Psychotropic medication use among adolescents and young adults with an autism spectrum disorder: Parent views about medication use and health care services

Johanna K. Lake, Ph.D.[1,2*]

Vanessa Vogan, M.A. [1,3]

Amanda Sawyer, M.D. [1,2]

Jonathan A. Weiss, Ph.D., C. Psych.[4]

Yona Lunsky, Ph.D., C. Psych.[1,2]

[1] Centre for Addiction and Mental Health

[2] Department of Psychiatry, University of Toronto

[3]Department of Applied Psychology and Human Development, Ontario Institute for Studies in Education

[4]Department of Psychology, York University

*Corresponding author: Johanna K. Lake, Dual Diagnosis Service, Centre for Addiction and Mental Health, 1001 Queen St. W., Unit 4-3, Toronto, ON M5V 2B4 Canada; phone: (416) 535-8501 x37823, fax: (416) 603-9120; johanna.lake@camh.ca

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Abstract

Objectives: Psychotropic medications are frequently used to treat mental health and behavioral issues in adolescents and adults with an autism spectrum disorder (ASD). Although parents of individuals with ASD frequently take on medication management for their child, there is limited literature on parent *perspectives* of their child's medication use or their views about the health care services they receive, particularly in adulthood. The current study examined and compared parents of adolescents and of young adults with ASD on their child's psychotropic medication use and their views about health care services. **Methods:** One hundred parents of adolescents and young adults with ASD (ages 12-30 years) completed an online survey about their experience with their child's health care services and medication use. **Results:** Parents of young adults were less likely to use non-pharmacological services before using a psychotropic medication compared to parents of adolescents. Parents of young adults were also less likely to believe their prescribing health care provider had adequate expertise in ASD and were less satisfied with how their prescriber monitored their child's medication use. **Conclusion:** Findings highlight the need to build capacity among health care providers supporting individuals with ASD as they transition into adulthood. There is also a need for improved medication monitoring and increased awareness of the different mental health challenges individuals with ASD encounter as they age.

Key words: autism spectrum disorder; psychotropic medication; young adults; adolescents; health care provider, parent experiences

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Individuals with an autism spectrum disorder (ASD) are frequently prescribed psychotropic medications (Coury et al. 2012; Hsia et al. 2013; Logan et al. 2012; Memari et al. 2012; Rosenberg et al. 2010; Schubart et al. 2013; Spencer et al. 2013), with over three quarters taking psychotropic drugs by the time they reach adulthood (Esbensen et al. 2009; Spencer et al. 2013). Despite their widespread use, literature on psychotropic medication use in adolescents and young adults with ASD remains limited. Of the few studies conducted to date, most have examined medication rates or associated demographic and clinical variables (Coury et al. 2012; Esbensen et al. 2009; Lake et al. 2012; Lake, Weiss, Dergal and Lunsky, in press; Spencer et al. 2013), but not the *experience* of using medication, such as knowledge about or satisfaction with medication monitoring.

Associated mental health issues, and deficits in social, communicative and cognitive functioning often impede individuals with ASD from managing their own health care (Bruder et al. 2012). Consequently, the responsibility for coordinating and managing health care and service provision for their adolescent or adult child, including medication use, frequently falls on parents or other caregivers (Bruder et al. 2012; Carbone et al. 2010; Howlin et al. 2004; Levy and Perry 2011). Despite this, the little we know about parent perspectives regarding their child’s health care and medication use comes from studies of children. Generally, this literature suggests that parents are dissatisfied with the health care services that their child receives (Carbone et al. 2010;

Harrington et al. 2006; Kogan et al. 2008; Liptak et al. 2006; Mackintosh et al. 2012; Mitchell and Hauser-Cram 2008).

We know even less about parent perspectives as individuals with ASD enter adulthood, when the needs of patients and families may change (Graetz 2010). This transition can be particularly challenging for individuals with ASD, not only in terms of physiological changes, but also because of possible changes to residence, education, and employment. Additionally, young adults may encounter significant changes in service eligibility or accessibility, and some adults may no longer be eligible or have access to funded non-pharmacological services or supports. For example, adolescents access services through children's services and the school system, whereas young adults receive services within the adult system. Further, young adults must move from the pediatric to the adult health care system, where access to health care professionals and trainees who have the capacity and expertise to care for individuals with ASD is sparse (Bruder et al. 2012; Cheak-Zamora et al. 2013; Marrus et al. 2014). Lastly, medication efficacy, tolerability, and the reason(s) for prescribing medication or the individual's psychiatric presentation, may also differ between the two groups. For these reasons, there is a clear need to better understand the unique experience of medication use among transitioning youth with ASD, and how these experiences differ from younger adolescents.

In the only study to examine parent perspectives on psychotropic medication use among adolescents and adults with ASD, we identified a number of key concerns related to medication use and prescribing health care providers (Lake, Milovanov, Sawyer and Lunsky, in press). Specifically, our qualitative study found that parents voiced concerns about side effects and medication efficacy, as well as concerns related to the low frequency and lack of standardization of medication monitoring. Parents also commented on the need for prescribers with expertise in ASD, and for a better integrated system with enhanced communication among health care professionals and an interdisciplinary approach to treatment. While findings represent an important first step on this topic, quantitative research is needed to follow up this qualitative, exploratory study more systematically, and with a larger cohort of individuals (Goering and Streiner 1996).

