel mir schwer mehr als 100 Meter zu Fuß zu gehen.	☐	☐	☐	☐	☐
Es fiel mir Kind schwer zu rennen.	☐	☐	☐	☐	☐
Es fiel mir schwer an sportlichen Aktivitäten teilzunehmen.	☐	☐	☐	☐	☐
Es fiel mir schwer etwas Schweres aufzuheben.	☐	☐	☐	☐	☐
Es fiel mir schwer Aufgaben im Haushalt zu erledigen.	☐	☐	☐	☐	☐
Ich hatte Angst.	☐	☐	☐	☐	☐
Ich war traurig.	☐	☐	☐	☐	☐
Ich war sauer.	☐	☐	☐	☐	☐
Ich machte mir Sorgen, was mit mir passieren wird.	☐	☐	☐	☐	☐
Ich hatte Schwierigkeiten mit anderen Jugendlichen gut auszukommen.	☐	☐	☐	☐	☐
Andere Jugendliche wollten mit mir nicht befreundet sein.	☐	☐	☐	☐	☐
Andere Jugendliche hänselten mich.	☐	☐	☐	☐	☐
Es fiel mir schwer im Unterricht aufzupassen.	☐	☐	☐	☐	☐
Ich vergaß Dinge.	☐	☐	☐	☐	☐
Es mir schwer, das zu erledigen, was ich in der Schule und für die Schule tun sollte.	☐	☐	☐	☐	☐

D.5 RSPM

Zu Beginn sollst du ein paar Aufgaben lösen.

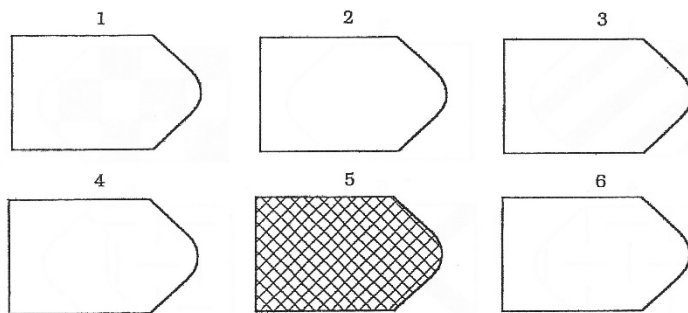
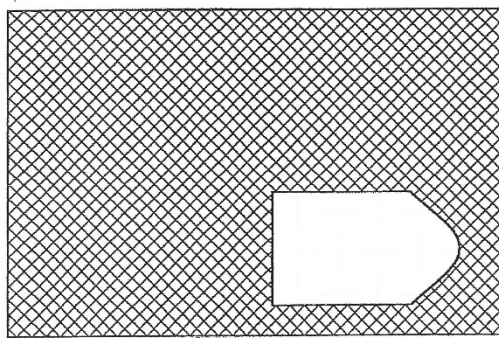
Welches Blättchen müsste man einsetzen, um das Muster richtig zu ergänzen?



Die richtige Antwort hier ist Blättchen 4.

Am Anfang sind die Muster einfacher, nach und nach werden sie schwieriger.

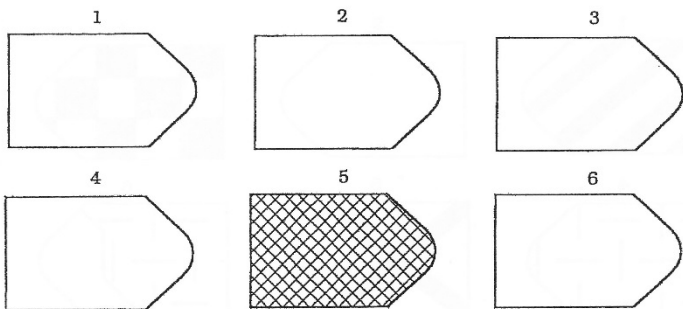
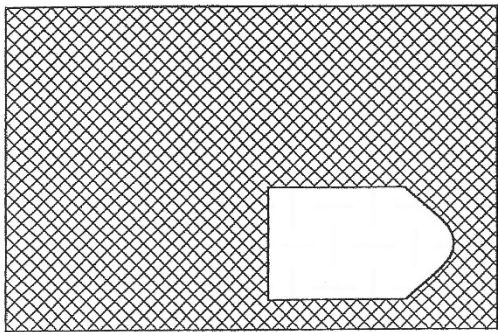
Welches der 6 Muster passt hier am besten hinein? Kreuze die richtige Zahl an.



