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Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature



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ABSTRACT

This review study was conducted to synthesize the existing research on the level of quality of life (QoL) in individuals with autism spectrum disorders (ASD) and the factors associated with their QoL. A total of 16 studies were included for this review. This study found that (a) the majority of the individuals with ASD had poor QoL; (b) behavior problems and leisure activities were associated with the QoL of the majority of adults with ASD; (c) autism severity, age, behavior problems, social skills, adaptive behavior, education, and comorbid psychiatric conditions were associated with the QoL of the majority of children with ASD. These findings may provide critical information to parents/caregivers of individuals with ASD and practitioners providing services to them.

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1. Introduction

Quality of life (QoL) is defined by the WHO as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1998, p. 11) and this concept suggests that “persons’ physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment” should be considered when measuring QoL (World Health Organization, 1998, p. 11). The concept of QoL not only provides guidance to enhance one’s well-being but also serves as a common language for people to collaborate on making positive changes (Schalock, 2004).

QoL of individuals with autism spectrum disorders (ASD) has been reported by previous studies. Some studies have reported good QoL in individuals with ASD, but others have reported poor QoL in these individuals. For example, Billstedt, Gillberg, and Gillberg (2011) conducted a prospective long-term follow-up study of 120 individuals with ASD from childhood into late adolescence/early adult life and reported that the majority of the individuals with ASD (88%) in their study had average to very good QoL. Gerber, Baud, Giroud, and Carminati (2008) examined QoL of adults with ASD and intellectual disabilities (ID) ($N = 30$, mean age = 39 years) and reported that these individuals had a good QoL. But, Jennes-Coussens, Magill-Evans and Koning (2006) compared QoL of individuals with Asperger syndrome (AS) ($N = 12$, mean age = 20 years) to that of individuals without AS ($N = 13$, mean age = 20 years) and found that the participants with AS rated their QoL lower than the participants without AS. Kuhlthau et al. (2010) measured QoL of children with ASD ($N = 286$, age range = 2–17 years) and reported that QoL of children with ASD was significantly lower than the national norm for a generally healthy population. Limbers, Heffer and Varni (2009) examined QoL of children with AS ($N = 22$, mean age = 9 years) and reported that the QoL of these children was significantly lower than that of healthy children. The inconsistent findings from previous studies seem to suggest that some factors may be associated with QoL of individuals with ASD.

1.1. The factors that may associate with QoL

1.1.1. QoL assessment

Individuals with ASD are characterized by qualitative impairment in social interaction and communication as well as displaying repetitive and stereotyped patterns of behavior and interests (American Psychiatric Association, 2000). Many individuals with ASD have language development delay (Weismer, Lord, & Esler, 2010) and cognitive development delay (Ray-Subramanian, Huai, & Weismer, 2011). Thus, it may not be possible for every individual with ASD to conduct a direct assessment on his/her QoL (Persson, 2000). Therefore, many studies have had their family members or residential staff to evaluate these individuals’ QoL (e.g., Billstedt et al., 2011; Gerber et al., 2008; Kose et al., 2013). However, the results from objective QoL assessments may be different from subjective QoL assessments.

1.1.2. Cognitive and adaptive functioning

Individuals with AS differ from individuals with autistic disorder (AD) in language and cognitive development (American Psychiatric Association, 2000). Individuals with ASD without ID are more likely than individuals with ASD with ID to participate in employment (Chiang, Cheung, Li, & Tsai, 2013). Many individuals with ASD who have limited spoken language skills have behavior problems (Chiang, 2008). Behavior problems may negatively affect QoL of individuals with ASD (Garcia-Villamisar & Dattilo, 2010). Thus, QoL of individuals with ASD may be affected by individual’s cognitive and adaptive functioning.

1.1.3. Age

Adults with ASD have more years of special education and related services experience than do children with ASD but many of the adults with ASD do not have the opportunity to participate in early intervention services, whereas, nowadays

participating in early intervention services is very common in children with ASD. The advancement in the intervention services for individuals with ASD may have an influence on QoL of individuals with ASD (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996). Thus, QoL of adults with ASD may be different from QoL of children with ASD.

1.1.4. Others

Receiving residential program services is important to adults with ASD but the quality and types of the residential programs may be varied across different programs, and thus, this may affect QoL of adults with ASD (Gerber et al., 2008). Participation in leisure activities is one of the indicators within the QoL physical well-being domain (Schalock, 2004). Thus, being able to participate in leisure activities may be associated with QoL of individuals with ASD. Given that more males are diagnosed with ASD than females (American Psychiatric Association, 2000), gender may be associated with QoL of individuals with ASD.

QoL is an important outcome measure for individuals with ASD (Gerber et al., 2011). In order to enhance QoL of individuals with ASD, we will need to know what factors are positively correlated with their QoL. However, there is a lack of review studies synthesizing the existing data on the level of QoL and the factors that are associated with QoL in individuals with ASD across studies. Thus, the purpose of this review was to synthesize the existing research on the level of QoL in individuals with ASD and the factors associated with QoL of these individuals. The finding of this study may provide critical information to parents of children with ASD and the practitioners who work with individuals with ASD.

