Published in final edited form as:
J Autism Dev Disord. 2009 September ; 39(9): 1339–1349. doi:10.1007/s10803-009-0750-3.

A Longitudinal Investigation of Psychotropic and Non-Psychotropic Medication Use Among Adolescents and Adults with Autism Spectrum Disorders

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Abstract

Medication use was examined in 286 adolescents and adults with ASD over a 4.5 year period. A total of 70% were taking a psychotropic or non-psychotropic medication at the beginning of the study. Both the number of psychotropic and non-psychotropic medications taken, and the proportion of individuals taking these medications, increased significantly over the study period, with 81% taking at least one medication 4.5 years later. Our findings suggested a high likelihood of staying medicated over time. Thus, adolescents and adults with ASD are a highly and increasingly medicated population.

Keywords

ASD; medication; psychotropic medication; non-psychotropic medication

Individuals with autism spectrum disorders (ASD) have persistent impairments across the life course and therefore have an ongoing need for services and treatment, often including medications (Aman, Lam, Van Bourgondien, 2005; Martin, Scahill, Klin & Volkmar, 1999). Only one medication, risperidone, has been approved by the Food and Drug Administration specifically for use among individuals with ASD who have serious behavior problems (Scahill, Koenig, Carroll & Pachler, 2007) and there are few clinical studies addressing the effectiveness of medications in this population (Matson & Dempsey, 2008). There is a limited, but growing, body of research on psychotropic medications used by individuals with ASD. Traditionally, most trials in the population have been open label (Matson & Dempsey, 2008), although controlled trials are becoming more common (Myers, 2007). Whereas advances have been made in pharmacological management of children with ASD (RUPP, 2002, 2005), less is known about medication treatment for adolescents and adults with this diagnosis (Broadstock, Doughty & Eggleston, 2007). Similarly, although there are several studies of medication prevalence in children and adolescents with ASD (Aman, Lam & Collier-Crespin, 2003; Aman, Van Bourgondien, Wolford & Sarphare, 1995; Langworthy-Lam, Aman & Van Bourgondien, 2002; Witwer & Lecavalier, 2005), less is known about the prevalence of medication during adolescence and especially adulthood in this population, which is the focus of the present study.

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The prevalence of prescription medications for children with ASD is high. Surveys indicate that one-half to two-thirds are prescribed at least one medication of any type, and about 45% are prescribed at least one psychotropic medication (Aman et al., 2005; Witwer & Lecavalier, 2005). The most commonly prescribed psychotropic medications are antidepressants, stimulants, and antipsychotics (Langworthy-Lam et al., 2002; Martin et al., 1999). However, non-psychotropic medications are also prescribed at high rates for individuals with ASD, although few studies have been conducted to benchmark the prevalence of medications to treat physical health symptoms in this population. One exception to this gap in data about medication for physical health symptoms concerns anticonvulsant medication. The reported prevalence of anticonvulsant medication is approximately 5% among children with ASD (Witwer & Lecavalier, 2005) and 11-13% among individuals across the life course (Aman et al., 2005).

There is evidence that psychotropic medications are currently more frequently prescribed for individuals with ASD than they were in the past. Separate cross-sectional analyses of medication data collected from members of the North Carolina Autism Society in 1993 and 2001 suggested a 48% increase in psychotropic medication use during this eight-year period (Aman et al., 2005). A higher prevalence of antipsychotic medications, antidepressants, psychostimulants, and alpha agonists and beta blockers was observed in 2001 than 1993, whereas a lower prevalence of hypnotics and anxiolytics was observed in 2001. There was no difference in the prevalence of other psychotropic medications such as mood stabilizers and opiate blockers between 1993 and 2001. During this same time period, the use of non-psychotropic medications, such as anticonvulsants, did not significantly change, although differences were observed in the types of anticonvulsants used (Aman et al., 2005).

Prescription practices among individuals with ASD are influenced by the complex relationship between behavior problems and psychopathology (Brereton, Tonge & Einfeld, 2006; Tsakanikos, Costello, Holt, Sturmey & Bouras, 2007). Among individuals with ASD, the symptoms of autism and behavior problems change with age (Fecteau, Mottron, Berthiaume & Burack, 2003; Mawhood, Howlin & Rutter, 2000; Seltzer, Krauss, Shattuck, Orsmond, Swe & Lord, 2003; Shattuck et al., 2007), which potentially leads to differences in the medications that are prescribed at different life stages. Thus, there is a need to understand the prevalence and patterns of medication use among adolescents and adults with ASD and how these may change with age.

