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Youth With Autism Spectrum Disorders: Self- and Proxy-Reported Quality of Life and Adaptive Functioning

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Abstract

Quality of life (QoL) for persons with Autism Spectrum Disorders (ASD) and factors associated with QoL are not well understood. Prior literature has relied on parent-report though this is changing. It may be important to consider both parent-reported QoL and self-report. This study explored QoL in 22 Canadian adolescents (3 girls, 19 boys) ages 13 to 18 years (*M* = 15.2 years). Adolescents completed the 10 subscales of the *KIDSCREEN-52*, a standardized questionnaire, while their parents completed the proxy form of the measure and the *Adaptive Behavior Assessment System–II*. Both parents and adolescents reported mean QoL scores in the lower average range. Intra-class correlation coefficients between parent and self-report were similar to adolescents without special needs except for four subscales. Correlations between QoL and the General Adaptive Composite score were remarkably low. Adolescents with ASD respond differently from their parents in some areas and both reports should be considered.

Keywords

quality of life, adaptive skills, self-report

Introduction

Persons living with an Autism Spectrum Disorder (ASD) must manage difficulties associated with impairments in social communication/interaction and stereotyped or repetitive interests (American Psychiatric Association [APA], 2000, 2013). These difficulties may be present across multiple contexts and are likely to have a substantial impact on their quality of life (QoL). The impact may be particularly evident during adolescence when social interactions with peers become increasingly important to most young people (Humphrey & Lewis, 2008). The current prevalence rate of ASD is as high as 1 in 88 children (Baio, 2012). A substantial number of families, health care providers, and educators are supporting adolescents and need to understand their QoL, both from their own perspective and that of their parents.

QoL is a complex multidimensional concept with a variety of definitions (Rapley, 2003). Using objective indicators such as independence, income, employment, and social relationships, some researchers examining QoL in adults with ASD (e.g., Eaves & Ho, 2008; Howlin, 2000; Howlin, Goode, Hutton, & Rutter, 2004) found lower overall QoL compared with peers. Others, such as Jennes-Coussens, Magill-Evans, and Koning (2006), found few differences from peers on education, living arrangements, and number of friends for young adult men. Lee, Harrington, Louie, and Newschaffer (2008) found greater effects on QoL for children and adolescents with ASD and their families than for typical controls or persons with attention deficits using indicators such as missing school, activity participation, attending religious services, and family outings. Significant predictors of positive outcomes have been early communication skills and IQ scores above 70 (Howlin, 2000; Howlin et al., 2004), a supportive social network, and access to support services (Howlin & Yates, 1999; Lord & Venter, 1992).

Many argue that QoL must be considered at the level of the individual's perceptions. Rapley (2003) explored several definitions that focus on perceptions and summarized the commonalities as "an individual psychological perception of the material reality of aspects of the world" (p. 50). An individual forms a perception of functioning across many areas based on their context (World Health Organization, 2002). Research examining perceptions of

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adults with ASD has indicated lower self-reported social and physical QoL (Jennes-Coussens et al., 2006; Kamp-Becker, Schroder, Muehlan, Remschmidt, & Bachmann, 2010), lower psychological QoL and total QoL (Kamp-Becker et al., 2010), lower total QoL (Renty & Roeyers, 2006; Saldana et al., 2009), and positive parent-reported QoL despite significant dependence on parental/caregiver support (Billstedt, Gillberg, & Gillberg, 2011).

Health-related quality of life (HRQoL) addresses the impact of having a specific health condition on QoL (Kuhlthau et al., 2010). Measures such as the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999) have generic scales as well as condition-specific scales (e.g., asthma, cardiac) and may include objective measures and subjective perceptions. There are no measures specific for persons with ASD. Some authors (e.g., Plimley, 2007; Tavernor, Barron, Rodgers, & McConachie, 2013) argue for a condition-specific measure for ASD while others who have reviewed a broader literature (e.g., Davis et al., 2007; Wallander, Schmitt, & Koot, 2001) feel that condition-specific measures may focus on "ill-being" when health is only one domain that impacts QoL.

