

The Ontario Drug Policy Research Network Drug Class Review on Atypical Antipsychotics in Dementia Care

Final Report of Qualitative Study Results

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

Alekhya Mascarenhas, Radha Sayal, and Julia Moore

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Executive Summary

Background: The Ontario Drug Policy Research Network (ODPRN) conducted a drug class review of atypical antipsychotics (AAP) for the management of behavioural and psychological symptoms of dementia (BPSD), which was selected as part of a formulary modernization initiative by the Ontario Public Drug Programs. This report highlights the findings of the qualitative study performed within the drug class review to determine the experiences of managing BPSD with AAP.

Methods: We used qualitative methods in a framework approach. One-on-one telephone interviews were conducted with 8 family members of dementia patients, 8 physicians (primary care physicians [PCPs], long-term care physicians, geriatricians, geriatric psychiatrists), 3 health navigators (nursing home administrator, community care access center (CCAC) worker, Behaviour Support Ontario worker), and 4 nurses/support staff. Interviews were recorded and analyzed using a framework for pharmaceutical policy analysis (i.e. the “Triple-A” framework: affordability, appropriateness, and accessibility of medications). Emergent findings were integrated to our framework, and the framework was adapted to convey specific experiences and perceptions relevant to appropriateness and accessibility of AAP.

Key Findings: Findings in this report are summarized to represent common experiences and perceptions described across family member and clinician groups.

There are multiple factors which may influence the prescription of AAP in dementia care: These include – consideration of harms versus benefits, caregiver burnout, as well as availability and effectiveness of alternative medications and non-pharmacological approaches. Risperidone and quetiapine were perceived as the most commonly used AAP. The varying effects of sedation, risk of extrapyramidal syndrome, and timeliness of drug effects were commonly described reasons for choosing between AAP drugs.

The appropriateness of AAP in dementia care may vary from one case to another: Participants perceived that it is challenging to come to a universal conclusion about appropriateness because there are multiple individual level considerations. Clinicians described the importance of using clinical judgment about the underlying causes of responsive behaviours (e.g., depression, delirium, chronic confusion, etc.), and informed discussions with family members.

Participants believe that there is a place for AAP in dementia care but that there are occasions where their use can be avoided: There may be fewer prescriptions in the community, though it may be more challenging to monitor patients who use AAP. Participants described a greater use of AAP in acute care and long-term care due to the severity of patients’ dementia and the environmental triggers in these settings. They perceived that there is more awareness now about the safety concerns with this drug class and significant efforts are being made to encourage optimal prescription. However, there may be occasions where AAP use could be avoided or monitored more carefully.

Participants described some key barriers to the appropriate use of AAP in dementia care: The key barriers include: improper transfer of patient medical information across settings, high staff turnover, inability to provide individualized care, limited health care provider expertise, provider resistance to appropriate prescribing practices, varied implementation of existing policies. and supports to encourage appropriate prescribing.

Conclusion: The findings from the qualitative study of the AAP drug class review informed the methods of other ODPRN research units conducting studies as part of the review and helped to contextualize the review’s results. Overall, our findings shed light on the experiences of prescribing AAP for the management of dementia and unveil important information that has the potential to impact dementia care across Ontario.

Part 1: Introduction and Background

The Ontario Drug Policy Research Network (ODPRN) is conducting a series of drug class reviews as part of an initiative to update the public drug formulary (i.e. formulary modernization) in Ontario. In collaboration with the Ontario Public Drug Programs (OPDP) and the Ministry of Health and Long-Term Care (MOHLTC), atypical antipsychotics (AAP) for the management of behavioural and psychological symptoms of dementia (BPSD) were selected as a key priority area and topic for the ODPRN’s sixth drug class review.

AAP is a group of drugs which can be used for the management of BPSD. While there are 9 AAP available in Canada, only one (i.e., risperidone) is officially labeled for use in dementia. All the remaining AAPs are labeled for psychosis in conditions such as schizophrenia, bipolar disorder, and/or depression. The 2012 Canadian Consensus Guidelines recommended that risperidone, olanzapine, and aripiprazole be used for severe agitation, aggression, and psychosis associated with dementia, where there is risk of harm to the patient or others (Gauthier, 2012). However, given that these drugs have a black box warning, the potential benefit of all antipsychotics must be weighed against the significant risks, such as cerebrovascular adverse events and mortality.

Currently, there is some speculation regarding the use of AAP for elderly dementia patients in long-term care (LTC). A recent study revealed that serious adverse events—which cause hospital admission or death, are frequent following the short-term use of antipsychotic drugs in older adults with dementia (Rochon, 2008). There is limited information on how physicians decide to prescribe AAP and on the context for AAP use in LTC facilities, acute care, and the community.

The purpose of the qualitative study being conducted as part of the ODPRN drug class review on AAP was to explore the various factors that may be related to AAP prescription and use for the management of BPSD. This information was needed to understand and contextualize prescribing and usage patterns in Ontario, as well as to highlight any health equity issues that may be prevalent but are currently unknown. The findings from the qualitative study were also used to inform the research plans of the other drug class review research units to ensure that stakeholder issues and priorities were being considered in their analysis.

Part 2: Methods

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 than alternative qualitative procedures. However, the approach also maintains the flexibility of qualitative methodology to incorporate new ideas, emergent issues, or unanticipated results. The framework selected for this study was the “Triple-A” framework (see **Appendix A**) for pharmaceutical policy analysis developed by Morgan et al. (2009). This framework highlights the need to explore affordability, accessibility, and appropriateness of drug classes when determining policy-relevant issues.

