

MEDICATIONS FOR ATTENTION DEFICIT HYPERACTIVITY DISORDER IN ADULTS

FINAL QUALITATIVE REPORT

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Prepared by the ODPRN Knowledge Translation Unit, Li Ka Shing Knowledge
Institute Knowledge Translation Program, St. Michael's Hospital

Alekhya Mascarenhas, Radha Sayal, David Flaherty, Sobia Khan, and Julia E.
Moore

Conflict of Interest Statement

No study members report any affiliations or financial involvement (e.g., employment, consultancies, honoraria, stock options, expert testimony, grants or patents received or pending, or royalties) that may present a potential conflict of interest in the Attention Deficit Hyperactivity Disorder in Adults Drug Class Review.

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Study Team

Qualitative Team: Julia E. Moore, Alekhya Mascarenhas, Radha Sayal, David Flaherty, and Sobia Khan, from the Knowledge Translation Program at the Li Ka Shing Knowledge Institute

Note

Some details are censored in this report so as not to preclude publication. Publications (when available) and/or final unpublished reports will be available on the ODPRN website (www.odprn.ca).

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Executive Summary

Background: The Ontario Drug Policy Research Network (ODPRN) conducted a drug class review of medications for attention deficit hyperactivity disorder (ADHD) in adults, which was selected as part of an initiative by the Ontario Public Drug Programs to update the public drug formulary. This report highlights the findings of the qualitative study performed within the drug class review to determine the experiences of managing and treating adults with ADHD.

Methods: We conducted 25 semi-structured telephone interviews with stakeholders, including patients, primary care physicians, pharmacists, and psychiatrists. We analyzed the data using the framework approach for policy analysis.

Key Findings: Findings in this report are summarized to represent common experiences and perceptions described across patient, physician, and pharmacist groups.

Diagnosis of adult ADHD: Patient and physician participants described that the process of diagnosis of adult ADHD includes an extensive battery of tests and consideration of childhood history of symptoms. Patient participants were promoted to ask their doctor about ADHD in different ways. For example, some patients were motivated to inquire about ADHD after viewing a documentary or reading a book on ADHD where others requested information after their child or a family member was diagnosed with ADHD. Physician participants had concerns about the possibility of symptom mimicry that occurs when alternative conditions, such as depression or anxiety, can present with ADHD-like symptoms. They perceived that a key part of diagnosis should include specific investigation to rule out these conditions.

Management of ADHD: Physician participants preferred to prescribe long-acting stimulant medications to their adult ADHD patients because adults need to be active for more hours than children and because long acting medications are more difficult to misuse. In general, both clinician and patient participants found stimulant medications to be the most effective medication for ADHD management. Some physician participants perceived that the generic version of some ADHD medications (e.g., methylphenidate) may be easier to abuse than the brand name version (e.g., Concerta[®]) and may also be less effective. There was an overall consensus between clinician and patient participants that non-pharmacological approaches in combination with medications are important for proper management of ADHD.

Access to ADHD medications: Physicians and patients felt that Ontario Drug Benefit (ODB) coverage of ADHD medications is fair and reasonable. Patient participants who were receiving ODB coverage did not report any barriers to access. No patients reported having had experience obtaining medications through the exceptional access program (EAP). Most clinician participants also did not have experience with EAP or awareness of the therapeutic notes associated with Adderall[®]. Physicians may be playing an important role in access to ADHD medications because of their pharmacological and non-pharmacological treatment preferences, their willingness to provide drug cards, and the length of their referral list.

Conclusion: Overall, our findings shed light on the experiences of prescribing and using medications for ADHD in adults and unveil important information that can impact how patients in need can access these drugs across Ontario.

Background

The Ontario Drug Policy Research Network (ODPRN) recently received funding to conduct a series of drug class reviews as part of an initiative to update the public drug formulary (i.e., formulary modernization). As such, the ODPRN works closely with the Ontario Public Drug Programs (OPDP) at the Ministry of Health and Long-Term Care (MOHLTC) to select key priority areas and topics for formulary modernization, conduct independent drug class reviews, and disseminate the results of the reviews to the OPDP to facilitate informed decision making on public drug funding policies. Medications for the treatment of Attention Deficit Hyperactivity Disorder (ADHD) in adults were selected as the topic for the ninth drug class review.

Currently, there is limited information on how physicians diagnose adult ADHD and how they prescribe ADHD medications to adults. Phase 1 of the ODPRN qualitative unit work involved exploring the various factors that may be related to prescribing, dispensing, and using ADHD medications in adults. This information is important for understanding and contextualizing prescription and usage patterns in Ontario, as well as to highlight any health equity issues that may be prevalent but are currently unknown. Phase 2 of the ODPRN qualitative work assessed the social acceptability and feasibility of the final results and recommendations proposed by the ODPRN research team.

