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Attention deficit and hyperactivity disorder and use of psychostimulants in Aotearoa, New Zealand: exploring the treatment gap

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ABSTRACT

Introduction. Attention deficit and hyperactivity disorder (ADHD) is a common neurodevelopmental disorder affecting about 7% of those aged up to 12 years, 5% of teenagers and 3% of adults. It is associated with poor academic performance, substance abuse, criminality, poor social functioning and other negative outcomes. Psychotherapeutic treatment is moderately successful, whereas pharmacotherapy with stimulant medication is more efficacious and is recommended in many international guidelines. Anecdotal evidence suggests underuse of these medications in Aotearoa, New Zealand. **Aim.** To estimate how many patients with ADHD are prescribed psychostimulants in Aotearoa, New Zealand. **Methods.** National prescribing data for dexamphetamine and methylphenidate in 2022 were obtained and matched against estimated prevalence of ADHD by age. **Results.** There is a significant treatment gap for which inability to access first-line medication is likely to be the predominant explanation. **Discussion.** The data suggest failure of our health system to provide reasonable health care for a significant number of people with ADHD, and results in inequity in outcomes. New approaches are needed that will increase access to first-line medication, yet maintain appropriateness of diagnosis and limit risk of medication diversion.

Keywords: access to medication, attention deficit hyperactivity disorder, dexamphetamine, health care inequity, methylphenidate, psychostimulants, primary health care, treatment gap.

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Introduction

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by a cluster of overlapping early onset and persistent symptoms of inattention, hyperactivity, and impulsivity that interfere with daily functioning and age-appropriate activities.[1] It is formulated in the DSM-5 and ICD-11 diagnostic manuals, thus implying that it is a single categorical element with clear boundaries that distinguish it from other disorders and from those without disorder.[2] Historically, it has been conceptualised as a disorder that starts in childhood, is stable and undergoes some remission in late adolescent and adult years. More recent research provides a different picture. Onset in adolescent or early adult years is now recognised, casting concern over the usual diagnostic requirement of unambiguous early childhood onset.[3–5] Similarly, not all with ADHD have stable symptoms, with some showing remission and relapse.[6] Understanding of prevalence by gender has also changed with recent studies, suggesting that in childhood, there is three-fold the prevalence in males, but by adulthood, the gender distribution is equal. Although there is a strong genetic contribution to developing ADHD, not all cases are explainable simply on the basis of genetics.[7] An umbrella review of 65 meta-analyses found an association with environmental factors of maternal pre-pregnancy obesity, childhood eczema, hypertensive disorders during pregnancy, pre-eclampsia maternal acetaminophen exposure during pregnancy and maternal smoking during pregnancy.[8]

Prevalence estimates of ADHD are fraught with confounding variables relating to differing diagnostic methods and data collection. The New Zealand Health Survey for

WHAT THIS GAP FILLS

What is already known: Limited evidence suggests there are barriers to accessing psychostimulants for those with ADHD. This leaves many without the option to access and use the most effective medications.

What this study adds: This research indicates that the use of psychostimulants is low. Although some fraction of the treatment gap might be explainable by other reasons, barriers to access remains significant.

2021/22 provides data on the prevalence of ADHD in children up to age 14 years.[9] From a sample size of 1323, the response to the question 'Have you ever been told by a doctor that [child's name] has attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD)?' was 3% reporting that they had. Meta-analysis and systematic review of prevalence in the adult population suggests the prevalence of persistent adult ADHD (symptoms persisting from childhood) was 2.58% (CI 1.51–4.45), and that of symptomatic adult ADHD was 6.76% (4.31–10.61)[10] In adults aged >50 years, the prevalence is 2.18% (1.51–3.16) using validated scales.[11]

A strong correlation is found between ADHD and development of anxiety, mood and substance disorders in adults.[12] Physical health conditions such as epilepsy, migraine, obesity, dermatitis and some immune disorders, are more common in those with ADHD.[13] A systematic review of 351 studies concluded that without treatment, people with ADHD often experience poorer long-term outcomes (lower academic achievement, antisocial behaviour, problematic driving, non-medicinal drug use/addictive behaviour, obesity, occupational problems, high use of health services, poor self-esteem, and poor social function).[14]

