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Parent Perspectives on Psychotropic Medication Use and Interactions With Prescribing Health Care Providers Among Adolescents and Adults With an Autism Spectrum Disorder

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Abstract

Adolescents and young adults with an autism spectrum disorder (ASD) are often prescribed psychotropic medications to treat mental health and behavioral issues, and parents of these individuals play a crucial role in overseeing this care. Despite this, little is known about parents' experiences managing and monitoring their child's medication treatment, or their experience interacting with prescribing health care providers. To learn more about parents' perspectives on psychotropic medication use in their adolescent or young adult with ASD, a focus group was conducted with seven mothers whose adolescent or adult child with ASD was prescribed one or more psychotropic medications. Results are summarized according to emergent themes including parent perception of child experience with medication, side effects, medication efficacy, medication monitoring, expertise issues, and service issues. Parents also provided medication recommendations, including a desire for health care providers with greater expertise in ASD, information on medication, and tools for medication monitoring.

Keywords

adults, adolescents, autism spectrum disorder, support systems, parents, medication, health care providers

Mental health and behavior issues are extremely common among individuals with an autism spectrum disorder (ASD) and, as a result, these individuals are often highly medicated (Broadstock, Doughty, & Eggleston, 2007; Matson & Dempsey, 2008; Matson & Hess, 2011; Myers, 2007; Spencer et al., 2013). Recent studies suggest that between 60% and 80% of adolescents and adults with ASD are prescribed psychotropic drugs to manage behavior or mental health issues (Coury et al., 2012; Esbensen, Greenberg, Seltzer, & Aman, 2009; Lake, Balogh, & Lunsky, 2012; Mandell et al., 2008). While a number of studies have considered factors associated with or predictive of psychotropic medication use in children (Coury et al., 2012; Logan et al., 2012; Spencer et al., 2013), fewer studies have investigated these issues in adulthood, when access to non-pharmacological services and supports become increasingly limited. Furthermore, results of a recent study suggest that core features of ASD, including social impairment and repetitive behavior, are only weakly related to medication use (Mire, Nowell, Kubiszyn, & Goin-Kochel, 2013).

Because of the complexity of their mental health problems, as well as deficits in social and communicative functioning, parents of individuals with ASD are often the ones who take on the role of coordinating their child's health care, including medication management (Carbone, Behl, Azor, & Murphy, 2010). This care typically involves careful monitoring of behavior and side effects as well as documentation of changes in behavior or mood (Schall, 2002). As part of this process, family members are frequently in contact with health care providers, and may be relied upon to report treatment effects or to assess their child's experience taking medication (e.g., side effects, behavior changes; Tsakanikos et al., 2006).

Although few studies have been conducted on the parent experience with prescribing health care providers and perceptions of medication use, a number of studies have

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examined parent satisfaction with health care services and the working relationship between health care professionals and parents of children with ASD more generally (Carbone et al., 2010; Kogan et al., 2008; Liptak et al., 2006; Mackintosh, Goin-Kochel, & Myers, 2012; Mitchell & Hauser-Cram, 2008). Results of these studies suggest that parents are often dissatisfied with the primary care provided to their children (Liptak et al., 2006; Mackintosh et al., 2012). More specifically, they feel health care providers lack expertise in ASD (Harrington, Patrick, Edwards, & Brand, 2006), are unaware of community resources and supports, and do not value or recognize the role of parents in decision-making (Carbone et al., 2010; Liptak et al., 2006; Mackintosh et al., 2012).

To date, only two studies on medication use have examined parent perceptions about psychotropic medication use among children with ASD. The first study examined seven parents of children with ASD, and the second, survey-based study, examined 489 parents of children and youth with ASD. In the first study, parents reported that they were comfortable using medication for their child with ASD, but held negative attitudes about its effectiveness (Swiezy & Summers, 1996). Parents also felt that while they played some role in the decision to medicate, they were not provided with a lot of information on the purpose and potential effects of their child's medication (Swiezy & Summers, 1996). In a more recent survey-based study which examined parents' experiences seeking and using a number of different treatments for their child with ASD, including medication, parents expressed concern about giving their child medication, had fears about adverse effects, and sometimes doubted its effectiveness (Mackintosh et al., 2012). Furthermore, over one third of parents reported stress or anxiety related to choosing an appropriate treatment for their child (Mackintosh et al., 2012). Taken together, these two studies suggest some parent concerns related to medication use, but their focus is limited to children and youth with ASD. Given our knowledge that older adolescents and adults are more likely to use psychotropic medications (Coury et al., 2012; Esbensen et al., 2009; Logan et al., 2012; Spencer et al., 2013) and that over time medications are added, not removed (Esbensen et al., 2009; Spencer et al., 2013), there is a critical need to study the experiences of parents of older adolescents and adults.