Sampling

Stakeholders identified for the atypical antipsychotics drug class review include: primary care physicians (PCPs), LTC physicians, geriatricians, geriatric psychiatrists, pharmacists, health navigators, nurses, support staff, and family members of patients. Inclusion criteria are: clinicians (PCPs, geriatricians, geriatric psychiatrists, LTC physicians) who have prescribed or dispensed atypical antipsychotics to elderly dementia patients and family members of elderly dementia patients who have current or prior experience using atypical antipsychotics. The nursing and support staff group includes nurses or personal support workers, who have experience providing care and administering atypical antipsychotics to elderly dementia patients. The health navigator group includes staff from community care access centers, such as case managers or nurse practitioners, as well as hospital discharge workers or social workers, who may have experience coordinating care for elderly dementia patients.

A purposive sampling approach was used to obtain a convenience sample in order to elicit the specific perceptions and opinions of those who will be involved in or affected by drug policy decisions related to atypical antipsychotics. Given the rapid timelines for this study, we aimed to recruit 6-8 participants from all stakeholder groups (clinicians, family members, and health navigators). We anticipate 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 (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, semi-structured telephone interviews that were 30 to 45 minutes in length and conducted between August and November 2014. All interviews

were conducted with a semi-structured interview guide 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. Interviews were transcribed and 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 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 to the “Triple-A” framework (Morgan et. al., 2009). This comprised the coding framework, which was reviewed by the qualitative research team and was then 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 engaged in mapping and interpretation of the coded data to generate the final themes.

Research Ethics

This study was approved by the St. Michael’s Hospital Research Ethics Board in Toronto, Ontario, Canada in August 2014.

Part 3: Findings

Participant Demographics

Family Members of Patients

A total of eight family members of patients with dementia were interviewed (family members and individuals with dementia will from here on be referred to as participants and patients, respectively). The patient group was composed of 5 (63%) males and 3 (37%) females. Across the group there were a variety of different dementia diagnoses, such as vascular, temporal, Lewy body, and Alzheimer’s. The most popular AAP being prescribed was quetiapine (Seroquel[®]) (n=5, 63%).

Physicians

There were a total of eight physicians that participated in the study; 2 from each clinical stakeholder group (i.e., primary care physicians (PCPs), LTC physicians, geriatricians, and geriatric psychiatrists. Majority of the clinicians have been practicing for more than 15 years (n=7, 87%). Of the clinicians that were included in the study, 6 (75%) practiced in urban settings and 2 (25%) practiced in rural settings.

Health Navigators

There were three health navigator participants: a LTC home administrator, a community care access center (CCAC) case manager, and a Behaviour Support Ontario worker. The majority of participants work in urban settings (n=2, 67%) and have been practicing for fewer than 5 years (n=2, 67%).

Nurses & Support Staff

Nurses with current or past experience in each of the practice settings (hospital, community, not-for-profit LTC home, and for-profit LTC home) were interviewed for the study. The majority of participants worked in urban settings (n=3, 75%) and have been practicing for more than 15 years (n=3, 75%).

Pharmacists

We were not successful with recruiting pharmacists to participate in this study. Pharmacists who have experience specifically with dispensing antipsychotics in the elderly are only a subset of all Ontario pharmacists.

Detailed participant demographics can be found in **Appendix B**.

Key Themes Related to the Management of Dementia with Atypical Antipsychotics

The following findings are based on the experiences and perceptions of interview participants, which have been summarized into four themes.

Prescription of atypical antipsychotics in dementia care

- Rationale for prescription
- Non-pharmacological approaches
- Alternative Medications

Perceptions of appropriateness of atypical antipsychotics in Ontario

- Clinicians
- Family Members

Perceptions of prescription trends of atypical antipsychotics in Ontario

- LTC
- Community
- Acute care

Factors that influence the prescription & use of atypical antipsychotics across settings

- Inadequate information transfer
- Staff turnover
- Lack of individualized care
- Stakeholder resistance
- Limited health care provider expertise
- Varied implementation of existing policies

Detailed findings on each of these themes are described below.

Prescription of atypical antipsychotics in dementia care

Common Rationale for Prescription & Monitoring

There are many factors that physicians may consider when prescribing AAP to the elderly population. Most physician participants within our sample used the Canadian Consensus Guidelines for the Treatment of Dementia as a guide for when to prescribe AAP to their elderly patients (Gauthier, 2012). These guidelines state that AAP can be used for agitation, aggression, and psychotic symptoms. Although participants' prescribing decisions were aided by the guidelines, they emphasized that there are various contextual factors that need to be examined; for example, they may consider responsive behaviour triggers, non-pharmacological approaches, access to health services, type of accommodation (community or long-term care), caregiver burnout, co-morbidities, alternative medications, and the patient's risk of harming themselves or others. Physician participants further explained that if they believe potential benefits outweigh medication risks they will prescribe AAP. When asked about the AAP black box warnings, most did not perceive that the introduction of these had any significant impact on their prescription habits or those of other physicians across Ontario. They also described their preferences for specific drugs within this class. *Table 1* summarizes participants' thoughts on the pros and cons of various AAP medications.

