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Quality of life in adolescents and adults with autism spectrum disorder: Results from a nationwide Danish survey using self-reports and parental proxy-reports

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ABSTRACT

Background: Quality of life (QoL) in individuals with autism spectrum disorder (ASD) is essential to investigate with regard to knowledge about factors of importance for QoL and concordance between self-reported and parental proxy-reported QoL.

Aims: This study investigated QoL in adolescents and adults with ASD using both self-reports and parental proxy-reports.

Methods: From a nationwide survey, 1738 individuals diagnosed with ASD in childhood, were included for this study. The individuals themselves and/or their parents completed the INICO-FEAPS scale. Concordance between self-reports and proxy-reports were examined, and factors associated with QoL were explored via linear regression models.

Results: Compared to proxy-reported QoL scores, self-reported QoL scores were significantly but only slightly higher and not in every QoL domain. Independent of respondent type it was found that psychiatric comorbidity, sleeping difficulty, intellectual disability, maladaptive behavior, adaptive functioning, autism symptomatology, main daytime activity and residence were associated with QoL.

Conclusion: Proxy-reported QoL is different from self-reported QoL and should be considered as an alternative source of information. QoL might be enhanced when factors associated with QoL are improved. However, large variations in QoL were found for most factors, suggesting the need to involve the individuals with ASD and/or their families when improving their QoL.

What this paper adds

Knowledge about factors of importance of Quality of life (QoL) in adolescents and adults with autism spectrum disorder (ASD) is emerging but still needs further investigation. Furthermore, the concordance between self-reported QoL and parental proxy-reported QoL is not well-investigated for adolescents and adults with ASD, however about to gain insight into. In this study it was found that psychiatric comorbidity, sleeping difficulty, intellectual disability, maladaptive behavior, adaptive functioning, autism symptomatology, main daytime activity and residence were associated with QoL, independent of respondent type. Importantly, large variations in QoL were found for most factors suggesting individual differences within the sample, which should be taken into account when

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planning intervention. Furthermore, differences between self-reported QoL and parental proxy-reported QoL were found indicating that parental proxy-reported QoL constitute an alternative source of information on an individual's QoL.

1. Background

The assessment of quality of life (QoL) as an outcome measure for individuals with autism spectrum disorder (ASD) was suggested by Burgess and Gutstein (2007) a decade ago. Further, Jonsson et al. (2017) emphasized the importance of including the subjective perspective of wellbeing in addition to the assessment of symptom severity and adaptive functioning in individuals with a mental or behavioral disorder. Recently, QoL research involving children, adolescents and adults with ASD has been published, as well as comprehensive reviews and a meta-analysis (Ayres et al., 2017; Chiang & Wineman, 2014; Ikeda, Hinckson, & Krägeloh, 2014; Van Heijst & Geurts, 2015), which indicate, with few exceptions (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016; Moss, Mandy, & Howlin, 2017), that individuals with ASD have lower levels of QoL compared to typically developing individuals. This finding is valid for different informants reporting on QoL; however, there is a tendency for self-reports to result in a higher QoL score compared to parental proxy-reports or standard parental reports (Ikeda et al., 2014).

Whether individuals with ASD can rate their own QoL, due to language difficulties, for example, has been questioned (Persson, 2000). However, increasing evidence supports the idea that individuals with ASD, children as well as adults, can rate their own QoL reliably (Hong et al., 2016; Shipman, Sheldrick, & Perrin, 2011; Stokes, Kornienko, Scheeren, Koot, & Begeer, 2017) when essential modifications are made to the actual QoL scale and/or to the administration of the scale (Hong et al., 2016; Shipman et al., 2011). Since QoL by definition involves a subjective perspective, the use of proxy-reports to determine QoL has also been questioned, and it has been concluded that self-reports cannot simply be replaced by proxy-reports (Verdugo, Schalock, Keith, & Stancliffe, 2005). However, proxy-reports should not necessarily be discarded but rather employed as an alternative source of information on an individual's QoL (Clark, Magill-Evans, & Koning, 2015; Egilson, Ólafsdóttir, Leósdóttir, & Saemundsen, 2017).

Several scales for measuring QoL exist, and even though no consensus has been reached in the area of ASD for the optimal estimation of QoL, the WHOQOL-BREF scale (The WHOQOL Group, 1998) is often applied in studies of QoL in adults with ASD (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017; Hong et al., 2016; Jennes-Coussens, Magill-Evans, & Koning, 2006; Kamio, Inada, & Koyama, 2013; Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Lin, 2014; Moss et al., 2017) and recently, nine additional ASD specific items was developed to the WHOQOL-BREF (McConachie et al., 2017). While WHOQOL-BREF produces comparable QoL results across countries, the scale is only usable for self-administration, if the individuals have the ability to do this; otherwise assistance is recommended in terms of, for example, carrying out an interview (World Health Organization, 1996). Accordingly, the WHOQOL-BREF may not be easily self-administrated by individuals with ASD and intellectual disability (ID). Instead, the INICO-FEAPS scale¹ (Gomez, Verdugo, & Arias, 2015) was chosen to investigate QoL in the present study. The INICO-FEAPS scale is based on the theoretical framework of QoL by Schalock and Verdugo (2002). It consists of two forms (self-report and report of others) and is specifically developed for adolescents and adults with ID and/or developmental disabilities. Hence, applying a customized scale may facilitate a larger group of individuals with ASD to self-report, including individuals with ID in addition to ASD.

Growing interest in and increased research on the factors important for the QoL of individuals with ASD in all age groups have developed. For adolescents and adults, factors such as symptoms of ASD, psychiatric comorbidity, adaptive behavior, and employment status have been investigated for their associations with QoL. However, contradicting results for these factors have been found, with some studies finding associations with QoL whereas others did not (Clark et al., 2015; Helles, Gillberg, Gillberg, & Billstedt, 2017; Hong et al., 2016; Kamp-Becker et al., 2010; Lin, 2014; Moss et al., 2017; Saldana et al., 2009). Therefore, more studies are needed to investigate which specific factors are associated with QoL.

The aim of this study was to explore QoL in a large and nationwide sample of adolescents and adults with ASD by applying the INICO-FEAPS scale. First, concordance in ratings of QoL across self-reports and parental proxy-reports will be examined, as well as levels of QoL in different domains in accordance with the INICO-FEAPS scale. Second, different factors will be investigated for potential associations with QoL when measured via self-reports as well as parental proxy-reports. A wide range of external factors, such as current main daytime activity, current residence, and age of diagnosis of ASD, and internal factors such as psychiatric comorbidity, sleeping difficulty, ID, maladaptive behavior, adaptive functioning, and autism symptomatology will be explored and might thereby contribute to the emerging knowledge about which factors are associated with QoL.