The current study adds to the limited literature on parent perspectives of psychotropic medication use among adolescents and young adults with ASD, and expands previous qualitative work using a larger, more diverse sample, divided into two subgroups: one of adolescents and the other of young adults with ASD. Our specific study objectives include: 1) to describe and compare the number and type of medications prescribed in the two groups; and 2) to describe and compare parent perspectives of their adolescent or young adult child's medication use (i.e., reason for medication prescription, comfort with medication use, medication side effects, and medication efficacy) and parent perspectives regarding health care services received (i.e., expertise issues, use of previous services prior to medication use, satisfaction with medication monitoring, availability and accessibility of non-pharmacological services).

Methods

The analyses reported here are part of a larger project examining health service utilization patterns among individuals with ASD. Participants were recruited across Ontario through flyers, websites, and announcements targeted at relevant support groups, recreational programs, community agencies and schools. Efforts were made to reach families living in all regions of the province, including remote and rural settings where individuals may be marginalized economically or geographically. Parents from this larger project who noted that their child had been prescribed psychotropic medication (*n*=363), were invited to participate in a follow-up survey. Parents were deemed eligible if they had a child with ASD between 12 and 30 years of age who was currently prescribed at least one psychotropic medication. Of the 363 parents contacted, 113 parents completed the follow-up survey. Two of these parents had a child under the age of 12, and 11 did not have a child who met the recommended Social Communication Questionnaire (SCQ; Rutter et al. 2003) research cut-off score of ≥12 (Brooks and Benson 2013). As a result, 13 parents were excluded from our analysis resulting in a final sample size of 100 participants. Respondents were not paid to complete the survey, and participants understood that their responses would be linked to their longitudinal data. Individuals with ASD were classified as adolescents if they were between 12 and 18 years of age, and young adults if they were between 19 and 30 years.

Participants

Adolescents with ASD (*n*= 55) had a mean age of 15.45 years (*SD*= 1.68), and young adults (*n*= 45) a mean age of 22.2 years (*SD*= 3.17). Parents had a mean age of 45.74 years (*SD*=6.13) and 52.3 years (*SD*= 4.78), respectively. No significant differences were identified among adolescents and young adults in terms mean SCQ score. Over three-quarters of adolescents and young adults with ASD were male, most were Caucasian, and almost all were living with family (Table 1). No significant group differences were observed in terms of gender ratios, ID status, rates of medical or psychiatric comorbidity, residence, or ethnicity. Compared to young adults, more adolescents were engaged in structured daytime activities, likely because they were still attending mandatory schooling.

Materials/Procedure

Background and socio-demographic characteristics, along with information about the child's medication use and experience with prescribing health care providers, were all obtained via an online survey. This included information on medication and side effects; parent comfort regarding their child's medication use; satisfaction with prescriber medication monitoring; and access to and satisfaction with prescribing health care providers. Survey development was informed by findings obtained from a focus group of seven parents with an adolescent or adult child prescribed psychotropic medication (see "Author" under review, for further detail on the focus group). During this previously conducted focus group, parents discussed their experience with medication use and interactions with prescribers. Emergent themes from the group helped frame the final version of the current survey and also formed the basis of subsequent analyses in the present study. Prior to launching the survey, measures were piloted among participants of the focus group and adapted accordingly. The final version of the survey took approximately 20 minutes to complete and could be completed online or by phone. All parents provided informed written consent after being provided with a detailed description of the study. This study received ethics approval through the relevant institution's institutional review board.

Study Variables

Demographic and Clinical

The following demographic and clinical variables were examined at the descriptive level: gender, intellectual disability status (ID), ethnicity, residence, structured daily activity, medical comorbidity, psychiatric comorbidity, body mass index (BMI) and ASD severity**.** Individuals were classified as having ID if parents indicated that their child had a diagnosis of mild, moderate, severe, or profound ID. ASD symptom severity was measured using the SCQ (Rutter et al. 2003), a validated parent-report instrument of autism severity. The SCQ consists of 40 items, based on the Autism Diagnostic Interview-Revised (ADI-R), which has demonstrated validity (Chandler et al. 2007; Howlin and Karpf 2004; Witwer and Lecavalier 2007) and good internal consistency, with Chronbach alphas ranging from 0.81-0.93 (Naglieri and Chambers 2009). Information on BMI was obtained through parent reported child height, weight, and pant size/waist circumference.