Physician participants were in agreement that monitoring is a vital component of their AAP prescription protocol. They explained that their monitoring strategy differed by practice setting; in a LTC facility they are able to monitor patients more closely than in the community, where patients are not monitored 24 hours by health care providers. Study participants explained that during the monitoring process close attention is given to patient factors, such as number of behaviour incidents, gait, tiredness, and mood. Most physician participants stated that after initial prescription of AAP they engage in a two week monitoring period to determine how patients are responding to the medication. This is followed by quarterly medication reviews to determine whether AAP is still beneficial for the patient. Physician participants explained that if there is a sustained decrease in responsive behaviours, they will begin to taper the dosage of AAP with the goal of discontinuing use.

Table 1. Perceived Pros and Cons of Atypical Antipsychotic Drugs

Drug Name	Perceived Pros	Perceived Cons
Risperidone (Risperdal[®])	<ul style="list-style-type: none"> • More commonly used, more clinical experience with dose range • Does not overly sedate patients • Works well for active delusions, hallucinations, & 	<ul style="list-style-type: none"> • Risk of extrapyramidal syndrome • More side effects than other AAP • May cause restlessness and akathisia in some patients

	<ul style="list-style-type: none"> paranoia • Has Health Canada approval • Fast acting –compared with other AAP 	
Quetiapine (Seroquel®)	<ul style="list-style-type: none"> • More commonly used, more clinical experience with dose range • Less risk of extrapyramidal syndrome • Useful for patients with night-time disturbances or insomnia 	<ul style="list-style-type: none"> • Risk of over sedation & falls • Perception that recent literature that may show it is less efficacious • Effects take a while to manifest
Olanzapine (Zyprexa®)	<ul style="list-style-type: none"> • Recommended by Canadian consensus guidelines 	<ul style="list-style-type: none"> • May cause increases in blood pressure – not ideal for diabetic patients
Aripiprazole (Abilify®)	<ul style="list-style-type: none"> • Does not overly sedate patients 	<ul style="list-style-type: none"> • Still developing comfort level with dose range

Non-Pharmacological Approaches

There was one prevalent non-pharmacological approach that emerged across all stakeholder interviews. This approach integrated both a patient and clinician driven component. The patient driven component involved individualizing care by understanding the patients' history. This entailed gaining knowledge of patient preferences, dislikes, hobbies, personality, and medical history. The clinician driven component focused on behaviour modification around approaching patients for care. Clinician participants have noticed that a health care provider's tone of voice, gestures, and body language can have a significant impact on interactions with patients. Some clinical participants have used the Physical, Intellectual, Emotional, Capabilities, Environment, and Social (PIECES) approach (Collins, 2010) to gain a deeper understanding about their patients; clinician participants felt this approach better equipped them to manage patient triggers. Other clinician participants have used the Gentle Persuasive Approach (GPA) (Advanced Gerontol. Ed., 2010), which is a set of techniques designed for a healthcare professional to aide dementia patients in a non-punitive, dignified, and self-protective manner by focusing on unmet needs, personhood, and body-containment strategies.

“PIECES, GPA, they are all, I feel the basic ideas is about the same. When it comes to behaviours, behaviour problems of dementia, a lot of them we call it responsive behaviours because it's the patients' response to their perception of the environment. So when the staffs approach them for care they might perceive it as a threat. So they feel they are being threatened and they get scared and they attack as a response, so that's why we call it responsive behaviours and I find the present, how the staff present themselves is very important, how they approach the person and for example the way they talk. There was one personal support worker that I know, she was able to provide care much better than some of the others, and then she basically, her study is talking to them. So during the whole care provided she would talk to them and make it as casual as possible and make them feel comfortable and feel, not feeling anxious or anything.” - nurse

One clinician gave the example of a patient who refused care during bath time because she was only accustomed to taking bubble baths. So, the clinician worked with the home to accommodate this preference and the patient's responsive behaviours subsided. Other strategies around individualized care that can help patients manage their triggers are engaging them in activities that they enjoyed prior to their diagnosis, such as socially stimulating activities, listening to a favourite band, going for walks, or being around animals. Clinicians and family members of patients described the use of these approaches was dependent on individual staff as well as the culture within a LTC home. The participants described non-pharmacological approaches as beneficial in the management of BPSD. Participants felt an increase in non-pharmacological approaches could help reduce the use of AAP in certain circumstances; however, they believe these approaches are labour intensive and are not always feasible to implement within the current LTC home staffing and resource structure.

Alternative Medications

Physician participants explained that they would use an alternative medication to an AAP if there were either safety or onset of effectiveness concerns. The two most common groups of alternative medications described by participants were typical antipsychotics and antidepressants. Typical antipsychotics such as haloperidol (e.g., Haldol®) were prescribed usually in an acute care setting when immediate and short-term relief was required. Some perceived that the black box warnings implemented for atypical antipsychotics may have influenced some physicians to defer to typical psychotics.

“In an acute situation like that, more often I see Haldol® being used, right? If somebody is trying to leave the hospital, they're agitated, they're getting physically aggressive, they may use Haldol® or Ativan® to calm them down. They wouldn't probably use the atypicals in that situation.” – geriatrician

Antidepressant medications (e.g., trazodone, citalopram) propose fewer risks than an AAP; therefore, when trying to manage BPSD, participants would sometimes start a trial of an antidepressant first. Another alternative medication reported by participants was benzodiazepines (e.g., lorazepam); however, participants limited the use of this medication because of its associated risks. Overall, physician participants stated there are few alternative medications to AAP for the management of BPSD.

Theme Summary:

There are multiple factors which may influence a physician's decision to prescribe an atypical antipsychotic to an elderly dementia patient, but it usually involves:

- Careful examination of harms versus benefits
- Consideration of alternatives
- Follow-up with monitoring of quality of life and effectiveness.