2. Method

2.1. Search strategy and study selection criteria

A systematic literature search was conducted to locate studies that reported QoL data of individuals with ASD [e.g., autistic disorder, Asperger syndrome, Pervasive developmental disorder not otherwise specified (PDD-NOS)]. The search was limited to English-language and peer-reviewed journal articles which were published between 1994 and 2013. Publications were identified by using the following steps. First, electronic searches were conducted in the major databases, including Web of Science, Medline, PsycINFO, PubMed, and Educational Resources Information Center (ERIC) by using these Keywords: autism; autistic disorder; Asperger's disorder; Asperger syndrome; pervasive developmental disorder; autism spectrum disorder (ASD); and quality of life. Second; the reference lists from literature review articles identified by the electronic searches were reviewed to identify additional articles. Third; hand searches of the key journals (e.g.; Journal of Child Psychology and Psychiatry; Autism; Journal of Autism and Developmental Disorders; Research in Autism Spectrum Disorder; Focus on Autism and Other Developmental Disabilities) were conducted to identify additional studies. The literature search yielded a total of 78 articles potentially relevant to this review. To be included in this review; the study must include participants with ASD and quantitatively evaluate and report their total/overall QoL. The first and second authors screened the potential 78 articles to identify the studies that met the criteria of inclusion for this review. A point-by-point method (agreements divided by agreements plus disagreements and multiplied by 100) was used to calculate reliability for identifying studies that met criteria and the reliability was 100%.

3. Results

A total of 16 studies met the inclusion criteria for this review. The basic information (e.g., author, participants, country) of these 16 studies are presented in Table 1. These studies were published between 2002 and 2013. A total of 4321 individuals with ASD were included in these studies, including 398 adults (aged ≥ 18 years) and 3923 children (aged < 18 years). Children accounted for 91% of the total participants with ASD for this study. The participants from the studies recruited for this review aged between 2 and 62 years. These participants were from Sweden, Spain, Switzerland, Canada, Germany, Turkiye, and U.S.A. The sample sizes across studies ranged from 7 to 3066.

A total of six studies included more than 100 participants. The study by Sikora, Vora, Coury and Rosenberg (2012) had the most participants (i.e., 3066) and these participants accounted for 71% of the total participants in this review. A total of 14 studies reported participants' gender and these studies included 3575 males and 703 females.

A wide variety of QoL assessment tools were used in the studies for this review (e.g., Quality of Life: Autism-Friendly Environment, Parent/Caretaker Rating of Individual's Well-Being, Quality of Communication Life Scale, Quality of Life Survey, Quality of Life Questionnaire-Spanish Version, Quality of Life Inventory in a Residential Environment, WHOQOL-Brief Version, Pediatric Quality of Life Inventory 4.0, Comprehensive Quality of Life Questionnaire, The Health Utilities Index, Quality of Well-Being Self-Administered).

QoL of individuals with ASD was assessed by the individuals with ASD themselves, their parents, their residential staff, and/or researchers in the studies for this review. Only about 38% of the studies ($N=6$) recruited for this review asked individuals with ASD to complete QoL assessments or interviewed them to rate their own QoL.

3.1. QoL of individuals with ASD

The results of the studies focusing on adults are presented in Table 2 and the results of the studies focusing on children are presented in Table 3.

Table 1
Basic information of QoL studies.

Author	Participants	Country
*Billstedt et al. (2011)	108 Individuals (77 males, 31 females) with autistic disorder or atypical autism Mean age = 25 years (range = 17–40 years) IQ range = < 50–85	Sweden
Burgess and Turkstra (2010)	<i>Asperger syndrome (AS)</i> 15 Individuals (15 males, 0 female) with AS Mean age = 16 year (range = 13–19 years) Mean IQ = 104 <i>Typical development (TD)</i> 15 Individuals (15 males, 0 female) with TD Mean age = 15 years (range = NA) Mean IQ = 112	USA
Garcia-Villamisar et al. (2002)	<i>Sheltered workshop group</i> 26 Individuals (18 males, 8 females) with ASD Mean age = 21 years (range = NA) Mean IQ = 55 <i>Supported work group</i> 25 Individuals (21 males, 4 females) with ASD Mean age = 21 years (range = NA) Mean IQ = 57	Spain
Garcia-Villamisar and Dattilo (2010)	<i>Experimental (leisure program) group</i> 37 Individuals with ASD (22 males, 15 females) Mean age = 31 years (range = 17–39 years) Mental age = 63 months <i>Control (waiting list) group</i> 34 Individuals with ASD (19 males, 15 females) Mean age = 30 years (range = 24–38 years) Mental age = 61 months	Spain
Gerber et al. (2008)	<i>Residential setting1 [Programme Autisme Methode Structuree (PAMS1)]</i> 8 Individuals with ASD and 2 individuals with Fragile-X syndrome (7 males, 3 females) Mean age = 43 years (range = 32–58 years) Intellectual disability (ID) level = moderate – severe <i>Residential setting2 (PAMS2)</i> 7 Individuals with ASD, 1 individual with childhood disintegrative disorder, and 1 individual with Fragile-X syndrome (7 males, 2 females) Mean age = 45 years (range = 30–62 years) ID level = moderate – profound <i>Residential setting3 (No-PAMS)</i> 10 individuals with ASD and 1 individual with childhood disintegrative disorder (8 males, 3 females) Mean age = 32 years (range = 24–45 years) ID level = moderate –profound	Switzerland
Gerber et al. (2011)	<i>PAMS</i> 20 Individuals with PDD and ID Mean age = 43 years (range = 24–62 years) IQ = NA <i>No-PAMS</i> 11 Individuals with PDD and ID Mean age = 32 years (range = 24–62 years) IQ = NA	Switzerland
Jennes-Coussens et al. (2006)	<i>AS</i> 12 Individuals with AS Mean age = 20 years (range = NA) IQ = NA <i>Without AS</i> 13 Individuals without AS Mean age = 20 years (range = NA) IQ = NA	Canada