2. Method

2.1. Study population

A total of 1738 individuals with ASD were included in this study. For 710 individuals, both self-reports and parental proxy-reports on the QoL questionnaire were available. For 165 individuals with ASD, self-reports only were available, and for 863 individuals with ASD, only parental proxy-reports were available. Parents were allowed to assist their son/daughter in completing the QoL questionnaire, but it was emphasized that the individuals with ASD should decide how to rate the items themselves. Of the 875 self-

¹ The name of the scale, INICO-FEAPS, is explained in the manual of the INICO-FEAPS scale: "The University Institute on Community Integration (INICO) of the University of Salamanca and of the Spanish Confederation of Organisations in Favour of Individuals with Intellectual or Developmental Disabilities (FEAPS)" (Verdugo Alonso et al., 2013) (p. 9).

reports, 24.6% of the individuals with ASD indicated that they were assisted in completing the questionnaire.

The participants were drawn from a nationwide Danish survey of adolescents and adults with ASD conducted in 2016 (Knüppel, Telléus, & Lauritsen, 2018). In short, all participants were born between 1990 and 1999, diagnosed with ASD before 14 years of age at Danish child psychiatric hospitals, and registered in the Danish Psychiatric Central Research Registry (Mors, Perto, & Mortensen, 2011) with one of the following ICD-10 diagnoses: Infantile autism (F84.0), atypical autism (F84.1x), Asperger's syndrome (F84.5), or pervasive developmental disorder, other (F84.8). The survey consisted of a questionnaire about ASD outcomes sent to adolescents/adults with ASD through their parents. The parents themselves were also asked to complete a questionnaire about their child with ASD, and the invitations to the survey was sent by mail. The survey procedure is described in detail in Knüppel et al. (2018), in which representativeness of the study population has also been evaluated by comparing responders and non-responders of the survey on the following variables: psychiatric history of the individuals with ASD including frequencies of ICD-10 autism diagnoses, and socio-demographics of the individuals with ASD as well as of their parents. In these comparisons, merely minor differences were found, nevertheless there was a tendency that socioeconomically advantaged families more often answered the questionnaire (Knüppel et al., 2018).

2.2. Measures

2.2.1. Quality of life measurement

The INICO-FEAPS scale (Gomez et al., 2015), available in Spanish as well as English, was applied to measure QoL using the self-report form and the report of others form; the latter form was filled in as parental proxy-report. The INICO-FEAPS scale consists of 72 items divided into the following eight subdomains: self-determination, rights, emotional wellbeing, social inclusion, personal development, interpersonal relationships, material wellbeing, and physical wellbeing. The self-report form includes both written and visual instructions for completing the scale, whereas the report by others has written instructions only. Each item is measured on a 1–4 Likert scale. For this study, raw scores of the INICO-FEAPS scale were linearly converted into a 0–100 point scale for easier interpretation, as suggested by Cummins and Lau (2005). A higher score indicates a higher level of QoL. With respect to parental proxy-reports, we aimed to measure QoL as close as possible to the ratings the individuals with ASD would report. Accordingly, the parents were instructed to rate their child's QoL as they thought their child would do themselves (Hong et al., 2016; Sheldrick, Neger, Shipman, & Perrin, 2012).

Gomez et al. (2015) constructed the items in the INICO-FEAPS scale on the basis of an exhaustive review of the scientific literature and existing QoL instrument as well as through a Delphi study with 12 experts on QoL, who listed the best items according to suitability, importance, sensitivity, and observability. Furthermore, Gomez et al. (2015) validated the INICO-FEAPS scale in a Spanish population of adolescents and adults with ID or developmental disabilities using confirmatory factor analysis for exploration of several predefined models with the eight first-order factor model showing the best fit to the data. Additionally, numerous internal consistency indexes were applied with results showing good reliability of the scale (Gomez et al., 2015). The psychometric properties of the INICO-FEAPS scale translated from English to Danish have also been investigated in the same ASD population used in the present study with analyses of internal consistency (average item total correlation, ordinal alpha, ordinal theta, McDonald's omega, and average variance extracted), internal structure applying confirmatory factor analysis with a predefined model of eight correlated first-order factors, and convergent validity comparing results of the INICO-FEAPS with results from other QoL scales. Acceptable psychometric properties overall were found (Knüppel, Jakobsen, Lauritsen, & Telléus, 2018).

2.2.2. Measurements of the characteristics of individuals with ASD

A wide range of factors and their potential association with QoL were explored in this study. Information about the characteristics of the individuals with ASD were derived from the parental questionnaire (adaptive behavior, autistic symptomatology, psychiatric comorbidity, residence, ID, main daytime activity, sleeping difficulty, and maladaptive behavior) or drawn from the Danish national registers (age of diagnosis of ASD, current age, and gender of individuals with ASD).

The Adaptive Behavior Assessment System-II (ABAS-II) was applied for the comprehensive assessment of adaptive behaviors and skills (Harrison & Oakland, 2004), and the form for relatives (age group 16–89 years) was used. ABAS-II consists of nine domains and an optional domain (work), which was not applied in this study. Raw scores were converted into a General Adaptive Composite Score (GAC), which has a mean of 100 (SD = 15). A higher score indicates better adaptive functioning. McDonald's omega values for each of the domains in ABAS-II were found to be in the range of 0.894 to 0.959, indicating excellent internal consistency within each domain.

The RAADS-14 Screen is an instrument for the assessment of autistic symptoms (Eriksson, Andersen, & Bejerot, 2013). It is based on the Ritvo Autism and Asperger Diagnostic Scale-Revised (Ritvo et al., 2011) and contains three domains. Although originally constructed as a self-report instrument, it has been tested in a small sample of parents of adults with ASD (J.M. Eriksson, personal communication, May 16, 2015). Therefore, for this study, it was applied as a parental report. The scale comprises 14 items scored on a 0–3 Likert scale, with higher scores indicating more ASD symptoms. One of the response alternatives was slightly modified given that a subgroup of this study population was 16 years old (Table 4), making it difficult to use the response alternative “true only when he/she was younger than 16”. Consequently, the age of 16 years was changed to 15 years. McDonald's omega values for each domain in the RAADS-14 Screen were 0.526, 0.664, and 0.824, indicating acceptable internal consistency overall.