Effective treatment is available for those with ADHD. Treatment improves long-term outcomes of ADHD for many individuals, but not necessarily to baseline. With pharmacological treatment, there is reduced criminality, reduced substance abuse, less mood disorders, reduced risk of traumatic brain injury, less motor vehicle crashes, reduced rates of emergency department visits and better academic outcomes.[15] Although not everyone who is prescribed medication will respond, the overall efficacy of stimulant medication is considered to be high.[16,17] About 25% of children with ADHD either do not tolerate the medication or do not respond to it.[18] Non-pharmacological treatments have been tested for effectiveness, but with mixed results.[19] A meta-analysis of 32 studies concluded that cognitive behavioural therapy and /indfulness was associated with an improvement in core symptoms.[20] Combining behavioural therapy with medication (either stimulant or non-stimulant) appears to give superior results to monotherapy.[21] Behavioural therapies are rarely funded by the public health system in Aotearoa, New Zealand, and privately funded therapies are often prohibitively expensive.

Clinical guidelines have been developed by several countries and give recommendations on what specific pharmacological therapies should be considered as first line and the evidence-base behind the recommendation. The Australian guidelines recommend the use of methylphenidate or dexamphetamine as first-line pharmacological therapy in the 5- to 17-year age group and methylphenidate, dexamphetamine or lisdexamphetamine in the 18 years+ age group.[22] The Canadian guidelines state 'Long-acting psychostimulants are first-line treatment agents. First-line pharmacological treatments for ADHD are medications approved by Health Canada that have the best evidence base, risk-benefit profile, effectiveness as measured by effect size, and duration of effect'.[23] The NICE guidelines from the United Kingdom recommend methylphenidate for those aged over 5 years as first-line pharmacological treatment, and lisdexamfetamine or methylphenidate in adults.[24] The European Consensus Statement recommends methylphenidate in child and adolescent populations and amphetamines in adult populations as first-line pharmacological therapy.[25] New Zealand guidelines were discontinued in 2022, but did state 'The stimulants, methylphenidate and dexamphetamine, are regarded as pharmacological agents of first choice in ADHD'.[26]

As discussed above, it is clear that ADHD causes distress and disability with significant social cost and it is also clear that stimulant medication is an effective treatment and is widely recommended as first-line pharmacological therapy. The side effect profile of these medications is well understood and data suggest that overall, they are well tolerated; a systematic review and network meta-analysis concluded that there was no significant difference in the number of discontinuations or serious adverse events compared to placebo, but there was an increased withdrawal rate due to some adverse event.[27] There are limited data on withdrawal rate due to adverse effects, but it is likely to be between 12 and 20% in adults.[28,29] Under such circumstances, it is reasonable to expect timely and equitable access to such therapy in Aotearoa, New Zealand. Media reporting suggests that this is not occurring, with only one-quarter of those with ADHD receiving specialist assistance, and discrimination occurring on the basis of socioeconomic decile.[30,31] Previous research in Aotearoa, New Zealand, found lack of equity in dispensing medication for ADHD on both ethnic and socioeconomic grounds that disadvantaged Māori , Pasifika and those in low socioeconomic groups.[32,33] ADHD is unusual in that it is a common disorder for which effective, relatively cheap first-line medications are available that have reasonable safety profiles, but access to this therapy is restricted in law to secondary care psychiatrists and paediatricians.[34,35] An apparent treatment gap has been noted previously in the literature, where the prevalence of treated ADHD was less than half of the prevalence of clinically diagnosed ADHD.[10] It thus becomes important to attempt to quantify the treatment gap

between those who might benefit from stimulant medication and those who are prescribed it in Aotearoa, New Zealand.

Methods

A request was made to Pharmac for data on the age breakdowns of all people who were prescribed either methylphenidate or dexamphetamine in 2022. The request was '… details on how many people in Aotearoa were prescribed either methylphenidate or dexamphetamine in 2022 as well as what the demographic background of age that such people were'. This information was received in an Microsoft Excel spreadsheet (Microsoft Corporation, Redmond, WA, USA) titled 'Only Dexamfetamine sulfate OR Methylphenidate hydrochloride (including extended-release tablet) dispensings with a recorded NHI in the community in Calendar year 2022 (ended in December 2022) have been included'. Data on estimated demography for Aotearoa, New Zealand in 2022 were obtained from the Tatauranga Aotearoa (Stats NZ) website.[36] Data cleaning were not required for the datasets. Three of the above references that give estimates of prevalence of ADHD by age were used to estimate numbers of those with ADHD in Aotearoa, New Zealand.[9–11]

Ethics

Ethics approval was not sought as the data used are available in the public domain and are both aggregated and deidentified.