Measures that have been used for persons with ASD often have a self-report and a parent/caregiver proxy form. For children and adolescents with ASD, parents report significantly lower QoL on all domains of the PedsQL compared with published norms (Kuhlthau et al., 2010; Limbers, Heffer, & Varni, 2009). Adolescents report scores more than one standard deviation below the mean in physical functioning and below the mean on other domains (Shipman, Sheldrick, & Perrin, 2011). Tavernor and colleagues (2013) summarized five QoL studies of children/adolescents and eight studies of adults with ASD published since 2006. Six studies used only proxy-report, four used only self-report (all with adults), and the remainder used both self-report and proxy-report. Concerns about using self-report relate to deficits associated with ASD such as difficulty with communication (e.g., interpreting items, understanding emotions, and emotional vocabulary; Tavernor et al., 2013), and difficulty reflecting on their own affective state (Happe, 1993; Siegel, 1996). Shipman et al. (2011) demonstrated that adolescents' QoL self-report scores were internally reliable with concurrent validity. Although strong agreement between parent-report and self-report is not expected (Limbers et al., 2009), recent articles have compared QoL from the perspective of the child/adolescent with ASD with that of caregivers. In Shipman et al.'s (2011) study of 39 adolescents, correlations ranged from $r = .22$ to $r = .46$. Parents rated their teen's QoL lower, similar to Kamp-Becker et al. (2010). Sheldrick, Neger, Shipman, and Perrin (2012) demonstrated that parents were aware of their adolescents' likely response on QoL measures but held different opinions resulting in the lower scores.

While evidence is emerging related to QoL for adolescents with ASD, the results are mixed and limited to a few measures. Little is known about what factors are associated with QoL for adolescents with ASD. Kamp-Becker and colleagues (2010) found that higher self-reported HRQoL in young adults with ASD was associated with better daily living skills. Similarly, Kuhlthau and colleagues (2010) found increases in social QoL associated with increased scores on the Adaptive Behavior Composite score of the Vineland-II for 286 children and adolescents.

The purpose of this study was to build on previous research by examining both adolescents' and parents' perspectives of the adolescents' QoL to identify the unique information provided by each informant and variables that might influence reports of QoL. The relationship between adaptive living skills and self-reported QoL for persons with ASD is also examined.

Objectives

1. Assess the QoL of youth aged 13 to 18 years with ASD using a standardized self-report measure, KIDSCREEN-52 (KIDSCREEN Group Europe, 2006).
2. Assess the QoL of youth with ASD using a standardized proxy parent-report measure.
3. Evaluate the relationship between parent and youth report on a standardized measure.
4. Examine the relationship of QoL to adaptive functioning as measured using the *Adaptive Behavior Assessment System*, second edition (Harrison & Oakland, 2008) for youth with ASD.

Method

Participants

Participants were recruited through an invitation mailed to parents of appropriate aged persons in the Autism Clinic data base at a tertiary hospital, an advertisement through a local autism society, and information posted on bulletin boards. Inclusion criteria were *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; APA, 1994) diagnosis of autism, Asperger syndrome, or Pervasive Developmental Disorder–not otherwise specified; age 13 to 18 years; speak English and able to read at a Grade 6 level to complete questionnaires based on parent-report; and living in northern Alberta or the Northwest Territories. Youth with ASD or their parents were excluded if the inclusion criteria were not met. The diagnosis was confirmed by chart review and the process was explored during a phone interview with the parent, confirming that the adolescent continued to have services based on a diagnosis of ASD. If there was any question about the diagnosis, the participant was excluded. One parent of each family needed to agree to complete two questionnaires. The questionnaires and consents were returned to the researchers via a self-addressed and stamped envelope.

Three girls and 19 boys with ASD (*M* age = 15.2 years; *SD* = 1.7) with 21 mothers and 1 father participated. Most were Caucasian (*n* = 17), with 1 person having an Aboriginal background and the remainder reporting a mixed background. Eleven of the youth had at least one other diagnosis (anxiety = 2, anxiety + obsessive compulsive disorder [OCD] = 1, asthma = 2, depression = 2, Tourette's = 1, OCD = 1, attention-deficit hyperactive disorder [ADHD] + OCD = 1, ADHD + developmental coordination disorder = 1). Five mothers were primarily homemakers while the remainder of parents worked outside the home.