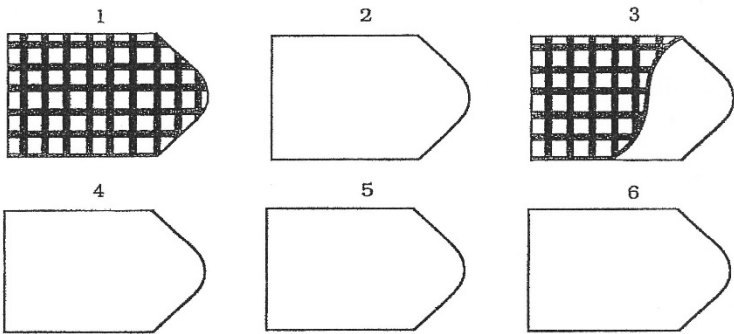
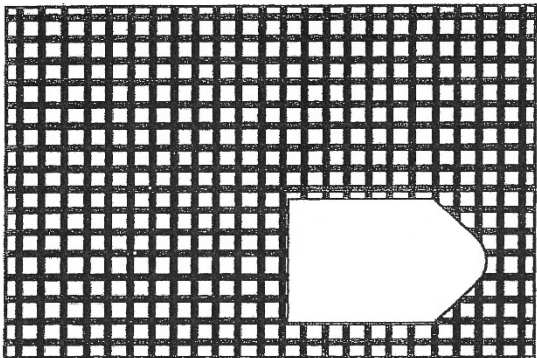
*Hier wäre es richtig **5** anzukreuzen.*

(Falls du das Rätsel noch nicht verstanden hast, kannst du deine Eltern fragen. Es ist aber wichtig, dass du die Rätsel ab dann ohne die Hilfe deiner Eltern machst.)

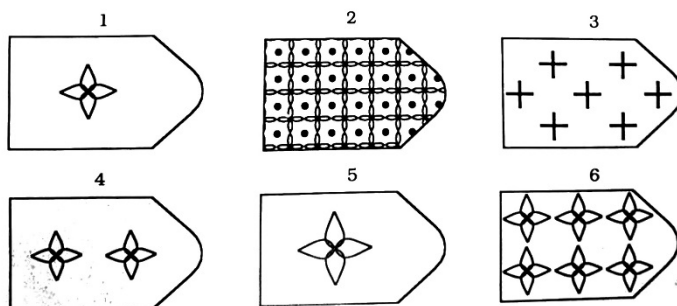
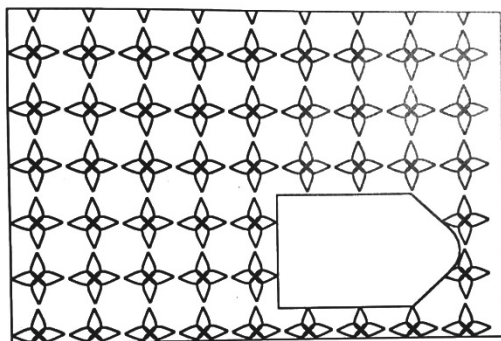
Nun bist du dran! Kreuze bei jeder Aufgabe das Blättchen an, das am besten passt.