Results

The results are divided into three separate sections, based on age groupings. Each section uses different datasets to estimate the prevalence of those with ADHD within the age group. Prescribing data were aggregated by age range used in the prevalence studies. An estimate of the prevalence of ADHD by number in Aotearoa, New Zealand, was made by multiplying population data by prevalence data. By comparing the calculated prevalence data with numbers who were prescribed a stimulant, the percent of those diagnosable with ADHD who were prescribed a stimulant can be calculated.

Table 1 provides data on the 5- to 9 and 10- to –14- year age group using baseline data from The New Zealand Health Survey.[9]

Table 2 provides data on the 18- to 49-year age group using prevalence data specific to this cohort.

Table 3 provides data for the 50- to 70-year age cohort using specific meta-analysis of prevalence for this more elderly cohort.

Discussion

The data in this research suggest that there is a significant treatment gap for those with ADHD between best pharmacological practice and what is currently prescribed. This is in accordance with the very limited data available in the literature on treatment gaps in ADHD. Caution is needed in

Table 1. Prescribing data for stimulants in the 5- to 14- year age group.

Age range (years)	Population number	Prevalence (%)[9]	*n* told they have ADHD	Number prescribed stimulant	% treated
5–9	322 180	2.7	8699	5328	61
10–14	339 120	4.9	16617	9986	60

Table 2. Prescribing data for stimulants in the 18- to 49-year age group.

Age range (years)	Population number	Prevalence (%)[10]	Possible *n* with diagnosable ADHD	Number prescribed stimulant	% treated
18–24	447 920	5.05	22 620	7489	33
25–29	354 410	4.00	14 176	4790	34
30–34	388 560	3.29	12 784	4227	33
35–39	347 090	2.70	9.371	2968	32
40–44	317 250	2.22	7705	2167	31
45–49	314 660	1.82	5774	1680	29

Table 3. Prescribing data for stimulants in the 50- to 70-year age group.

Age range (years)	Population number	Prevalence (%)[11]	Possible *n* with diagnosable ADHD	Number prescribed stimulant	% treated
50–70	1 261 930	2.18	27 510	2612	9

interpretation of the data for a number of reasons. International prevalence data were used to estimate prevalence in some age groups in Aotearoa, New Zealand, and it is possible that prevalence rates are different. It should be noted that the data on the 5-to 14-year age group based on the New Zealand Health Survey are only those who have been diagnosed with the condition and therefore most probably is undercounting the true prevalence of ADHD and underestimating numbers who might benefit from stimulant treatment but are not on it. When considering the treatment gap, there are several plausible explanations for the discrepancy. Not all those with symptoms that suggest ADHD will be diagnosed and therefore will not get the opportunity of access to treatment. This might occur because some might believe that their symptoms do not represent a treatable condition, or some might be aware that the public health system, as currently structured, is unlikely to assist them to access first-line pharmacological or behavioural treatment. There are some who do not want pharmacotherapy for ADHD and are content with an explanation for their symptoms and perhaps behavioural therapy. For those who are prescribed stimulants, although accepting that stimulants have overall high efficacy and tolerability, not everyone will benefit therapeutically and, even for those who do benefit, between 12 and 20% will cease medication use because of side effects.

The analysis reveals considerable variation in the treatment gap between age groups. There are likely several explanations for this; increasing public awareness of the condition and its treatable nature over recent years means greater numbers seeking clarification on diagnosis. School teachers and the schooling system are organised and trained to identify and manage ADHD in ways that are increasingly effective. Older adults who have never been diagnosed might have found work and social circumstances in which the symptoms are less bothersome. Although such adjustments are good, they might also represent lost opportunities in life.