However, the literature on change in medication use by individuals with ASD suffers from two methodological limitations. First, repeated cross-sectional designs have been used to investigate both *changes* in medication use over time and *age-related differences* in medication use. Such designs can be affected by changes in prescription practices, not just the maturation and aging of the population of individuals with ASD. For example, atypical antipsychotics and SSRIs were developed in the 1990s and rapidly grew in popularity. Further, the use of risperidone among children with ASD has grown dramatically as a result of research demonstrating its effectiveness in treating tantrums, aggression and self-injury (RUPP, 2002). Repeated cross-sectional studies are useful measures of general prescription practices but are neither informative of within-individual medication change, nor of differences in medication practices for children as compared to adults with ASD.

A second limitation of past research is that it has primarily focused on the use of psychotropic medications for individuals with ASD, with less investigation of the use of medications for other conditions in this population. Given the prevalence of comorbid physical health symptoms in individuals with ASD (e.g., seizures, gastrointestinal symptoms), additional research is warranted.

The present longitudinal analysis is unique because it examines changes in medication use over a period of 4.5 years in a community sample of individuals with ASD ranging in age from 10 to 48 years at the start of the study. For this analysis, we addressed two research questions. First, we asked whether medication use changes over time for adolescents and adults with ASD. We examined change using both measures of the proportion of individuals taking medication and the number of medications taken. Further, we examined if changes over time are different among adolescents as compared to adults with ASD. Second, we determined the odds of starting or stopping medication over the study period. For both of our aims, we examined psychotropic medications in separate analyses from non-psychotropic medications.

Methods

The analyses reported here are based on data from a larger ongoing longitudinal study of families of 406 adolescents and adults with confirmed ASD that began in 1998 (Seltzer et al., 2003). Half of the sample lived in Massachusetts and the other half lived in Wisconsin. The aims of the larger study are to examine the impact of autism on the family and the reciprocal impact of the family environment on the individual with ASD (for more details regarding the larger study, see Greenberg, Seltzer, Hong & Orsmond, 2006; Lounds, Seltzer, Greenberg & Shattuck, 2007; Shattuck et al., 2007). Over the 12-year study period, repeated measures about the change in the family and in the individual with ASD are collected, including data on medications. All families volunteered to participate and were recruited through service agencies, schools, diagnostic clinics, and the media. The data for the present analyses were taken from the first wave of data collection which took place from October 1998 to April 2000, and the fourth wave of data collection which took place from January 2004 to February 2005 (referred to as Time 1 and Time 4, respectively). Data on medication were collected during in-home interviews with mothers, that typically lasted two to three hours.

Sample

The current analyses focus on families of adolescents and adults with ASD for whom complete medication data were available at Time 1 and Time 4 (n=286, 47% from Massachusetts, 53% from Wisconsin). Of the sample members not included in the current analysis, 6 individuals with ASD had died before Time 4, 7 mothers were deceased or incapacitated before Time 4, 21 families participated but did not complete the questions about medication at Time 4, 20 families moved and could not be located at Time 4, and 66 families dropped out of the study. Adolescents and adults with ASD included in the present analysis did not significantly differ from those not included with respect to demographic characteristics or medication patterns at Time 1.

The adolescents and adults with ASD included in this analysis averaged 21.1 years of age (*SD* = 9.4) when the study began. Over one-half were between the ages of 10 and 19, three-quarters were male, and two-thirds were living with their parents (see Table 1). The large majority of the adolescents and adults were Caucasian. As shown in Table 2, all sample members had at least one diagnosis on the autism spectrum, and many had been assigned multiple such diagnoses, including Autistic Disorder, PDD-NOS, Asperger's Disorder and Childhood Disintegrative Disorder. Seventy percent of the sample had intellectual disability (ID). The majority of sample members had additional mental health conditions or developmental disabilities. The characteristics of the present sample with respect to gender, the prevalence of ID, and comorbidities are consistent with what would be expected based on epidemiological studies of Autistic Disorder (Bryson & Smith, 1998;Canitano, 2007;Fombonne, 2003).