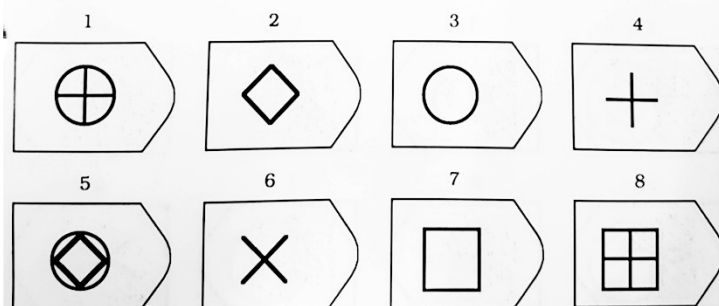
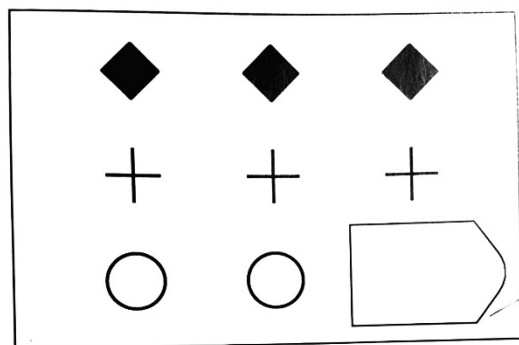
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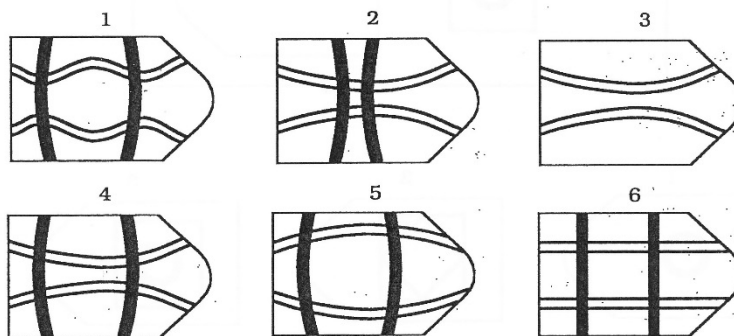
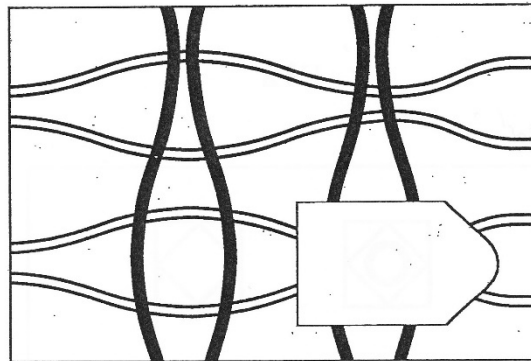
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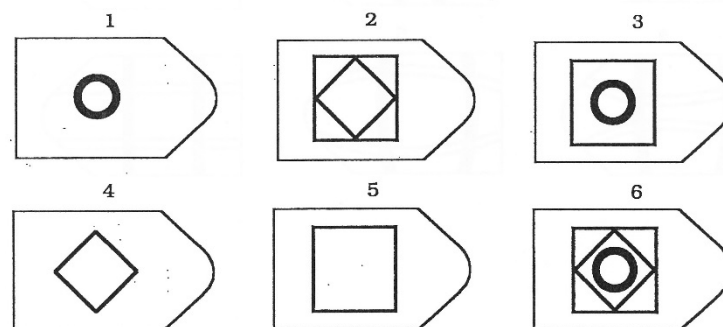
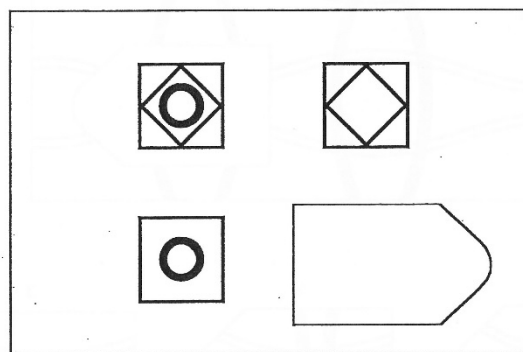
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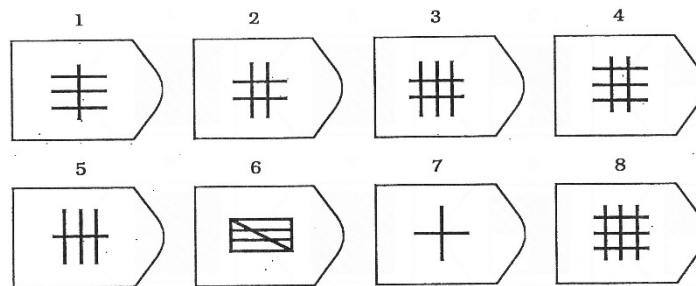