Non pharmacological approaches may be effective and can include:

- Strategies aimed at understanding individual patient behaviour (e.g., PIECES)
- Strategies aimed at changing clinician approaches to care (e.g., Gentle Persuasive Approach)

The most commonly mentioned atypical antipsychotics used were risperidone and quetiapine. The most commonly mentioned alternative medications for dementia patients were anti-depressants and typical antipsychotics.

Perspectives on appropriateness

Discussions about appropriateness are important given the safety concerns associated with this drug class. Following conversations about rationale for prescription, participants went on to describe their perspectives on appropriateness.

Clinician Perspectives

Clinician participants believed that the term “appropriate” may be not be interpreted adequately by decision makers, researchers, and journalists. Due to recent attention in the media, some have felt that all use of AAP has been deemed as “inappropriate” without proper understanding of the availability of alternatives, caregiver burnout, patient quality of life, and the nature of dementia. In some cases, participants described patients who started a course of AAP and “came back to life”, with both family members and clinicians noticing a marked improvement in quality of life.

“So, there's this disconnect between my... as a clinician, seeing somebody who's psychotic, and attacking people, and we've done all the behaviour management we can, but we need to use the anti-psychotics for the safety of that individual and everyone else, that's gonna be triggered at the Canadian Institute for Health Information as inappropriate anti-psychotic use. So, it's... unless we can address that data quality, or that data point it's going to be an uphill battle, because sometimes it is appropriate to use these medications and our guidelines support that. There is Health Canada approval for at least one of these medications. So, that to me is the big elephant in the room that's making this discussion way more complicated than it really should be” –LTC physician

Clinicians explained that the decision to prescribe is a complicated one and that “appropriateness” should be determined on a case by case basis – rather than blanket statements or provider-driven

protocols. What is appropriate for one patient may be different for another patient, depending on the individual and the processes and causes that are underlying their responsive behaviours. For example, a patient may need a short course of AAP because of temporary delirium or depressive illness and another may need a longer course of AAP because they may have significant dementia and misinterpretation of their environment in a chronic way. Similarly, what was appropriate for one patient at one time may no longer be appropriate for the same patient in a different circumstance.

“I remember this one lady said to me after we struggled for about 6 or 7 months and identified, I identified that perhaps we needed to look at, and this was the first time that I did it, identified a possibility of using an antipsychotic, and we came to the conclusion after the conversation that this was probably appropriate. And she came to me a week and a half later and she said good grief Dr. XXX why? I have my mother back, why didn’t you tell me about this before? And so I stopped her from having the information to be able to make the kinds of decisions that she needed to make and the array of decisions along with her mother about this particular issue.” – geriatric psychiatrist

Overall, clinicians in our sample believed that there is a place for AAP use in LTC and that most severe dementia patients need a combination of both non-pharmacological approaches and medications. A few clinicians were more cautious than others, but all mentioned that they are very cognizant of safety concerns with this drug class.

Family Member Perspectives

Family members had various levels of knowledge about AAP and this, along with their personal beliefs, influenced their perceptions of appropriateness. With the exception of two family members, most participants wished they had more information about the use of AAP and the ability to make informed decisions about their loved one; the remaining participants included one retired nurse and another who made it her mission to do her own research on medications for dementia. One family member described an experience where LTC staff told her that her father could be legally charged for responsive behaviours if he was not put on regular AAP. To a lesser degree, a few other participants described feeling obligated to agree with the doctor’s recommendation to prescribe AAP, without a complete understanding of the drugs’ purpose or side effects. Only later in their journey of learning about dementia did some form a clearer understanding of AAP to develop stronger beliefs and opinions. Some see AAP as a form of “chemical restraint” or “snowing” a sick parent, while others see it as a lesser of two evils – a necessary measure to ensure their loved one’s comfort and safety as well as the safety of others. Both family member and clinician participants expressed that the decision about what is “appropriate” should include an informed discussion with the family member and the inclusion of their beliefs about appropriateness.

“In the beginning, in those hospital days, I think they did more harm than good. And maybe lasting harm, I don’t know, right. I will never know. But now at the home I feel that she, I don’t think she could live without atypical antipsychotics with any sense of peace. No matter what they did behaviourally. I think they are doing both and they are doing both well. But back then, not so much.”—family member

“There is another head nurse there who I enjoy her company and her personality very much, but she is the first one to give him a PRN (as needed dose) so he is cooperative, so that is how she deals with it, because of her coping skills, or she is not as intelligent or whatever it is, she has also been there a long time, but her approach is different. So and her approach isn’t my approach. Now it might be somebody else’s approach, it might be fine with somebody else to just drug your loved one up more. But it’s not mine.” –family member

Please note that, after this section, we will be defining “appropriate use” as the necessary and safe use of AAP in dementia care, with the goal of improving quality of life and reducing imminent harms.

We will define “inappropriate use” as:

- a) Unnecessary prescription of AAP which could be avoided with non-pharmacological approaches
- b) Unnecessary prescription of AAP which could be avoided with proper monitoring and tapering strategies
- c) Unusually high doses of AAP in the elderly which are used only in younger adults

These definitions are based on the findings from interviews.

Theme Summary:

The discussion about appropriateness is a complicated one and conclusions may vary from one case to another. It was suggested that some stakeholders may not have a complete understanding of the complexities surrounding the term “appropriateness”.

Conclusions about appropriateness can be influenced by:

- Family member knowledge & beliefs
- Clinician interpretation of underlying causes of responsive behaviours (i.e., Depression, delirium, chronic confusion, etc.)