Table 1 (Continued)

Author	Participants	Country
Kamp-Becker et al. (2010)	26 Individuals (26 males, 0 female) with AS or high functioning autism (HFA) Mean age = 21 years (range = 17–28 years) Mean IQ = 99	Germany
*Kose et al. (2013)	ASD 102 Individuals (84 males, 18 females) with ASD Mean age = 8 years (range = 3–18 years) IQ = NA TD 39 Individuals (16 males, 23 females) with TD Mean age = 9 years (range = NA) IQ = NA	Turkiye
*Kuhlthau et al. (2010)	286 individuals (236 males, 50 females) with ASD Mean age = NA (range = 2–17 years) IQ = ≤ 70 (52%) – ≥ 70	Turkiye
Limbers et al. (2009)	22 Individuals (20 males, 2 females) with AS Mean age = 9 years (range = 6–12 years) IQ = NA	USA
Saldana et al. (2009)	74 Individuals (63 males, 11 females) with ASD Mean age = 24 years (range = 18–40 years) IQ = NA	Spain
Sheldrick et al. (2012)	39 Individuals (28 males, 11 females) with ASD Mean age = 14 years (range = 12–18 years) IQ > 70	USA
*Sikora et al. (2012)	3066 Individuals (2586 males, 480 females) with ASD Mean age = NA (range = 2–18 years) IQ = < 70 (34%) – ≥ 70	USA
*Tilford et al. (2012)	150 Individuals (128 males, 22 females) with ASD Mean age = 8 years (range = 4–17 years) Mean IQ = 75	USA
*Varni et al. (2012)	243 Individuals (215 males, 28 females) with autistic disorder (AD) Mean age = 9 years (range = 6–17 years) IQ = NA	USA

* The study had more than 100 participants.

3.1.1. Adults

Two studies (Billstedt et al., 2011; Gerber et al., 2008) reported that adults with ASD had good QoL ($N = 133$). Two studies reported that (Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Saldana et al., 2009) QoL of adults with ASD ($N = 100$) was lower than that of the healthy population. The number of the participants in the studies reporting good QoL was higher than that in the studies reporting poor QoL.

3.1.2. Children

Six studies (Kose et al., 2013; Kuhlthau et al., 2010; Limbers et al., 2009; Sheldrick, Neger, Shipman, & Perrin, 2012; Sikora et al., 2012; Varni et al., 2012) reported that QoL of individuals with ASD ($N = 3758$) was lower than that of the healthy population. One study (Burgess and Gutstein, 2007) reported that QoL of individuals with ASD ($N = 15$) was similar to that of the comparison group (i.e., individuals with TD). The number of the participants in the studies reporting poor QoL was higher than that in the studies reporting good QoL.

3.2. Factors Associated with QoL

3.2.1. Autism diagnosis/autism severity

3.2.1.1. *Adults.* Two studies (Kamp-Becker et al., 2010; Saldana et al., 2009) reported that severity of autistic symptoms was not associated with QoL of adults with ASD ($N = 100$).

Table 2
The QoL studies: adults.