Measures

Medication—Based on standard drug classifications in the Physicians Desk Reference (PDR) Drug Guide for Mental Health Professionals (Comer, 2002), the medications were coded and classified into their respective drug categories and subcategories. These classifications were reviewed and verified by a pharmacist with over 20 years of practice experience. To provide an example of the coding system, if a mother reported that her son or daughter took fluoxetine (Prozac), it was given a code that reflected both the larger category of "antidepressant" and the more specific subcategory of "SSRI," distinguishing it from other types of antidepressants. The coding system is available from the second author.

Medications were separated into psychotropic and non-psychotropic categories. The sub-categories of psychotropic medications included antipsychotics, antidepressants, anxiolytics and sedative-hypnotics, and CNS stimulants. All other psychotropic medications were grouped together, and included antimanic medication, anticonvulsant medications that were prescribed to an individual with *no* comorbid diagnosis of epilepsy or seizures (usually for bipolar symptoms), and hypotensive medications that were prescribed to an individual with *no* comorbid diagnosis of hypertension.

The subcategories of non-psychotropic medications included anticonvulsants (for seizures), antiparkinson medications, and other non-psychotropic medications. All antiparkinson medications were prescribed for side effects of antipsychotic medications (i.e., there were no cases of Parkinson's disease in this sample). All other non-psychotropic medications were grouped together, and included antilipemics, antibiotics, antiemetics, and medications for hypertension, thyroid, diabetes, respiration, hormones, ocular, gastrointestinal (GI), and other miscellaneous purposes. Excluded from our analysis were over-the-counter medications, such as analgesics, laxatives, vitamins, antifungal medication, antacids, and topicals.

We created four measures characterizing medication use. The first measure is a dichotomous variable indicating whether the individual with ASD was (1) or was not (0) prescribed *any psychotropic* medication. The second measure is another dichotomous variable indicating whether the individual with ASD was (1) or was not (0) prescribed *any non-psychotropic* medication. The third measure is a continuous variable indicating the *number of psychotropic* medications that the individual was prescribed. And the fourth measure is another continuous variable indicating the *number of non-psychotropic* medications that the individual was prescribed.

Demographics—Demographic variables included age at Time 1 and state (0 = Wisconsin, 1 = Massachusetts).

Method of Data Analysis

To test our first research aim, two-way repeated measures analyses of variance were used to examine changes in the proportion of individuals taking medications and in the number of medications taken over time. These analyses were conducted separately for psychotropic and for non-psychotropic medications. In these analyses, the between-subject factor was age group; differences in the two types of medication use were examined across two age groups (10-19 years, and over 20 years at Time 1). The within-subject factor of time was defined by measures of medication use at Time 1 and at Time 4. State of residence was controlled in these analyses.

To test our second research aim, conditional probabilities were used to examine the odds of starting or stopping medications over the 4.5 year study period, between Time 1 and Time 4. Starting medications was defined as taking no medication at Time 1 and taking at least one medication at Time 4. Stopping medications was defined as taking at least one medication at

Time 1 and taking no medication at Time 4. Four probabilities are used to create these outcomes: the probability of never taking medication (A), the probability of starting medication (B), the probability of stopping medication (C), and the probability of staying on medication (D). The odds of starting medication are a ratio of the probability of going on medication as compared to never going on medication (B/A). The inverse is the odds of staying non-medicated (A/B). The odds of stopping medication are a ratio of the probability of going off medication as compared to staying on medication (C/D). The inverse is the odds of staying medicated (D/C). The odds ratios were also calculated for any psychotropic medication, and any non-psychotropic medication.

Results

Changes in medication use over time

The data regarding the type of medications taken are presented in Table 3. Among the psychotropic medications, antidepressants and antipsychotics were the most common medications taken at Time 1. At this time point, atypical antipsychotic medications were the most common subcategory of medications taken by adolescents, and SSRIs were the most common for the adults. By Time 4, SSRIs were the most common psychotropic medications taken by both adolescents and adults.