Current psychiatric comorbidity was rated by the parents, who were given the opportunity to mark any common psychiatric diagnosis listed or to write the diagnosis/diagnoses themselves. The information on diagnoses were coded into a binary variable (no current psychiatric comorbidity, current psychiatric comorbidity). Presence of ID and current sleeping difficulty were rated by the

parents and coded as binary variables (present vs. not present). Maladaptive behavior was coded as a binary variable, with the behavior coded as present if the existence of the behavior was evaluated by the parents to result in problems in everyday life for the individual with ASD or his or her surroundings. Behavior classified as self-destructive, breaking belongings, defiant, disruptive, hurtful to others and/or socially offensive was coded as presence of maladaptive behavior. Information on residence was coded into a categorical variable with three groups: 1) living with one or both parent(s), 2) living independently without support, or 3) living outside the family home with support (including living in institutions or group homes). Information from the parents on the main daytime activity was coded as a categorical variable with three groups: 1) involvement in any job-related occupation (including competitive work, supported work, sheltered workshop, and both part- and fulltime occupations), 2) enrolled in education (any level of education, eventually combined with a part-time job), or 3) no regular daytime activity.

2.3. Ethics

The study was registered at The Danish Data Protection Agency (record no. 2008-58-0028), and data were anonymized prior to statistical analysis. Informants of the study (i.e., both parents and individuals with ASD) were given thoroughly written information about the study, including that participation was voluntary. Additionally, one of the authors (AK) could be contacted by phone or e-mail in case of further questions.

2.4. Statistical analyses

Descriptive statistics were used to describe the different subgroups within the study population. Each scale (INICO-FEAPS, ABAS-II, and RAADS-14 Screen) had some incomplete observations and as a maximum, we accepted one missing item in each domain in INICO-FEAPS, two missing items in each domain in ABAS-II, and one missing item in total in the RAADS-14 Screen. The patterns of missing data in each scale were investigated following Enders (2010), and data was estimated to be missing at random. Missing data in the applied scales were handled with multivariate imputation using chained equations, with five imputations for each missing value. McDonald's omega was calculated for the estimation of internal consistency of the applied scales. Comparison of mean QoL scores between self-reports and matched proxy-reports was examined using linear regression analysis with self-report and proxy-report INICO-FEAPS total scores as the outcome and type of report (self- or proxy-report) as the independent variable. Associations between mean total scores and mean domain scores of the INICO-FEAPS between self-reports and matched proxy-reports were examined through Pearson's correlation analyses. Furthermore, multiple linear regression analyses were conducted to investigate factors associated with self-reported QoL and with proxy-reported QoL. Each variable was investigated in a separate regression model that was controlled for current age and gender of the individual with ASD. In this way, the overall effect of each factor on QoL could be studied separately unlike a multiple regression model that usually includes more variables as control variables, which would increase the risk of multicollinearity and overfitting and make it harder to interpret the general association between QoL and the variable of interest. Model check was conducted for each regression model by examination of the residuals and the coefficient of determination and by conduction of an F-test. Furthermore, the independent variables in the regression models were checked for multicollinearity. Boxplots were made for every categorical independent variable with the purpose of illustrating the variation in total INICO-FEAPS score for each group. Statistical analyses were conducted using the statistical packages STATA version 14.2 (StataCorp, 2015) and R version 3.2.5 (R Core Team, 2016). Significance level for p-values was set at 0.05.

3. Results

3.1. Mean and domain scores of INICO-FEAPS for the different respondent groups

INICO-FEAPS total and domain mean scores are seen in Table 1 for self-reports with/without matched proxy-reports and for proxy-reports with/without matched self-reports, and comparisons of the mean scores of self-reports and matched proxy-reports are depicted in Table 2. For the matched self- and proxy-reports ($n = 710$), the total mean score for self-reports was significantly but only slightly higher compared with the mean score of proxy-reports (total mean scores: 79.40 vs. 78.48, respectively, $p = 0.047$). At the domain level, significant differences were found for two domains, social inclusion and interpersonal relationships, with self-reports having higher scores compared to proxy-reports (social inclusion mean scores: 79.00 vs. 75.62, respectively, $p < 0.001$; interpersonal relationships mean scores: 71.88 vs. 66.02, respectively, $p < 0.001$) (Table 2).

Across all respondent groups, the lowest rated QoL domains were emotional wellbeing (range of means = 71.10–74.05) and interpersonal relationships (range of means = 65.07–71.88), and the highest rated QoL domains were rights (range of means = 83.79–86.21) and material wellbeing (range of means = 83.01–86.20) (Table 1). For three subgroups of responders (both self-report groups and proxy-reports with matched self-reports), the domains of self-determination (range of means = 80.85–81.73) and personal development (range of means = 81.80–82.24) were rated at almost equally high levels (Table 1).

3.2. Associations between self-reports and matched proxy-reports of INICO-FEAPS

Associations between self-reports and proxy-reports of INICO-FEAPS were investigated for the matched respondent groups only ($n = 710$) and depicted in Table 3. Between domains, Pearson correlations in the range of 0.35–0.61 were found, with the highest correlation for the domain of personal development (0.61) and the lowest correlation for the domain of rights (0.35). Except for the

Table 1

INICO-FEAPS total mean scores and domain mean scores for self- and proxy-report subgroups.

	n	mean	SE	95% CI
Self-reports, all respondents	875	79.14	0.28	[78.59, 79.69]
Proxy-reports, all respondents	1573	77.15	0.25	[76.66, 77.65]
Self-report with matched proxy-report	710			
Total score		79.40	0.31	[78.80, 80.01]
Self-determination		81.73	0.38	[80.99, 82.46]
Rights		85.88	0.34	[85.22, 86.53]
Emotional wellbeing		72.77	0.52	[71.76, 73.79]
Social inclusion		79.00	0.43	[78.15, 79.84]
Personal development		82.24	0.40	[81.46, 83.01]
Interpersonal relationships		71.88	0.52	[70.87, 72.89]
Material wellbeing		85.22	0.41	[84.42, 86.02]
Physical wellbeing		76.52	0.38	[75.77, 77.27]
Proxy-report with matched self-report	710			
Total score		78.48	0.35	[77.81, 79.16]
Self-determination		80.85	0.45	[79.97, 81.73]
Rights		86.21	0.38	[85.46, 86.95]
Emotional wellbeing		74.05	0.48	[73.11, 74.99]
Social inclusion		75.62	0.51	[74.62, 76.61]
Personal development		81.80	0.48	[80.86, 82.73]
Interpersonal relationships		66.02	0.61	[64.82, 67.23]
Material wellbeing		86.20	0.40	[85.41, 86.99]
Physical wellbeing		77.12	0.42	[76.30, 77.94]
Self-report without matched proxy-report	165			
Total score		78.01	0.66	[76.70, 79.32]
Self-determination		81.73	0.80	[80.15, 83.31]
Rights		84.08	0.75	[82.61, 85.56]
Emotional wellbeing		71.10	1.22	[68.69, 73.51]
Social inclusion		77.27	0.91	[75.47, 79.07]
Personal development		81.89	0.79	[80.33, 83.45]
Interpersonal relationships		70.08	1.12	[67.87, 72.29]
Material wellbeing		83.08	0.88	[81.34, 84.82]
Physical wellbeing		74.84	0.81	[73.24, 76.44]
Proxy-report without matched self-report	863			
Total score		76.06	0.35	[75.37, 76.75]
Self-determination		77.53	0.50	[76.56, 78.51]
Rights		83.79	0.40	[83.00, 84.58]
Emotional wellbeing		71.75	0.45	[70.86, 72.64]
Social inclusion		73.90	0.49	[72.94, 74.86]
Personal development		77.61	0.50	[76.64, 78.59]
Interpersonal relationships		65.07	0.56	[63.97, 66.18]
Material wellbeing		83.76	0.40	[82.98, 84.54]
Physical wellbeing		75.08	0.40	[74.29, 75.87]