Participants believed that AAP are a key drug class in the treatment of dementia and that family members should be included in informed discussions about appropriateness.

Perceptions of prescription trends in the community, acute care, and LTC

We asked participants to describe their perceptions of the differences in prescription of AAP across different settings.

Community Setting

“You have to remember that, that it’s very difficult for, you know, an 80-year-old frail spouse to do behaviour modification or to change the environment” –Geriatric Psychiatrist

Most participants perceived that AAP use in the community is not as common as in LTC because dementia patients may be less advanced in their disease. However, in some cases physicians may choose to prescribe AAP if a severe patient is either waiting to get into LTC or the family prefers to keep them in the community. Caregivers in the community may not be equipped to manage BPSD and this is an important factor that physicians and specialists in the community may be taking into consideration when prescribing AAP. There was some concern about inappropriate use of AAP in the community, mostly due to a lack of expertise amongst physicians and the challenges with monitoring and tapering patients. Unlike acute care and LTC, primary care physicians may only see outpatients once a week or less. As a result, it is difficult to document behavior and gauge the effectiveness of medication trials. This may also mean that patients in the community are on longer courses of AAP than those in other settings.

Acute Care Setting

“I would see patients with responsive behaviours in the acute care setting, and I felt we were poorly equipped to manage those behaviours, both from an understanding of the behaviours, and then having the tools to manage those behaviours” –nurse

“Acute care is for acute care issues. Unfortunately people with dementia sometimes have acute care issues and then in, in a new environment, behaviours escalate.” –primary care physician

Participants across groups believed that AAP use is high in acute care settings. This is because patients who end up in hospital are usually in crisis and may be experiencing delirium. In addition, the environment in acute care can be over stimulating (e.g., overcrowding, noise, neighbouring patients, etc.) and can trigger more responsive behaviours for patients who are unused to this setting. In most cases, participants described that AAP is prescribed for short term use during acute care stays. However, there may be instances where AAP prescription could have been avoided. Suspected reasons for inappropriate use of AAP in acute care were mainly health care providers’ lack of expertise and time to devote to complex patients. Participants explained that many dementia patients’ experience with AAP can begin in an acute care setting.

LTC Setting

“I think that with the media [describing AAP over-use], they need to go and spend some time in a LTC home and see the types of behaviours that are really there, right?” –health navigator

“I think there was probably an over-use at some point. I would say now that there’s probably judicious use. I think it’s used carefully now. I’m seeing less use. There’s a place for it, and no, I don’t see that the patients are routinely over-sedated on anti-psychotics. That’s not what I see.” –nurse

“Some physicians tend to use it more often and some do not use it that much, so there’s a big difference between different nursing homes when it comes to the use of antipsychotic drugs and I really, I don’t think it’s overused” – nurse

There were a variety of perceptions about AAP use in LTC. However, across all groups, participants believed that the media has over exaggerated concerns about overuse of AAP in LTC. While some definitely perceived areas for improvement, the overall perception was that there is more awareness now about the safety concerns of AAP than in the past, and some significant efforts are being made to encourage optimal prescription and monitoring. Many LTC homes regularly access supports, such as Behavioural Supports Ontario (BSO) or the Geriatric Mental Health Outreach Teams (GMOT). These groups were cited as important resources for aiding staff to prepare individual plans for BPSD management, which include AAP as well as non-pharmacological approaches. However, not all homes across the province may be accessing these supports and there may be some inappropriate use of AAP still occurring in LTC. Similar to acute care and the community, health care provider lack of expertise, time, and workload were key obstacles to implementing appropriate prescribing practices in LTC.

Theme Summary:

Participants perceived slightly different trends in prescription across settings.

Community:

- not as commonly prescribed as in LTC, because patients may be less severe
- proper monitoring can be challenging

Acute care:

- highly prescribed because of crisis situations (i.e., delirium or illness)
- environment contains triggers for increased responsive behaviours

Long term care:

- not over-used as compared with perceptions in the media
- more awareness now about the safety concerns and significant efforts being made to encourage optimal prescription

Barriers to the appropriate use of atypical antipsychotics across settings

The previous section alluded to a number of factors which may impact AAP across the community, long-term care, and acute care settings. Some factors influence the use of AAP when it could have been avoided and others act as obstacles to the use of AAP when it would have increased a patient's quality of life and reduced the potential for harm to themselves or others. Each of these is described in more detail below.

Inadequate information transfer across settings

“They come with a nice CCAC, you know, portfolio and information, but that’s not enough for me, as a receiving physician, to determine whether they should stay on the medications that they’re on” –LTC physician

All participant groups mentioned that insufficient collection and transfer of patient medical history can play a key role in the prescription of AAP. In certain cases, lack of information may have influenced physicians to keep patients on a course of AAP for longer than necessary as they transfer from one setting to another (e.g., acute care to LTC). Community care access center (CCAC) case managers conduct interviews with family members and patients, however, participants described that the information gathered is not adequate. CCAC patient reports are used by LTC physicians when a new patient is admitted from either the community or acute care into a LTC home. The interviews are typically conducted in the mornings or afternoons when the patient is more likely to be lucid. Many dementia patients suffer from what is known as “sun-downing”, where they display severe responsive behaviours in the evenings. It was suggested that the CCAC may not be capturing the true picture of a patient’s condition and this may impact their access to care and appropriate treatment.