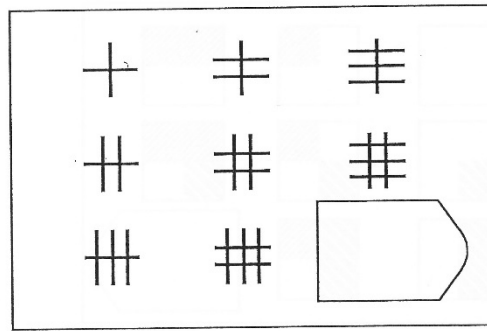
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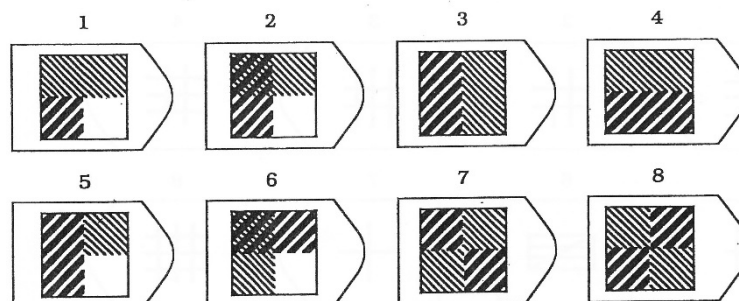
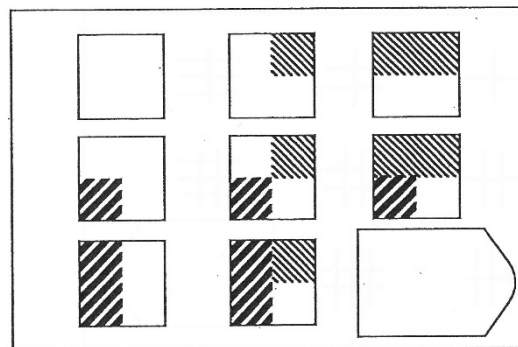
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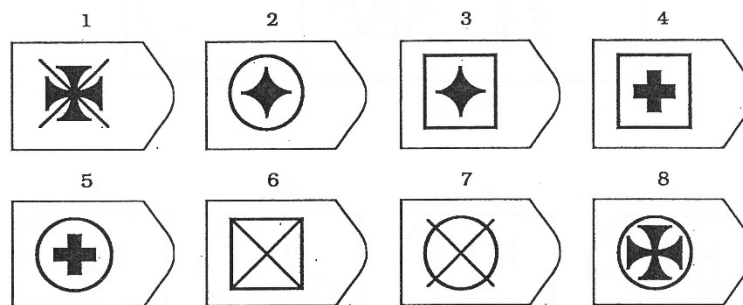
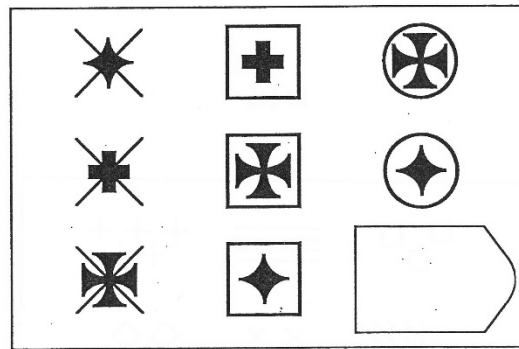
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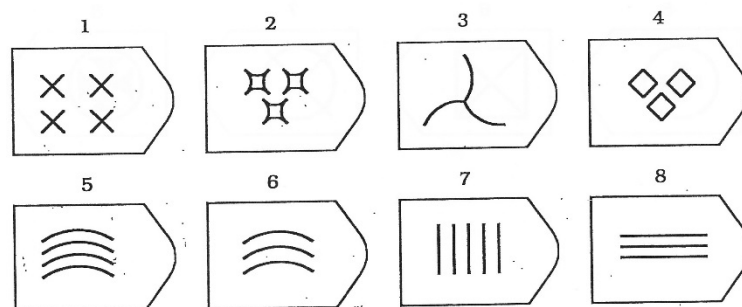