Study	QoL measurement(s)	Factors examined	Results
*Billstedt et al. (2011)	<p><i>Tool</i> Quality of life: Autism-friendly environment (QoL1)</p> <p>Parent/caregiver rating of individual's well-being (QoL2)</p> <p><i>Procedure</i> QoL1 was completed by researchers. QoL2 was completed by parents/caregivers.</p>	<p><i>IQ</i></p> <p><i>Accommodation type</i> (e.g., with parents, group home, own apartment)</p> <p><i>Occupational activities</i> (e.g., school work, supported work, activity center, no activity)</p> <p><i>Regular recreational activities</i></p>	<p><i>QoL level</i></p> <ul style="list-style-type: none"> • 88% of the participants with ASD had an average to very good QoL. • 91% of the families reported that their children with ASD had a good to very good QoL. <p><i>Factors associated with QoL</i></p> <ul style="list-style-type: none"> • Regular recreational activities were positively correlated with QoL. • IQ, accommodation type, or occupational activities was not associated with QoL.
Garcia-Villamizar et al. (2002)	<p><i>Tool</i> Quality of Life Survey (QLS)</p> <p><i>Procedure</i> Participants were interviewed in 1996 and 2000. If a participant had no verbal communication skills, the job coach was interviewed.</p>	<p><i>Sheltered workshop program</i></p> <p><i>Supported work program</i></p>	<p><i>QoL level</i></p> <ul style="list-style-type: none"> • Both group showed similar QoL in 1996. • The supported work group showed better QoL than the sheltered work group in 2000. <p><i>Factors associated with QoL</i></p> <ul style="list-style-type: none"> • Participation in the supported work program was positively correlated with QoL.
Garcia-Villamizar and Dattilo (2010)	<p><i>Tool</i> Quality of Life Questionnaire-Spanish version (QoL)</p> <p><i>Procedure</i> The QoL was administered by an interviewer who asked participants questions and the interviewer scored participants' responses. The QoL was administered before and after the program.</p>	<p><i>A 1-year group leisure program</i></p>	<p><i>QoL level</i></p> <ul style="list-style-type: none"> • The experimental and control groups showed similar QoL at pre-test. • The QoL improvement in the experimental group was significantly higher than that in the control group. <p><i>Factors associated with QoL</i></p> <ul style="list-style-type: none"> • Participation in the leisure program was positively correlated with QoL.
Gerber et al. (2008)	<p><i>Tool</i> Quality of Life Inventory in a Residential Environment (I.Q.V.M.R)</p> <p><i>Procedure</i> IQVMR was completed by residential program staff and by a family member at the beginning of the study (2005) and after 1 year of the study (2006).</p>	<p><i>Residential programs</i> (e.g., PAMS1, PAMS2, No-PAMS)</p> <p><i>Behavior problems</i></p>	<p><i>QoL level</i></p> <ul style="list-style-type: none"> • The QoL scores from staff evaluation were higher than those from family evaluation. • The participants with ASD had good QoL. The QoL of the participants with ASD was higher than the reference mean. <p><i>Factors associated with QoL</i></p> <ul style="list-style-type: none"> • Participation in the PAMS1 was positively correlated with QoL. • The relationship between behavior problems and QoL could not be confirmed.
Gerber et al. (2011)	<p><i>Tool</i> Quality of Life Inventory in a Residential Environment (I.Q.V.M.R)</p> <p><i>Procedure</i> IQVMR was completed by residential program staff at the beginning of the study (2005) and at the end of the study (2008).</p>	<p><i>Residential programs</i> (e.g., PAMS, No-PAMS)</p> <p><i>Behavior problems</i></p>	<p><i>QoL level</i></p> <ul style="list-style-type: none"> • The PAMS and No-PAMS groups showed similar QoL in 2005. • The PAMS group showed a significant improvement in QoL in 2008. <p><i>Factors associated with QoL</i></p> <ul style="list-style-type: none"> • Participation in the PAMS was positively associated with QoL. • Behavior problems were negatively associated with QoL.
Jennes-Coussens et al. (2006)	<p><i>Tool</i> WHOQOL-Brief Version</p> <p><i>Procedure</i> Participants were interviewed by an interviewer.</p>	<p>NA</p>	<p><i>QoL level</i></p> <ul style="list-style-type: none"> • The participants with AS rated their QoL lower than the participants without AS. <p><i>Factors associated with QoL</i></p> <p>NA</p>

Table 2 (Continued)

Study	QoL measurement(s)	Factors examined	Results
Kamp-Becker et al. (2010)	<i>Tool</i> WHOQOL-Brief Version	<i>IQ</i>	<i>QoL level</i> • The participants with ASD had poor QoL. The QoL of the participants with ASD was significantly lower than the reference population of healthy individuals.
	<i>Procedure</i> Questionnaires were mailed to individuals with ASD. Those who were willing to participate in the study sent back the completed questionnaires.	<i>Autism severity</i> <i>Adaptive behavior</i> <i>Psychopharmacotherapy</i>	<i>Factors associated with QoL</i> • IQ, autism severity, adaptive behavior, or receiving psycho-pharmacotherapy was not associated with QoL.
Saldana et al., 2009	<i>Tool</i> Comprehensive Quality of Life Questionnaire (ComQoL)	<i>Services and support</i> (e.g., day center, educational center, work scheme, residence, family relief, home support)	<i>QoL level</i> • The participants with ASD had poor QoL. The QoL of the participants with ASD was lower than the normative subjects.
	<i>Procedure</i> Families and individuals with ASD were interviewed to complete the questionnaire.	<i>Size of social networks</i> (e.g., one person, two more different people, three different people, four or more different people)	<i>Factors associated with QoL</i> • Services and support, the size of social networks, autism severity, or adaptive behavior was not associated with QoL.
		<i>Participant characteristics</i> (e.g., autism severity, adaptive behavior)	

* The study had more than 100 participants.

Table 3
The QoL studies: children.