Measures

The KIDSCREEN-52 (KIDSCREEN Group Europe, 2006) is a standardized cross-cultural measure of health-related QoL in children 8 to 18 years. The 52-item questionnaire has 10 dimensions: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance (bullying), and financial resources. Norms are based on a representative sample of 22,827 children in 13 European countries. Children and parents rate statements on a 5-point scale that requires them to reflect on the past week. *T* values (*M* = 50; *SD* = 10) based on the international data are used for comparison. Higher values indicate higher HRQoL. Cronbach's alphas (internal consistency) range from .76 to .89 for self-report, and .77 to .90 for proxy-report. The intra-class correlations (ICCs) between the self-report and proxy-report range from .45 to .62. There is additional support for reliability with satisfactory scores on Rasch measurement analysis. Support for separate but related constructs for the different domains are indicated by acceptable ICC scores. Validity was assessed using groups of children expected to differ on QoL such as lower socioeconomic status, special health care needs, mental health issues, or behavior problems. There were small to moderate effect sizes between groups. Correlation coefficients between PedsQL, *Child Health and Illness Profile–Adolescent Edition*, and *Youth Quality of Life Instrument* scales and KIDSCREEN dimensions assessing similar constructs were moderate (*r* = .44-.61) demonstrating acceptable validity.

The *Adaptive Behavior Assessment System–II* (ABAS-II; Harrison & Oakland, 2008) assesses areas such as communication, community use, functional academics, school/home living, health and safety, leisure, self-care, self-direction, social and motor skills. These skills combine to form three domains (conceptual, social, practical) as well as the Global Adaptive Composite (GAC) that have means of 100 and standard deviations of 15. Higher scores indicate better adaptive functioning. The measure was standardized on a representative sample in the United States stratified for age, race, gender, region, parental education, and community size. Reliability was indicated by moderate to high test–retest reliability and inter-rater reliability. Internal consistency was .98 for the GAC and .75 to .96 for domain scores for children with autistic disorder. Validity is based on a comprehensive review of the literature for test content, differences between age groups, and factor analyses confirming that the ABAS-II is a measure of a single global factor of adaptive skill. Correlations with other measures of adaptive functioning are moderate to high. In the manual, school-aged children and adolescents with ASD (*n* = 32) assessed by their classroom teacher had a mean GAC score of 54, compared with 101 for matched controls with significant differences on all areas.

Procedures

Ethical approval was obtained from the University ethics board prior to data collection. Written informed consent was obtained from the parents with assent from the youth if the parent felt it was appropriate. Packages of questionnaires were mailed to participants along with a self-addressed and stamped envelope for their return.

Data Analysis

The data were analyzed using SPSS version 16 (SPSS Inc.). Cronbach's alphas were used to assess the internal reliability of the KIDSCREEN-52 when used with adolescents with ASD and their parents. For adolescents, values ranged from .72 (Autonomy, School Environment) to .89 (Parent Relation/Home Life) with a mean of .80 overall. For parents, values ranged from .78 (Social Support/Peers) to .92 (Moods and Emotions) with a mean of .84 overall.

KIDSCREEN-52 scores and ABAS-II were interpreted in light of the normative ranges. Ravens-Sieberer et al. (2005) suggested a threshold of half a standard deviation from the mean as a noticeable difference from normal but this was based on a sample size of at least 50. One full standard deviation was considered more appropriate for interpreting scores in this study.

The relationships between the youth and parent KIDSCREEN-52 scores were assessed using ICC coefficients allowing comparison with self-report and parent values for the KIDSCREEN-52 in the manual (KIDSCREEN Group Europe, 2006). In addition, paired *t* tests were done and effect sizes calculated. Correlations were used to address the relationship of KIDSCREEN-52 scores to the parent-reported ABAS-II General Adaptive Composite standard score.

Results

QoL Using Self-Report and Proxy-Report (Objectives 1 and 2)

Information describing QoL based on self- and parent-report is in Table 1. The mean self-report QoL scores on all 10 dimensions fell between 40 and 50 or within one standard deviation of the mean of 50. The lowest mean score was for the Social Support/Peers dimension and the highest mean score was for school-related items. One adolescent (#22) reported scores that were more than one standard deviation above the mean (60 or more) on 4 dimensions. None of the adolescents had all of their scores below 40 although one adolescent reported scores in this range on 8 of the 10 dimensions.

For parents, mean scores were 40 and above for 7 dimensions. The highest mean score was for Financial Resources. The 3 dimensions with mean scores more than one standard deviation below the mean were Moods/Emotions, Social Support/Peers, and Social Acceptance/Bullying. One parent (#22) reported scores that were more than one standard deviation above the mean on three dimensions. No parent reported all scores below 40 although three parents reported scores in this range on 7 or 8 of the 10 dimensions.