Medication and Side Effects

Medications were categorized into the following 11 medication classes for standard use: a) Psychotropic medications: antidepressants, anxiolytics, atypical antipsychotics, typical antipsychotics, stimulants, mood stabilizers, and b) Non-psychotropic medications: anticonvulsants, antihypertensives, medications for gastrointestinal issues, medications for sleep issues (e.g., melatonin, zoplicone), and other non-psychotropic medications. Only antihypertensive medications which had evidence for the treatment of hyperactivity, inattention, or impulsivity, such as clonidine or guanfacine, (Arnsten et al. 2007; Posey et al. 2004) were categorized as psychotropic medication, as was done by others (Aman et al. 2003; Lake et al., in press; Langworthy-Lam et al. 2002; Logan et al. 2012). Similarly, the distinction between mood stabilizers and anticonvulsants was made by classifying medications (e.g., valproate and carbamazepine) as mood stabilizers for all individuals who did not have a diagnosis of seizure disorder, as has been done previously (Esbensen et al. 2009; Lake et al. 2012; Spencer et al. 2013). Parents were also asked if their child had experienced side effects as a result of medication use (yes, no, don't know), what side effects their child had experienced (open-ended), and what effect, they felt, medication (s) had on their child's psychological wellbeing (good or mostly good, neutral, bad or mostly bad). Medication side effects were then classified into the following categories: metabolic (e.g., weight gain, increased appetite, increased blood pressure, increased blood sugar), cardiac (e.g., increased heart rate), movement (e.g., muscle stiffness, tics, involuntary movements), fatigue/sleep (e.g., lethargy, somnolence, sedation, nightmares), general neurological change (e.g., headaches, dizziness, disorientation, slowed down, subdued), behaviour change (e.g., mania, fixed thoughts, aggression, anxiety, irritable, depression), serious neurological events (e.g., seizure), endocrine (e.g., lactation, breast growth), dermatological (e.g., acne), gastrointestinal (e.g., constipation, loose bowels, nausea), hematological (e.g., nose bleed, low iron), temperature dysregulation (e.g., heat sensitivity, fever), weight loss, thirst, sexual (e.g., sexual dysfunction), and genitourinary (e.g., urinary retention). Classifications were based on literature on medication side effects (AHFS, 2014; Matson et al., 1998), and side effects were independently verified and coded by two authors (VV, AS).

Parent Views about Medication

We examined the following variables regarding parents' views about medication: reason(s) for medication prescription (targeted symptoms) and parental ratings of their comfort with medication(s) (comfortable, neutral, uncomfortable). Targeted symptoms were classified into the following four behavior or mental health categories based on parent-report of why their child was prescribed medication: externalizing behaviours (e.g., repetitive, aggressive, oppositional or self-injurious behavior, ADHD symptoms), internalizing problems (e.g., anxiety, depression, bipolar), social issues (e.g., social appropriateness, eye contact, understanding emotional cues), and psychotic disorder (e.g., schizophrenia, schizoaffective disorder).

Parent Views about Health Care Services

We examined the following variables related to parents' views about health care services: prescriber expertise in ASD (yes/no), use of previous supports or services prior to medication use (yes/no), satisfaction with how medication is monitored by prescribing health care provider (satisfied, neutral or dissatisfied), and role of non-pharmacological services (health care provider/school/service suggested medication, no access/availability of non-pharmacological services, non-pharmacological services not/partially working).

Data Analysis

Descriptive statistics were used to describe demographic and clinical information for the sample (numbers and percentages for count data and means and standard deviations for continuous variables). Bivariate analyses were conducted to compare the views of parents of adolescents versus those of young adults with ASD in terms of their child's medication use, the type and number of medications their child was prescribed, and their views about health care services. Statistical analyses were conducted using SPSS version 20.0.

Results

Medication and Side Effects

As shown in Table 2, antipsychotic medications were the most commonly prescribed medication among the total sample (56%), and among adolescents specifically (54.5%). Young adults (68.9%) were significantly more likely to use antidepressant medications than adolescents (41.8%), $\chi^2_{(1)}$=7.3, p=0.007, and adolescents (40.0%) were more likely to use stimulants than young adults (15.6%), $\chi^2_{(1)}$=7.18, p=0.007. Parents of adolescents (85.5%) were significantly more likely to have a child prescribed psychotropic medication for externalizing behaviours compared to parents of young adults (61.4%), $\chi^2(1)$=7.52, p=0.006. Forty percent of young adults used non-psychotropic medications in addition to a psychotropic medication, while only 25% of adolescents used these medications. On average, young adults were prescribed more psychotropic and non-psychotropic medications (M = 2.27) than adolescents (M = 1.91), and almost half of all adolescents (43.7%) and young adults (48.9%) were taking two or more psychotropic medications concurrently.

Parents of adolescents (70.9%) were more likely to report that their child had experienced side effects as a result of psychotropic medication use compared to parents of young adults (48.8%), $\chi^2(2)$=7.27, p=0.003 (Table 4). Specifically, parents of adolescents were more likely to report that their child had experienced weight loss as a side effect of medication use, and although not statistically significant, metabolic side effects were also more common among adolescents (30.9%) than young adults (19.5%) (Table 3), Almost half of the total sample fell in either the overweight (24.4%) or obese (20.0%) BMI category, and nearly one-quarter of parents of young adults reported that they did not know if their child had experienced medication side effects, compared to only 6% of adolescents. Most parents in both groups (adolescents=77.4%; young adults=80.0%) believed medication had a good/mostly good effect on their child's behavior or mental health, and approximately one third of parents of both adolescents and young adults reported that they were comfortable with the medication(s) their child was taking.

Parent Views about Health care Services

Most parents of adolescents (80.0%) and young adults (84.4%) indicated that their child's prescriber monitored their child's medications 2-3 times a year or less. Parents of young adults were less satisfied with how their prescriber monitored their child's medication, $\chi^2(1)=4.48$, $p=0.03$, and were less likely to feel their prescriber had adequate expertise in ASD, $\chi^2(1)=5.14$, $p=0.02$. Compared to parents of adolescents, parents of young adults were also less likely to use previous supports or services before trying medication ($p=0.05$). Finally, almost one-third of adolescents and one-quarter of young adults reported that non-pharmacological services or supports were not or only partially working for behavior or mental health problems (Table 5).