Methods: Phase 1

Design

We used a framework approach to qualitative research (Ritchie & Spencer, 1994). This approach helps researchers focus on specific areas of interest when exploring a topic using qualitative methods, which can make the findings more applicable to policy contexts than alternative qualitative procedures. However, the approach also maintains the flexibility of qualitative methodology to incorporate new ideas, emergent issues, or unanticipated results.

Sampling

Stakeholders identified for the ADHD drug class review include primary care physicians (PCPs), psychiatrists, patients, and pharmacists. Inclusion criteria were: clinicians (PCPs, psychiatrists, pharmacists) who have prescribed or dispensed ADHD medications to adults; and patients over 18 years of age who have experience using ADHD medications.

A purposive sampling approach with a convenience sample was used in order to elicit the specific perceptions and opinions of those who will be involved in or affected by drug policy decisions related to ADHD medications. Given the rapid nature of study timelines, we aimed to recruit 6-8 participants from both stakeholder groups (i.e., clinicians and patients). We

anticipated that this amount of participation may be sufficient to reach saturation amongst relatively homogenous groups of participants (Kuzel, 1999).

Recruitment methods included: a) cold calling; b) e-mailing and faxing; c) recruiting at primary care and specialist clinics; d) sending recruitment letters through e-mail distribution lists of professional organizations and advocacy groups; e) posting recruitment notices to the ODPRN website and social media (e.g., Twitter, Facebook) accounts; and g) snowball sampling (i.e., asking participants to connect with individuals they know who may be able to offer valuable insight to the issue for the purpose of recruitment to the study).

Data Collection and Analysis

Qualitative data were collected through one-on-one, telephone interviews that were 30 to 45 minutes long and conducted between March and June 2015. All interviews were conducted with a semi-structured interview guide that was developed using the “Triple-A” framework for pharmaceutical policy analysis (Morgan et. al., 2009) and input from clinicians and the drug class review team. Each interview was audio recorded and transcribed. The interviews transcripts comprised the primary source of data. The interviewer and/or a note taker took field notes during the interview to serve as a secondary source of data.

The framework approach was used to guide qualitative data analysis. Two independent analysts engaged in familiarization of the data by reading all primary and secondary data sources and generating initial codes that could be incorporated into the “Triple-A” framework (Morgan et. al., 2009). These initial codes comprised the coding framework, which was reviewed by the qualitative research team and applied to the data by two analysts during in-depth analysis. Inter-rater reliability between the two analysts was > 80%. The analysts and the qualitative research team mapped and interpreted the coded data to generate the final themes.

Phase II of the qualitative research study is described below.

Research Ethics

This qualitative study was approved by the St. Michael’s Hospital Research Ethics Board in Toronto, Ontario, Canada.

Part 3: Findings

A total of 25 participants took part in the study: 14 patients, 4 psychiatrists, 5 primary care physicians, and 2 pharmacists. Detailed participant demographics can be found in **Appendix B**.

Key Themes Related to the Prescription and Use of Medications for ADHD in Adults

DIAGNOSIS OF ADULT ADHD

- Patient diagnosis stories
- Physician diagnosis strategies
- Perceptions of adult ADHD diagnosis trends

MANAGEMENT OF ADHD

- Perceptions of factors that influence prescription
- Perceptions of effectiveness of ADHD medications
- Perceptions of misuse
- Non-pharmacological approaches

ACCESS TO ADHD MEDICATIONS

- Experiences with the Ontario Drug Benefit program
- Physicians as gatekeepers to access

Detailed findings on each of these themes are described below.

Diagnosis of adult ADHD

PATIENT DIAGNOSIS STORIES

Patient participants spoke of various journeys to discovering their diagnosis of ADHD. The majority described experiencing symptoms of ADHD since childhood, such as inability to concentrate in school, exceptional hyperactivity, and impulsivity. Participants were prompted to ask their doctor about ADHD in different ways, such as watching a documentary or reading a book on ADHD, receiving the results of workplace vocational tests, having a child diagnosed with ADHD, and receiving suggestions from others (e.g., their professor) to look into it. Only a minority of participants reported that they asked a doctor about ADHD without any external prompting.

Most patient participants who asked their family doctor about ADHD were able to get a referral to a psychiatrist, at which point participants were asked to undergo extensive testing. The testing included questionnaires, analysis of old school report cards, a psychometric battery of tests, and interviews with family members. A few participants described having challenges with getting a referral to a psychiatrist because of long wait times or due to a lack of ADHD specialists in their geographic location.