n = sample size, SE = standard error, CI = confidence interval.

Table 2

Linear regression analyses with self-reported and proxy-reported INICO-FEAPS total scores as outcomes and type of report (self- or proxy-report) as the independent variable (matched groups only, n = 710).

		coef. (SE)	p	95% CI
INICO-FEAPS total	Self-report*	0.92 (0.46)	0.047	[0.01, 1.83]
Self-determination	Self-report*	0.88 (0.59)	0.135	[-0.27, 2.03]
Rights	Self-report*	-0.33 (0.51)	0.512	[-1.32, 0.66]
Emotional wellbeing	Self-report*	-1.27 (0.71)	0.071	[-2.66, 0.11]
Social inclusion	Self-report*	3.38 (0.67)	0.000	[2.08, 4.69]
Personal development	Self-report*	0.44 (0.62)	0.480	[-0.78, 1.65]
Interpersonal relationships	Self-report*	5.85 (0.80)	0.000	[4.28, 7.43]
Material wellbeing	Self-report*	-0.97 (0.57)	0.089	[-2.10, 0.15]
Physical wellbeing	Self-report*	-0.60 (0.57)	0.287	[-1.72, 0.51]

coef = unstandardized regression coefficient; SE = standard error; CI = confidence interval; n = sample size in analysis.

* Proxy-report reference group.

Table 3

Pearson correlations between the total and domain scores of the INICO-FEAPS for matched self-reports and proxy-reports (n = 710).

INICO-FEAPS	Pearson's <i>r</i>
Total score	0.64
Self-determination	0.55
Rights	0.35
Emotional wellbeing	0.59
Social inclusion	0.56
Personal development	0.61
Interpersonal relationships	0.60
Material wellbeing	0.50
Physical wellbeing	0.49

Pearson's *r* = Pearson's correlation coefficient.

n = sample size in analysis.

correlation of the domain of rights, correlations were at least 0.49. Total score correlation was 0.64.

3.3. Characteristics of individuals with ASD - descriptive results

The means or frequencies of the independent variables studied for association with QoL are shown in Tables 4 and 5 for three respondent groups (a total self-report group and the proxy-reports with/without self-reports groups). Because there was substantial overlap in parental reported data between the respondent group of self-reports and the respondent group containing proxy-reports with self-reports, the characteristics of the individuals with ASD in these two groups are similar. By comparison, all three respondent groups had nearly equal frequencies of gender, and nearly equal values for current mean age, mean age of diagnosis of ASD, and mean RAADS-14 Screen total score. However, the respondent group proxy-report without self-report had on average a lower mean score on ABAS-II (proxy-report without self-report: 79.81 vs. self-report: 85.21; proxy-report with self-report: 85.32) and a higher proportion of individuals with ID (19.3% vs. 10.7%; 10.7%) and maladaptive behavior (33.3% vs. 24.6%; 24.8%). Furthermore, this respondent group also had on average a higher proportion of individuals involved in any job-related occupation (19.1% vs. 12.0%; 12.3%) and covered individuals who were to a lesser extent living with parents (54.4% vs. 63.6%; 63.8%) and to a higher extent living outside the family home with support (25.5% versus 16.9%; 17.0%) compared with the other respondent groups.

3.4. Factors associated with QoL

Results from linear regression analyses for all independent variables and respondent groups are shown in Table 6. Additionally, regression analyses including the variables used for adjustment (age and gender of the individuals with ASD) were conducted (for both variables separately and together) for all informant groups. For all respondent groups, the presence of the following factors was significantly associated with a lower level of QoL when adjusting for gender and age: psychiatric comorbidity (coefficient (coef.) = self-report: -3.07; proxy-report with self-report: -5.09; proxy-report without self-report: -4.49, $p < 0.001$); ID (coef. = -3.32; -6.65; -9.10, $p \leq 0.001$); sleeping difficulty (coef. = -4.10; -5.51; -6.74, $p < 0.001$); and maladaptive behavior (coef. = -5.10; -6.72; -9.98, $p < 0.001$). Additionally, for all respondent groups, a higher score in the ABAS-II (better adaptive functioning) was significantly associated with a higher QoL score (coef. = 0.22; 0.37; 0.41, $p < 0.001$), and a higher score in the RAADS-14 Screen (more autistic symptomatology) was significantly associated with a lower QoL score (coef. = -0.39; -0.62; -0.70, $p < 0.001$). It was found for all respondent groups that being involved in any job-related occupation (coef. = 5.55; 6.40; 9.59, $p < 0.001$) or enrolled in education (coef. = 4.41; 6.89; 11.06, $p < 0.001$) was significantly associated with a higher level of QoL compared to individuals without any regular daytime activity. Regarding residence, significant associations were found for all respondent groups, with lower levels of QoL

Table 4

Characteristics of individuals with ASD (continuous variables).

	Self-report*				Proxy-report with self-report				Proxy-report without self-report			
	n	mean	min	max	n	mean	min	max	n	mean	min	max
Current age (years)	875	20.46	16.50	26.46	710	20.60	16.50	26.45	863	20.80	16.51	26.28
Age of diagnosis of ASD (years)	875	9.34	1.62	14.00	710	9.34	2.23	14.00	863	9.12	1.05	14.00
ABAS-II: GAC	563	85.21	40.00	120.00	546	85.32	40.00	120.00	604	79.81	40.00	120.00
RAADS-14 Screen total score	698	24.13	0.00	42.00	677	24.15	0.00	42.00	744	24.80	0.00	42.00

n = sample size, ASD = autism spectrum disorder, ABAS-II GAC = adaptive behavior assessment scale II: general adaptive composite score, RAADS-14 Screen = The Ritvo Autism Asperger Diagnostic Scale-14 Screen.