Discussion

This is the first study to examine parent perspectives of their child's psychotropic medication use by comparing the experiences of parents of adolescents to parents of young adults transitioning out of the pediatric health care system. Findings highlight key differences between the experiences of adolescents and their parents and the experiences young adults and their parents. The two groups differed in terms of their medication profiles, medication side effects, satisfaction with care from prescribers, and relative use of other health care services. Differences point to target areas for intervention and opportunities for intervention with youth and their families prior to adulthood.

Consistent with previous studies (Aman et al. 2005; Mandell et al. 2008), the most frequent reason for a medication prescription among adolescents was externalizing behaviours, while internalizing problems were more common among young adults. Medication profiles reflected these differences with stimulant medications more frequently prescribed among adolescents (adolescents=40%; young adults=16%), and antidepressants among young adults (adolescents=42% young adults=69%). Better evidence of the efficacy of antidepressant use in adults with ASD may in part explain this difference (Doyle & McDougle, 2012).

In terms of medication side effects, parents of adolescents were more likely to report that their child had experienced side effects compared to parents of young adults. This finding may reflect differences in the metabolism of specific medications in adolescents versus adults (Ginsberg et al. 2002), but it may also be that with chronic medication use, parents of young adults become less aware of medication side effects compared to parents of adolescents. Another possibility is that the greater number of side effects observed in adolescents is linked to higher stimulant use which is associated with more frequent reports of weight loss and movement abnormalities. In our study, nearly one quarter of parents of young adults reported that they did not know if their child was experiencing medication side effects. The mean number of medications for young adults (2.27) was higher than for adolescents (1.91) in the current study, perhaps making it difficult to discern side effects.

One of the most concerning side effects of medication use is weight gain. In the current study, almost half of all young adults and adolescents were overweight or obese, a finding consistent with studies of young adults with ASD (Eaves and Ho 2008), but higher than what has been reported in studies of children with ASD (Zuckerman et al. 2014). This rate is also more than double the rate among the general adolescent population (Roberts et al. 2012). Similarly, almost one third of adolescents reported metabolic side effects, which is not surprising given that 84% were prescribed antipsychotic drugs. More specifically, 71% of these individuals were prescribed atypical antipsychotic medications (e.g., Risperidone, Olanzapine Aripiprazole, Paliperidone), all medications with known metabolic effects. While medication use is one contributor of obesity, there are a number of other factors that may also contribute, including restrictive eating patterns, motor impairments, cognitive impairments, and medical comorbidities, all common among individuals with ASD (Egan et al. 2013; Zuckerman et al. 2014). Alongside high rates of metabolic side effects, parents of adolescents were more likely to report weight loss or decreased appetite as a result of medication use, however this may be due to greater use of stimulants among adolescents. For these reasons, there is an even greater need for prescribers to monitor for metabolic side effects when prescribing psychotropic medications that have the potential to cause weight gain or loss among individuals with ASD.

In the current study, approximately 80% of individuals using medication had their medication monitored only two to three times a year or less, despite almost half of the sample taking two or more psychotropic medications concurrently. This finding is concerning in the context of recent guidelines for the primary care of persons with developmental disabilities which recommend medication monitoring every 3 months

(Sullivan et al. 2011). Guidelines developed by the National Institute for Health and Care Excellence (NICE; NICE 2012) suggest medication monitoring every two to three weeks during the initiation phase of a psychotropic medication prescription, but do not specify ongoing monitoring requirements. Canadian guidelines for the monitoring of antipsychotic medications recommend monitoring antipsychotic medications every three to six months, and more frequently in vulnerable populations, including individuals with ASD (Cohn and Semyak 2006; McCracken 2005). Individuals with ASD are more sensitive to medication side effects, adding to the need to carefully monitor medication use in this population (McCracken 2005). This may be linked to the finding that some parents were dissatisfied with how their child's medications were monitored. Unfortunately, this problem may be compounded by challenges finding a prescribing health care provider who is comfortable or familiar prescribing and monitoring medications for individuals with ASD, especially in adulthood. Together, findings highlight the need for prescribers to monitor psychotropic and non-psychotropic medications, particularly as individuals with ASD age and may be at greater risk for comorbid conditions and the use of multiple medications.

Compared to parents of adolescents, parents of young adults with ASD were significantly less likely to believe their prescriber had adequate expertise in ASD and also felt less satisfied with how their prescriber monitored their child's medication. This finding is particularly concerning given heightened rates of comorbid psychiatric (Doshi-Velez et al. 2014; Kohane et al. 2012) and medical problems (Bauman 2010; Doshi-Velez et al. 2014; Kohane et al. 2012) among adults with ASD. As individuals age the likelihood of developing a comorbid medical problem increases, and although our sample of adults was relatively young, almost half of them were prescribed non-psychotropic medications in addition to a psychotropic medication prescription. Going forward it will be important to understand *why* young adults are prescribed non-psychotropic medications (e.g., to counteract effect of psychotropic drugs or for health issues), as well as how best to support the complex medical and psychiatric needs of this population.