Regarding the number of individuals who took medications, as shown in Table 3, at Time 1, 70% of the sample was taking medications. This percentage increased to 81% at Time 4. Not shown in Table 3 is that almost a quarter (24.1%) took both psychotropic and non-psychotropic medications at Time 1, and by Time 4, this percentage grew to over one-third (33.6%). A significantly higher proportion of individuals took psychotropic and non-psychotropic medications over time. There were significant changes over time in the proportion of individuals taking psychotropic medications, [57% at Time 1 vs. 64% at Time 4, $F(1,283) = 4.22$, $p < .05$], and non-psychotropic medications [37% at Time 1 vs. 50% at Time 4, $F(1,283) = 9.28$, $p < .01$]. Additionally, there was a significant main effect of age group on the proportion of individuals taking non-psychotropic medications, [adolescents, 35%; adults, 55%; $F(1,283) = 17.00$, $p < .001$], with more adults taking non-psychotropic medications than adolescents. There were no significant interactions of time and age group in the proportion of the sample taking either psychotropic or non-psychotropic medications.

The data regarding the number of medications taken by sample members are shown in Table 4. Sample members took an average of 1.6 medications at Time 1 (range 0-8), and this increased to 2.4 medications at Time 4 (range 0-11). A significantly greater number of psychotropic and non-psychotropic medications were taken over time. Significant increases in medication use were observed for psychotropic [from 1.0 medication at Time 1 to 1.4 at Time 4, $F(1,283) = 20.51$, $p < .001$] and non-psychotropic medications [from 0.6 medication at Time 1 to 1.0 at Time 4, $F(1,283) = 47.66$, $p < .001$] (see Table 4). There was a significant main effect of age group on the number of non-psychotropic medications taken, [adolescents, 0.6 medications; adults, 1.1 medications; $F(1,283) = 21.83$, $p < .001$]. Adults took a greater number of non-psychotropic medications than adolescents. There were no significant interactions between time and age group for the number of psychotropic or non-psychotropic medications taken.

For illustrative purposes, Table 4 also presents the percentage of sample members taking specific numbers of medications. These data show that the number of individuals taking zero medications decreased dramatically during the study period (from 30.4% to 19.2%), whereas the number taking three or more medications showed an even larger increase (from 24.5% to 40.6%). These changes were evident for both adolescents and adults, and for both psychotropic and non-psychotropic medications.

Thus, with regard to our first research aim, the data indicate an increase in both psychotropic and non-psychotropic medication use by adolescents and adults with ASD over the study period. At both points in time, non-psychotropic medications were more likely to be prescribed for adults than adolescents, but the pattern of psychotropic medication prescription was similar for the two age groups.

Probability of changing medication status

Our second research aim examined the odds of starting or stopping medication use over the study period. We first examined the percentage who started and stopped medication use during the study period. Fully 44 (15.4%) individuals who took no psychotropic or non-psychotropic medications at Time 1 started taking medications by Time 4, but only 12 (4.2%) of those who took prescription medications at Time 1 stopped taking all medications by Time 4. The majority (190 or 66.4%) were medicated at both Time 1 and Time 4, and only 43 (15.0%) were not medicated at either Time 1 or Time 4.

With regards to *psychotropic* medications, 36 (12.6%) individuals started taking psychotropic medications between Time 1 and Time 4, 14 (4.9%) stopped taking psychotropic medications between Time 1 and Time 4, 148 (51.7%) were medicated at both Time 1 and Time 4, and 88 (30.8%) were not taking psychotropic medications at either Time 1 or Time 4.

With regards to *non-psychotropic* medications, 54 (18.9%) individuals started taking non-psychotropic medications between Time 1 and Time 4, 18 (6.3%) stopped taking non-psychotropic medications between Time 1 and Time 4, 88 (30.8%) were medicated at both Time 1 and Time 4, and 126 (44.0%) were not taking non-psychotropic medications at either Time 1 or Time 4.

We next converted these percentages into odds ratios (see Table 5). The odds of stopping all medications during the 4.5 year study period were very low -- 0.06. Thus, the likelihood of staying medicated was very high -- 15.83 times the likelihood of going off all medication. Similarly, the odds of staying medicated with psychotropic or non-psychotropic medications were also high – for psychotropic medication the likelihood of staying medicated from Time 1 to Time 4 was 10.57 times the likelihood of discontinuing medication by Time 4, and for non-psychotropic medication the likelihood of staying medicated was 4.89.

The odds of *starting* any medications during the 4.5 year study period were 1.02 (see Table 5). This means that individuals who were not taking medications at Time 1 were equally likely to start taking medications by Time 4 as to remain non-medicated. The odds of either starting psychotropic (0.41) or non-psychotropic (0.43) medications during the study period were even lower. Thus, individuals who were not taking either type of medication at Time 1 were over twice as likely to continue to stay non-medicated by Time 4 as they were to start these medications. Still, of the sample members not medicated at Time 1, 51% began taking medication during the 4.5 year study period. Specifically, 29% began taking psychotropic medications and 30% began taking non-psychotropic medications during the study period.