Study	QoL measurement(s)	Factors examined	Results
Burgess and Turkstra (2010)	<i>Tool</i> Quality of Communication Life Scale (QCL)	NA	<i>QoL level</i> • The participants with AS had poor QoL. Their QoL was significantly lower than the TD group. • The participants with AS rated their QoL more positively than their mothers.
*Kose et al. (2013)	<i>Procedure</i> Participants and their mothers completed the ratings independently.	<i>Gender</i>	<i>Factors associated with QoL</i> NA
		<i>Age</i>	
		<i>Autism severity</i>	
		<i>Psychotropic medication</i>	
		<i>Special education</i>	
*Kuhlthau et al. (2010)	<i>Tool</i> The parent-report version of the Pediatric Quality of Life Inventory 4.0 (PedsQL)	<i>Fist sign age</i>	<i>QoL level</i> • The participants with ASD had poor QoL. Their QoL was significantly lower than the TD group. • The QoL of the AD group was significantly lower than the AS group and the PDD-NOS group.
		<i>Diagnosis age</i>	
		<i>Treatment age</i>	
		<i>Age</i>	
		<i>ASD diagnosis</i>	
	<i>Procedure</i> The PedsQL was completed by parents.	<i>Psychotropic medication</i>	<i>Factors associated with QoL</i> • Gender and age was not associated with QoL. • Autism severity, taking psychotropic medication, and receiving special education were negatively associated with QoL. • First sign age, diagnosis age, and treatment age were positively associated with QoL.
		<i>Special education</i>	
		<i>Fist sign age</i>	
		<i>Diagnosis age</i>	
		<i>Treatment age</i>	
	<i>Tool</i> The parent-report version of the Pediatric Quality of Life Inventory 4.0 (PedsQL)	<i>Gender</i>	<i>QoL level</i> • The participants with ASD had poor QoL. Their QoL was significantly lower than the healthy sample.
		<i>Age</i>	
		<i>ASD diagnosis</i>	
		<i>IQ</i>	
		<i>Social responsiveness</i>	
		<i>Repetitive behavior</i>	<i>Factors associated with QoL</i> • Gender, ASD diagnosis, or IQ was not associated with QoL. • Age was negatively associated with QoL. • Social impairment, repetitive behavior, and behavior problems were negatively associated with QoL.
		<i>Behavior problems</i>	

Table 3 (Continued)

Study	QoL measurement(s)	Factors examined	Results
Limbers et al. (2009)	<i>Tool</i> Pediatric Quality of Life Inventory 4.0 (PedsQL) <i>Procedure</i> The PedsQL was completed by parents.	NA	<i>QoL level</i> • The participants with AS had poor QoL. Their QoL was significantly lower than the healthy sample. <i>Factors associated with QoL</i> NA
Sheldrick et al. (2012)	<i>Tool</i> Pediatric Quality of Life Inventory 4.0 (PedsQL) <i>Procedure</i> The PedsQL was completed by individuals with ASD and their parents. Their parents were asked to report their own opinions of their child's QoL (standard parent report) and answer as they believe the QoL their children would have (parent proxy report).	NA	<i>QoL level</i> • The participants with ASD had poor QoL. Their QoL was lower than the population average. • The QoL scores reported by individuals with ASD were significantly higher than the parent proxy report and the standard parent report. • The parent proxy QoL score was significantly higher than the standard parent report QoL score. <i>Factors associated with QoL</i> NA
*Sikora et al. (2012)	<i>Tool</i> Pediatric Quality of Life Inventory 4.0 (PedsQL) <i>Procedure</i> The PedsQL was completed by parents of individuals with ASD.	ADHD	<i>QoL level</i> • The participants with ASD and the participants with ASD+ADHD had poor QoL. Their QoL was lower than the population mean. <i>Factors associated with QoL</i> • ADHD was negatively associated with QoL.
*Tilford et al. (2012)	<i>Tool</i> The Health Utilities Index (HUI) 3 Quality of Well-Being Self-Administered (QWB-SA) <i>Procedure</i> Primary caregivers completed the surveys.	ASD diagnosis Autism severity Adaptive behavior Cognitive functioning	<i>QoL level</i> • The participants with ASD had poor QoL. Their QoL was lower than the people with perfect health. <i>Factors associated with QoL</i> • Children with AD had poorer QoL than children with AS. • Adaptive behavior and cognitive functioning were positively correlated with QoL. • Autism severity was negatively associated with QoL.
*Varni et al. (2012)	<i>Tool</i> The Pediatric Quality of Life Inventory (PedsQL) <i>Procedure</i> The PedsQL was conducted at baseline and week 8 or at the time of early discontinuation.	A pharmacologic treatment (i.e., Aripiprazole)	<i>QoL level</i> • The participants in the experimental group and the control group had poor QoL. Their QoL was lower than the population average. <i>Factors associated with QoL</i> • Receiving Aripiprazole was positively associated with QoL.

* The study had more than 100 participants.

3.2.1.2. *Children.* One study (Kuhlthau et al., 2010) did not find a relationship between specific autism diagnosis and QoL of children with ASD ($N = 286$) but two studies (Kose et al., 2013; Tilford et al., 2012) found that autism severity was negatively associated with QoL of children with ASD ($N = 252$). The number of the participants in the studies reporting no relationship between autism diagnosis/severity and QoL was higher than that in the studies reporting the existence of a relationship between autism diagnosis/severity and QoL.