PHYSICIAN DIAGNOSIS STRATEGIES

Physician participants described a variety of diagnostic tools that they use to determine if a patient has ADHD. Some participants specifically mentioned using the tools available on the Canadian ADHD Resource Alliance website. Across all physician interviews, two key components of diagnosis were mentioned: a) looking for childhood history of symptoms and b) watching for symptom mimicry. Physician participants described not diagnosing an adult with ADHD if the patient or their family cannot recall symptoms from childhood. They believe that ADHD is a lifelong disease and not something that spontaneously arises in adulthood. Secondly, participants mentioned that certain conditions, such as anxiety or depression, can also present with ADHD-like symptoms. This phenomenon was referred to as “symptom mimicry”. Therefore, a key part of diagnosis, according to these participants, should include an in-depth investigation to rule out these conditions. They went on to say that this can be particularly challenging since most ADHD patients have additional mental health conditions. It was also suggested that patients who are going through particularly stressful life events (e.g., death of a loved one) may also temporarily experience ADHD-like symptoms.

PERCEPTION OF ADULT ADHD DIAGNOSIS TRENDS

Clinician participants perceived a rise in adult ADHD diagnosis. They attribute this primarily to the rise in awareness and resources about the condition. There were some suggestions that the level of awareness may differ amongst different geographic regions and may be dependent on the availability of local ADHD champions. Participants said that in recent years, PCPs and psychiatrists have had more access to factual, case-based information on adult ADHD diagnosis and management through clinical rounds offered at hospitals and universities. They also admitted that a large proportion of the evidence available is industry sponsored and that the drug manufacturer representatives are a visible presence both in the hospitals and in the community.

“I am much more comfortable prescribing now, than I was ten years ago.”—Primary Care Practitioner

Although awareness about adult ADHD has increased, clinician participants were somewhat concerned that not all ADHD diagnoses may be accurate. These participants believed that not all physicians are aware of the potential for ADHD symptom mimicry. They explained that physicians need to be more diligent with ruling out conditions, such as generalized anxiety disorder or depression, as well as getting a holistic picture of the patient’s health and personal life.

“Too often a quick diagnosis is made, you know if it looks like a horse, it is a horse, therefore it is a horse, ergo I am going to treat it like a horse, it gets put down as a diagnostic on the patient’s chart and forever on then the patient has adult ADHD. That degree of root cause analysis and asking the question why multiple times, why is the patient presenting this way, why do they have this, why are they experiencing this, etc. etc., is unfortunately not done in a way that I would say is an existing trend in not just Ontario but also Canada.”—Psychiatrist

Management of ADHD

PERCEPTION OF FACTORS THAT INFLUENCE PRESCRIPTION

Long-acting versus short-acting medications

Long-acting ADHD medications (e.g., Vyvanse[®], Concerta[®], Biphentin[®]) can potentially disrupt sleep. As a result, physician participants described that they prefer to prescribe longer-acting medications to their adult ADHD patients because adults need to be awake for more hours in the day compared to children. Physician participants explained that they advise adults to adjust their dosage depending on their needs for the day. For example, if the patient has a long day with multiple tasks scheduled, a physician may recommend to the patient that they take a stronger dose for a longer lasting effect. Typically, physicians said they will start patients on a low dose and titrate upwards to reach a dose that the patient is comfortable with. Patient participants also described adjusting their doses periodically to suit their daily or weekly needs.

Pharmacist participants noticed that Vyvanse[®] and Concerta[®] are commonly prescribed to adults with ADHD, and Ritalin[®] is not as commonly prescribed as it used to be. They also added that adults who are using Ritalin[®] are more likely to be using the slow release (SR) version. This finding was consistent among physician interviews. The reason for this, as described by participants, is because they want to reduce the risk for misuse of short-acting medications, such as Ritalin[®] or Adderall[®]. Both patient and clinician participants highlighted that the longer-acting formulas, such as Concerta[®], are difficult to crush, snort, or self-inject and their effects are not immediate.

“Concerta[®] is good because you can’t bypass it; it’s a multi phased, multi PH delivery system. If you were to scrape off the core then 22% of the medication will be provided, if you try to dissolve it and snort it it’s like snorting a wet noodle, and if you try to put it into a solution and mainline it, it’s impossible. It’s sort of an ideal drug for clinically to use for patients where there is a risk of dependence and misusability” – Pharmacist

Stimulant versus non-stimulant medications

Physicians described that they prefer to start ADHD patients on a stimulant medication from either the methylphenidate class or the amphetamine class. They perceived that most patients respond well to these medications. They also noticed that most patients are already self-medicating with stimulants (e.g., coffee) so they perceived it to be more natural to start them on a stimulant medication. They may prescribe non-stimulants such as atemoxetine for patients who have struggled with addiction or who have adverse reactions to stimulants. However, most clinicians in our sample did note that they rarely prescribe non-stimulants and therefore have limited experience with their use.