To begin to understand a particular topic, in this case, parent perception of their child's medication use, it can be useful to adopt a qualitative approach. Focus groups facilitate discussion and consensus, which allow researchers to carefully identify themes common between parents (Goering, Boydell, & Pignatiello, 2008; Morgan, 1997). Focus groups have been used to study parent perspectives on medication use in other populations, including children with ADHD (Charach, Skyba, Cook, & Antle, 2006; Coletti et al., 2012) and asthma (Meng & McConnell, 2002), but have yet to be applied to adolescent and adult children with ASD. The dearth of research on parent perceptions of psychotropic medication use, particularly in adolescents and adults with ASD, is concerning. Furthermore, no studies have considered the parent experience of managing their adolescent or adult child's medication use over time. For example, it is not clear how parents monitor medications, how comfortable they are with follow-up care from prescribing health care providers, or how they perceive their child's experience using medication over time.

The current study addresses these gaps by taking an in-depth look at parents' experiences with psychotropic medication use among a group of seven mothers of adolescents and adults with ASD. Specifically, we explored the following topics: (a) positive and negative aspects of medication use (e.g., side effects, medication efficacy), (b) parent role in medication monitoring (e.g., tools, target behaviors), (c) experience interacting with prescribing health care providers (e.g., expertise, access), (d) parent perception of child experience with medication use (e.g., comfort, knowledge, independence), (e) involvement in the decision to pursue medications, and (f) suggestions for parents and prescribing health care providers. In doing so, we identified specific issues and concerns related to medication use, identified areas for further, more extensive research, and provided recommendations on how better to support and improve parent experiences with prescribing health care providers for their adolescent and adult children.

Method

Participants

A focus group was conducted with seven mothers of adolescents and young adults with ASD living in Toronto, Canada. These parents were part of a larger ongoing study ($n = 363$ participants) examining health care utilization patterns among adolescents and adults with ASD. Participants of the larger study resided in Ontario and were recruited through support groups, recreational programs, community agencies, and schools, using flyers, websites, and other announcements. 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. All participants from this larger study were invited, by email, to participate in the current focus group on medication use. Of the 182 parents who had a child currently prescribed psychotropic medication, 11 indicated their interest in participating. Four of these parents were unable to attend due to scheduling conflicts, resulting in the final seven participants.

Participants were told they would be asked to discuss their experience with medication use and their interactions with prescribing health care providers. They were also notified

Table 1. Demographic and Clinical Characteristics of Parent and Child Participants ($N = 7$).

	Child characteristics						Parent characteristics			
Participant ID	Age	Gender	Autism diagnosis	Comorbid psychiatric disorders	IQ level	Residence	Age	Ethnicity	Education	Marital status
P1	24	F	PDD-NOS	Anxiety	Moderate ID	Group home	65	Caucasian	Graduate degree	Married
P2	21	F	Asperger Syndrome	Anxiety, OCD, ADHD, borderline personality disorder	Normal intelligence	With family	59	Caucasian	Undergraduate degree	Married
P3	12	M	Asperger Syndrome	ADHD	—	With family	—	Caucasian	—	—
P4	21	M	PDD-NOS	None	Mild ID	With family	44	South Asian	College diploma	Single
P5	21	F	PDD-NOS	OCD	Mild ID	With family	56	Caucasian	Partial college	Single
P6	28	M	Asperger Syndrome	OCD, anxiety	Normal intelligence	With family	62	Caucasian	Graduate degree	Single
P7	28	M	PDD-NOS	Bipolar, ADHD	Mild ID	With family	57	Caucasian	Graduate degree	Single

Note. ID = intellectual disability; PDD-NOS = pervasive developmental disorder–not otherwise specified; OCD = obsessive compulsive disorder; ADHD = attention deficit hyperactivity disorder; "—" = information not available.

that their responses would be linked to their longitudinal data. Parents were not paid to participate in the group, but were provided with a light dinner and reimbursement for transportation. At the end of the focus group, all participants were provided with community resources for families and individuals with ASD, including links to websites and print resources on services and supports for their child.

Demographic information pertaining to parent participants and their children (see Table 1), including history of medication changes (e.g., medications increased, decreased, added, removed; see Table 2) was collected as part of the larger study. Information about history of medication changes was available for six of the seven participants. This study received ethics approval from the hospital Research Ethics Board.