* Includes both self-report with and without proxy-report.

Table 5
Characteristics of individuals with ASD (categorical variables).

	Self-report ^a % (n)	Proxy-report with self-report % (n)	Proxy-report without self-report % (n)
Sex, % male	78.5% (687)	78.9% (560)	82.7% (714)
Psychiatric comorbidity			
No diagnosis	58.3% (395)	58.2% (382)	54.8% (399)
1 or more	41.7% (283)	41.8% (274)	45.2% (329)
Residence			
Independently without support	19.5% (139)	19.2% (131)	20.1% (166)
Parents	63.6% (454)	63.8% (436)	54.4% (450)
Outside family home with support	16.9% (121)	17.0% (116)	25.5% (211)
ID, % yes	10.7% (75)	10.7% (73)	19.3% (156)
Main daytime activity			
No regular occupation/education	16.7% (121)	16.5% (115)	18.9% (158)
Involvement in any job-related occupation	12.0% (87)	12.3% (86)	19.1% (160)
Enrolled in any education	71.2% (515)	71.2% (498)	62.0% (519)
Sleeping difficulty, % yes	37.3% (261)	37.3% (253)	42.8% (323)
Maladaptive behavior, % yes	24.6% (173)	24.8% (169)	33.3% (252)

n = sample size, ID = intellectual disability.

* Includes both self-report with and without proxy-report.

among individuals living with their parents (coef. = -2.88; -4.91; -6.14, $p \leq 0.004$) and among individuals with ASD living outside the family home with support (coef. = -3.95; -6.83; -11.39, $p < 0.001$) compared to individuals living independently without support. We found significant associations between an older age of diagnosis of ASD and a lower level of QoL for two respondent groups (self-report and proxy report with self-report: coef. = -0.42; -0.28, $p \leq 0.009$), although with small regression coefficients.

Variation in INICO-FEAPS total score for the binary variable psychiatric comorbidity is illustrated in Fig. 1, and boxplots for the remaining categorical variable are shown in Appendices A–C. As found in the regression analysis and depicted in Fig. 1, individuals with psychiatric comorbidity were, on mean level, found with a lower QoL. Yet, from Fig. 1 it is seen that the individual variation is large with both high and low QoL scores in both the group with and the group without psychiatric comorbidity. The same trend was found for the remaining categorical variables (Appendices A–C).

4. Discussion

This study investigated QoL in a large sample of adolescents and adults with ASD by looking at the concordance between self-reports and parental proxy-reports, levels of QoL across respondent groups, and by conducting several linear regression analyses, with the aim of exploring the associations between QoL and different characteristics of individuals with ASD.

For almost every factor studied across respondent groups, significant associations with QoL were found in the study population with ASD, and, furthermore, the sizes of the regression coefficients were considered of clinical importance across respondent groups. This finding was true for psychiatric comorbidity, sleeping difficulty, ID, maladaptive behavior, adaptive functioning, autism symptomatology, main daytime activity, and residence. Some studies on QoL in adolescents and adults with ASD have found similar results for adaptive functioning, psychiatric comorbidity, and autism symptomatology as those found in our study (Helles et al., 2017; Kamp-Becker et al., 2010; Lin, 2014; Moss et al., 2017), but this is not the case for other studies (Clark et al., 2015; Hong et al., 2016; Renty & Roeyers, 2006). This difference might derive from differences in methodology as, for example, assessment of QoL as addressed by Moss et al. (2017). Our results also illustrate that regardless of respondent-group, the same factors are considered to influence QoL in adolescents and adults with ASD, a finding that contrasts some studies where factors of significance for QoL were found to be dependent on respondent group (Hong et al., 2016; Moss et al., 2017). As discussed by Jonsson et al. (2017), parents may have a tendency to evaluate the functioning of their children with ASD instead of their QoL. The results by Hong et al. (2016) support this hypothesis, with level of independence in daily activities being associated with QoL for proxy-reports only and not for self-reported QoL. As mentioned, in the present study, adaptive functioning was associated with QoL independent of respondent group, indicating that better adaptive functioning is to some extent associated with a higher level of QoL. Similarly, it was found that living independently without support was associated with higher levels of QoL compared with living with parents and especially living outside the family home with support. Hence, independent individuals with ASD seem to have a higher level of QoL. The impact of daytime activity on QoL for adolescents and adults with ASD is, to date, sparsely investigated, and existing studies have applied different methods, which may account for the contradicting results (Garcia-Villamisar, Wehman, & Diaz Navarro, 2002; Helles et al., 2017; Lin, 2014). Daytime activity is, however, an important area of research since it is possible to find appropriate activities for individuals with ASD independent of their intellectual or functional level. It is important to note that involvement in all types of occupations and education were included in the factors investigated and found to be associated with QoL in this study.

Large variation in QoL scores were found for the independent variables investigated. As exemplified with psychiatric comorbidity, there were individuals with low and high QoL scores in both the group with and without psychiatric comorbidity. This might be due to the broad categorization made by transforming psychiatric comorbidity into a binary variable. For example, the impact of a specific psychiatric disorder on QoL might differ dependent on severity of the disorder and/or the number of psychiatric disorders

Table 6
Separate linear regression models with INICO-PEAPS total score as outcomes for proxy-reports subgroups and self-report.