“1 in 5 people preferentially respond to either a Methylphenidate molecule or the amphetamine molecule, so if they fail the first trial of one or the other you have to try the other molecule” –Psychiatrist

Patient affordability

Most clinician participants described that they have noticed a shift towards long-acting medications for adult ADHD. However, some physician participants explained that they may resort to prescribing shorter-acting medications (e.g., Ritalin SR[®]) for patients who do not have private coverage and who do not qualify for Ontario Drug Benefit (ODB). They shared that the Ritalin SR[®] is the cheapest formulation available. An alternative strategy they described using for patients who pay out of pocket was to prescribe a short-acting drug that can be taken as needed in addition to a lower dose of a slightly longer-acting medication (e.g., Dexedrine[®] capsules as needed along with a daily prescription of Adderall[®]). In this way, the patient can top-off the effect of a long-acting medication with a cheaper short-acting formulation.

PERCEPTION OF EFFECTIVENESS OF ADHD MEDICATIONS

Patient perceptions

The majority of patient participants found their ADHD medication to be helpful for improving their quality of life and easing symptoms. They described improvements in the following ways:

- *“allows me to make room for judgements, and censoring what I’m going to say, before I say it”*
- *“I’m less lethargic”*
- *“reduced distractability”*
- *“stilled my mind and helped me to concentrate”*
- *“able to put my thoughts in order”*
- *“everybody else becomes more reasonable”*
- *“feels like my mind has been freed, somewhat, from being under a fog”*
- *“they’ve changed my life.”*
- *“feel a complete shift in my consciousness, my awareness and my ability to slow my thoughts down”*

A few participants perceived a difference between the brand name methylphenidate products (e.g., Concerta[®], Ritalin[®]) and the generic versions. They described that the generic form sticks to the back of their throat and that it is hard to swallow. They also perceived that it does not work as well as the brand name form.

Some participants experienced side effects to their ADHD stimulant medication, such as insomnia, loss of appetite, dry mouth, mood swings, and heart palpitations. Most participants were able to find relief from these side effects once they found an appropriate dose, with the help of a physician. Participants who described persistent side effects were also those who were using Adderall[®].

There were a few participants who are currently using, or have tried, non-stimulant or alternative medications, such as Wellbutrin[®] and modafinil. These individuals had extreme side effects to first line ADHD stimulant medications. None of these participants found non-stimulant medications (e.g., atemoxetine) to be effective.

Clinician perceptions

Clinician participants perceived that the stimulant ADHD medications are equally effective for most patients with a correct ADHD diagnosis. They observed increased focus, better

academic results, better concentration, and other improvements in their patients. However, they did mention that dose titration is key to achieve the desired effect for the desired period of time, with minimal side effects. The side effects they have seen in their patients include insomnia, weight loss, and anxiety. In addition, participants perceived that the long-acting stimulants are the most preferred for patients because they experience less highs and lows in ADHD symptom management and have to take fewer doses. When comparing generic and brand name formulations, participants believed that the methylphenidate generic version of Concerta[®] does not work as well. They perceived that the generic version delivers the same amount of medication, but not over the same time period.

When discussing non-stimulants, the majority of clinician participants did not perceive Strattera[®] or any of the other drugs in this class to be especially effective. However, most participants admitted that they did not have much experience prescribing these medications. In the case of Strattera[®], some described that it can take a long time before the patient can perceive a difference in ADHD symptoms, if at all. In terms of alternatives, a few physician participants mentioned that they have used bupropion (Wellbutrin[®]) in some patients and have found these to be effective for patients who have history of substance abuse.

PERCEPTION OF MISUSE

We asked patients about their experiences with misuse of ADHD medications. While all patient participants have heard of misuse, only a handful reported direct experience with it. Many seemed to be aware that the long-acting stimulants are less abused than the short-acting stimulants. A few patients mentioned that they have been approached to sell their medication for recreational purposes and have friends who are addicted to ADHD medication (e.g., Adderall[®]). A few other patients admitted to experimenting with a friend's ADHD medication before requesting a prescription from their doctor. The remaining patient participants did not have these experiences, but described hearing about the non-prescription use of ADHD medications amongst university students in the media and through friends/family. They speculated that some of the use may be for undiagnosed ADHD and some of it may be inappropriate use (e.g., to pull all-nighters for exams).

“I know there’s a couple people who have [had] a hard time getting a prescription... whether they really need it or whether it’s more to abuse it. There’s a demand for [ADHD medication] because not everyone can get a prescription for it. There’s a lot of scrutiny right now in terms of prescribing it to people – you have to go through more hurdles than we have in the past because of what’s happened in the last five years with prescription abuse” –Patient

“People make jokes about [misuse of ADHD medication];... Especially now that I’m back to school... some people say, “Okay. So, you’re going to school. So, are you going to sell your ADHD medication?”... It’s just jokes, but because it’s culturally...it’s part of the discourse. They think that, “Oh. You have speed there,” and... So, it’s just like a cultural kind of thing, but no. Like, seriously, no, nobody has approached me, or anything” –Patient

Most patient participants expressed that they have no desire to sell their medication because they believe it has improved their quality of life and they feel they need to reserve all of it for

their own use.