Design

The focus group met once over a 120-min time period and was facilitated by a licensed clinical psychologist (Y.L.). The facilitator led the discussion by asking general questions about parents' experiences with their child's medication use, their experiences with prescribing health care providers, and recommendations for prescribers and other parents. Prompts and specific follow-up questions were used throughout the session to guide discussion and to clarify topics and issues raised by participants. The session was digitally recorded and transcribed by two of the authors (J.K.L., A.S.).

Qualitative Coding

Transcripts were independently analyzed by three authors (J.K.L., A.M., A.S.) and emerging themes were identified. Open coding was employed independently by the three aforementioned authors to create conceptual labels, which identified emerging themes from the data (Charmaz, 2007). Themes were then compared to ensure rigor in coding and analysis (Taylor & Bogdan, 1998). When inconsistencies occurred, notes were discussed and a consensus was agreed upon. Themes were refined to capture the range of topics covered during the group. Quotes that exemplified these themes were then selected.

Results

Themes

Content analysis of parents' experiences with their child's medication use, across all questions, consistently revealed two broad categories: parent experience with medication and parent experience interacting with health care providers. From this, the following six themes emerged: child experience with medication, side effects, medication efficacy, medication monitoring, expertise issues, and service issues. Parents also provided medication recommendations for health care providers and other parents. Ideas and experiences expressed by parents sometimes related to more than one theme and were classified accordingly. To represent the range of responses, quotes were taken from a variety of participants with each quote identified by speaker (e.g., P1).

Experience with medication. Parents were asked to describe their own and their child's experience with medication, including positive and negative aspects.

Child experience. Parents reported different experiences in terms of their child's beliefs, comfort, or feelings about taking medication. Four parents indicated that their child was independent in taking medication, and just over half reported no issues in giving their child medication: "I have

Table 2. History of Medication Changes ($N = 7$).

Participant ID	No. and class of psychotropic medications (baseline)	2 months	4 months	6 months	8 months	10 months	1 year
P1	1 atypical antipsychotic	NA	—	—	—	—	—
P2	1 antidepressant, 2 anxiolytics, 2 stimulants	X anxiolytic ↓ stimulant	—	—	—	NA	—
P3	1 stimulant, 1 atypical antipsychotic	NA	NA	NA	NA	NA	NA
P4	1 stimulant	—	+ stimulant	+ stimulant	↑ stimulant, X stimulant + (norepinephrine reuptake inhibitor)	NA	—
P5	1 antidepressant	—	—	—	—	NA	—
P6	1 antidepressant	—	—	—	—	—	—
P7	1 atypical antipsychotic, 3 mood stabilizers, 1 stimulant		↑ mood stabilizer, ↑ atypical antipsychotic, ↓ atypical antipsychotic	NA	NA	NA	NA

Note. + = added; X = removed; ↑ = increased; ↓ = decreased; "—" = no change; NA = no data.

no trouble at all. She will remind me, for both of us. She sets them on the table. I call them vitamins—'get the vitamins.' She takes it with dinner" (P5). Two parents experienced challenges getting their child to take medication: "I still don't know why [he stopped taking medication]. He is verbal, but he can't seem to give me a reason why. Could be because he doesn't know why or he just can't verbalize why" (P4). Another parent spoke of medications being overused on an as needed basis (pro re nata [PRN] medication); namely, that her child self-administers these medications for minor things, or more often than intended. This same parent noted that her daughter was very knowledgeable about the medications she was prescribed and that she advocated for new medication to her health care providers.

Side effects. All parents expressed concerns related to medication side effects including weight gain, cognition (e.g., cognitive loss, inability to focus), fatigue, affect (e.g., lethargy, low mood, personality), and short- (e.g., double vision, nausea) or long-term (e.g., osteoporosis, Parkinson's) health issues. For example, one parent said, "Does anybody remember a big personality change when their child first started taking medication? Cause I felt like I almost had to say goodbye to the old [child's name] and get to know the new one" (P3). Two parents indicated that their child had to discontinue a medication because of side effects. Several parents mentioned fears related to the lack of research on long-term outcomes associated with medication use: "It's a really big fear for parents I think—health—especially when they're still growing and the brain is still developing" (P5). It was also noted by several parents that medication use was a balancing act whereby side effects were constantly weighed against treatment benefits.

In addition to expected side effects, a number of parents reported that their child had odd or unique reactions to medications. Parents expressed this sentiment both in the context of concerns around medication interactions, and also in terms of the need to consider how reactions may vary from person to person: "But a lot of medications interact with each other. I know that when they change one of my medications, the pharmacist will say, 'well you're on this other thing, maybe you should ask for a different thing or something'" (P6). Two parents felt their child responded differently to generic versus brand name medication, but noted that prescribing health care providers did not acknowledge these differences.

Medication efficacy. Parents had both positive and negative things to say about medication efficacy. Some parents reported that medications were extremely effective and that the positive changes they observed in their child were both profound and immediate. Furthermore, three parents noted that medication allowed their child to function better, improved their quality of life, or helped their ability to cope: "But it helped. It needed to take that edge off so she could feel more confident and we could do more. Immediate [change after med use], immediately happier, and I don't have to worry about depression" (P5). In contrast, three parents reported that medication was not effective, and that they had to trial multiple medications before finding one that worked. For example, three of the six parents for whom we had medication history information for, had experienced changes to their child's medication (e.g., medications added, removed, increased, or decreased) over the course of a 12-month period. Furthermore, just over half of parents reported feeling that finding an effective medication was a process of trial and error: "Yeah at times we just played around with different medications. Obviously we had a doctor prescribe the medication, but it just seemed like it was a crapshoot" (P4).

Medication monitoring. Most parents (5) indicated that they were responsible for monitoring their child's medication use. Of these five parents, three parents used a standardized chart or table that had been created in conjunction with their child's teacher or therapist, whereas two created their own chart or recorded personal observations: "I did careful notes, taking notes every time—we increased her dose to such and such and this is what happened, what various doctors have said" (P2). The most commonly monitored symptoms or behaviors included sleep, aggression, and energy.

A number of challenges and recommendations were noted in terms of medication monitoring. For example, one parent said, "with regard to monitoring it's hard to know, especially my daughter, she is not so verbal. She becomes more whiny, she is more depressed" (P1). Several parents felt it was difficult to monitor medication effects in different environments, namely school or day program settings. Parents highlighted the need to involve and obtain the cooperation of other professionals as part of this process: "You need the cooperation of the teachers [for monitoring], and not always do they cooperate" (P4). Two parents reported a desire for structured monitoring tools, and three parents wished to see prescribing health care providers more often for monitoring purposes.

Experience interacting with health care providers

Expertise issues. Five parents brought up issues related to lack of physician expertise. Three parents felt there were very few physicians, even among psychiatry, with sufficient knowledge of ASD: "[The pediatrician] said Paxil, and it works for [his problems], but then he leaves him on it forever. I wonder if there would be a better assessment done . . . with someone who had expertise in autism or Asperger Syndrome" (P6). Several parents wanted prescribing health care providers to have more expertise in the use of medication for behavior or mental health issues among individuals with ASD. Specifically, parents wanted health care providers to exhibit confidence in recommending and prescribing medications, as well as demonstrate knowledge of dosage, side effects, and possible interactions between multiple medications: "I would have liked a little more from him [prescribing physician]. A little more confidence: you know try this and we will look at it. Really talk to you about side effects" (P5).

Two parents stressed the need for physicians to appreciate the distinct effects medications may have on different individuals: " . . . because she has odd reactions to medications, sometimes the psychiatrist was kind of dismissive. With Buspar, for example, the doctors were like, 'why are you on Buspar? It does nothing.' So many doctors told us that" (P2). One mother noted that she would have appreciated more information about other patients in similar situations who received successful treatment with medications.

Service issues. Most (5) parents were not satisfied with the support and assistance provided by their physician and felt that prescribing health care providers fell short of fulfilling their roles. Parents commented that prescribing health care providers did little other than provide diagnostic consultation and medication checks: "Well for my son it would be nice if there was more than just medication review . . . Yeah, [the psychiatrist] might give him a little bit of fatherly advice, listen to him and say, 'yeah it's tough . . . here's your script and we'll see you in 6 weeks'" (P7). Furthermore, they noted that prescribing health care providers did not refer them to specialists, and could not provide non-pharmacological services such as behavior support and therapy. Four parents were also concerned that prescribing health care providers did not take the time to really understand and get to know their child, and could not, therefore, properly address or monitor their needs.

Several parents felt that there was poor communication between doctors, patients, and parents, and raised concern about the physician's failure to acknowledge parents' opinions, concerns, and suggestions: "You go to a new psychiatrist, [show him the notes of] what she's tried—they don't look at it" (P2). Poor communication resulted in parents feeling that they lacked knowledge about the type of medication their child was taking, side effects, and long-term outcomes.

Four parents reported that the health care professionals they encountered were reluctant to take on the primary responsibility for monitoring medication effects and for ensuring that medications were used in the most beneficial manner. Some parents stated that it was them or their child, rather than prescribers, who were responsible for prescribing medication: "My daughter feels she's prescribing for herself. She goes in and she says, what about Wellbutrin, that seems to fit my profile. And they said, well go ahead, try it . . . why am I prescribing for myself?" (P2). Parents believed that prescribing health care providers did not show enough initiative and concern, and in many cases, left it to the parents to monitor medication effects, adjust dosages, and bring up health concerns: "Little more information about, little more firm knowledge about it rather than me kind of pulling teeth: I've heard of these things, what do you think? The PRN, what is that? It was ME bringing it up all the time, not him" (P5).

Four parents felt in a constant state of flux having to monitor and adjust medications with little outside support. However, not all comments regarding prescribing health care providers or prescribing practices were negative; one parent said that she appreciated having the ability to monitor and adjust her child's medication herself.

One of the most common issues raised by six of the seven parents was difficulty finding and accessing essential services and supports. Four parents noted that their child with ASD rarely saw their prescribing physician, and when they did it was only for brief periods of time: "[prescribing physician] sees him twice a year, and he will re prescribe the Paxil and says that [my son] has to come in and see me every 6 months" (P6). Subsequently, parents felt that they were on their own to manage the difficulties of their child, which was particularly overwhelming in times of crisis. Four parents mentioned difficulty accessing psychiatry, and one parent noted that even when she did access psychiatry services, the services were time-limited and only provided temporary relief: "Everything is so time-limited. You get going and you feel sort of secure that you have someone you can call and at a certain age, and school ends, and then everything falls apart again" (P5).

Many parents felt that there was little integration within the health care system. For example, three parents indicated that the transition from the pediatric system to the adult system was very difficult: "He's been with the same psychiatrist since he was 13/14 at one hospital, the youth psychiatry program and now he's 28, so it's when are they going to kick him out?" (P7). Another mother said that her child, despite being in his late 20s, was still seeing a pediatrician. Furthermore, parents believed communication was lacking with health care professionals, resulting in poor consistency of service, unnecessary redundancy, and overall lower quality of service. Parents reported that physicians tended to provide consultations rather than comprehensive services: "And then if I have a crisis or something I go see a psychiatrist who will say, well we can up [the medication] for now. It's not a very holistic approach" (P6).

Several parents believed that at least some of the aforementioned problems could be alleviated with an interdisciplinary approach, including the one parent who had a successful experience with this type of service.

Recommendations. Parents were asked what advice they would give other parents and other prescribing health care providers about medication use. In terms of education to other parents, they spoke of the need to be persistent and to be a strong advocate for your child. They also discussed the importance of identifying an observable behavior to target: "You have to be able to say, they're sleeping 6 more hours a day, or there's something that you can actually [see] or you will never know whether the medication is working or not" (P2). Three parents expressed the need for a strong support network and the importance of connecting with parents who also have children with ASD taking medications. Finally, several parents noted that it was important to take time for yourself, not to feel guilty about your treatment choices, and to remember that you will make some mistakes along the way. In terms of advice for prescribing health care providers, parents generally expressed a desire for improved communication among health care professionals, a proactive rather than a reactive approach to care, better coordinated transitions between providers and systems, and that health care providers listen to parents more.

Discussion

Input from participating parents pointed to a number of important concerns around the use of medication in adolescents and adults with ASD. Consistent with existing literature on health care services in ASD, parents identified a critical need for prescribing health care providers to have expertise in ASD (Carbone et al., 2010; Rhoades, Scarpa, & Salley, 2007). This type of expertise is essential to the development of effective treatment plans for this population. Parents also identified a number of concerns related to their child's medication use including side effects and medication efficacy. Some concerns were consistent with challenges expressed by parents of children with ADHD (Charach et al., 2006; Coletti et al., 2012), asthma (Meng & McConnell, 2002), and findings of young children and youth with ASD (Mackintosh et al., 2012; Swiezy & Summers, 1996). These included parent concerns related to adverse medication effects (e.g., insomnia, tics, gastrointestinal issues, appetite change; Charach et al., 2006; Coletti et al., 2012; Mackintosh et al., 2012; Meng & McConnell, 2002; Swiezy & Summers, 1996), medication efficacy (Charach et al., 2006; Coletti et al., 2012; Mackintosh et al., 2012; Swiezy & Summers, 1996), and a desire for prescribing health care providers to involve parents in the decision to medicate or consider non-pharmacological treatments (Coletti et al., 2012). Parents also noted different responses to generic versus brand name medication, a finding consistent with literature on other disorders (Borgheini, 2003; Roman, 2009; Rosenthal, Kong, Jacobs, & Katzman, 2008; Van Ameringen, Mancini, Patterson, & Bennett, 2007). In terms of medication monitoring, parents pointed to the need for accessible, standardized monitoring tools that would facilitate the input and cooperation of various professionals (e.g., teachers and doctors). This finding supports results of a recent study examining medication monitoring across professionals, which suggested that medication monitoring was not well monitored or coordinated among children with ASD (Koegel, Krasno, Taras, Koegel, & Frea, 2013).

