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Psychotropic Medication Use to Manage Behaviours of Concern for Young People with Cognitive Impairment/Disability: A Quality Assurance Project

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Abstract

Introduction: A recently released Clinical Care Standard provides a quality assurance framework for reviewing current practice regarding the use of psychotropic medications to manage behaviours of concern for those young people living with cognitive impairment or disability, who have been admitted to a tertiary paediatric centre.

Method: An audit sample was obtained by cross referencing inpatient medication orders with diagnostic code over a 12-month period, before further refining the sample via desktop casefile review to confirm applicability of the Clinical Care Standard.

Findings: On review of the 6 casefiles against the set of indicators listed in the Clinical Care Standard, there was strong evidence of a person-centred approach to care, thorough assessment and a commitment to trialling non-pharmacological strategies in the first instance. The main area of non-compliance was in the formal documentation of medication monitoring once prescribed longer than 1 month, and there is also opportunity to strengthen existing communication processes between all members of the care team, including community disability providers involved in the young person's care.

Conclusion: This quality assurance activity has demonstrated generally positive performance at our paediatric tertiary healthcare centre against the requirements of the Clinical Care Standard.

Keywords: Cognitive impairment disability; Psychotropic medication; Quality assurance

Introduction

In May 2024, a new Clinical Care Standard (CCS) was released by the Australian Commission on Safety and Quality in Health Care to help standardise clinical practice in the use of psychotropic medications for those living with cognitive impairment or disability, aiming to reduce inappropriate usage of these medications in this specific patient cohort [1]. This follows multiple Royal Commissions into the aged care and disability sectors in Australia and internationally have identified psychotropic medicines being both misused and overused in patients living with cognitive disability or impairment, often as a form of restrictive practice to control the behaviour of people who exhibit behaviours of concern [2,3]. Psychotropic medications are broadly defined as "any drug capable of affecting the mind, emotions and behaviour", with the three main classes being antidepressants, anxiolytics and antipsychotics [4]. If used over a long period of time without adequate review and monitoring, psychotropic medications can cause harm including anticholinergic burden, tardive dyskinesia, weight gain, and development of metabolic syndrome, all of which increase the risk of morbidity and mortality [5]. Intellectual disabilities are defined by the DSM-5 as being "neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living" [6]. Those with intellectual and development disabilities are often treated with psychotropic medications, for both on and off label purposes, with polypharmacy commonplace and adverse side effects and drug-drug reactions prevalent [7,8]. Long term use of psychotropic medications in this cohort may also mask other emerging diagnoses eg ADHD, which may respond positively to treatment options other than psychotropic medication [9]. Prevalence rates of psychotropic medication use in Australian adolescents with intellectual disability were described as 20%, with higher usage in males and in those with major behaviour problems [10]. The appropriateness of this level of medication use was questioned by Song et al (2020), particularly for those in the transitional adolescence period, where mood and behaviour changes frequently occur irrespective of health concerns [11]. In their study, over 80% of adolescents with intellectual disability experienced at least one occasion of off label and/or inappropriate use of psychotropic medications [11]. Once prescribed, deprescribing psychotropic medications can be problematic, with limited consistency in approach across health settings and often minimal consumer engagement in the planning and process of deprescribing [5]. Interdisciplinary models of care, as well as patient centred medicine optimisation, in this circumstance are associated with more positive outcomes [5].