Findings suggest that the pathway to medication use may be different for parents of young adults compared to adolescents. Not only did the medication profiles of adolescent and young adults with ASD differ, but so did their experiences with health care services. There are a number of possible explanations for these differences – results could be explained by a cohort effect where older parents simply have different experiences than younger parents. It could also be the case that when parents start their child on medication later in life, they are less likely to pursue other services and supports. Or it may be that parents of young adults experience greater difficulty finding and accessing services or supports for their adult child once they are no longer eligible for services funded through the educational or pediatric health care systems. Despite the fact that a number of evidence-based non-pharmacological practices for individuals with ASD exist, including intensive behavior intervention, positive behavior supports, and cognitive behavior therapy (Perry and Condillac 2003), medication may be the only readily available, accessible, and funded treatment option for many young adults. Other studies have shown that there may be barriers to accessing appropriate non-pharmacological services once individuals with ASD reach adulthood (Gerhardt & Lainer, 2011; Shattuck, Wagner, Narendorf, Sterzing & Hensley 2011; Shattuck et al., 2012). Regardless of age, it is important that all individuals with ASD follow guidelines which argue for access to psychosocial interventions prior to medication use for the treatment of mental health issues among individuals with ASD (NICE 2012; Sullivan et al. 2011).

The study is subject to a number of limitations. First, findings are based on parent report data, and we did not have access to corroborating sources to validate diagnoses or medications. However, only individuals with an SCQ score at or above the recommended cutoff (≥12; Brooks and Benson 2013) were included in these analyses. It is possible that some individuals in this study would not meet full DSM-V criteria for ASD; however, previous studies suggest that parent-reported ASD diagnoses produce prevalence estimates comparable to population-based studies using validated medical records or diagnostic tools (CDC 2012, 2013; Kogan et al. 2008). While we recognize that our sample may not be representative of all individuals with ASD, most individuals with ASD tend to reside with their parents well into adulthood (Howlin and Moss 2012), thus findings from parent report surveys have considerable value in understanding adolescents and young adults with ASD. In addition, the authors did not have access to longitudinal medication information. This information could help clarify, for example, the relationship between satisfaction with medication monitoring and medication side effects, efficacy, comfort, or prescriber expertise. Similarly, despite its constraints, a number of studies have used similar survey-based methods to study this population (Blumberg et al. 2013; Mazurek 2013; Mazurek et al. 2011; Montes and Halterman 2007) including the 2011-2012 National Survey of Children's Health (CDC 2013) and the 2011-2012 National Health Interview Survey (CDC 2012).

Conclusions

In the current study, young adults with ASD accessed fewer non-pharmacological supports before trying a medication prescription, and parents felt their prescribers had less expertise in ASD. This may suggest that young adults face particular challenges accessing services and supports once they age out of the pediatric system—a concerning finding given heightened rates of comorbid psychiatric disorders and medication use in adulthood. Given high rates of medication use observed in this population, an important next step will be to identify ways to support and train health care providers in obtaining the expertise to effectively care for these individuals. This will also involve ensuring that medications are prescribed and monitored according to best practice guidelines.

Clinical Significance: This is the first study of adolescents and young adults with ASD to examine parent perspectives of their child's psychotropic medication use and their views about health care services. Findings identified that compared to parents of adolescents; parents of young adults were less likely to access non-pharmacological services and supports prior to initiating a psychotropic medication. Parents of young adults were also less likely to feel their prescriber had expertise in ASD, and were less satisfied with how their child's medications were monitored. This may suggest there are limited non-pharmacological services for young adults with ASD, and also highlight the need to build capacity among clinicians providing care to young adults where there are fewer mental health professionals who feel equipped to provide care to this population.

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References

Aman MG, Lam KSL, Van Bourgondien ME: Medication patterns in patients with autism: Temporal, regional, and demographic influences. J Child Adolesc Psychopharmacol 15:116–126, 2005.

Aman MG, Lam KSL, Collier-Crespin A: Prevalence and patterns of use of psychoactive medicines among individuals with autism in the autism society of Ohio. J Autism Dev Disord 33:527–534, 2003.

American Society of Drug Information: AHFS Drug Information 2014. Bethesda, MD, AHFS, 2014.

Arnsten A, Scahill L, Findling R. Alpha-2 adrenergic receptor agonists for the treatment of attention-deficit/hyperactivity disorder: Emerging concepts from New Data. J Child Adolesc Psychopharmacol 17:393–406, 2007.

Bauman ML: Medical comorbidities in autism: challenges to diagnosis and treatment. Neurotherapeutics 7:320-327, 2010.

Blumberg SJ, Bramlett MD, National Center for Healt1510.h Statistics, Kogan MD, Maternal and Health Bureau, Schieve LA, National Center on Birth Defects and Developmental Disabilities, Jones JR, Lu MC, Maternal and Child Health Bureau: Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011–2012. National Health Statistics Reports 65: 1-11, 2013.

Brooks WT, Benson BA: The validity of the social communication questionnaire in adults with intellectual disability. Res Autism Spect Dis 7:247-255, 2013.

Bruder MB, Kerins G, Mazzarella C, Sims J, Stein N: Brief report: The medical care of adults with autism spectrum disorders: identifying the needs. J Autism Dev Disord 42:2498-24504, 2012.