Relationship Between Parents' and Adolescents' QoL Scores (Objective 3)

Parents' mean scores were significantly lower than the adolescents on Social Acceptance/Bullying and significantly higher on Financial Resources. Parents' scores were generally lower. ICC coefficients between parents and adolescents' perceptions on the dimensions are shown in Table 1 ($M = .39$). Coefficients were very low for Self-Perception, Autonomy, and Parent Relation/Homelife even though the mean scores were similar. These low ICCs are markedly different from the ones reported for parents and children and adolescents in the KIDSCREEN-52 manual (KIDSCREEN Group Europe, 2006). The highest coefficients were for Moods/Emotions and for Financial Resources. Four coefficients were greater than or equal to .50. The average correlations were similar ($M\ r = .39$) to the Shipman et al. (2011) study of persons with ASD ($M\ r = .35$) but lower than the average ($M\ r = .52$) reported in the KIDSCREEN-52 manual.

Table 1. Adaptive Behavior Assessment System–II (ABAS-II), Quality of Life (QoL) Mean Scores (Standard Deviations), and Correlations Between Respondents.

	Youth	Parents	ICCs[a]	Normative ICCs[b]	Δ Effect size
Composite ABAS-II[c]					
General Adaptive	67.5 (14.7)				
Conceptual	73.9 (14.0)				
Social	71.2 (10.7)				
Practical	68.1 (17.3)				
HRQoL[d]					
School	48.6 (7.7)	45.9 (6.5)	.50	.62	2.7 0.38
Financial Resources	48.0 (10.8)	53.8 (8.6)	.55	.53	−5.8* 0.60
Self-Perception	47.8 (9.3)	46.7 (10.0)	.06	.53	1.1 0.11
Autonomy	47.3 (7.2)	48.5 (8.5)	−.17	.48	−1.2 0.15
Parent Relations/ Home Life	46.4 (9.5)	46.5 (8.7)	.17	.50	−0.1 0.01
Social Acceptance (Bullying)	45.3 (12.2)	37.3 (12.5)	.50	.68	8.0** 0.65
Psychological	44.6 (10.4)	40.8 (7.4)	.42	.51	3.8 0.43
Physical	43.0 (9.0)	40.3 (8.1)	.46	.62	2.7 0.32
Moods/ Emotions	42.2 (8.6)	38.5 (11.1)	.66	.45	3.7 0.38
Social Support/ Peers	41.0 (6.4)	37.1 (12.5)	.44	.48	3.9 0.41

Note. HRQoL = Health-Related Quality of Life; ICC = intra-class correlation.

[a] ICC coefficients between youth and parent scores. [b] ICCs reported in manual for children and adolescents, $N = 16{,}162$ to 16,463. [c] Composite scores; Normative mean = 100; $SD = 15$; $N = 20$. [d] Normative mean = 50; $SD = 10$; $N = 22$.

ΔDifference in means—positive means higher self-reports than proxies.

$*p = .008$. $**p = .006$.

Relationship Between Parent-Reported ABAS-II and the QoL Scores (Objective 4)

Table 2 reports the correlations of ABAS-II General Adaptive Composite and the 10 dimensions of the KIDSCREEN-52. Using self-report QoL scores, most correlations were low and some were unexpectedly negative (e.g., Psychological Well-Being). The highest correlation was for Social Acceptance (Bullying) with the shared variance (r^2) for the two variables being 19%. The correlations of ABAS-II GAC scores and parent-reported KIDSCREEN-52 scores were also low. The highest correlations were for the Physical Well-Being and Social Support/Peers dimensions and in both cases the r^2 was only 13%. Overall, there appears to be a limited relationship between General Adaptive Composite score and QoL as measured using the KIDSCREEN-52.

Table 2. Correlation of General Adaptive Composite Score of the Adaptive Behavior Assessment System–II (ABAS-II) and Health-Related Quality of Life (HRQoL) for Youth and for Parents ($n = 20$).