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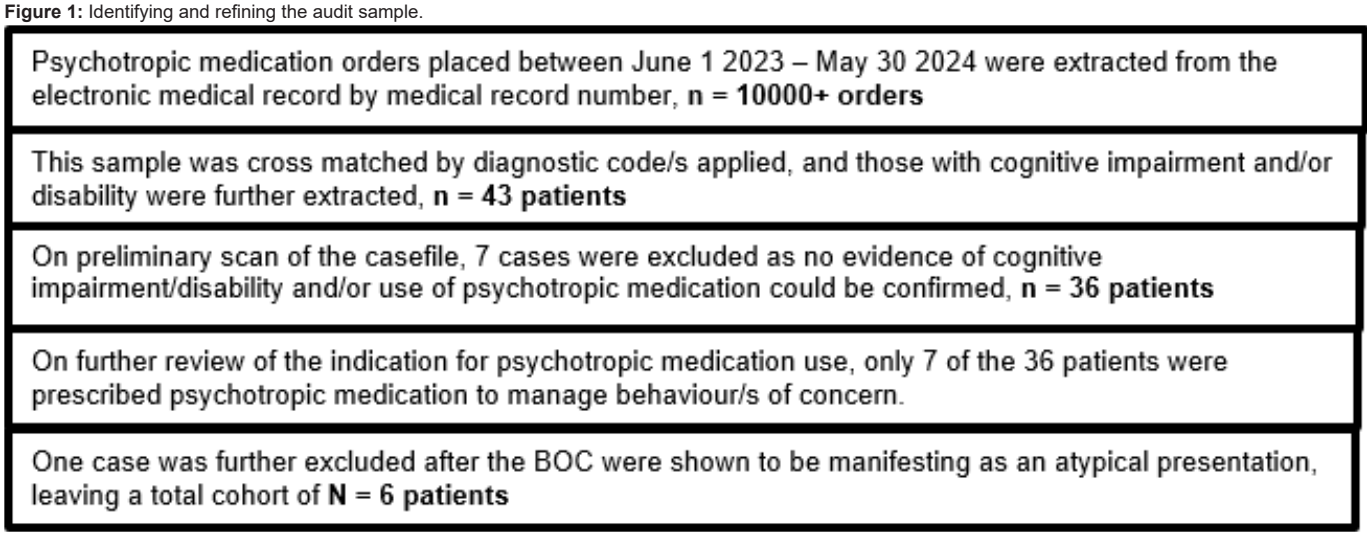
Figure 1: Identifying and refining the audit sample.



A common rationale for the use of psychotropic medications in this patient cohort is to manage behaviours of concern (BOC), which is a term used to describe behaviours that have the potential to cause harm (to self and/or others) or behaviours that do not meet cultural / societal expectations [5,12]. These behaviours are more prevalent in children living with intellectual disability, autism and other neurodevelopmental impairments, than children who do not live with a disability, with prevalence rates of 10-18% reported in the literature [5,12,13]. There is limited RCT-level evidence in support of psychotropic medication to manage these behaviours, with limited marketing authorisations to manage behaviours of concern in the absence of mental health conditions with these medications and, instead, evidence-based support for non-pharmacological interventions such as positive behaviour support [5,8,14,15]. At the core of clinical practice, it is imperative that approaches to managing BOC are focussed on enhancing the child's quality of life and reducing the use of practices that may restrict the child's rights and freedoms.

Clinical Care Standards provide a quality assurance framework for evaluating current clinical practice against a core set of Quality Statements. The quality statements for the Psychotropic Medication CCS cover domains such as patient centred care, informed consent, shared decision making and effective communication. This paper summarises the main findings of this clinical practice assurance and evaluation activity, and highlights potential service improvements for a paediatric tertiary centre in Australia, that may be pertinent and relevant for other health services.

Methods

Ethics Approval

This evaluation of retrospectively conducted practice, in accordance with a list of indicators provided within the Clinical Care Standard, is a quality assurance activity and did not require human research ethics approval to be conducted.

Data Sample

Psychotropic medication orders made for children and young people admitted to the XXX between June 1 2023 and May 30 2024 were extracted in a secure raw data file. These medication orders, as assigned to individual patients against their unique medical record number, were then cross matched with the diagnostic code/s for the admission to create an audit sample. On reviewing the electronic medical record for the subset of patients with a cognitive disability and/or impairment diagnostic code and at least one psychotropic medication order/s, a small group of patients were subsequently excluded as no evidence of cognitive impairment diagnosis and/or psychotropic medication use could be found, leaving a sample of 36 casefiles to be further reviewed, primarily with respect to the rationale for medication use. Where the rationale was to manage behaviours of concern, the casefiles were further reviewed, looking for evidence of each of the indicators outlined in the CCS.

Audit Tool

The Clinical Care Standard outlines eight Quality Statements, describing key practice points that support the delivery of safe, quality care in this clinical context. Seven of the eight Quality Statements reference indicators of performance/assurance that were used to form the audit tool used in this retrospective evaluation of practice. Each medical file was reviewed against the audit tool criteria, and results collated on a password protected Excel spreadsheet.

Analysis

Data were analysed using descriptive statistical methods.

Results

The audit sample was further refined, as per Figure 1. On review of the included case files against the audit criteria, psychotropic medications were indicated for reasons other than behaviours of concern in over 80% of patients (n = 29/36), such as to support sleep hygiene, control seizure activity, manage anxiety and mood, and/or to reduce pain. Of the seven patients where psychotropic medications were prescribed and administered for behaviours of concern, one case was later excluded as the initial behaviours subsequently manifested as a functional neurological disorder (pseudo-seizures and pain), which is an atypical presentation of BOC. Of the six patients forming the final audit sample, all were assigned male gender at birth, with the average age of 10 years 8 months (as at 30/5/2024) and an age range of 6 – 14 years. All six patients had a diagnosis of cognitive disability,

Table 1: Evaluation of practice against audit criterion.