Carbone PS, Behl DD, Azor V, Murphy NA: The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. J Autism Dev Disord 40:317-324, 2010.

Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. MMWR 61:1–19, 2012.

Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey. 2011-2012 National Survey of Children's Health Frequently Asked Questions. April 2013. Available from URL: http://www.cdc.gov/nchs/slaits/nsch.htm

Chandler S, Charman T, Baird G, Simonoff, E, Loucas, T, Meldrum D, Scott S, Pickles A: Validation of the Social Communication Questionnaire in a population cohort of children with autism spectrum disorders. J Am Acad Child Adolesc Psychiatry 46:1324-1332, 2007.

Cheak-Zamora NC, Yang X, Farmer JE , Clark M: Disparities in transition planning for youth with autism spectrum disorder. Pediatrics 131:447-454, 2013.

Cohn TA, Sernyak MJ: Metabolic monitoring for patients treated with antipsychotic medications. Can J Psychiat 5:492-501, 2006.

Coury DL, Anagnostou E, Manning-Courtney P, Reynolds A, Cole L, McCoy R, Whitaker A, Perrin JM: Use of psychotropic medication in children and adolescents with autism spectrum disorders. Pediatrics 130:S69-S76, 2012.

Doshi-Velez F, Ge Y, Kohane I: Comorbidity clusters in autism spectrum disorders. An electronic health record time-series analysis. Pediatrics 133:54-63, 2014.

Doyle, CA, McDougle CJ: Pharmacologic treatments for the behavioral symptoms associated with autism spectrum disorders across the lifespan. Dialogues Clin Neurosci 14: 263-279, 2012.

Eaves LC, Ho HH: Young adult outcome of autism spectrum disorders. J Autism Dev Disord 38: 739-747, 2008.

Egan AM, Dreyer ML, Odar CC, Beckwith M, Garrison CB: Obesity in young children with autism spectrum disorders: Prevalence and associated factors. Child Obes 9:125-131, 2013.

Esbensen AJ, Greenberg JS, Seltzer MM, et al: A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. J Autism Dev Disord 39:1339-1349, 2009.

Gerhardt PF, Lainer I: Addressing the needs of adolescents and adults with autism: A crisis on the horizon. J Contemp Psychother 41:37-45, 2011.

Ginsberg G, Hattis D, Sonawane B, Russ A, Banati P, Kozlack M, Smolenski S, Goble R: Evaluation of child/adult pharmacokinetic differences from a database derived from the therapeutic drug literature. Toxicol Sci 66:185-200, 2002.

Goering PN, Streiner DL: Reconcilable differences: the marriage of qualitative and quantitative methods. Can J Psychiat 41:491-497, 1996.

Graetz JE: Autism grows up: Opportunities for adults with autism. Disabil Soc 25:33-47, 2010.

Harrington JW, Patrick PA, Edwards KS and Brand DA: Parental beliefs about autism: Implications for the treating physician. Autism 10:452-456, 2006.

Howlin P, Goode S, Hutton J, Rutter M: Adult outcome for children with autism. J Child Psychol Psyc 45:212-229, 2004.

Howlin P, Karpf J: Using the Social Communication Questionnaire to identify autistic spectrum disorders associated with other genetic conditions – findings from a study of individuals with Cohen Syndrome. Autism 8:175-182, 2004.

Howlin P, Moss P: Adults with autism spectrum disorders. Can J Psychiat 57:275-283, 2012.

Hsia Y, Wong AY, Murphy DG, Simonoff E, Buitelaar JK, Wong IC: Psychopharmacological prescriptions for people with autism spectrum disorder (ASD): a multinational study. Psychopharmacology. Doi: 10.1007/s00213-013-3263-x, 2013

Kaplan G, McCracken JT: Psychopharmacology of autism spectrum disorders. Pediatr Clin North Am 59:175-187, 2012.

Kogan MD, Strickland BB, Blumberg J, Singh GK, Perrin JM, van Dyck PC: A national profile of the health care experiences and family impact of autism spectrum disorder among children in the Unites States, 2005-2006. Pediatrics 122:e1149-e1158, 2008.

Kohane IS, McMurry A, Weber G, MacFadden D, Rappaport L, Kunkel L, Bickel J, Wattanasin N, Spence S, Murphy A, Churchill S: The co-morbidity burden of children and young adults with Autism Spectrum Disorders. PloS One 7:e33224, 2012.

Lake JK, Balogh R, Lunsky Y: Polypharmacy profiles and predictors among adults with autism spectrum disorders. Res Aut Spect Dis 6:1142-1149, 2012.

Lake JK, Milovanov A, Sawyer A, Lunsky Y: Parent perspectives on psychotropic medication use and interactions with prescribing healthcare providers among adolescents and adults with autism spectrum disorders. Focus Autism Other Dev Disabl, in press.

Lake, JK, Weiss JA, Dergal J, Lunsky Y: Child, parent and service predictors of psychotropic polypharmacy among adolescents and young adults with an autism spectrum disorder. J Child Adol Psychop, in press.

Langworthy-Lam KS, Aman MG, Van Bourgondien ME: Prevalence and patterns of use of psychoactive medicines in individuals with autism in the Autism Society of North Carolina. J Child Adolesc Psychopharmacol12:311–321, 2002.