	Youth (r)	Parents (r)
QoL		
School	−.15	.18
Financial Resources	−.19	.08
Self-Perception	.09	.05
Autonomy	.06	−.02
Parent Relations/Home Life	−.08	−.02
Social Acceptance (Bullying)	.44	.21
Psychological	−.25	.17
Physical	−.06	.36
Moods/Emotions	.01	.05
Social Support/Peers	.29	.36

The participants had deficits in overall adaptive behavior as measured using the ABAS-II. The mean score was more than two standard deviations below the mean or extremely low (see Table 1). These low scores are in keeping with marked impairments in everyday functioning, one of the diagnostic criteria for ASD (APA, 2000, 2013). The social (e.g., relationships, self-esteem) and conceptual (e.g., language, money, self-direction) composite mean scores were slightly higher and fell in the borderline range.

Discussion

Overall, youth with ASD report their QoL on the KIDSCREEN-52 in the lower end of the typical range, similar to Shipman et al. (2011) where mean total *T* scores and three subscale scores (Emotional, Social, and School Functioning) on the PedsQL ranged from 41 to 46 for 39 adolescents living in the United States. The highest mean scores were for school functioning in both studies despite the use of different QoL measures. Youth who are able to complete the self-report measures are likely doing relatively well at school with supports such as aides or adapted programs. They may be comfortable within the structure of the school setting. Parents also viewed school functioning as relatively positive. Using a QoL measure with a school functioning subscale may give educational staff a method for tracking the success of supports and accommodations provided from the perspective of the adolescent.

The lowest self-report scores were in the dimension of Social Support/Peers; this was also the area rated the lowest by parents, similar to other studies of adolescents and using parent-report (Kuhlthau et al., 2010; Tavernor et al., 2013). Low mean scores in this area are not surprising given the social deficits of persons with ASD. Tavernor et al. (2013) raised the issue as to whether a preference for time alone to pursue strong interests may result in lower scores on social QoL. The dimension of Moods and Emotions had a low mean score for both adolescents and parents. This is an area that needs to be considered when evaluating adolescents with ASD given the possibility of depression (Strang et al., 2012). Understanding how the adolescent perceives QoL in these two areas can help parents and school staff initiate conversations about feelings and provide a basis for possible interventions such as teaching social skills to the adolescent or implementing strategies to create a supportive social environment. The effects of intervention efforts can be measured by changes in QoL in areas of concern.

Variability across QoL dimensions indicates that the youth are able to differentiate areas where QoL is more or less positive. This differentiation across areas might be used as a source of student input when considering priorities for goals on individual program plans. On average their scores are below that of typically developing adolescents indicating an awareness of their challenges. Having a similar pattern of results to one of the few other studies using self-report for adolescents increases confidence in the study's results despite a smaller sample size. The Cronbach's alphas indicate that their reports are internally consistent with all values above .70. Overall, these results suggest that their self-report answers are valid and provide useful information for families, health care providers, and educators.

Some adolescents had generally positive perceptions and some had more negative perceptions. The fact that the parent of the adolescent with the highest pattern of scores also reported higher scores for her son increases the likelihood that his self-report was valid and represents the range of perceptions. QoL needs to be considered on an individual basis rather than assuming lower perceptions of QoL simply because of a diagnosis.

Parents reported generally lower scores or similar scores compared with the adolescents with the exception of the Financial Resources dimension in our study and the Physical domain of the PedsQL in the Shipman et al. (2011) study. Lower parent-report scores are not an unexpected finding given the results of other QoL studies for persons with ASD (Kamp-Becker et al., 2011). Given differences between respondents, it is important to consider the perspectives of both parents and adolescents when determining areas for intervention. It may be particularly important in areas such as Self-Perception, Autonomy, and Parent Relations/Home Life where coefficients were particularly low. Sheldrick et al. (2012) found that agreement between parents and adolescents with ASD increased when parents were asked to complete the proxy measure pretending to be their adolescent although differences between respondents remained. Davis et al. (2007) noted the moderate correlations between parent proxy-report and child self-report in general on QoL measures. Based on a qualitative study to understand the reasons for differences, they concluded that differences may be due to different response styles and reasoning.

Ellert, Ravens-Sieberer, Erhart, and Kurth (2011) concluded that proxy-report cannot replace self-report QoL for typically developing adolescents and parent-report should be viewed as providing supplementary information. It would appear that the same is true for adolescents with ASD as Limbers et al. (2009) recommended using both children's and parents' responses as each provides unique and useful information.