Quality Statement (QS)*	Audit criterion	Yes	No	N/A	% compliance
QS 2 Informed consent	Is there documented evidence of informed consent when prescribing the psychotropic medicine?	6	0	0	100
QS 3 Assessing behaviours of concern	Is there evidence of an initial assessment of behaviours of concern to determine immediate risks to their safety and others?	6	0	0	100
	Have reasonable adjustments been made to facilitate involvement of the patient in this assessment?	1	0	5	100
	Have existing behaviour support and care plans been accessed?	6	0	0	100
	Is there documented evidence of family and/or support person involvement in the assessment (in accordance with the patient's wishes)?	6	0	0	100
	Has this assessment been undertaken by a suitably trained health professional?	6	0	0	100
	Is the assessment documentation thorough and holistic?	6	0	0	100
QS 4 Non-medication strategies	Have non-medication strategies been selected and implemented, based on the findings of the initial assessment?	5	0	1	100
	What are the non-medication strategies that have been implemented?	Examples included: distractions (eg iPad, bubbles, balloon, food), use of own equipment for comfort, sleep hygiene, low stimulation environment, positive behaviour therapy, comfort room, physical contact/touch (eg cuddles) from parent			
	Has the patient's response to non-medication strategies been monitored and documented?	5	0	1	100
QS 5 Behaviour support plan	Does the patient have an existing behaviour support plan?	4	2	0	67
	Is there a current "Consent to Exchange Information form (PS-3)" to allow for the sharing of this behaviour support plan to/from their disability or aged care provider?	2	1	3	67
	Is there evidence that the patient's behaviour support plan been used during the episode of care?	4	0	2	100
	Where updates to the behaviour support plan may be recommended, is there evidence these have been communicated back to the disability or aged care provider?	1	0	5	100
QS 6 Appropriate reasons for prescribing psychotropic medicine	Is there clearly documented evidence of the reason for psychotropic medicine prescription?	6	0	0	100
	Is there clearly documented evidence of factors contributing to the behaviours of concern?	6	0	0	100
	Is there clearly documented evidence that the person was also receiving non-medication strategies at the time of prescription?	5	0	1	100
QS 7 Monitoring, reviewing and ceasing psychotropic medicine	Is there documented evidence of a timeframe to review the medicine?	6	0	0	100
	At each review, is there documented assessment of the effectiveness of the medicine on the target symptoms and any adverse effects?	6	0	0	100
	If prescribed greater than 1 month duration, is there evidence of the use of the Antipsychotic Medicine Monitoring Chart?	0	5	1	0
QS 8 Information sharing and communication at transitions of care	Is there evidence that behaviour support information (including a behaviour support plan if one exists) is shared between care settings?	6	0	0	100
	Has a complete medication list been shared between care settings?	6	0	0	100
	Is there evidence of a discharge summary sent to the clinician responsible for their care on discharge?	6	0	0	100
	Is there evidence of a discharge summary sent to the disability or aged care service provider on discharge?	3	2	1	60
	Is there documented evidence of information about the medicine provided to the patient/family/support person on discharge?	6	0	0	100

*QS 1 = Person Centred Care; there are no listed indicators provided within the CCS for this QS.

with co-morbid diagnoses present for all children including: severe autism, Trisomy 10, attention deficit hyperactivity disorder (ADHD), and global developmental delay. Each of the six patients were admitted under a Paediatric Medicine bed card (Department of General Medicine 5, Neurology 1) and ward (Adolescent 2, Medical Short Stay 1, Cassia 3). All six patients had received input and/or had been referred to the Child and Adolescent Mental Health Services. None of the six patients were started on psychotropic medications during the audit period - the psychotropic medications administered during this time included Olanzapine, Clonidine, Amitriptyline, Diazepam, Risperidone, Fluoxetine, Valproate and Lisdexamfetamine. None of the 6 patients had their psychotropic medication weaned or ceased during the audit period (Table 1).