	Self-report ^a				Proxy-report with self-report				Proxy-report without self-report			
	coef. (SE)	p	n	95% CI	coef. (SE)	p	n	95% CI	coef. (SE)	p	n	95% CI
Gender	–1.93 (0.68)	0.005	875	[–3.26, –0.59]	–2.20 (0.84)	0.009	710	[–3.85, –0.54]	–1.53 (0.93)	0.100	863	[–3.36, 0.29]
Age (years)	0.29 (0.10)	0.004	875	[0.09, 0.49]	0.27 (0.12)	0.029	710	[0.03, 0.52]	0.27 (0.13)	0.038	863	[0.01, 0.52]
Gender	–1.87 (0.68)	0.006	875	[–3.20, –0.54]	–2.15 (0.84)	0.011	710	[–3.80, –0.50]	–1.52 (0.93)	0.103	863	[–3.34, 0.31]
Age (years)	0.28 (0.10)	0.005	–	[0.08, 0.48]	0.26 (0.12)	0.034	–	[0.02, 0.51]	0.27 (0.13)	0.040	–	[0.01, 0.52]
Age of diagnosis of ASD ^a (years)	–0.42 (0.09)	< 0.001	875	[–0.59, –0.25]	–0.28 (0.11)	0.009	710	[–0.50, –0.07]	0.19 (0.11)	0.079	863	[–0.02, 0.40]
Psychiatric comorbidity ^a	–3.07 (0.64)	< 0.001	678	[–4.32, –1.82]	–5.09 (0.71)	< 0.001	656	[–6.47, –3.70]	–4.49 (0.77)	< 0.001	728	[–5.99, –2.98]
Residence ^a			714				683				827	
Parents	–2.88 (0.99)	0.004		[–4.81, –0.94]	–4.91 (1.11)	< 0.001		[–7.09, –2.72]	–6.14 (1.03)	< 0.001		[–8.17, –4.11]
Outside family home with support	–3.95 (1.02)	< 0.001		[–5.95, –1.96]	–6.83 (1.14)	< 0.001		[–9.06, –4.60]	–11.39 (1.00)	< 0.001		[–13.37, –9.42]
ID ^a	–3.32 (1.00)	0.001	703	[–5.28, –1.35]	–6.65 (1.11)	< 0.001	681	[–8.83, –4.46]	–9.10 (0.86)	< 0.001	809	[–10.79, –7.41]
Main daytime activity ^a			723				699				837	
Occupation	5.55 (1.13)	< 0.001		[3.32, 7.77]	6.40 (1.26)	< 0.001		[3.92, 8.88]	9.59 (1.08)	< 0.001		[7.48, 11.70]
Education	4.41 (0.85)	< 0.001		[2.75, 6.08]	6.89 (0.96)	< 0.001		[5.02, 8.77]	11.06 (0.93)	< 0.001		[9.24, 12.88]
Sleeping difficulty ^a	–4.10 (0.63)	< 0.001	699	[–5.33, –2.88]	–5.51 (0.70)	< 0.001	679	[–6.88, –4.14]	–6.74 (0.73)	< 0.001	754	[–8.17, –5.30]
Maladaptive behavior ^a	–5.10 (0.70)	< 0.001	704	[–6.47, –3.73]	–6.72 (0.77)	< 0.001	682	[–8.24, –5.20]	–9.98 (0.72)	< 0.001	757	[–11.41, –8.56]
Adaptive behavior ^a	0.22 (0.02)	< 0.001	563	[0.19, 0.25]	0.37 (0.01)	< 0.001	546	[0.34, 0.40]	0.41 (0.01)	< 0.001	604	[0.38, 0.43]
Autism symptomatology ^a	–0.39 (0.03)	< 0.001	698	[–0.45, –0.33]	–0.62 (0.03)	< 0.001	677	[–0.68, –0.57]	–0.70 (0.03)	< 0.001	744	[–0.76, –0.64]

coef. = unstandardized regression coefficient; SE = standard error; CI = confidence interval; n = sample size in analysis; ID = intellectual disability.

Definition of variables and reference group (RG): **Gender** = female, male (RG); **psychiatric comorbidity** = 1 or more disorder(s), no disorders (RG); **residence** = living with parents, living outside family home with support, living independently without support (RG); **ID** = yes, no (RG); **main daytime activity** = involvement in any job-related occupation, enrolled in any education, no regular daytime activity (RG); **sleeping difficulty** = yes, no (RG); **maladaptive behavior** = yes, no (RG); **adaptive behavior** = composite score of ABAS-II (GAC); **autism symptomatology** = total score of RAADS-14 Screen.

^a In each of the separate linear regression analyses, adjustments were made for the age and gender of the individual with ASD.

^{**} Includes both self-report with and without proxy-report. A maximum of 0.52% of the total values in each analysis were imputed.

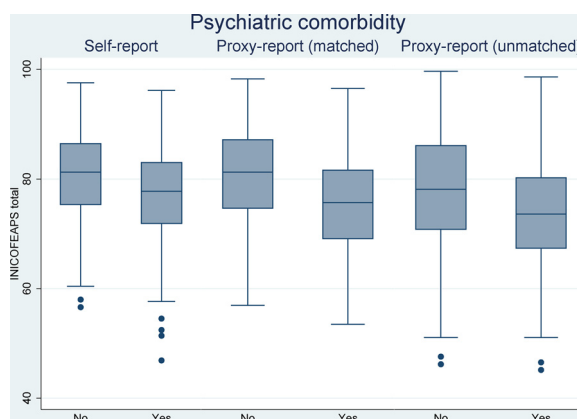


Fig. 1. Boxplot with INICO-FEAPS total score for three subgroups of responders (self-report, proxy-report with matched self-report, proxy-report without self-report) divided between groups with and without psychiatric comorbidity.

each individual has. Yet, the variation might also suggest that the impact of a contributing factor on the level of QoL differs across individuals with ASD. This emphasizes the need for the involvement of individuals with ASD and/or their families when professionals aim to improve QoL, a notion that is already accentuated by [Schallock, Verdugo, Gomez, and Reinders \(2016\)](#). Overall, the results from the present study indicate that treating psychiatric comorbidity, reducing maladaptive behavior, raising the level of independence, and offering individuals with ASD an opportunity to be involved in any job-related occupation or to receive education may raise the level of QoL, but the extent to which these factors influence QoL may vary among individuals with ASD. Additionally, the level at baseline for a specific factor may influence how intervention affects QoL ([Cummins, 2015](#)). For example, dependent on the initial level of adaptive functioning, a certain increase in adaptive functioning may affect the level of QoL differently. Furthermore, interventions focusing on one factor may influence other factors positively. For example, as illustrated by [Taylor, Smith, and Mailick \(2014\)](#), engagement in vocational activities was related to subsequent reductions in autism symptoms and maladaptive behavior as well as improvements in daily living activities. Thus, covariations may occur for distinct groups of factors evaluated in our study, for example, daytime activity, autism symptomatology, maladaptive behavior, and adaptive functioning, as illustrated by [Taylor et al. \(2014\)](#). With regard to the association between QoL and the age of diagnosis of ASD, the study by [Kamio et al. \(2013\)](#) supports the idea that early diagnosis is associated with better QoL. However, in our study, the low regression coefficients found for age of diagnosis should be noted. This finding may be a result of the narrow interval of age of diagnosis due to sampling criteria (0–14 years), which may diminish the effect because of the small variability in data. Hence, the impact of age of diagnosis of ASD on QoL needs further investigation, for example, by comparing individuals diagnosed with ASD in childhood with individuals diagnosed with ASD in adulthood.