Thus, with regard to our second research aim, the data indicate that individuals with ASD who are already medicated rarely discontinue the use of medication over a 4.5 year period.

Discussion

To the best of our knowledge, this is the first longitudinal study of prescription medication prevalence in ASD. We found evidence for longitudinal increases in medication use for both adolescents and adults and for cross-sectional age-related differences in non-psychotropic

medication use. Further, our study is the first to examine the probability of individuals with ASD going on or off medication.

Changes in medication use over time

Our survey of medication use over a 4.5 year period indicated that adolescents and adults with ASD are increasingly likely to be prescribed psychotropic and non-psychotropic medications. At Time 1, 70% took at least one prescription medication, fully 57% took one or more psychotropic medications, and 37% took at least one non-psychotropic medication. By the end of the study period 4.5 years later, these individuals were taking significantly more medications of both types than when the study began.

Our data revealed that the use of antidepressant, antipsychotic, and anticonvulsant medications exceeded previous reports of medication prevalence (e.g., Aman et al., 2005). It is certainly possible that this higher proportion of psychotropic medications was due to the older age of the present sample, which included adolescents and adults who averaged 21 years of age at Time 1 and 26 years of age at Time 4. In contrast, the mean ages in the Aman et al. (2005) studies ranged from 13 to 15 years. Furthermore, Aman et al. found that older age was the single strongest risk factor for medication use, so the higher proportions found here should perhaps not be surprising. The higher proportion of psychotropic medications in our sample is also consistent with the well-documented increased risk of new psychiatric disorders and new seizure disorders during adolescence (American Psychiatric Association, 2000; Cicchetti & Rogosch, 2002), and our sample members showed an increase in both mental health diagnoses and seizures during the study period.

The pattern of increasing medication use described in this paper is particularly striking because it was during the same 4.5 year period that our sample members also evidenced a significant reduction in reported behavior problems (Shattuck et al., 2007). A question for future research is to determine the extent to which behavior problems become less prevalent due to maturation or due to increased medications (or both), and the potential impact of psychotropic medications versus non-psychotropic medications on global changes in behavior problems.

The increase in psychotropic medications that we observed may also reflect recent changes in prescription practices. Use of atypical antipsychotics has become more common during the study period (20% at Time 1; 30% at Time 4), consistent with recent reports in the literature that these medicines are being used to reduce irritability, behavior problems, and repetitive behaviors in individuals with ASD and developmental disabilities (Aman & Madrid, 1999; McDougle et al., 2000), to treat mood disorders (Keck, 2005), and consistent with advantages over typical antipsychotics in terms of neurological side effects and possibly in therapeutic effects. Two recent reviews of trials with atypical antipsychotics among individuals with ASD revealed a pattern of varied results (Myers, 2007; Posey, Stigler, Erickson & McDougle, 2008). Four controlled trials with risperidone were all positive, with significant and robust reductions in tantrums, aggression, irritability, hyperactivity, and stereotypic behaviors. Of three open-label trials with olanzapine, two were positive and suggested overall global improvement as well as more isolated effects on hyperactivity, self injury, aggression, and irritability. Of two open-label trials with ziprasidone, one was clearly positive and the other failed to show much improvement when patients were switched from other atypical antipsychotics. Two open-label trials of aripiprazole in youth with Asperger's disorder suggested improvements in irritability as assessed on the Aberrant Behavior Checklist, and in aggression and self-injury. Studies of quetiapine have been largely, although not exclusively, negative (Myers, 2007; Posey et al., 2008). Thus, the increases in the use of atypical antipsychotics that were documented in the present study occurred against a backdrop of inconsistent, although largely positive, data about the effectiveness of such medications in individuals with ASD.