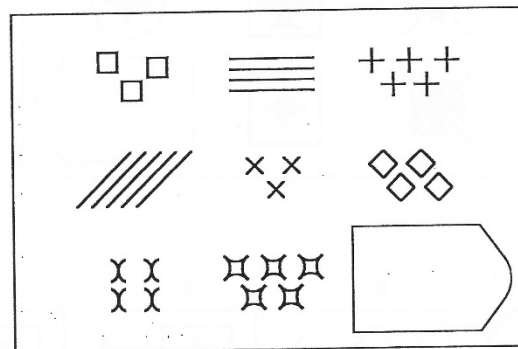
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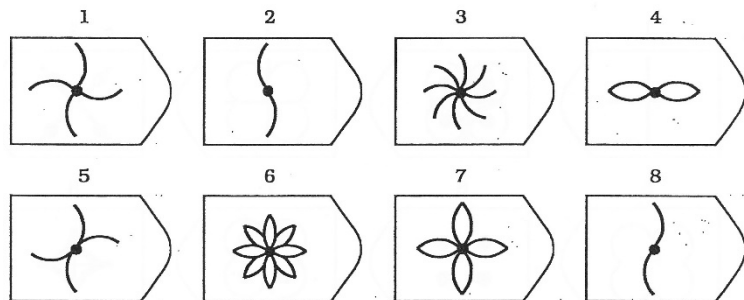
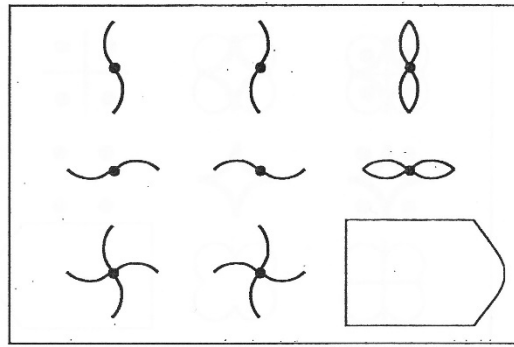
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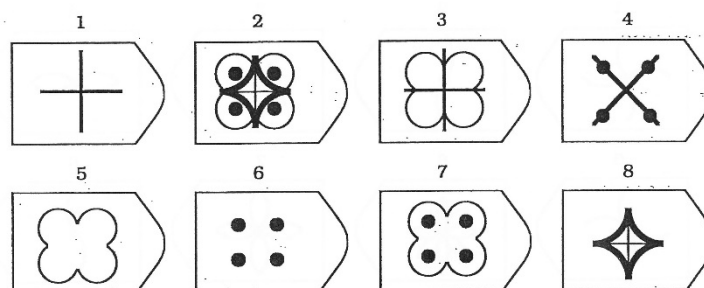
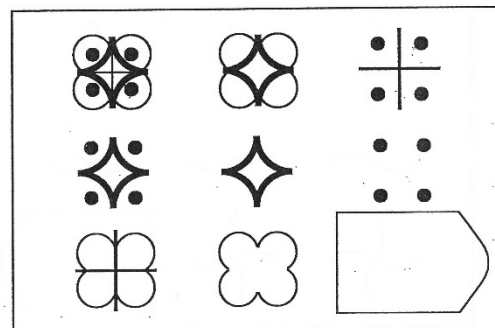
Aufgabe 10:



Aufgabe 11:



Aufgabe 12:



Aufgabe 13:

