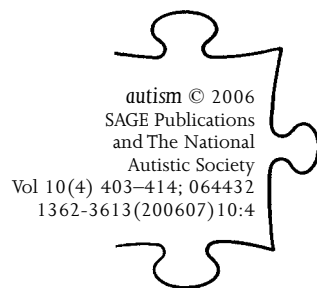


The quality of life of young men with Asperger syndrome

A brief report



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ABSTRACT Factors influencing quality of life for persons with Asperger syndrome are not yet understood. Men, ages 18 to 21, completed the World Health Organization Quality Of Life measure, the Perceived Support Network Inventory, and a semi-structured interview. Asperger syndrome affects quality of life beyond the obvious social impact. The 12 men with Asperger syndrome reported a significantly lower social and physical quality of life than did the 13 men in the control group. Education, living arrangements, and number of friends were remarkably similar between groups. Those with Asperger syndrome had less positive employment experiences and showed more preference for solitary activities. Interventions need to be based on a holistic model.

KEYWORDS
Asperger syndrome;
quality of life;
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Asperger syndrome occurs in around 2 per 10,000 people (Fombonne, 2001) and is characterized by difficulties in social relationships and restrictive and repetitive patterns of behaviours, interests and activities (American Psychiatric Association, 2000). The impact of the syndrome in adulthood on outcomes such as work or school functioning and individuals' social lives needs study. In determining outcome, the interaction of the environment and the person needs to be considered (Dalrymple and Ruble, 1996). The environment supplies protective factors such as supports and adaptations that counterbalance risk factors such as personal and environmental challenges. Outcome studies need to consider a person's subjective quality of life and the effects of environmental variables that could be altered by intervention.

Studies of functioning in adulthood have begun to appear. Most individuals with Asperger syndrome or autism rely heavily on the support of their families and remain highly dependent (Dalrymple and Ruble, 1996; Engstrom et al., 2003; Howlin, 2000). Employment is disappointing (Engstrom et al., 2003; Goode and Howlin, 1998). Jobs are low status and/or end prematurely, often because of social difficulties (Mawhood and Howlin, 1999). The failure to use training and skills, or to find suitable work, results in frustration, loss of self-esteem and for some, a cycle of anxiety and depression or other psychiatric disturbance (Howlin, 2005). With supported employment, individuals can find and maintain suitable employment (Mawhood and Howlin, 1999).

According to Tantam (1991), the effects of Asperger syndrome are greatest in adolescence and young adulthood. This transition period includes completing school, finding work, developing a social network, contributing to a household, and participating in a community (Collins et al., 2000). It is during this transition period that individuals with Asperger syndrome frequently suffer from mental health problems such as depression and anxiety (Kim et al., 2000; Stoddart, 1999). The quality of life and social support of persons with Asperger syndrome during this transition period has not received systematic study (Dalrymple and Ruble, 1996). Quality of life is defined as a person's position in relationship to his/her context and goals and is affected by 'physical health, psychological state, level of independence, social relationships, and relationships' to the environment (World Health Organization Quality of Life Group: WHOQOL Group, 1998, p. 551). Perceived social support, a multidimensional concept (McCull, 1997), is positively correlated with wellbeing among adults and adolescents (Cause et al., 1994; Dalrymple and Ruble, 1996).

Socially, individuals with Asperger syndrome continue to have marked difficulties at follow-up (Alisanski et al., 2000; Engstrom et al., 2003). Howlin et al. (2004) found that few adults marry and only 15 to 20 percent had friendships with shared enjoyment. Social contacts often result from special interests and skills rather than close friendships (Howlin, 2000), which may limit social support. Some individuals take refuge in routines and private preoccupations (Tantam, 2000), leaving them further isolated.

To further explore these areas, this study:

- 1 compared the quality of life of young men with and without Asperger syndrome
- 2 examined differences in the perceived support network
- 3 described independence, friendship and dating relationships, and leisure activities.

Methods and procedures

Participants were recruited from the Koning and Magill-Evans (2001) sample of 29 adolescents with a diagnosis of Asperger syndrome. This homogeneous sample is relatively unique among outcome studies, as high-functioning individuals with autism were not included and persons with Asperger syndrome were matched to 28 persons without the syndrome.

Participants

The current 12 participants with Asperger syndrome had been diagnosed with Asperger syndrome as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV: APA, 1994) by four paediatric psychiatrists. To verify the diagnosis, the referring psychiatrist completed the Ehlers and Gillberg (1993) checklist for screening of Asperger syndrome on each participant. Scores ranged from 28 to 42 out of a possible 54 ($M = 34.00$, $SD = 4.58$). Boys diagnosed with psychosis at any time were excluded.

The 13 participants without Asperger syndrome were matched to previous participants with Asperger syndrome on the basis of age and Wechsler Intelligence Scale for Children—Third Edition (WISC—III: Wechsler, 1991) vocabulary test scores. Teachers identified students who spoke English as a first language and had average social skills and peer relationships but were not particularly socially skilled.

Six years after the initial study, 32 participants from the prior sample did not participate. One, a control, was in a serious accident after agreeing to participate; six refused (three AS); three did not respond to calls (one AS); and the remainder were untraceable. Participants did not differ from non-participants on socioeconomic status, age, or Asperger syndrome screening questionnaire scores. Thus, the current sample is representative of those in the original study.

The mean age of participants with Asperger syndrome was 20.3 years ($SD = 1.3$) and that of participants without Asperger syndrome was 20.5 years ($SD = 1.3$). There were no significant differences between groups for prior WISC vocabulary scores, $t(1, 23) = 0.99$, $p = 0.33$, though the group with Asperger syndrome had a lower mean, 10.33 ($SD = 3.6$) versus 11.62 ($SD = 2.8$). Overall, 64 percent of the sample lived in communities with a population greater than 30,000 while 36 percent lived in smaller urban or rural settings. Most were white. The Health Research Ethics Board approved the study and all participants gave consent.

Measures

Two self-administered mailed questionnaires and a semi-structured interview were used for data collection. Questionnaires were collected at the

time of the interview. The WHOQOL–Brief Version (WHOQOL Group, 1998) is suitable for a range of diagnoses and ages (Couston et al., 2000). Scored on a five-point scale, the 24 items form four domain scores (physical health, psychological health, social relationships and environmental) with three to eight items per domain. Two additional questions address overall quality of life and health. Higher scores indicate better quality of life. Cronbach alphas ranged from 0.66 (social) to 0.84 (physical). Test–retest reliabilities ranged from 0.66 (physical) to 0.87 (environment). The reading level is grade 5.1. The measure discriminated between persons with and without somatic and psychiatric diseases (Angermeyer et al., 2001). Correlations between the WHOQOL–BREF and three quality of life measures ranged from 0.04 (social) to 0.80 (physical) (Melbourne WHOQOL Field Study Centre, 2002).

The Perceived Support Network Inventory (PSNI) (Orritt et al., 1985) measures network characteristics, perceptions regarding social support, and support seeking activities. Respondents name up to 12 people that they would turn to in times of stress and sort the individuals into relationship categories such as family member, friend, or co-worker. Each person named is rated on a seven-point Likert scale addressing initiation of support, perceived availability of support, satisfaction with support, support reciprocity, perceived conflict, and perceived multidimensionality. Test–retest reliability was 0.88 for the total PSNI score and 0.72 to 0.87 for the subscales with internal consistency of 0.60 to 0.77. Correlations related to construct validity ranged from 0.21 to 0.57. The reading level of the PSNI with simplified instructions was grade 8.5.

There were concerns about using only self-report measures of variables such as friends because others (Barnhill et al., 2001; Koning and Magill-Evans, 2001) have found that persons with Asperger syndrome rate their social skills higher than do their parents and teachers. Therefore, a semi-structured interview was used to probe for complete information. The interview addressed level of independence, leisure activities, and social relationships. Information about income can be viewed as a more objective measure of quality of life. The semi-structured interview was pilot tested on five persons.

Procedures

Most participants were interviewed in their homes for 30 to 130 minutes. As some participants lived in remote areas, phone interviews were done with six young men, four with and two without Asperger syndrome. The interviewer was blind to diagnosis but behaviour during the interview often suggested challenges consistent with the syndrome. To limit bias, all interviews were recorded. A research assistant who was unfamiliar with

Asperger syndrome randomly rated four (16 percent) interviews. Inter-rater reliability using double coding of the information obtained during the interviews was $r = 0.97$. Data were analysed using the Statistical Package for Social Sciences (version 11.0).

Results

Quality of life scores for persons with Asperger syndrome were more variable in the physical domain ($SD = 15.0$ versus 6.2) (see Table 1) and were not included in the multivariate analysis of variance (MANOVA). The MANOVA with four dependent variables, $F(4, 20) = 4.04$, $p = 0.02$, effect size = 0.45 , power = 0.83 indicated that young men with Asperger syndrome rated their quality of life lower than did young men without Asperger syndrome. Scores were significantly lower for the social domain, $F(1, 23) = 12.22$, $p = 0.002$, effect size = 0.35 , power = 0.92 , with no significant differences for the other scores. A t -test for unequal variances indicated that persons with Asperger syndrome had significantly lower scores on physical health, $t(1, 23) = 3.18$, $p = 0.006$, effect size = 1.33 .

Total social support scores, obtained by adding the mean subscale scores, were not significantly different between groups, $t(1, 23) = 1.16$, $p = 0.27$, effect size = 0.52 , although persons with Asperger syndrome had lower and more variable scores: $M = 26.2$ ($SD = 9.5$) versus $M = 29.5$ ($SD = 3.3$). Therefore, the subscales were not analysed separately. Network composition was remarkably similar except for professionals. For those with Asperger syndrome, as many as two professionals were included in their support network (compared to 0). Total PSNI scores and the overall quality of life item on the WHOQOL-BREF were correlated, $r = 0.54$, $p = 0.005$, suggesting that viewing one's social network as supportive is associated with greater overall quality of life.

Independence was measured by examining education, employment, income, living arrangements, and mobility. There were individuals pursuing

Table 1 Quality of life scores

	Participants with AS			Participants without AS		
	<i>M</i>	(<i>SD</i>)	<i>Range</i>	<i>M</i>	(<i>SD</i>)	<i>Range</i>
Overall	3.7	(0.7)	3–5	4.1	(0.6)	3–5
Physical	65.4	(15.0)	44–88	80.2	(6.2)	69–94
Psychological	61.0	(13.4)	44–88	69.8	(13.9)	44–88
Social	49.5	(23.0)	0–75	78.4	(18.2)	31–100
Environment	67.4	(11.3)	50–88	71.7	(9.6)	44–81

post-secondary education and individuals who had not completed high school even in a modified programme in both groups (see Table 2). Many of the young men with Asperger syndrome described academic problems, often related to social and communication deficits. Many had completed high school, similar to previous research (Howlin, 2003; Myles and Simpson, 2002). Participants reported feeling happier and less stressed once they finished or quit high school. One-third of those with Asperger syndrome were neither working nor going to school, unlike any of the young adults without Asperger syndrome.

Related to employment, most young adults without Asperger syndrome were employed, compared to half of those with Asperger syndrome (see Table 2). Two men in each group were not working as they were students. Two individuals with Asperger syndrome had never had a paid job. Jobs were classified based on the Four-Factor Index of Social Status (Hollingshead, 1975). The job categories were similar, though the jobs of men with Asperger syndrome had fewer social demands and resulted in less income (\$732 versus \$1451 Canadian). The difference was not significant, $t(1, 21)$

Table 2 Education and employment

	<i>Participants with AS</i>	<i>Participants without AS</i>
	<i>N (Total = 12)</i>	<i>N (Total = 13)</i>
Current status:		
University	2	3
College	0	2
High school	1	0
Level of education completed:		
College diploma	0	3
High school diploma	7	8
Finished grade 12 (not enough credits)	2	0
Junior high	3	2
Employment:		
Full-time	3	9
Part-time	3	2
None	6	2
Employment type:		
Semi-professional	0	1
Clerical and sales	0	2
Skilled manual	2	3
Semi-skilled machine operator	2	2
Unskilled	2	3

= 1.84, $p = 0.08$. Two persons with Asperger syndrome received government subsidies as their only source of income.

The living arrangements in both groups were remarkably similar (see Table 3) with a high proportion living with family members. Four men with Asperger syndrome indicated that they were not able to live independently as they could not handle all the tasks needed such as cooking, doing laundry, or managing finances, unlike men without the syndrome.

In terms of social relationships, the number of close friends was very similar (Table 3). However, half of the men with Asperger syndrome had never dated and only two (17 percent) were currently dating. Social problems were the main reason cited for lack of success in developing intimate relationships. The association of group and dating history was not significant, $\chi^2 (N = 25) = 2.50, p = 0.11$.

For leisure activities, the groups were very similar (Table 4) in their participation in organizations or volunteer groups. Men with Asperger syndrome spent significantly more time in leisure ($M = 39.9, SD = 21.8$) compared to those without Asperger syndrome ($M = 24.8, SD = 10.0$), $t(1, 23) = -2.26, p = 0.04$, which reflects differences in employment. Persons with Asperger syndrome spent their time watching TV and movies, surfing the Internet, playing video games, and reading. Those without Asperger syndrome engaged in a variety of sports. Both groups watched movies, played video games, went to bars and spent time with friends.

Table 3 Living arrangements, friends, and dating

	<i>Participants with AS</i>	<i>Participants without AS</i>
	<i>N (Total = 12)</i>	<i>N (Total = 13)</i>
Living arrangements:		
Living by himself	1	1
With partner	0	1
Friends/roommates	2	3
Family	9	8
Number of close friends:		
None	2	1
Between 1 and 3	5	5
Between 4 and 6	3	5
More than 7	2	2
Dating:		
Yes	2	6
No	4	5
Never	6	2

Table 4 Leisure activities

	<i>Participants with AS</i>	<i>Participants without AS</i>
	<i>N (Total = 12)</i>	<i>N (Total = 13)</i>
<i>Leisure preference:</i>		
Primarily social activities	1	10
Social and solitary	4	1
Primarily solitary activities	7	2
<i>Participation in volunteer group:</i>		
Yes	3	1
Previously but not current	5	7
Never	4	5

Eleven of the men without Asperger syndrome did activities primarily with friends, compared to six men with Asperger syndrome, $\chi^2 (N = 25) = 11.92, p = 0.003$.

Discussion

This study provides a snapshot of 12 men with Asperger syndrome during the early stages of their transition to adulthood. The results were very encouraging because there are a number of similarities between the young men with and without Asperger syndrome in areas such as living arrangements, education, social support, number of close friends, and overall quality of life. However, there were significant differences which were both anticipated and unanticipated.

Surprisingly, young adults with Asperger syndrome were less satisfied with their physical health. The physical domain included pain and discomfort, dependence on medical treatment, activities of daily living, work capacity, energy and fatigue, mobility, sleep and rest. The results may relate to clumsiness of movements or to sensory hypersensitivity. Deficits in motor skills are common in individuals with Asperger syndrome (APA, 2000; Baird et al., 2002; Cichetti et al., 1995) though estimates of prevalence are not available (Ghaziuddin et al., 1992; Szatmari et al., 1989; Tantam, 1991). The implications of such deficits are significant. Being clumsy limits participation in games during school years, exacerbating social deficits, and interferes with school activities, such as handwriting, art, and industrial arts. Participants in this study apologized for their 'bad' or 'messy' handwriting and indicated that this was a major concern during school. For some, labour-type jobs (e.g. assembly worker) were difficult due to coordination challenges. A few refused to learn to drive, as they

knew that their 'clumsiness' would limit their performance. Thus, clumsiness may be related to their ratings of physical health items such as work capacity and activities of daily living.

Sensory hypersensitivity is common in persons with Asperger syndrome (Alisanski et al., 2000; Dunn et al., 2002) and may have influenced their scores on physical health. Grandin (1995) argues that noise sensitivity and over-sensitivity to touch cause many behavioural problems and influence energy levels, sleep, and the capacity to work. Dunn et al. (2002) compared 42 children with and without Asperger syndrome. Parents of those with Asperger syndrome reported impairments in physical endurance and muscle tone, oral sensory sensitivity, distractibility and inattention, and problems regulating responses to sensory stimuli. Sensory sensitivity might have influenced participants' responses to items such as pain and discomfort, work capacity, energy and fatigue, and sleep and rest.

The extent, severity, and impact of clumsiness and sensory hypersensitivity need further investigation. Clumsiness and sensory hypersensitivity may decrease motivation to participate in physical activities, which in turn contributes to less optimal physical health. Other factors such as side effects of medication and other comorbid health issues also need to be explored.

Young men with Asperger syndrome reported a significantly different social and physical quality of life. Clearly, these men are aware of their social skills deficits and perceive an impact on their quality of life. Only half of the 12 young men with Asperger syndrome had dated. The interviews indicated that a lack of necessary skills was the most common reason these young men gave for not dating, similar to the findings of others (Nordin and Gillberg, 1998; Tantam, 1991). Efforts in the social area are still needed.

All but three of the young men with Asperger syndrome were educated in mainstream settings and completed high school, yet their unemployment rates were high (50 percent) compared to adult males in Alberta where only 4.7 percent were unemployed (Statistics Canada, 2001). Employment rates were in keeping with other studies of adults with Asperger syndrome and autism spectrum disorders (Bernard et al., 2001; Engstrom et al., 2003; Howlin et al., 2004) and similar to Canadians with a 'moderate' disability (Statistics Canada, 1995). For those working, the type of employment was in keeping with that of young men of a similar age, although those with Asperger syndrome were working at jobs requiring less social demands.

This study had limitations such as a small sample and a low level of power. While there were no apparent differences between those with Asperger syndrome who did not participate or could not be located and those who did, the groups may differ on other parameters that influence

quality of life such as mental health problems and family circumstances. The findings are exclusively based on self-perceptions with probes for detailed information to decrease overly positive or exaggerated responses. Future research that includes parents could verify the information but seems inappropriate for young adults. There was no confirmation that the persons with Asperger syndrome continued to meet the criteria for Asperger syndrome.

In summary, Asperger syndrome has an impact on quality of life. The physical and the social domain should be addressed to enhance quality of life and allow individuals to successfully participate in meaningful, age-appropriate activities. Intervention goals must shift from survival-oriented behaviours to more sophisticated abilities so that individuals are better able to share feelings and ideas with social partners leading to more satisfying, supportive and intimate relationships. Persons with Asperger syndrome are often seen in mental health settings where interventions focus on social or psychological challenges with little regard for physical functioning. Assessing motor skills, physical fitness, and sensory issues could help in selecting appropriate jobs. One young man wanted professionals to spend time educating potential and existing employers on ways to deal with or avoid problems, resulting in less stress in the workplace and better performance. There is a need to consider the impact of the syndrome within a holistic model of practice.

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