Levy AJ, Perry A: Outcomes in adolescents and adults with autism: A review of the literature. Res Aut Spect Dis 5:1271-1282, 2011.

Liptak GW, Orlando M, Yingling JT, Theurer-Kaufman KL, Malay DP, Tompkins LA, Flynn JR: Satisfaction with primary health care received by families of children with developmental disabilities. J Pediatric Health Care 20:245-252, 2006.

Logan SL, Nicholas JS, Carpenter LA, King LB, Garrett-Mayer E, Charles JM: High prescription drug use and associated costs among Medicaid-eligible children with autism spectrum disorders identified by a population-based surveillance network. Ann Epidemiol 22:1-8, 2012.

Mackintosh VH, Goin-Kochel RP, Myers BJ: “What do you like/dislike about the treatments you’re currently using?”: A qualitative study of parents of children with autism spectrum disorders. Focus Autism Other Dev Disabl 27:51-60, 2012.

Mandell DS, Morales KH, Marcus SC, Stahmer A, Doshi J, Polsky DE: Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. Pediatrics 121:441-448, 2008.

Matson JL, Mayville EA, Bielecki J, Barnes WH, Bamburg JW, Baglio CS: Reliability of the Matson Evaluation of Drug Side Effects Scale (MEDS). Res Dev Disabil 19:501-506, 1998.

Marrus N, Veenstra-VanderWeele J, Hellings JA, Stigler KS, Szymanski L, King BH, Carlisle LL, Cook EH, Pruett JR: Training of child and adolescent psychiatry fellows in autism and intellectual disability. Autism 18:471-475., 2014

Mazurek MO, Shattuck PT, Wagner M, Cooper BP. Prevalence and Correlates of Screen-Based Media Use Among Youths with Autism Spectrum Disorders. J Autism Dev Disord 42:1757–1767, 2011.

Mazurek MO: Loneliness, friendship, and well-being in adults with autism spectrum disorders. Autism. Epub ahead of print 2 October 2013. DOI 10.1177/1362361312474121, 2013.

McCracken JT: Safety issues with drug therapies for autism spectrum disorders. J Clin Psychiatry 66:32-37, 2005.

Memari AH, Ziaee V, Beygi S, Moshayedi P, Mirfazeli FS: Overuse of psychotropic medications among children and adolescents with autism spectrum disorders: Perspective from a developing country. Res Dev Disabil 33:563-569, 2012.

Mitchell DB, Hauser-Cram P: The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care. Res Dev Disabil 29:97-112, 2008.

Montes G, Halterman JS: Psychological functioning and coping among mothers of children with Autism: A population-based study. Pediatrics 119: e1040-e1046, 2007.

Naglieri J, Chambers: Psychometric issues and current scales for assessing autism spectrum disorders. In Assessment of Autism Spectrum Disorders. Edited by Goldstein S, Naglieri JA, Ozonoff S. New York: Guilford Press, 2009.

NICE: Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Clinical guideline 142: guidance.nice.org.uk/cg142, 2012.

Perry A, Condillac R: Evidence-based practices for children and adolescents with autism spectrum disorders: Review of the literature and practice guide. Children's Mental Health Ontario. Toronto. ON, 2003.

Posey DJ, Puntney JI, Sasher TM, Kem DL, McDougle CJ: Guanfacine treatment of hyperactivity and inattention in pervasive developmental disorders: A retrospective analysis of 80 cases. J Child Adolesc Psychopharmacol 14:233–241, 2004.

Roberts KC, Shields M, de Groh M, Aziz A, Gilbert JA: Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian Health Measures Survey. Health Rep: 37-41, 2012.

Rosenberg RE, Mandell DS, Farmer JE, Law JK, Marvin AR, Law PA: Psychotropic medication use among children with autism spectrum disorders enrolled in a National Registry, 2007-2008. J Autism Dev Disord 40:342-351, 2010.

Rutter M, Bailey A, Lord C: Social Communication Questionnaire (SCQ). Western Psychological Services, 2003.

Sawyer A, Lake JK, Lunsky Y, Liu S, Desarkar P: Psychopharmacological treatment of challenging behaviours in adults with autism and intellectual disabilities: A systematic review. Res Aut Spect Disord 8:803-813, 2014.

Schubart JR, Camacho F, Leslie D: Psychotropic medication trends among children and adolescents with autism spectrum disorder in the Medicaid program. Autism 2013. Doi:10.1177/1362361313497537\

Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF: Services for adults with an autism spectrum disorder. Can J Psychiatry 57:284, 2012.

Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M: Post–high school service use among young adults with an autism spectrum disorder. Arch Pediatr Adolesc Med 165:141-146, 2011.

Spencer D, Marshall J, Post B, Kulakodlu M, Newschaffer C, Dennen T, Azocar F, Jain A: Psychotropic medication use and polypharmacy in children with autism spectrum disorders. Pediatrics 132:833-840, 2013.

Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunsky Y, McMillan S: Primary care of adults with developmental disabilities: Canadian consensus guidelines. Can Fam Physician 57:541-553, 2011.