3.2.2. Age

3.2.2.1. *Adults.* No study had examined the relationship between age and QoL in adults with ASD.

3.2.2.2. *Children.* One study (Kose et al., 2013) found there was no relationship between age and QoL in children with ASD ($N = 102$), but one study (Kuhlthau et al., 2010) found a negative relationship between age and QoL in children with ASD

($N = 286$). The number of the participants in the studies reporting a relationship between age and QoL was higher than that in the studies reporting no relationship between age and QoL.

3.2.3. Behavior problems

3.2.3.1. *Adults.* Two studies (Gerber et al., 2008, 2011) reported that behavior problems were negatively associated with QoL of adults with ASD ($N = 56$).

3.2.3.2. *Children.* One study (Kuhlthau et al., 2010) reported behavior problems were negatively associated with QoL of children with ASD ($N = 286$) and one study (Varni et al., 2012) reported the medical treatment for irritability (e.g., tantrums, aggressiveness, self-injuries behavior, sudden mood changes) improved QoL of children with ASD ($N = 243$).

3.2.4. Social communication skills.

3.2.4.1. *Adults.* No study had examined the relationship between social communication skills and QoL in adults with ASD.

3.2.4.2. *Children.* One study (Kuhlthau et al., 2010) examined the relationship between social impairment and QoL of children with ASD ($N = 286$) and found a negative relationship between social impairment and QoL.

3.2.5. IQ.

3.2.5.1. *Adults.* Two studies (Billstedt et al., 2011; Kamp-Becker et al., 2010) reported that IQ was not associated with QoL of adults with ASD ($N = 134$).

3.2.5.2. *Children.* Two studies (Kuhlthau et al., 2010; Tilford et al., 2012) reported that IQ was not associated with QoL of children with ASD ($N = 436$).

3.2.6. Adaptive behavior.

3.2.6.1. *Adults.* Two studies (Kamp-Becker et al., 2010; Saldana et al., 2009) reported that adaptive behavior was not associated with QoL of adults with ASD ($N = 100$).

3.2.6.2. *Children.* One study (Tilford et al., 2012) reported that adaptive behavior was positively correlated with QoL of children with ASD ($N = 150$).

3.2.7. Gender

3.2.7.1. *Adults.* No study had examined the relationship between gender and QoL in adults with ASD.

3.2.7.2. *Children.* Two studies (Kose et al., 2013; Kuhlthau et al., 2010) investigated the relationship between gender and QoL of children with ASD. They reported that there was no relationship between gender and QoL in children with ASD ($N = 388$).

3.2.8. Support

3.2.8.1. *Adults.* One study (Saldana et al., 2009) examined the relationship between support and QoL of adults with ASD and found there was no relationship between support (e.g., different types of support, the size of social networks) and QoL of adults with ASD ($N = 74$).

3.2.8.2. *Children.* No study had examined the relationship between support and QoL in children with ASD.

3.2.9. Education

3.2.9.1. *Adults.* No study had examined the relationship between education and QoL in adults.

3.2.9.2. *Children.* One study (Kose et al., 2013) examined the relationship between education and QoL of children with ASD and found not receiving special education was positively associated with QoL of children with ASD ($N = 102$).

3.2.10. Leisure activities

3.2.10.1. *Adults.* Two studies (Billstedt et al., 2011; Garcia-Villamisar & Dattilo, 2010) investigated the relationship between participation in leisure activities and QoL of adults with ASD ($N = 179$). Both studies reported that participation in leisure activities was positively associated with QoL of adults with ASD.

3.2.10.2. *Children.* No study had examined the relationship between leisure activities and QoL in children.

3.2.11. *Occupational activities.*

3.2.11.1. *Adults.* One study (Billstedt et al., 2011) reported occupational activities were not associated with QoL of adults with ASD ($N = 108$), but one study (Garcia-Villamizar, Wehman, & Navarro, 2002) reported there was a positive relationship between participation in supported work and QoL of adults with ASD ($N = 51$). The number of the participants in the studies reporting no relationship between occupational activities and QoL was higher than that in the studies reporting the existence of a relationship between occupational activities and QoL.

3.2.11.2. *Children.* No study had examined the relationship between occupational activities and QoL in children with ASD.

3.2.12. *Comorbid psychiatric conditions*

3.2.12.1. *Adults.* One study (Kamp-Becker et al., 2010) reported there was no relationship between receiving psychopharmacotherapy and QoL of adults with ASD ($N = 26$).

3.2.12.2. *Children.* Two studies (Kose et al., 2013; Sikora et al., 2012) reported that having comorbid psychiatric conditions was negatively associated with QoL of children with ASD ($N = 3168$).

3.2.13. *Residential status*

3.2.13.1. *Adults.* One study (Billstedt et al., 2011) reported that residential status was not associated with QoL of adults with ASD ($N = 108$), but two studies (Gerber et al., 2008, 2011) reported residential status was associated with QoL of adults with ASD ($N = 56$). The number of the participants in the studies reporting no relationship between residential status and QoL was higher than that in the studies reporting the existence of a relationship between residential status and QoL.

3.2.13.2. *Children.* No study had examined the relationship between residential status and QoL in children with ASD.

4. Discussion

Having a good QoL is critical for all persons, including individuals with ASD. Improved QoL is considered an important treatment outcome for individuals with ASD (Kamio, Inada, & Koyama, 2013). In order to improve QoL of individuals with ASD, we will need to know the factors associated with their QoL. This study reviewed the studies focusing on QoL of individuals with ASD published between 1994 and 2013 and synthesized the results in terms of the overall QoL and the factors associated with the overall QoL in individuals. The findings from this review study are discussed below.

4.1. *QoL of individuals with ASD*

The prevalence of ASD has increased dramatically in the past 20 years since pervasive developmental disorders (PDD) were first included in DSM-IV in 1994. Our understanding of the characteristics of people with ASD and the education and support services provided to them have been improved in the last 20 years. Thus, it may be assumed that the positive changes in the last 20 years have enhanced QoL of individuals with ASD and we can see many people with ASD now have good QoL. However, this study found that the majority of the participants in the studies for this review did not have good QoL, especially children with ASD. It seems that the positive changes in the support services provided to individuals with ASD in the past do not result in positive changes in their QoL. This suggests a need for more empirical QoL studies for individuals with ASD.

The majority of the participants with ASD for this study lived in USA but they did not have good QoL. The individuals with ASD who had been reported to have good QoL lived in Sweden and Switzerland. Although it was not possible to do cross country comparisons in this study, the different QoL findings from different countries may suggest a need to understand the different support services for individuals with ASD across countries and how different countries perceive QoL.

4.2. *Factors associated with QoL*

Although the majority of the participants for this study did not have good QoL, some did. Learning the factors associated with QoL of individuals with ASD may provide critical information to policy makers and practitioners to improve QoL of these individuals.

4.2.1. *Factors associated with QoL of adults with ASD*

Behavior problems and leisure activities were associated with QoL of the majority of the adults with ASD. The more behavior problems an adult with ASD had, the poorer the QoL he or she could have. Interpersonal relationship is one of the

core QoL domains (Schallock, 2004), but behavior problems could disrupt social relationships (Kamio et al., 2013). The finding about the relationship between behavior problems and QoL suggested that QoL of the adults with ASD could be enhanced by having adults with ASD receive appropriate interventions to decrease their behavior problems. Participation in leisure activities was positively associated with QoL of adults with ASD. Leisure is one of the indicators of the QoL physical well-being domain (Schallock, 2004). Participation in leisure activities improves one's physical well-being. The finding about participation in leisure activities suggested the importance of providing leisure activities to adults with ASD and allowing the opportunities for these adults to participate in such activities.

Autism severity, IQ, adaptive behavior, support, occupational activities, comorbid psychiatric conditions, and residential status were not related to QoL of adults with ASD. The finding about the relationship between disability related factors (e.g., autism severity, IQ, adaptive behavior) and QoL seemed to confirm the hypothesis proposed by Renty and Roeyers (2006) that QoL of adults with ASD is not mainly determined by the disability severity. Thus, we may not assume that adults with milder autism severity, higher IQ and higher adaptive behavior have better QoL than those with more severe autism, lower IQ and lower adaptive behavior.

The differences in QoL across different types of support (e.g., day center, educational center, work scheme, residence, family relief, home support) and the size of social networks were examined in the study by Saldana et al. (2009) and they found that no difference existed in QoL across adults with ASD receiving different support services and across adults with ASD having different sizes of social networks. These findings seemed to suggest that no particular support could produce better QoL outcome in adults with ASD. Given that different adults with ASD may have different needs, a wide range of support services should be available to them. In addition to the type of support services, the quality of the support services may have influence on QoL of adults with ASD. However, the quality of the support services had not been examined by Saldana et al. (2009). Future studies may want to examine the relationship between the quality of support services and QoL in adults with ASD.

Participation in employment is critical in improving QoL of individuals with ASD (Stodden & Mruzek, 2010). Some adults with ASD have participated in employment but others do not (Chiang et al., 2013). It is generally believed that the adults who have jobs have better QoL than those who do not. However, surprisingly, the findings from this study suggested that there was no difference among the adults with ASD who participated in school work, supported work, activity center, or no activity (Billstedt et al., 2011) although the adults who participated in supported work program showed better QoL than did those who participated in sheltered workshop program (Garcia-Villamisar et al., 2002). These findings seemed to suggest that the relationship between job and QoL in adults with ASD was more complicated than what we had generally believed. Simply placing adults with ASD in to a work placement may not result in improving their QoL. The quality of the work, whether the work corresponds to their interests, and salary and benefits may influence their QoL.

Various residential options (e.g., parents' home, community-based group homes, apartments with community-based support, own apartment with occasional help from relatives) are available to adults with ASD. Various factors (e.g., culture, financial support, independent living skills, one's own preference) may affect their housing decisions. The finding of this study suggested that no particular housing could produce better QoL outcome in adults with ASD. Given that different adults with ASD may have different housing needs and the quality of housing may be varied across different available housing options, a wide variety of housing options should be available to adults with ASD.

Finally, age, social communication skills, gender, and education factors were not examined by the studies in this review. Future studies may be interested in determining if these factors are associated with QoL of adults with ASD.

4.2.2. *Factors associated with QoL of children with ASD*

Age, behavior problems, social communication skills, adaptive behavior, education, and comorbid psychiatric conditions were associated with QoL of the majority of the children with ASD in this study. Age was negatively associated with QoL of children with ASD. The older a child was, the poorer the QoL he or she could have. This finding suggested the need for adjusting the support services provided to children with ASD across different age levels. As children with ASD grow older, they may experience different difficulties and changes (e.g., transitioning from one school to another, having different therapy hours, having different teachers, building friendships) and have different needs. Thus, the support services for them should be tailored to meet their different needs at different age levels.

The relationship between behavior problems and QoL in children with ASD was the same as that in adults with ASD. Thus, addressing behavior problems in individuals with ASD is critical to improve QoL of individuals with ASD. Social impairment was negatively associated with QoL of children with ASD (Kuhlthau et al., 2010). The higher the social impairment a child had, the poorer the QoL he or she could have. Thus, having children with ASD participate in social skills interventions may not only improve their social skills but also QoL. Adaptive behavior was positively correlated with QoL of children with ASD. The higher the adaptive behavior a child had, the better the QoL he or she could have. This finding suggested that the educational services for children with ASD should aim to improve these children's adaptive behaviors. It is interesting to note that there was a relationship between adaptive behavior and QoL in children with ASD but there was no such relationship in adults with ASD. Adaptive behavior refers to the skills needed for an individual to perform daily activities and it becomes more complex as he/she grows older (Sparrow, Cicchetti, & Balla, 2005). Having adequate adaptive behavior is important for children and adults with ASD. However, having good adaptive behavior was not associated with good QoL in adults with ASD. This finding may suggest that the factors other than personal characteristics (e.g., financial support, environment adaption, housing arrangement, family support) have more influence on QoL in adults with ASD.

Children with ASD in the U.S. who have individualized education programs (IEP) receive free special education and related services under the Individuals with Disabilities Education Act (IDEA). However, different countries may have different educational systems and services provided to children with ASD. The study conducted by Kose et al. (2013) in this review found that the children with ASD who did not continue special education showed better QoL than did those who did. The children who did not continue special education in the study by Kose et al. (2013) were those who did not have severe autism symptoms and those who continued special education were the children with severe autism symptoms. These findings seemed to suggest the importance of having children with ASD receive general education. For children without severe autism, receiving general education may improve their QoL.

Finally, having comorbid psychiatric conditions was negatively associated with QoL of children with ASD. Thus, in order to improve QoL in children with ASD, the treatments for psychiatric conditions should be available to the children who may need this.

Leisure activities are important to everyone across different age levels. Students with ASD receive different types of job training at the high school level. However, the studies recruited for this review had not examined the relationship between participation in leisure activities and QoL and the relationship between participation in occupational activities and QoL in children with ASD. Future studies may be interested in exploring these relationships.

5. Limitations

Several limitations of this study should be addressed. First, it was not possible to conduct a meta-analysis to examine the level of QoL in individuals with ASD and to determine the factors associated with QoL due to different QoL measures used in the studies recruited for this review. Second, due to the review nature of this study, it was not possible to investigate possible compound effects of two or more factors associated with QoL of individuals with ASD or the factor(s) that may explain more amount of variance in QoL. Third, given that the purpose of this review study was to synthesize the level of QoL reported by previous studies, the QoL reported in this study refers to the overall QoL but not a particular domain/area of QoL. The factors associated with QoL were also for the overall QoL. Fourth, this review included studies published in different countries. Although it might be interesting to see the QoL differences across different countries, it was not possible to compare country differences since different QoL measurements were used across different studies. Fifth, to identify the factors associated with individuals with AD, AS, and PDD-NOS separately was beyond the scope of this study. Sixth, only a small number of the studies had asked individuals with ASD to assess their QoL directly and many studies had asked family members or other people who had known these individuals to assess their QoL. Thus, the quality of the QoL data might be varied across different data collection methods. Last, it should be noticed that the studies recruited for this review had quantitatively evaluate total/overall QoL in QoL of individuals with ASD. However, the contents of the QoL measurements used in these studies might be different and the differences in the QoL measurement contents might be due to cultural differences.

6. Conclusion

“An enhanced quality of life (QoL) is a realistic and obtainable goal for all persons” (Schalock, 2004, p. 203). However, the majority of the individuals with ASD do not have good QoL. Limited studies have been conducted to investigate the factors associated with QoL of individuals with ASD. In order to improve QoL of these individuals, we will need to know what factors have positive influence on QoL. Given that limited studies have been conducted to identify these factors, more studies should be conducted. The findings of this study may provide direction for future studies and may suggest important information for parents and practitioners.

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