Staff Turnover

“I feel that the full time consistent staff are adjusting the timing of the dose so that she sleeps through the night. The weekend staff, absolutely... I don’t think they are. I don’t... I have never seen, I guess, to see the hours, but they don’t seem as consistent staff. Do you know what I mean? It’s all these different people, and I don’t think they’re following it as best as we’d like it to be followed, because mostly, you know, weekends seem to be when she has her meltdowns, we call them. Pretty consistent it’s the weekends.” –family member of patient in LTC

Family members described having many different CCAC case managers, each starting with little to no knowledge of the patient’s history and the family’s concerns. This made it difficult for accurate and ongoing data collection on the patient’s care needs. Similarly they also described that personal support workers (PSWs) and nurses, either provided by the CCAC in the community or in other settings, were often not the same person and each would have various levels of expertise with dementia care. This resulted in suboptimal care and reduced opportunities for ongoing implementation of non-pharmacological interventions or AAP management strategies. The same challenge occurs in acute care where staff work on shifts and the same patient may receive care from multiple nurses throughout their stay.

Lack of individualized care

“It’s true that if you do everything you can do, for the behaviour management, you might be able to make it, like if you provide one to one care. If this person has a one to one, and then has free access to anything then maybe we can manage the behaviour without medications. But it’s not the reality, we can’t, we can’t provide one to one care. And there’s, the ratio in the nursing home is one to ten or more,

I mean one PSW to ten residents or even more. So how could you expect this one PSW to manage 10 people with severe behaviour issues without any medication?” –LTC nurse

Many clinician participants described that knowing each patient’s personal history, as well as likes and dislikes, can make a huge difference with mitigating responsive behaviours and reducing the number of occasions where an AAP dose is required. The turnover of staff across settings means that there are fewer opportunities for staff to observe patients over time and learn how to tailor their care strategies. Family members have described that patients may respond well to a particular health care provider (HCP) who knows their triggers and works to avoid them. Getting to know the person behind the disease was described as challenging given that LTC facilities and hospitals are short staffed, with each HCP potentially attending to a large case load of severe dementia patients. Clinician participants noticed a reduction in responsive behaviours in LTC residents who received individualized care from privately hired PSWs. One family member described her experience of living in the LTC facility a few days a week to provide one-one-care for her father while he transitioned into the new environment; she observed that the staff were stretched and would not have been able to provide the same care.

Limited Health Care Provider Expertise

“She wanted to leave, because she wanted to go to the bank, and she was at the door, “I want to go the bank. I want to go the bank. I want to go the bank. I want to go to the bank,” and one of the nurses on the floor said, “You can’t go to the bank. You’re on a From 1,” and so there was a catastrophic reaction, and then they gave her an anti-psychotic. Now, the other way of handling that is, when she says, “I want to go to the bank. I want to go to the bank,” if you’re understanding her, and understanding cognitive impairment, you can say to her, “it’s only 8 o’clock in the morning. The banks are closed right now. What do you think of...? Which bank do you go to? Oh, you go there. I go there too. What do you think of their service?” So, you can use diversion... and you may have to do that 20 times a day, because she’ll keep going back to the door, “I need to go to the bank,” but if you know how... the approaches with her, you can distract her, and not use any anti-psychotics.” –nurse

As mentioned in the previous section, participants described that a huge barrier to appropriate AAP use is that many HCPs do not have expertise in managing dementia patients and AAP across settings. One family member shared an experience of how her mother received a diagnosis of dementia only after calling the police. Her family doctor did not detect how severe the dementia was, though she went for regular checkups. In another example, acute care nurses pulled aside a family member warning her that her father’s prescribed medication was unnecessarily sedating him. The family member perceived that this physician in charge did not have the knowledge of appropriate dosing for the elderly. An elderly participant whose husband is in LTC described walking in on PSWs who were forcing him to undress without any sense of how to approach a patient with cognitive impairment.

Participants believed that in the community, especially in rural areas, there are fewer specialists, such as geriatricians or geriatric psychiatrists. They described the utility of consultants, such as the BSO or GMOT teams, who help HCP to develop care plans for particularly severe patients.

Participants explained that there is a need for specialists to take their knowledge and translate it outside the hospital – for example, by acting as regular consultants for family health teams. Some clinician and health navigator participants described providing educational meetings for physicians and other HCP in order to meet an expressed need and desire to learn more about dementia care and medication management.

Stakeholder Resistance

“You see physicians who maybe aren’t necessarily prescribing best practice for older adults, or, you know, derailing the plan that we had set forth in place, and not following the, the recommendations, trends.” –health navigator

“Sometimes you hear that the homes feel that if they call in the services then it makes them look like they don’t know how to handle the situation.” –health navigator

“We had some challenges to get buy in with our appropriate prescribing project especially for the front line staff for the approach and redirect, but then you know what, if we tell them what is our goal, what is our focus, why are we here? We are here because of the resident.” –nurse

While there is growing interest in appropriate prescribing practices amongst many stakeholders (e.g., HCP, family members, etc.) across Ontario, in part due to elder care champions, participants described that there are still some who are resistant to change. For example, BSO consultants may come into a LTC home and provide a care plan for severe dementia residents, but sometimes they discover that the care plan is not being followed after they leave. Some participants perceived that physicians who lack expertise are also more amenable to prescribing AAP because it is a “quick fix” for a difficult situation and it requires less time and effort. Additionally, family members may not be receptive to the advice of physicians, which can create a barrier to appropriate prescribing. Participants suspected that this may be due to a lack of education on dementia management. The exploration of alternatives and the monitoring of AAP effectiveness and behavior can be a lengthy and challenging process. Front line staff who are particularly burdened with large caseloads in homes or hospitals may be opposed to implementing new practices or approaches to care. This may be especially true after normal working hours, in the event of severe responsive behaviours, where there might be fewer staff available and no attending physician.