Discussion

This evaluation of current practice against a nationally agreed set of core practice principles has shown strong compliance with key supporting elements of safe, quality care in the use of psychotropic medications to manage behaviours of concern for children with cognitive impairment/disability at this tertiary paediatric healthcare organisation. During the 12-month audit period, the consumers (incorporating both the patient and their family/caregivers) appear

to have been well engaged throughout their care and comprehensive assessments have been undertaken in considering both non-pharmacological and pharmacological management approaches. The main area for practice improvement appears to be in the formal monitoring of psychotropic medication impacts, with 0% compliance with the organisation's existing Psychotic Medication Monitoring Chart (for use when medications have been prescribed / administered greater than 1 month duration). This is an area of practice concern previously highlighted in the literature, that children with cognitive impairment and cognitive disability are often over-medicated and potentially remain on medication for longer than necessary, with a reluctance from the parents or health care team to reduce or cease medication for fear of the behaviours of concern worsening and/or returning [16]. In this audit, it is possible that adverse effect monitoring was occurring in a less formal way but not captured in formal documentation processes, noting this form is paper-based (therefore sitting outside of the electronic medical record system used and needing to be manually uploaded into a casefile). It is also possible that these children were monitored for a short period after initial prescription but not ongoing – this is highlighted as a risk by McLaren and Lichtenstein (2019), with the long term effects of these medications on cognitive function, endocrine system, growth and behaviour not yet well known [13].

The NHS England established the STOMP-STAMP initiative in 2016-2018 (stopping the overmedication of people with intellectual disability, autism or both with psychotropic medicines – supporting treatment and appropriate medication in paediatrics). The STOMP-STAMP initiative is underpinned by a commitment to ensure that children and young people are receiving the right medication, at the right time, for the right reason, with the aim of achieving the maximum benefit with the minimum dosage of psychotropic medication and to establish a clear timeline for ceasing medication if possible [9]. Positive impacts on physical health parameters eg body mass index, have been demonstrated once psychotropics medications have been ceased in this patient group [5]. In our organisation, the process of monitoring, reviewing and ceasing psychotropic medications is anecdotally more closely adhered to for patients whose primary care team and/or admitting bed card is mental health, rather than the general medical or surgical teams. This highlights an area for further education and training in our non-mental health teams, in order to reduce the risk of short-, medium- and long-term harm from this practice. A further consideration is that a subset of our patients may also be concurrently managed in the community setting by private providers (eg private paediatrician), creating potential confusion about who is the primary care provider, who is taking accountability and responsibility for coordinating the patient's care - and ultimately then who is prescribing, monitoring and/or ceasing these medications.

There may also be practice improvements to be made in terms of communication between all members of the care team, specifically regarding the exchange of information. The small sample size reduces the ability to make generalisable statements of adherence to processes in this domain, with formal consent to share information processes and distribution of discharge summaries to community service providers occurring approximately 2/3 of the time in this audit. Timely and effective communication between all members of the care team is critical to the safe management of patients, especially when admitted for an acute presentation and where the two-way flow of information helps to shape the care pathway during admission and on discharge.

During the audit period, no patient in the sample was commenced on new or different psychotropic medications. Current practice on admission and at key transitions of care is for best possible medication history and reconciliation to be undertaken by staff, in consultation with the parent/caregiver. In each instance of this medication history and reconciliation, the parent/caregiver was referenced as providing the dose and rationale for the psychotropic medication for the patient, thereby demonstrating an understanding of the reason/s for medication (and therefore indirectly providing informed consent to the prescription and administration of the medication). It is a limitation of the audit that an example of a "new" prescription wasn't reviewed to be fully assured that informed consent had occurred and could be evidenced. Likewise, no patient had their psychotropic medication weaned or ceased during this audit period, and so no evidence was present to assess the level of consumer engagement in the weaning and/or cessation of these medications.

The data set for inpatient medication orders was readily available through the electronic medical record. This skewed the patient sample considered in this audit process to only include those who were administered psychotropic medications, in the presence of cognitive disability and/or impairment, who also required inpatient hospital admission – therefore excluding the patient cohort managed exclusively in the sub-acute and community setting. As the clinical care standard is not hospital specific, this area of patient care should be considered in future evaluation of practice for our organisation.

Conclusion

This quality assurance activity has demonstrated generally positive performance at our paediatric tertiary healthcare centre against the requirements of the psychotropic medication in cognitive impairment or disability clinical care standard, released by the Australian Commission for Safety and Quality in Health Care [1]. There was evidence of thorough and regular assessment of the child/young person, engagement with the family/caregivers, and consideration of non-pharmacological interventions in the first instance to manage behaviours of concern. Areas for practice improvement for our organisation relate to strengthening existing communication processes between all members of the care team, including community disability providers, as well as ensuring formal monitoring of psychotropic medication impacts and effects when prescribed greater than 1 month.

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