Use of antidepressant SSRIs also became more common during the study period (24% at Time 1; 36% at Time 4). This may reflect a growing tendency to prescribe SSRIs to treat anxiety symptoms and disorders in this population, as early reports suggested beneficial effects on "autistic behavior," perseverative behavior, self injury, aggression, and obsessions (Aman, Arnold & Armstrong, 1999). However, the findings of more recent controlled studies have indicated improvements that are more limited in scope, with reduced repetitive behavior reported most commonly and with occasional reports of improved self injury, anxiety, and irritability (Posey, Erickson, Stigler & McDougle, 2006). Recently, the Neuropharm Group, a pharmaceutical company focused on neurodevelopmental disorders, reported failure of fluoxetine to reduce repetitive behaviors in a large study of young people with ASD (http://www.neuropharm.co.uk/media_centre/news_release/?id=3542; accessed 03-30-2009), and a large NIH multi-site trial of citalopram in children with repetitive behaviors and ASD also reported negative findings (King et al., in press). Thus, the early reports of SSRI benefits appear to be overly optimistic, at least insofar as children are concerned, and therefore it is possible that the apparent enthusiasm for SSRIs demonstrated in the present study may decline in future prevalence studies.

CNS stimulants were observed to decline in use during the study period (12% at Time 1; 7% at Time 4), consistent with recent research findings that stimulants are not as effective among individuals with ASD as compared to the general population (Aman, 1996; Aman & Langworthy, 2000). Only about 50% of children with ASD showed a positive response to CNS stimulants, with a substantially higher rate of unacceptable side effects than seen with typically-developing children (Aman, Farmer, Hollway & Arnold, 2008). However, there have been three studies, all positive, of atomoxetine in young people with ASDs and inattention/overactivity, where adverse events appeared to be no worse than found in typically-developing children (Aman et al., 2008).

The significantly increasing number of psychotropic medications prescribed to individuals in our sample over the study period suggests growing polypharmacy (i.e., more than one psychotropic drug class) in this population. This is consistent with increasing national trends of polypharmacy in both adolescent and adult psychiatry. The use of non-psychotropic medication also became more widespread during the study period, and individuals were taking a greater number of non-psychotropic medications at Time 4 than Time 1. These changes in non-psychotropic medication use may be related to an age-associated increase in physical health problems. This likely is the case, as we found that the use of non-psychotropic medication was higher in the adults than the adolescents in our cross-sectional analyses. It is also possible that the increasing numbers of medications reflect prescriptions for side effects or for a lack of efficacy of a sole medication, but our data do not permit a test of these competing explanations.

Probability of changing medication status

The conditional probabilities of continuing or altering medication status are highly informative about medication practices over time. To our knowledge, our study is the first to use contingency analyses, making an important contribution to the field about the likelihood of starting or stopping medication use in adolescence and adulthood. Our data showed that there was considerable stability in psychotropic and non-psychotropic prescription patterns over the 4.5 year study period. This indicates that once adolescents and adults with ASD are prescribed medications, they are highly likely to *stay* medicated. This pattern was more pronounced for psychotropic medications (approximately eleven times more likely to *remain* on psychotropic medications than to *stop* taking them) than for non-psychotropic medications (nearly five times more likely to stay on non-psychotropic medications than to stop). Thus, a considerable number of individuals with ASD are being prescribed psychotropic medication, and once prescribed it

is likely that they will remain on these medications for many years. Although it is noteworthy that of the previously non-medicated sample members, during the short study period, about 30% began taking psychotropic or non-psychotropic medications. These patterns of prescription practices may be informative to families and clinicians in deciding whether or not to conduct a trial of medication. If the individual is not on medication by the time he or she reaches adolescence and adulthood, he or she is over twice as likely to stay non-medicated as to begin medication. Conversely, if the person is already taking prescribed medications, it is very unlikely that he or she will discontinue, at least over a 4.5 year period. This attests to the fact that these medications are not curative and that, once treatment is begun, there appears to be an ongoing need (or perception of need) for them.

The findings have important implications for public policy and service delivery. First, the decision to use medication early on may be a long-lasting decision. In light of this, it may be worth exploring alternative treatments, such as behavioral intervention, to try to avoid long-term medication treatment. Of course, it is very possible that the increase in medication use may reflect the scarcity of alternative treatments available to these individuals with ASD. Second, although these psychotropic medications have many beneficial effects, they all come with some risks in terms of adverse effects. It is well established that the early detection and treatment of side effects helps reduce their long-term adverse effects on health. Family members are the ones most likely to notice side effects first such as weight gain or fatigue but may not be aware that they may be due to medications. With the increased use of psychotropic medications for individuals with ASD, there is a greater need for psychoeducational programs for families of individuals with ASD that teach parents about medications and the signs and symptoms of potential side effects.