Recommendations

Findings from participating parents raised a number of critical recommendations pertaining to medication use in adolescents and adults with ASD. Parents identified a strong need for health care providers with expertise in ASD, and also of the need for prescribing health care providers to spend more time with patients and caregivers. Parents wanted health care providers to communicate meaningfully with patients and caregivers to fully understand the needs of their child. At the system level, parents expressed a desire for care that is better integrated, including enhanced communication with health care professionals, interdisciplinary approaches to treatment, and coordinated transition from the pediatric to the adult system.

In terms of medication monitoring, although some guidelines for monitoring psychotropic medication for individuals with ASD exist (Myers & Plauche Johnson, 2007; Schall, 2002; Williamson & Martin, 2012), parents advocated for guidelines that are written in language accessible to caregivers and individuals with ASD to successfully be used by them. Similarly, practical tools for families to improve medication monitoring and communication with health care providers about medication must be developed to support guideline compliance. Parents should play a role in the development of appropriate tools.

In addition, as many parents expressed feeling uninformed about medications, a comprehensive, concrete website or resource containing information on specific medications, side effects, and long-term effects, would be useful. Such a site could also provide a forum for parents to connect around the topic of medication use, which was a support that many parents indicated would be helpful. Toolkits to help parents with the decision to use medication exist, such as the ATN-AIR-P Medication Decision Aid (see http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/medication-guide), but similar toolkits to guide and support parents once their children have begun using medications must be created. Medication guides exist for parents of children with other disorders, including ADHD (American Academy of Child & Adolescent Psychiatry, and American Psychiatric Association, 2013) and bipolar disorder (American Academy of Child & Adolescent Psychiatry, 2010); however, comparable guides for parents of individuals with ASD do not exist.

Finally, parents highlighted the importance of identifying observable target symptoms, weighing the risk/benefit ratio of using medications, and assessing changes in behavior over time. While existing literature also stresses the consideration of these factors in medication prescribing (Owley, 2002), such information needs to be better and more widely disseminated to prescribing health care providers and to families with ASD using psychotropic medications.

Limitations and Future Directions

This study has several limitations that should be considered. Participants of the focus group consisted of only mothers residing in urban settings with similar levels of education. That being said, participants' children ranged in autism severity, age, history of medication changes, gender, and themes were consistently identified by all parents, regardless of their child's level of functioning or number of medication changes. A larger sample including both fathers and mothers from varying regions and educational backgrounds is needed to increase generalizability of findings. Moreover, participants may have been inclined to attend the focus group because of atypically negative experiences with medications. Future studies could address this possible source of bias by targeting a broader sample.

To improve the patient's medication experience, studies are needed to complement this work by soliciting the perspective of individuals with ASD, as well as health care providers involved in this type of care. There is also a need to better understand the impact of psychotropic medication on the quality of life of individuals with ASD, an area which to date, remains understudied (Bertelli et al., 2013; Moyal, Lord, & Walkup, 2014). This, and other exploratory studies of its kind, would help pave the way to larger quantitative studies with the ability to tap issues more systematically and with a broader sample. Areas flagged in this study as requiring further research include psychological and physiological effects of medication use, the relationship between pharmacological and non-pharmacological services and supports, and experience with specific monitoring tools and processes.

Given the significant psychological distress associated with parenting a child with ASD (Bromley, Hare, Davison, & Emerson, 2004; Cadman et al., 2012; Lin, 2010), particularly around the decision to medicate (Konstantareas, Homatidis, & Cesaroni, 1995), it is crucial we find better ways to deliver care and support caregivers. Results of this focus group highlight a number of important implications and next steps toward improving the lives of parents of adolescents and adults with ASD taking psychotropic medications.

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