Further, this study investigated the concordance between self-reports and parental proxy-reports for a subgroup of the total sample of individuals with ASD, which resulted in positive, moderately strong correlations. This result is comparable to the findings of [Sheldrick et al. \(2012\)](#) and [Hong et al. \(2016\)](#), who similarly investigated concordance in QoL reporting between adolescents and adults with ASD and their parents. Furthermore, this result supports the notion in QoL research that proxy-reports cannot validly substitute for self-reports ([Verdugo et al. \(2005\)](#)). Even though our results on the mean levels from both the total and domain scores of the INICO-FEAPS seemed rather equal in the matched respondent groups, the moderate correlations indicate that adolescents and adults with ASD rate their own QoL differently compared to parental proxy ratings. Accordingly, proxy-reports should be considered as another source of information to the QoL of individuals with ASD. As found in other studies ([Hong et al., 2016](#); [Ikeda et al., 2014](#); [Shipman et al., 2011](#)), self-reports have significantly higher QoL total mean scores compared to proxy-reports. However, the difference in total mean scores in this study was small, making the result of less clinical importance. Larger differences in total mean scores between self-reports and matched proxy reports were found for the domains of social inclusion and interpersonal relationships, indicating that individuals with ASD are more satisfied in these areas compared to what their parents think. However, on a mean level, the lowest rated domains for all respondent groups were emotional wellbeing and interpersonal relationships, a result similar to [Hong et al. \(2016\)](#); [Kamp-Becker et al. \(2010\)](#), and [Lin \(2014\)](#), who found low domain scores in the WHOQOL-BREF domains of psychological health and social relationships for adults with ASD. Altogether, these results indicate possible intervention areas for improving QoL for adolescents and adults with ASD.

This study benefits from a large, nation-wide sample, the possibility of including both self-reports and parental proxy-reports on QoL, and the inclusion of a wide range of different factors to be evaluated for associations with QoL. However, some limitations exist. The information on the characteristics of the individuals with ASD were collected via parental reports with no possibility of validating the information provided. Still, parents of children with ASD are typically involved in and informed about the lives of their children, making it likely that the parent-reported information is valid. Additionally, it could have been highly relevant to include variables describing perceived support, perceived stress and friendships, as has been done in several studies ([Bishop-Fitzpatrick et al., 2017](#); [Helles et al., 2017](#); [Hong et al., 2016](#); [Renty & Roeyers, 2006](#)) when investigating potential associations with QoL. Nevertheless, since we did not know the characteristics and resources of the self-report group of individuals with ASD beforehand, only a few questions

were included in the questionnaire that were addressed to the person with ASD because we did not want to increase the workload on this group. Moreover, studies including ASD samples both with and without ID found QoL levels comparable with the general population for at least some domains (Clark et al., 2015; Hong et al., 2016; Moss et al., 2017). It would have been interesting to investigate whether this finding was the case for our study population as well. However, the application of the INICO-FEAPS scale made it difficult to compare the level of QoL in our study population with the general population since this scale is not intended for administration in the general population.

5. Conclusion

In conclusion, a range of different factors including psychiatric comorbidity, sleeping difficulty, ID, maladaptive behavior, adaptive functioning, autism symptomatology, main daytime activity, and residence was found to be associated with QoL across respondent groups, but the importance of each factor for QoL seems to vary. In addition, the results regarding QoL in adolescents and adults with ASD support earlier findings that parental proxy-reports cannot validly substitute for self-reports but should be considered as an alternative source of information. On a mean level across respondent groups, the results indicate that low scores are found, especially in the areas of emotional wellbeing and interpersonal relationships. To improve QoL for individuals with ASD, increased focus on treating psychiatric comorbidity, increasing the level of independence in everyday life, and offering an appropriate daytime activity with a concurrent focus on involving the individuals with ASD themselves and/or their families appear to be important.