Summary and Conclusions

Our findings may help families formulate expectations for medication use by their adolescent or adult with ASD. The findings should also be informative to researchers in providing an understanding of the use of medications over the life course of individuals with ASD and interpreting the potential impact of medications on the health, behavior problems and symptom expression over time. The prevalence of comorbid diagnoses in this sample was high (67%, not including ID, by the end of the study period), but an even higher proportion (81%) took some type of prescription medication. The prevalence of both comorbid diagnoses and medications has implications for the health and social service systems that provide care and support for this population.

One of the limitations of the analyses presented in this paper is that they were based on a volunteer, largely Caucasian sample, which may affect the generalizability of the findings. In addition, analyses did not examine the level of impairment among individuals with ID as this information was not available for all members of the sample. Further, because we restricted our analyses to individuals with ASD who were 10 years of age or older at the start of the study period, we are unable to comment on factors that contribute to medication use prior to this age. Indeed, 57% of our sample was already taking psychotropic medication at the start of our study period. Also, our study design did not take into account dosage level changes, or use of non-medical interventions or complementary and alternative medicine (CAM). As 74% of families report using CAM with their children with ASD (Hanson et al., 2007), it is likely that some of the non-medicated (and medicated) participants in our study were using such approaches.

Despite these limitations, the study makes new contributions to understanding medication use among adolescents and adults with ASD. We extend past research by examining changes in medication use longitudinally in a community-based sample, and we contribute the first contingency analysis of starting and stopping medication. There are two central themes prominent in our findings. First, medication use is becoming more prevalent in that more people

with ASD are taking medications, and more medications are taken over time. And second, once a person begins to take medications, he or she tends to stay medicated over time. These findings are significant as they provide empirical support that medication use is rarely discontinued once initiated. Individuals with ASD are an increasingly medicated population, and continued research is needed to evaluate the safety and efficacy of psychotropic and non-psychotropic medications for individuals with ASD across the life span.

Acknowledgments

This manuscript was prepared with support from the National Institute on Aging (R01 AG08768), the National Institute on Child Health and Human Development (P30 HD03352), and the Autism Society of Southeastern Wisconsin.

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Table 1

Descriptive statistics on sample members (n=286).

Characteristic	%
Age	
10-19	57.7
20-48	42.3
Gender	
Male	74.8
Residence	
With parents	65.7
Ethnicity	
Caucasian	95.1

Table 2

Diagnoses of sample members (n=286).

	Time 1		Time 4	
Diagnosis	**n**	**%**	**n**	**%**
ASD Diagnosis[a]				
Asperger's Disorder	42	14.7%	42[a]	14.7%
Autistic Disorder	230	80.4%	230[b]	80.4%
Childhood Disintegrative Disorder	1	0.3%	1[b]	0.3%
PDD-NOS	67	23.4%	67[b]	23.4%
Any ASD diagnosis	286	100%	286	100%
Mental health diagnosis				
Anxiety Disorder	62	21.7%	82	28.6%
Attention Deficit Hyperactivity Disorder	44	15.4%	46	16.1%
Bipolar Disorder	12	4.2%	16	5.6%
Depression	39	13.6%	52	18.2%
Obsessive Compulsive Disorder	60	21.0%	70	24.5%
Oppositional Defiant Disorder	3	1.0%	4	1.4%
Schizophrenia	1	0.3%	3	1.0%
Any mental health diagnosis	121	42.3%	145	50.7%
Other developmental disability				
Blindness	8	2.8%	9	3.1%
Cerebral Palsy	8	2.8%	9	3.1%
Down syndrome	3	1.0%	3[b]	1.0%
Epilepsy	58	20.3%	62	21.7%
Fragile X syndrome	2	0.7%	2[b]	0.7%
Intellectual disability (ID)	199	69.6%	199[b]	69.6%
Landau Kleffner syndrome (other seizure, non-epilepsy)	3	1.0%	4	1.4%
Tourette syndrome	10	3.5%	11	3.8%
Any other developmental disability (excluding ID)	85	29.7%	92	32.2%
Any other developmental disability (including ID)	202	70.6%	203	71.0%
Any comorbid diagnosis (excluding ID)	172	60.1%	194	67.8%
Any comorbid diagnosis (including ID)	242	84.6%	251	87.8%

[a] Some individuals had multiple ASD diagnoses.