Witwer AN, Lecavalier L: Autism screening tools: An evaluation of the Social Communication Questionnaire and the Developmental Behavior Checklist-Autism

Screening Algorithm. Journal of Intellectual & Developmental Disability 32:179-187 2007

Zuckerman KE, Hill AP, Guion K, Voltolina L, Fombonne E: Overweight and Obesity: Prevalence and Correlates in a Large Clinical Sample of Children with Autism Spectrum Disorder. J Autism Dev Disord Epub ahead of print 2 February 2014. DOI 10.1007/s10803-014-2050-9, 2014.

Table 1. Descriptive statistics of sample (*n*=100).

Parameter	Adolescents (12-18) (*n*=55) %	Young Adults (19-30) (*n*=45) %	*p* value
Gender (male)	83.6	75.6	$\chi^2(1) = 1.01$, *p*= 0.32
Intellectual disability (yes)	54.0	50.0	$\chi^2(1) = .15$, *p*= 0.70
Caucasian	87.3	82.2	$\chi^2(1) = .50$, *p*= 0.48
Living with family	100.0	92.5	$\chi^2(1) = 4.03$, *p*= 0.05
Structured activity	98.2	75.6	$\chi^2(1) = 12.00$, *p*= 0.001***
Medical comorbidity	33.0	33.0	$\chi^2(1) = .004$, *p*= 0.95
Psychiatric comorbidity	63.3	73.6	$\chi^2(1) = 1.07$, *p*= 0.30

***p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001**

Table 2. Medication use associated with adolescents and young adults with ASD (*n*=100).

Parameter	Adolescents (*n*=55)		Young Adults (*n*=45)		*p* value
	%	Mean (SD)	%	Mean (SD)	
Medication drug classes					
Antipsychotic	54.5		57.8		χ^2(1)=0.11, *p*=0.75
Anxiolytic	7.3		6.7		χ^2(1)=0.01, *p*=0.91
Antidepressant	41.8		68.9		χ^2(1)=7.30, *p*=0.01**
Mood Stabilizer	0		4.4		χ^2(1)=2.49, *p*=0.11
Stimulant	40.0		15.6		χ^2(1)=7.18, *p*=0.01**
Non-psychotropic medication	25.5		40.0		χ^2(1)=2.41, *p*=0.12
Number of medications					
Mean number of total medications		1.91 (1.08)		2.27 (1.53)	*t*(98)=1.37, *p*=0.17
2 concurrent psychotropic medications	43.6		48.9		

*p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001

Table 3. Type and number of medication side effects associated with adolescents and young adults with ASD (*n*=100).

Parameter	Adolescents (*n*=55)		Young Adults (*n*=45)		*p* value
	%	Rank	%	Rank	
Medication side effects					
Yes	70.9		48.8		$\chi^2(2)=7.27$, *p*=.003**
No	23.6		29.3		
Don't know	5.5		22.0		
Top 5 most commonly reported medication side effects					
Metabolic	30.9	1	19.5	2	
Fatigue/sleep	23.6	2	22.0	1	
Weight loss	16.4	3	2.4	-	
Behaviour change	16.4	3	12.2	4	
Movement	14.5	4	7.3	5	
General neurological change	9.1	5	17.1	3	
Gastrointestinal	9.1	5	7.3	5	

***p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001**

Table 4. Parent perspectives on medication use among adolescents and young adults with ASD (*n*=100).

Parameter	Adolescents (*n*=55) %	Young Adults (*n*=45) %	*p* value
Reason for medication prescription			
Externalizing behaviours	85.5	61.4	$\chi^2(1)=7.52$, $p=0.006$**
Internalizing problems	70.9	84.1	$\chi^2(1)=2.38$, $p=0.12$
Social issues	12.7	11.6	$\chi^2(1)=0.03$, $p=0.87$
Psychotic disorder	5.5	9.1	$\chi^2(1)=0.49$, $p=0.48$
Comfort with medication use			
Comfortable	36.4	33.3	$\chi^2(3)=2.49$, $p=0.48$
Neutral	49.1	40.0	
Uncomfortable	3.6	8.9	
Other	10.9	17.8	
Medication efficacy			
Good or mostly good	77.4	80.0	$\chi^2(2)=0.44$, $p=0.80$
Neutral	17.0	12.5	
Bad or mostly bad	5.7	7.5	

***p ≤ 0.05, **p ≤ 0.01, ***p ≤ 0.001**

Table 5. Parent views about health care services associated with adolescents and young adults with ASD (*n*=100).

Parameter	Adolescents (*n*=55) %	Young Adults (*n*=45) %	*p* value
Views about prescribers			
Prescriber expertise in ASD			
Yes	69.1	43.9	$\chi^2(1)=5.14$, $p=0.02$*
No	30.9	56.1	
Satisfaction with prescriber medication monitoring			
Satisfied	53.7	38.1	$\chi^2(1)=4.48$, $p=0.03$*
Neutral or Dissatisfied	46.3	67.9	
Views about services			
Use of non-pharmacological services prior to initiating medication use			
Yes	81.8	64.4	$\chi^2(1)=3.88$, $p=0.05$*
Role of non-pharmacological services			
No access to or availability of non-pharmacological services	1.9	9.8	$\chi^2(3)=3.40$, $p=0.33$
Non-pharmacological supports not or only partially working	32.7	24.4	
Healthcare provider, school, or other service suggested medication	51.9	48.8	
Other	13.5	17.1	

***$p \le 0.05$, **$p \le 0.01$, ***$p \le 0.001$**