Participants did mention that LTC homes or geriatric acute care units that have management, which fully supports non-pharmacological approaches or appropriate prescribing initiatives, are more likely to see change. Larger LTC homes, which are part of a corporation, are able to roll out new procedures in a more formal fashion and may also have staff acting as champions; whereas, smaller homes may have more barriers and fewer resources – making it difficult to secure buy-in from staff.

Varied implementation of existing policies & supports

“You’re limited that if you make a care plan of how that’s disseminated through all the staff; how there’s the carry-over of the care plan, and the carry-over of the interventions.” –acute care nurse

“we had BSO, we’ve had nurse practitioner programs, we’ve had psychogeriatric outreach, we’ve had all of these nice little programs which are fragmented all over the place by the way but the issue is we have not gone to from the design to the initial implementation to what we know our business people tell us we need to scale up and spread. And if we could scale up and spread with that triple hat function using these resources, we would make a difference”-geriatric psychiatrist

“Despite having a behavioural support unit in our facility, we actually are at a 20 per cent rate with the anti-psychotics. So... and it’s gone down. We actually can see the trend. It’s come down after that process was put in place. So, I think it’s happening. It’s not happening across the board.” – LTC physician

Clinician participants explained that there are existing policies and programs in LTC facilities that are designed to encourage appropriate prescribing, but are not uniformly implemented across the province. These include quarterly reviews by LTC pharmacists and responsive behavior programs. The ministry has developed a compliance protocol and has inspectors who visit homes to assess responsive behavior programs; however, it was unclear from interview data whether these visits are done regularly and what happens with the information gathered. In addition, each Local Health Integration Network was given funding for behavioural supports and each has chosen to use the funding in different ways. The two most common approaches are to: a) have BSO staff embedded in LTC homes or b) have the BSO as an external team that is consulted when necessary. Participants stated that there may be a range of views about which model is more conducive to appropriate prescribing. Neither of these approaches has undergone any formal evaluation for effectiveness. It was suggested that larger homes with more experts or resources may be able to benefit from an embedded team model, while smaller homes may benefit from an external team, which is available to build capacity amongst staff.

In acute care, there may be initiatives or policies to improve dementia care overall but they are challenging to implement. One participant described creating a documentation tool with personal information about each patient (e.g., history, triggers etc.) in an effort to promote individualized care; however, with staff turnover and time constraints, this sheet was not used consistently by all staff. Another example is that some geriatric units may have funding devoted to hiring a recreation therapist on the floor who works to keep dementia patients active and adequately stimulated; although in one instance the staff person was hired, but then subsequently let go due to a withdrawal of funding.

Theme Summary:

The following factors were described as playing a role in impacting the appropriate use of AAP.

Inadequate information transfer across settings:

- CCAC interviews & patient summaries are not adequate for LTC physicians to make decisions about treatment

Staff turnover:

- Rotating CCAC workers make accurate data collection difficult
- Rotating nurses & PSWs make implementation of new strategies difficult (e.g., Medication management, non-pharmacological strategies)

Lack of individualized care:

- Personalized care strategies may reduce need for AAP use but are challenging given that many LTC facilities and hospitals are short staffed

Limited health care provider expertise:

- Many HCPs do not have expertise in managing dementia patients and AAP across settings, especially in rural communities

Stakeholder resistance:

- Some HCP may be resistant to AAP appropriate prescribing practices or non-pharmacological approaches because of front line pressures (e.g., time, workload)

Varied implementation of existing policies & supports:

- There are existing policies and programs in long term care facilities, designed to encourage appropriate prescribing, which may not uniformly implemented across the province

Discussion

Key Findings

The findings from this study highlight that while there are improvements to be made, AAP may not be overused in dementia care across Ontario. There are multiple factors which may influence the prescription of AAP in dementia care, such as caregiver burnout, availability and effectiveness of alternative medications, and non-pharmacological approaches. The discussion about appropriateness is complex because of the nature of dementia and the safety concerns associated with this drug class. Overall, participants believed that there is a place for AAP in dementia care and that most severe patients will need a combination of both medications and non-pharmacological approaches. There are some key barriers to the judicious use of AAP in dementia care. These

include: improper transfer of patient medical information across settings, staff turnover, lack of individualized care, limited health care provider expertise, clinician resistance to appropriate prescribing practices, and varied implementation of existing policies and supports to encourage appropriate prescribing. Underlying all of these obstacles is the lack of human resources and provider expertise to meet the complex needs of severe dementia patients.

Health Equity Considerations

Persons living with severe dementia are unable to advocate for themselves and therefore appoint a power of attorney (POA) to act as a substitute decision maker and make decisions about their health. In order to promote equitable access to AAP, it is important that substitute decision makers are included in informed discussions about the prescription of AAP. Findings from this study highlight that there may be instances where the POA may be pressured to agree to a prescription or may not have adequate information to develop an opinion about the appropriateness of a prescription.

Limitations

It should be noted that qualitative findings are not representative of the general population of individuals from which our study sample was drawn. There may be bias in sampling given that those who responded to interview requests may have been more likely than non-responders to be vocal about discussing the AAP use in dementia care and may be more involved in appropriate prescribing initiatives. In an attempt to limit bias, we engaged in negative case sampling, which is to select interview participants who differ from the response trend observed in the recruited sample to date, so as to introduce different viewpoints.