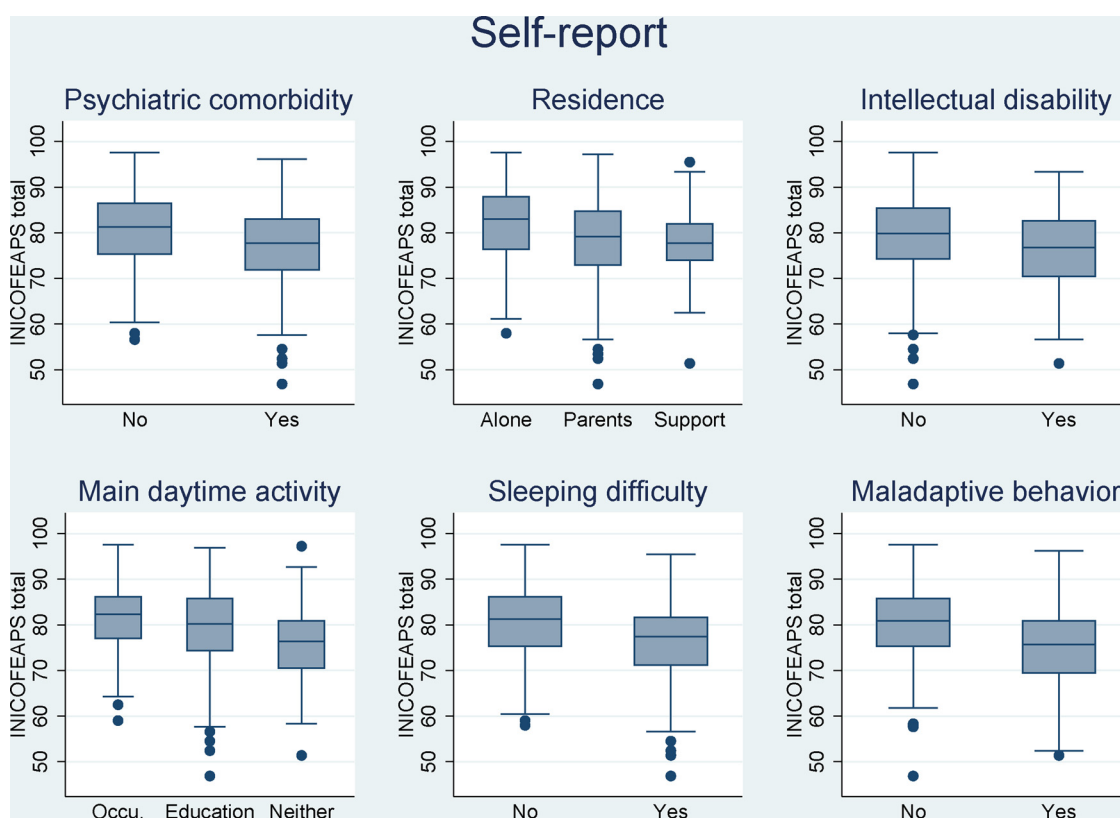
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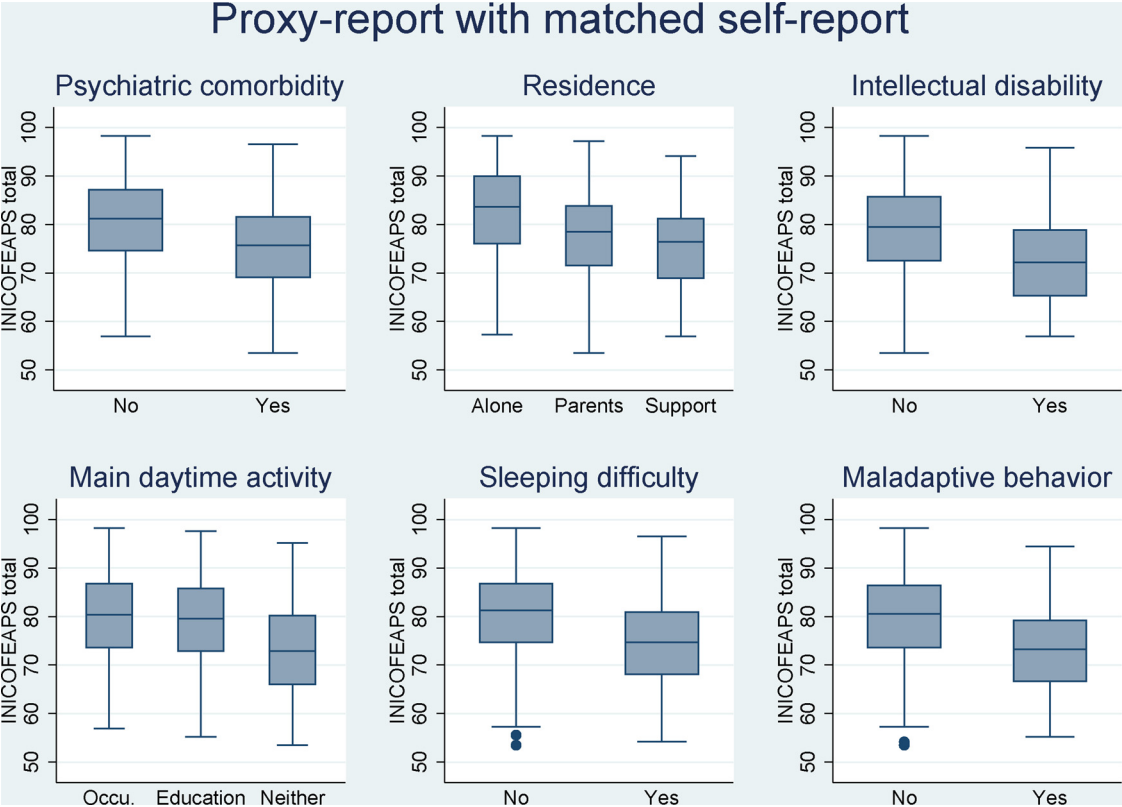
Conflicts of interest

The authors declare that they have no conflict of interests.

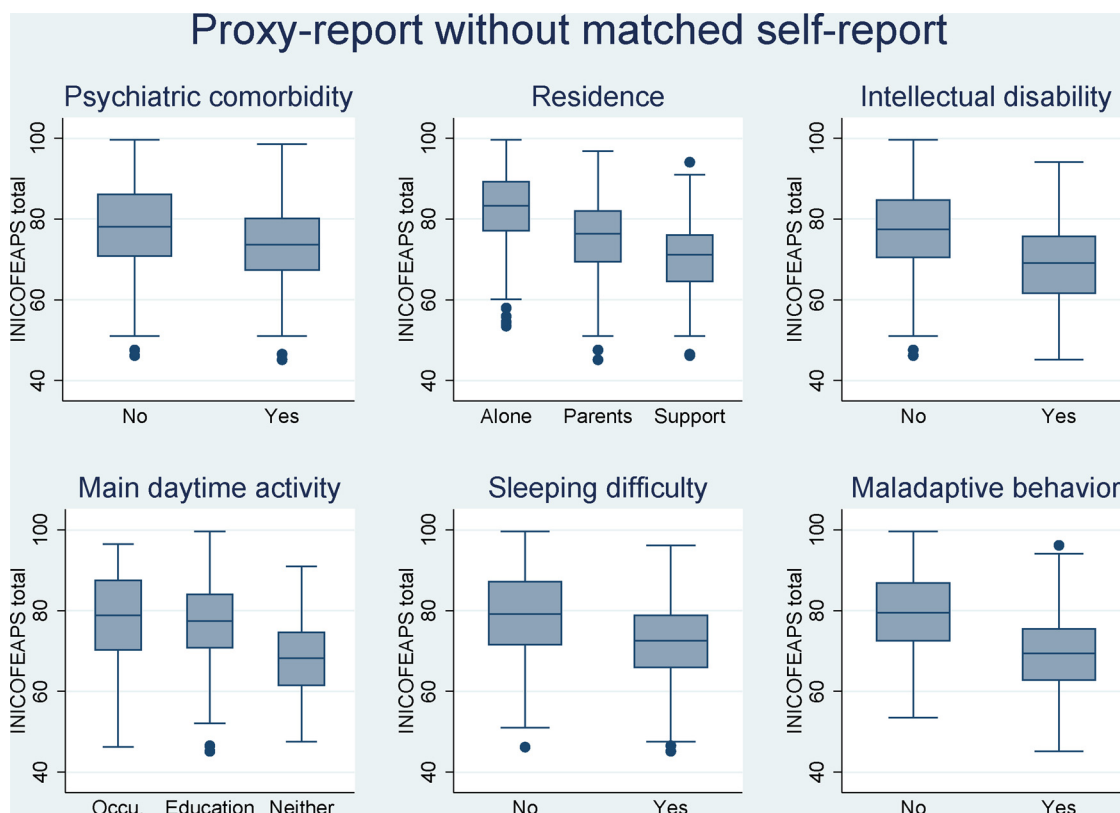
Appendix A



Appendix B



Appendix C



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