All clinician participants were also aware of the misuse of ADHD medications. As described earlier, the possibility of misuse is a decision making factor when prescribing these medications to patients. Clinician participants said they are aware that there are some patients who sell their medication illicitly.

“I think with ADHD we find that they are... It’s under-diagnosed, but also over-prescribed, which sounds weird, but it’s actually true, in my opinion. So, we have lots of kids that are actually under-diagnosed for it, but then we have lots of people that are just... Like, adults, they come in, they present the right information to the doctor, boom they get a prescription for 90, a hundred, and these people don’t even touch it. They sell it. So...definitely I’ve noticed an insane jump in ADHD-type medications, but I’m not convinced that most of it is... are for people that actually need it.” –Pharmacist

Some physician participants also pointed out that methylphenidate, the generic version of Concerta[®], may be easier to abuse than the brand name version. In cases like this, physicians described indicating “no sub” on the prescription in order to alert the pharmacy that the patient is to receive the brand name medication only. However, they also noted that the pharmacies do not always comply with this request. One patient participant described that her doctor was advocating for the brand name product but the pharmacy refused and said that they were under no obligation to offer it.

NON-PHARMACOLOGICAL APPROACHES

There is overall consensus between clinician and patient participants that non-pharmacological approaches are crucial to the proper management of ADHD. Clinician participants expressed that they tend to use a combination of pharmacological and non-pharmacological approaches. They stated that a more holistic approach is warranted since medications help reduce ADHD symptoms (e.g., hyperactivity, inattentiveness, and impulsivity); however, medications do not solve problems with planning, time management, organization, and forgetfulness. Clinician participants described three distinct categories of non-pharmacological approaches. ‘Standard motherhood’ strategies comprise the first category; these strategies promote a nutritional diet, more exercise, and better quality sleep. ‘Organizational skills’ comprise the second category; these strategies foster organizational and time management skills (e.g., using a daily planner, smart phone reminder applications) with the goal of providing structure and routine for patients. ‘Reflective exercise’ approaches comprise the third category; these approaches include cognitive behaviour therapy, biofeedback, coaching, education interventions, or peer support groups that are designed to promote self-awareness and mindfulness. Patient participants outside of the Greater Toronto Area (GTA) stated that access and availability to reflective approaches were limited. A potential fourth category identified by patient participants is naturopathic medications, such as fish oil, astaxanthin, and Khat (type of plant that is chewed); generally patients found these helped with the management of their ADHD. Clinician participants did not remark on naturopathic medications.

Access to ADHD Medications

EXPERIENCES WITH ONTARIO DRUG BENEFIT

Physicians and patients described feeling that the coverage of ADHD medications through the ODB is fair and reasonable. Some clinicians speculated that many adult ADHD patients are eligible for ODB because their condition may be rendering them unable to work.

“...with adult ADHD [one] is greatly impaired and thus their ability to work, their impairments as cognition is already higher, therefore the concern would be that they are not getting a real degree of re-integration back into the workplace that they would consider to be normal or comfortable with so I think it tends to be mainly provincial government mediated drug coverage” –Pharmacist

Patient participants who are receiving ODB coverage did not report any access barriers. No patients reported having had experience obtaining medications through the EAP. Most clinician participants also did not have experience with EAP or awareness of the therapeutic notes associated with Adderall[®]. This may be because of their preferences to prescribe stimulants rather than non-stimulants (e.g., Strattera[®]) and longer-acting agents, rather than shorter acting agents (e.g., Adderall[®]). A few physician participants described limited experience with submitting a handful of EAP applications, with mixed success. They perceived the administrative process to be time consuming. However, based on interview data, it appears that most physicians in our sample were generally not aware of the details regarding ODB's programs.

“I have learned to think a little bit more about these drug programs, [this interview] has been very useful so I am going to visit those websites and find out more about them. I have been only knowing about the Trillium program so I guess the other ones aren't as publicized” –Psychiatrist

Some psychiatrist participants were aware of the criteria; they felt that they were not in line with current clinical practice and that they need to be revised.

“...one of the difficulties with [the criteria] is they require prior treatment with short-acting meds, which really – clinically – is not what people do who treat ADHD. We don't use short-acting medicines as a starting point, because they're not as effective as the long-acting and they have a big problem with diversion so this recommendation is not a sensible one, but it's what's required by ODB– before they would approve one of the long-acting medicines and it seems to me to be a very outdated recommendation. It's not... up- to- speed with current clinical practice” –Psychiatrist

PHYSICIANS AS GATEKEEPERS TO ACCESS

Physicians may be playing an important role in access to ADHD medications because of their pharmacological and non-pharmacological treatment preferences, their willingness to provide drug cards, and the length of their referral list. Patient access to a specialist is also a key factor that determines whether they will receive a diagnosis and ultimately access to medication.

Physician provision of medication versus non-pharmacological strategies

A few patient participants expressed that they wished their doctor would have suggested non-pharmacological approaches for ADHD management, either before trying medication or in combination with their medication. They perceived that some physicians, though not all, are more inclined to prescribe medication first and offer less information on non-pharmacological approaches. Some patient participants did not enjoy the feeling of being on medication and described that they would have appreciated some guidance on other options for ADHD management. They felt that their access to ADHD medications was greater than their access to non-pharmacological strategies. Many participants learned about alternative strategies through personal research or through joining ADHD support groups.

“I’ve been encouraged to try [medications]. Now ... I realize I’m going to a psychiatrist, and I respect her very much, but it’s almost like... Yeah...I’ve been encouraged to try medications, rather than to do other potential skills-building things, or... that seems to be the first thing that’s offered to me a lot of times” –Patient

In contrast, most physician participants in our sample believed that medications must be combined with non-pharmacological strategies. They viewed medication as a tool that enables the patient to implement some non-pharmacological techniques (e.g., routines, reminders, mindfulness), which can help with long-term ADHD management.

Physician provision of drug cards

The majority of physicians in our sample mentioned that they give out drug equalizer cards or compassionate supply cards to their patients who do not have private insurance and who are not ODB-eligible. They described the cards as useful because the cards ensure that the patient is getting access to the brand name product (e.g., Concerta[®]) instead of the generic version which, as was described earlier, may not be as effective and may be more easily abused. Physicians reported a disadvantage of these cards: they are only available for a few agents and when they run out, the patient loses access to the brand name product. One example discussed was that Vyvanse[®] is useful for many patients, but is no longer available through compassionate supply.

Psychiatrist wait-times

Participants described that while ADHD may be overdiagnosed in some cases, there may also be many instances of underdiagnoses as well. A few patient participants explained that wait-times for psychiatrists can be very extensive and ADHD patients find it hard to keep track of appointments with such long time span between when an appointment is made and when it occurs. Patients described that those who have to wait a year or more for a referral through OHIP, and then miss it, will not be able to get access to an ADHD medication prescription, which will affect their quality of life, access to employment, and familial relationships.

“You have to go through a long wait list to get to see a psychiatrist for the diagnosis. It can be up to a year here, and so, in the meantime, if you have ADHD, you’re distracted, and you may move six times between now, and next year when you get a referral to a psychiatrist. So, the psychiatrist’s office will make a call to where you once lived, they’ll say the person no longer lives there, your name will get stroked, and the next time you talk to your doctor about it, the doctor will say, “Well, you didn’t keep the psychiatrist informed about your address change.” In the meantime, the

person is like, “What? You expected me to be organized? That’s exactly my problem.”—Patient

Part 4: Discussion

Key Findings

The experiences and perceptions from our interview participants have pointed to some main findings related to the prescription and use of ADHD medications for adults. First, an accurate diagnosis is a key step for adult patients to access appropriate medication. Physicians perceived that a crucial component of diagnosis should involve ruling out conditions that display ADHD-like symptoms. Once a diagnosis is obtained, physician participants prefer to prescribe long-acting stimulant medications to their adult patients mainly because these are more practical and more difficult to misuse compared to short-acting products. In general, both clinician and patient participants found the stimulant medications to be more effective than non-stimulants and other drug classes. A surprising finding was that the methylphenidate, the generic version of Concerta[®], was perceived as less effective and easier to misuse. ODB coverage of ADHD medications was perceived to be fair and reasonable and patient participants who were ODB-eligible did not describe any barriers to access. Most clinician and patient participants did not have much experience with EAP. Lastly, physicians may be playing an important role in access to ADHD medications because of their preferences for medication or non-pharmacological approaches, their willingness to provide drug cards, and the length of their referral list.

Healthy Equity Considerations

The findings from this study highlight a few key access issues for adult ADHD patients. Those who are under 65 and who do not have private insurance will have barriers to access the medication they need; this is common finding across the drug class reviews. While physicians may be able to provide drug cards, the drug card supply may be limited to certain agents or classes. If patients do not respond well to the only class for which there are cards available, they will have to pay for these medications out of their own pocket. In addition, patients outside of the GTA may find it difficult to access a psychiatrist who specializes in ADHD. Those who are able to find an appropriate psychiatrist may not be able to get an appointment in a timely fashion, since many psychiatrists have long referral lists.

Limitations

It should be noted that these interview and survey findings are not representative of the general population of individuals from which our study sample was drawn because the sample size is small and because there may be bias in sampling. The potential bias in sampling may exist because those who responded to interview or survey requests may have been more likely than non-responders to be vocal about discussing the impact of ADHD medications in adults and may be more highly involved in ADHD advocacy initiatives.

Conclusions

The findings from the qualitative study of this review on ADHD medications informed the methods of other ODPRN research units conducting studies as part of the review. Moreover, our qualitative study helped to contextualize the results of the systematic review, pharmacoepidemiological analysis, and environmental scan performed within the separate research units of this review. On a broader scale, our study findings fill a gap in knowledge on access to ADHD products for adult patients and how this may be impacted by physician and patient perceptions of these drugs. Overall, our findings shed light on the experiences of prescribing and using ADHD medications for adults, and unveil important information that can impact how patients in need can access these drugs across Ontario.

Part 5: Phase 2 Methods

Following the completion of this study and the accompanying ODPRN ADHD research studies, a consolidated report was drafted that includes a set of potential reimbursement options for the funding of ADHD medications for adults. Phase 2 of the qualitative work included assessing the social acceptability and feasibility of the options proposed through the two steps outlined below.

Soliciting Participant Feedback

Once the draft reimbursement options were developed, the qualitative interview participants from this study were invited to review all ODPRN reports from this drug class review. They were also invited to complete a brief survey about their impressions of the reimbursement options and the interpretation of the study results. This process invites participants to provide feedback on the authenticity of the study results, which is an important component of qualitative research. The survey also measured aspects of social acceptability, including affordability, accessibility, and appropriateness of policy recommendations. The survey was developed online in FluidSurvey. The study coordinator sent the survey link and report through e-mail to participants. The findings from this survey were used by the team to make any necessary revisions to the reports.

Citizens' Panel

We have recruited a diverse set of 15 individuals from the general public to form a Citizen's Panel. The Citizens' Panel provides feedback on recommendations from all drug class reviews. Feedback from participants was obtained in two surveys and a webinar using the RAND Appropriateness Method (Fitch, 2001). First, an online survey was distributed to Citizens' Panel members, asking them to read the final report and recommendations, to provide their input, and to rank the policy options. Next, Citizens' Panel members attended a webinar meeting, at which we presented key issues, findings, and policy implications, and engaged in group discussion on the recommendations. Citizens' Panel members completed a second survey after the meeting, enabling them to provide additional feedback and giving them the opportunity to re-rank the policy options. This approach allows each person to express their idea(s); each person's opinion is taken into account (compared to traditional voting where only the largest group is considered). The findings from the Citizens' Panel

surveys and discussion were used by the team to make any necessary revisions to the reports and draft reimbursement options.

Part 6: Phase 2 Results

Detailed results are censored in this report so as not to preclude publication. Publications (when available) and/or final unpublished reports will be available on the ODPRN website (www.odprn.ca).

Participant Feedback

All 25 interview participants from this study consented to being contacted to review the draft report and provide feedback on the draft options. Participants were asked to rate their level of agreement with the three draft policy options and provide comments on the two recommendations for consideration described below.

Draft Policy Options:

- 1) All stimulant products on General Benefit and atomoxetine on EAP (status quo).
- 2) List atomoxetine as Limited Use (for adults).
- 3) No age restrictions should be applied to stimulants or atomoxetine.

Recommendations for consideration:

- 1) Monitor the cardiovascular safety of stimulants and atomoxetine, especially in older adults with related medical conditions.
- 2) Health care practitioners should remain vigilant about the potential for misuse/abuse/diversion of stimulant medications.

Participants were in strong agreement with draft policy options two and three. However, there was a lot of variability with draft policy option 1 with the majority of responses being grouped at opposite ends of the spectrum. Participants did not provide any additional comments in regards to the draft policy options.

Overall, participants were in agreement with both recommendations for consideration. However, the participants expressed concern and caution with recommendation two because they believed this recommendation can increase stigmatization around the ADHD condition, which may result in a decrease of access for individuals that truly need the medication.

Citizens' Panel

The ODPRN Citizens' Panel meeting took place on Tuesday November 10th, 2015. There were nine members in attendance during the meeting. Seven members completed the pre-meeting and the post-meeting survey.

Overall, panel members found draft policy option two to be the most acceptable, which was followed by draft policy option three and one (Table 1). Panelists ranked policy option two as most acceptable because they believed it increased access to individuals who require a non-stimulant medication and the cost could be lowered through generic pricing. There was some

debate whether atomoxetine should be listed as general benefit as opposed to limited use. However, many agreed that there should still be some oversight in prescribing because of the limited research available for the broader population. Draft policy option three received mixed reviews with some feeling the age restriction should not be removed until more research in older age groups is conducted, whereas other felt the restriction should be lifted due to the growing adult population in need of these drugs. The panel was in unanimous agreement that the listing should not remain as status quo (the draft policy option 1). One person elaborated:

“Burdensome process for any patients who require atomoxetine. Limits access to non-stimulant option, and does not address the economic benefit that can be obtained from adding this drug to the formulary.”

Panel members were in favour of both recommendations for consideration. However, the group had questions as to how these recommendations would be enforced and monitored.