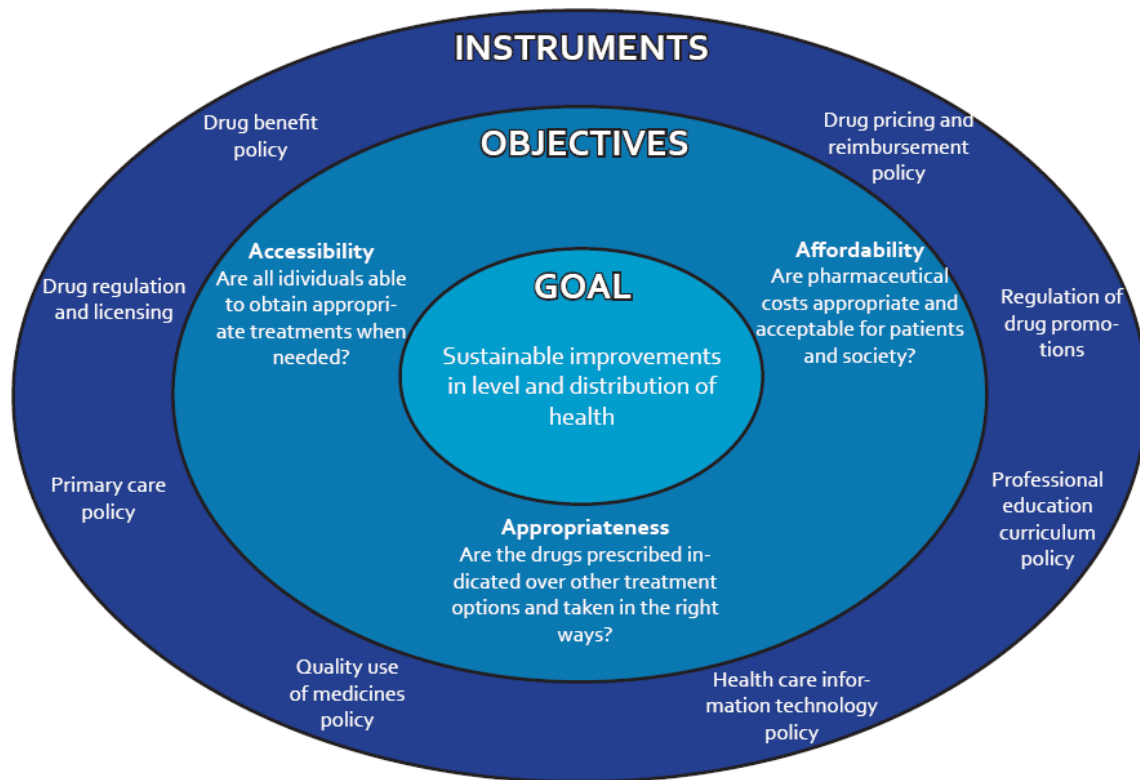
Conclusions

The findings from the qualitative study of the AAP drug class review aid in contextualizing the findings from other studies within the drug class review. On a broader scale, our study findings fill a gap in knowledge on AAP prescription and how this may be impacted by physician and patient factors. Overall, our findings shed light on the experiences of prescribing and using AAP for dementia, and unveil important information that can impact how dementia patients are prescribed these drugs across Ontario.

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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

Family Member of Patients

Demographic Characteristic (n=8)	n	%
Patient Gender		
Male	5	63%
Female	3	37%
Length of time on AAPs		
< 1 year	2	24%
2 years	4	50%
3 years	1	13%
5+ years	1	13%
Diagnosis of Dementia		
Yes*	8	100%
LTC Home		
Not for Profit	5	63%
For Profit	3	37%
First Prescribed By:		
Physician (PCP or LTC)	4	50%
Specialists (Geriatrician or Geriatric Psychiatrist)	3	37%
Emerge Physician	1	13%
AAP Family Member is Currently On:		
Risperidone (Risperdal [®])	2	24%
Quetiapine (Seroquel [®])	5	63%
Olanzapine (Zyprexa [®])	1	13%

*Types of dementia included temporal dementia, vascular, Lewy body, and Alzheimer's

Physicians (PCPs (n=2), LT (n=2), Geriatric Psychiatrist (n=2), Geriatrician (n=2))

Demographic Characteristic (n=8)	n	%
Years of practice		
5-15	1	13%
>15	7	87%
Geographic Location		
Urban	6	75%
Rural	2	25%

Health Navigators (LTC administrator (n=1), Behavioural Supports Ontario (n=1), CCAC (n=1))

Demographic Characteristic (n=3)	n	%
Years of practice		
<5	2	67%
>15	1	33%
Geographic Location		
Urban	2	67%
Rural	1	33%

Nurses and Support Staff (Behavioural Supports Ontario (n=1), Geriatric Mental Health Outreach Team (n=1), Clinical Nurse Specialist (n=1), Director of LTC Care (n=1))

Demographic Characteristic (n=4)	n	%
Years of practice		
5-15	1	25%
>15	3	75%

Geographic Location		
Urban	3	75%
Rural	1	25%

Appendix C: List of Abbreviations

LTC: LTC

CCAC: Community care access centre

BPSD: Behavioural and psychological symptoms of dementia

BSO: Behavioural supports ontario

AAP: Atypical antipsychotics

HCP: Health care provider

PSW: Personal support worker

LHIN: Local health integration network