Although a number of caveats have been given, this research suggests that inability to access to first-line medication is the major cause for the treatment gap. Inability to access first-line medication is a direct consequence of restricting initiation of these medications to paediatricians and psychiatrists under circumstances where access to these doctors is severely limited in the public system and can be onerously expensive in the private system. This has far-reaching consequences beyond the original purpose of reducing diversion of medication for recreational use. Anecdotally, some with ADHD symptoms will source illicit stimulants to self-medicate because they know that access to secondary care diagnostic services is either non-existent, have unrealistic waiting times or is prohibitively expensive. Publicly funded mental health services are increasingly reluctant to assess for ADHD, with some regions refusing to do any assessments. This is an unintended consequence of the decision to restrict prescribing, but has resulted in many people with ADHD being denied the opportunity to take the most effective medication for their condition. Those who can fund private psychiatrist costs can sidestep this barrier and obtain assessment and potentially medication, an option not available to those in lower socioeconomic deciles. Māori are disproportionately represented in low socioeconomic groups and therefore experience inequitable outcomes in access to self-funded care for ADHD.

The current system of care for those with ADHD leaves general practitioners in a difficult position. Without the ability to provide the most effective pharmacotherapy, second-line medications are commonly used. Although there is the need to prescribe 'off-label', bupropion has a reasonable, but not compelling evidence-base of effectiveness in ADHD.[37,38] Atomoxetine is indicated for use in those with ADHD and again has a reasonable evidence-base to support its use.[39] Medications such as modafinil, clonidine and guanfacine have limited evidence-base of effectiveness. None of the second-line medications are as effective as stimulants.[40]

It is clear that our current health system is failing to meet reasonable expectations for those with ADHD. It results in an inordinate burden of avoidable health and social issues, discriminates against those who cannot self-fund private psychiatric evaluation and is inequitable for Māori and Pasifika people. Further, the range of stimulant medications available in Aotearoa, New Zealand, is limited in comparison to many first-world nations. What is needed is a system that is accessible, affordable, culturally appropriate, provides accurate diagnosis and can prescribe first-line medications. Contrary to some beliefs, diagnosing ADHD is not limited to psychiatrists and paediatricians; only initiation of prescribing stimulants is. Clinical psychologists are well-positioned to diagnose ADHD as are some mental health nurses. It is possible to upskill some general practitioners to undertake diagnostic and prescribing roles. There are already examples of general practitioners working in extended scopes of practice that require some additional training (eg aviation medicine, sports medicine and geriatrics). Clinical pharmacists are experts in medication choice and management and could provide additional guidance. ADHD is also an outlier in our medical system. For almost all other chronic diseases, uncomplicated cases are managed entirely in primary care, with secondary care referral only for more complex cases. Such a system promotes efficiency, affordability and accessibility. When all cases of ADHD, including those that are uncomplicated, require specialist psychiatry or paediatric evaluation, efficiency and accessibility is lost.

Several simple changes are feasible; for example, removing the burden of having a psychiatrist review every 2 years as it is unnecessary and wasteful of scarce resources. Providing cognitive behavioural therapy, mindfulness and psychoeducation would represent valuable non-pharmacological assistance to those with ADHD and their families. Upskilling primary care prescribers in the use of non-stimulant pharmacotherapy would provide further choices for some with ADHD. Although this research has specifically focused on barriers to using

first-line medications, it is also important to acknowledge that a 'deficit model' is only one way of perceiving ADHD and that the positive attributes of cognitive dynamism, courtage and adventurousness, humanity and resilience can also be part of behavioural characteristics of the condition, and psychoeducation can support this.[41]

Extending initiation of first-line pharmacological treatment to general practitioners, where advice has been sought from clinical psychologists, mental health nurses, general practitioners with an extended scope of practice or nurse practitioners, is a possible way forward that would alleviate the current systemic flaws in ADHD care. It would also relieve pressure on scant secondary services that would manage only complex cases, and it would provide reassurance on the risk of medication diversion. Whether this model or other models of care are developed, the current state of ADHD care in Aotearoa, New Zealand, is unacceptable and there is need for change.

Strengths and limitations

The dataset provided by Pharmac on numbers of people treated with stimulants is highly likely to be accurate due to the electronic nature of prescribing in Aotearoa, New Zealand, and similarly, the population data are likely to be very accurate. This will give reliable data on percent treated with first-line medication. There is little published data on the numbers of people with ADHD who would choose not to use first-line medication, who find the medication ineffective or have unacceptable side effects and cease medication.

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Data availability. The data that inform this study will be shared upon reasonable request to the corresponding author.

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