Table 1. Overall post-meeting option ranking

	Mean Ranking (1 = Most Acceptable 3 = Least Acceptable)
	Post-meeting
Option 1: All stimulant products on General Benefit and atomoxetine on EAP (status quo).	2.9 (0.4)
Option 2: List atomoxetine as Limited Use (for adults).	1.1 (0.4)
Option 3: No age restriction should be applied to stimulants or atomoxetine.	2 (0.6)

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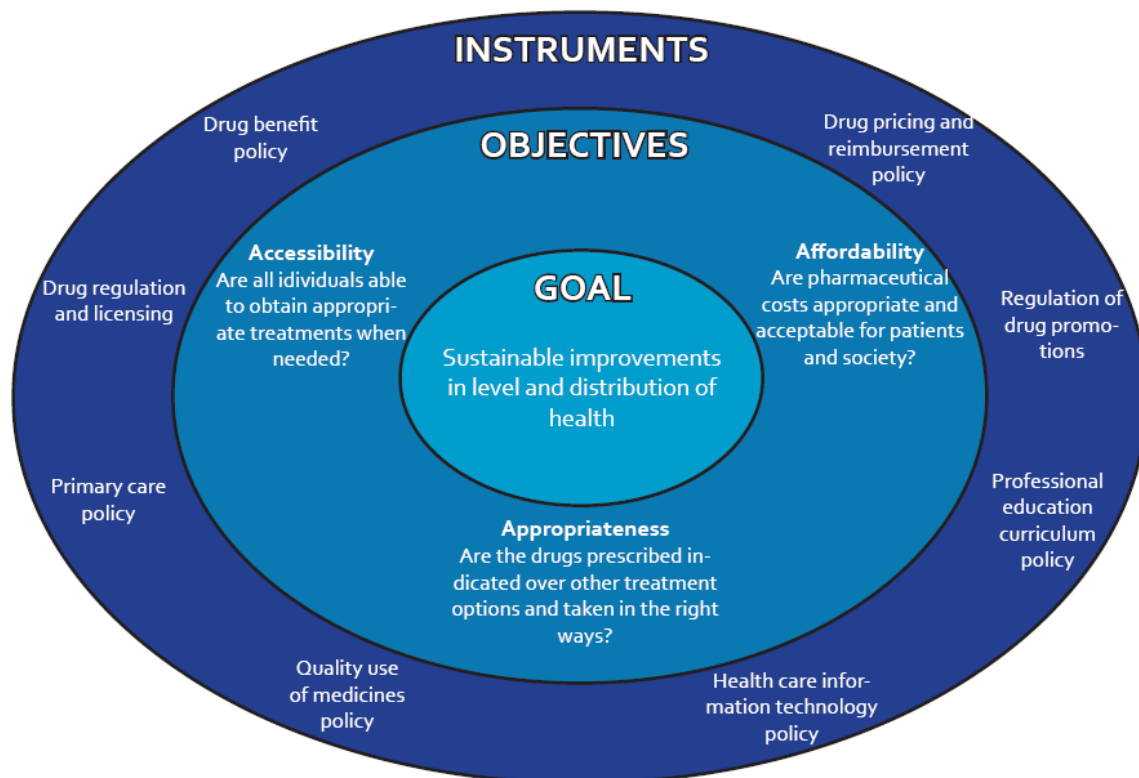
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Appendix A: “Triple-A” Framework for Pharmaceutical Policy Analysis



Adapted from: Morgan S, Kennedy J, Boothe K, McMahon M, Watson D and Roughead E. (2009) Toward an Understanding of High Performance Pharmaceutical Policy Systems: A “Triple-A” Framework and Example Analysis. *Open Health Services and Policy Journal*:2; 1-9

Appendix B: Participant Characteristics and Demographics

Clinician Demographics Characteristics (n = 11)		N	%
Type of Clinician			
Primary Care Doctor		4	36%
Psychiatrist		5	45%
Pharmacist		2	19%
Years of Practice			
3-15 years		3	27%
>15 years		8	73%
Work setting			
Urban		10	91%
Rural		1	9%

Patient Demographics Characteristics (n = 14)	N	%
Gender		
Male	9	64%
Female	5	36%
Years since diagnosis		
< 5 years	2	14%
5 - 15ears	7	50%
>15 years	5	36%
Current Medication		
Adderall XR	4	29%
Vyvanse	2	13%
Concerta	4	28%
Ritalin	1	7%
Strattera	1	7%
Modafinil	1	7%
Other (natural product astaxanthan and fish oil)	1	7%
Age		
25-34	1	7%
35-44	4	29%
45-54	5	36%
55-64	3	21%
65+	1	7%
Drug Coverage		
Ontario Drug Benefit	5	36%
Private Insurance	4	28%
Out of Pocket	5	36%