[b] No new cases identified between Time 1 and Time 4.

Table 3

Percentage[a] of individuals taking each subtype of medication, at Times 1 and 4, by age groups.

Medication	Time 1 Age groups[b]			Time 4 Age groups[b]		
	All ages (%)	10-19 (%)	Over 20 (%)	All ages (%)	10-19 (%)	Over 20 (%)
Type of medication						
Any medication	70	64	77	81	75	88
Psychotropic	57	54	60	64	60	70
Non-psychotropic	37	28	50	50	42	60
Subtype of medication						
Psychotropic medication drug classes						
Antipsychotic	24	24	26	33	30	38
Atypical[c]	20[d]	22	17[d]	30[d]	29	32[d]
Typical	6[d]	2	11[d]	4[d]	1	8[d]
Antidepressant	33	29	37	43	42	44
SSRI	24	20[d]	30	36[d]	33[d]	39[d]
Other antidepressants	9	10[d]	7	11[d]	12[d]	9[d]
Anxiolytics & sedative/hypnotics	10	8	13	14	11	19
CNS stimulants	12	16	5	7	10	3
All other psychotropic medication	21	21	21	28	25	31
Non-psychotropic medication drug classes						
Anticonvulsants	19	12	29	22	16	31
Antiparkinsons	1	1	2	2	1	2
All other non-psychotropic medication	24	21	29	40	33	48
N	286	165	121	286	165	121

Notes. SSRI: Selective serotonin reuptake inhibitor. CNS: Central nervous system.

[a] Percentages are based on the total sample size listed in the bottom row.

[b] All age groups are based on ages at Time 1.

[c] Includes aripiprazole, clozapine, olanzapine, quetiapine, risperidone, and ziprasidone.

[d] Subcategory percentages do not total the larger medication category as some individuals were taking more than one medication within this category.

Table 4

Number of medications at Time 1 and Time 4 by age group.

			Percentage taking specific number of medications [a]			
Age group	***M* (*SD*)**	**Maximum # of meds**	**0**	**1**	**2**	**3 or more**
All medication						
All ages T1	1.6 (1.6)	8	30.4	21.3	23.8	24.5
T4	*2.4 (2.1)*	*11*	*19.2*	*19.9*	*20.3*	*40.6*
10-19 T1	1.4 (1.4)	8	35.8	24.2	21.8	18.2
T4	*2.1 (2.0)*	*9*	*24.8*	*23.6*	*17.6*	*34.0*
Over 20 T1	2.0 (1.7)	8	23.1	17.4	26.4	33.1
T4	*2.9 (2.1)*	*11*	*11.6*	*14.9*	*24.0*	*49.5*
Psychotropic medication						
All ages T1	1.0 (1.2)	6	43.4	24.1	21.3	11.2
T4	*1.4 (1.4)*	*7*	*35.7*	*22.0*	*22.4*	*19.9*
10-19 T1	1.0 (1.2)	6	46.1	23.6	18.8	11.5
T4	*1.3 (1.5)*	*6*	*40.0*	*22.4*	*18.8*	*18.8*
Over 20 T1	1.1 (1.1)	6	39.7	24.8	24.8	10.7
T4	*1.5 (1.4)*	*7*	*29.8*	*21.5*	*27.3*	*21.4*
Non-psychotropic medication						
All ages T1	0.6 (0.9)	4	62.9	23.4	7.7	6.0
T4	*1.0 (1.4)*	*7*	*50.3*	*22.0*	*12.2*	*15.5*
10-19 T1	0.4 (0.6)	3	72.1	21.2	5.5	1.2
T4	*0.8 (1.2)*	*6*	*58.2*	*21.8*	*7.9*	*12.1*
Over 20 T1	0.9 (1.1)	4	50.4	26.4	10.7	12.5
T4	*1.4 (1.6)*	*7*	*39.7*	*22.3*	*18.2*	*19.8*

Regular font reflects Time 1 data. Italics reflect Time 4 data.

[a] Percentages sum to 100% across a row.

Table 5

Odds of changes in medication use over a 4.5 year period.

Medication	Odds of starting	Odds of staying non-medicated	Odds of stopping	Odds of staying medicated
Any medication	1.02	0.98	0.06	15.83
Any psychotropic	0.41	2.44	0.10	10.57
Any non-psychotropic	0.43	2.33	0.20	4.89