The theoretical literature on QoL (e.g., Rapley, 2003) cites many factors that are expected to have an influence on QoL. Persons with ASD are expected to have lower QoL because of the functional challenges associated with the diagnosis and negative stereotypes of those around them. It was also expected that having better adaptive behaviors would be associated with higher QoL (PedsQL) based on prior work by Kuhlthau et al. (2010) using the Vineland-II with 286 children with ASD. This was not the case in this study where correlations were low across most dimensions irrespective of whether the parent or adolescent was responding. There was enough variability in both ABAS-II and QoL scores to allow a correlation to be detected. In fact, higher adaptive behaviors were negatively associated with psychological QoL. Persons in this sample who were more able in terms of adaptive skills may have been more aware of negative perceptions in the environment and therefore rated their QoL lower.

Limitations for this study are largely those of a small sample (limited ability to generalize the results, potential for response bias, possible influence of outliers), limitations related to the HRQoL measure itself, failure to obtain recent measures of cognitive skills, and use of measures such as the *Autism Diagnostic Observation Scale* to verify diagnosis. The KIDSCREEN-52 scores of our Canadian sample are based on a European normative sample and this may have resulted in a potential scoring bias due to differing norms. In the absence of Canadian norms on this measure, this limitation cannot be evaluated. The KIDSCREEN-52 asks parents and teens to reflect on their experiences in the past week, which may not be a representative sample of their general experiences. While other researchers (Kuhlthau et al., 2010) have found that cognitive ability is not as important as other factors for QoL, having a clearer understanding of the cognitive level of participants would help in understanding the responses. Furthermore, the results of this study cannot be applied to participants with greater cognitive disabilities and more severe symptoms of ASD. Having only one father as a parent respondent also limits the generalization of parent responses.

Future research directions include exploring other factors that may be associated with QoL for adolescents beyond adaptive behaviors. The factors that define QoL in youth with ASD and the parents who care for them may be different from those for persons with more typical development and they may change over time with the changing challenges that are present in each stage of the developmental process. Also, it is important to understand the mechanisms associated with positive perceptions of QoL. Ellert et al. (2011) found that parents tended to underestimate QoL if the teen had emotional abnormalities and/or a poor state of health. One explanation was the response-shift phenomenon where children with chronic health problems develop improved strategies for coping (Sprangers & Schwartz, 1999) or adapted their internal assessment standards to their state of health, resulting in perceived higher QoL over time (Ellert et al., 2011). Understanding this shift and when it occurs, along with the personal, family and environmental factors that promote increased resilience, is important for community support and educational services. Qualitative research may be an important step in building this body of knowledge.

Proxy-reporting should not replace self-determined QoL ratings at least for those individuals capable of providing information. It may be helpful to include multiple proxy respondents such as teachers, coaches, or community support workers to understand how their perceptions correspond with the client's self-perceptions and the impact of differences in perceptions on supports, educational planning, and interventions. This information may give further insight into QoL in the context of the environment and every day activities.

In addition, it is important to further explore the validity of the KIDSCREEN-52 for use with adolescents with ASD. The full KIDSCREEN-52 has not been used with this population before. There were concerns about the small number of items (e.g., 3) for some of the dimensions. Qualitative work asking adolescents to think aloud while rating the items would add important information about their understanding of the items and their response style. This information would be useful for helping with the broader decision as to whether an ASD-specific QoL measure is actually needed.

While preliminary evidence is promising, there is much that needs to be explored with a larger sample. Follow-up from this study will provide opportunities to observe prospectively shifts in QoL over time, particularly as they transition to adulthood, and to identify the new variables and factors that are associated with both self- and proxy-reported QoL. In addition, questions related to when adolescents with ASD become aware of their differences, and the need to accommodate can be addressed. This type of research would support a more evidence-based approach to community supports and educational program planning for adolescents with ASD.

Conclusion

This study adds to a small but increasing body of evidence related to adolescents with ASD and their perceptions of QoL. Participants in this study were able to indicate dimensions of their lives that are more positive and areas that are more challenging. Not all of them reported lowered perceptions of their QoL. It is encouraging that average self-report scores are within one standard deviation of the mean in comparison with typically developing youth. Both parent and adolescent reports of QoL are important and when possible adolescent reports should be obtained to ensure that their perceptions are heard. Each respondent offers unique information to consider when planning intervention. This study provides a foundation for future work to understand variables that affect the QoL of adolescents with ASD.

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