

BCM J

BC Medical Journal

THEME ISSUE: **Autism today**



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and controversies**

**Evaluating and
managing irritability and
aggression in children and
adolescents with autism
spectrum disorder**

**Examinations under
anesthesia for children
and youth with
behavioral complexity**

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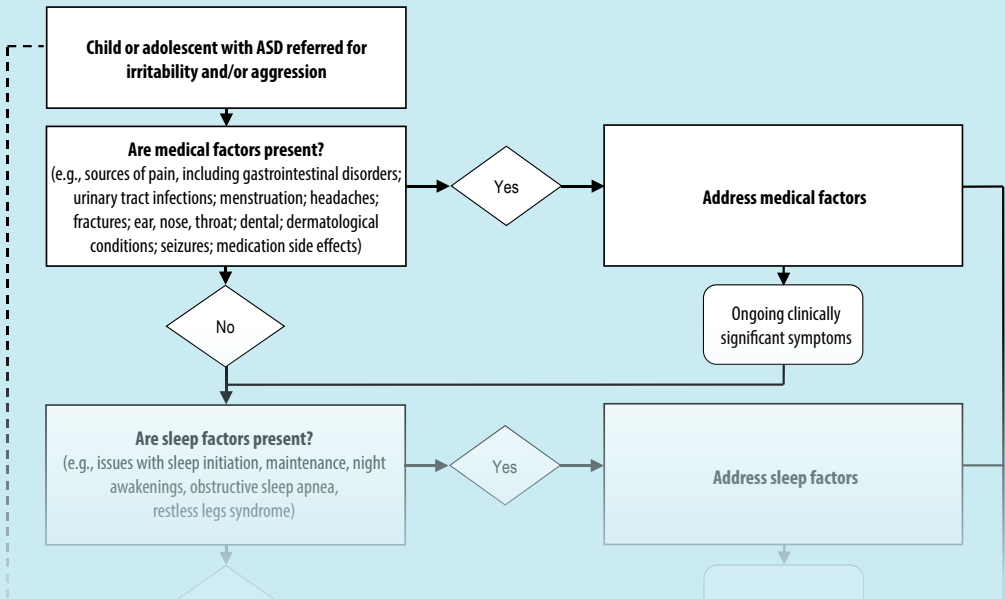
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ON THE COVER

Autism has had different symbols over the years; the heart and the infinity symbol are combined here to represent the potential people with autism spectrum disorder have, plus the care we provide as physicians. The theme articles begin on page 282..

Mission: The BCMJ is a general medical journal that shares knowledge while building connections among BC physicians.

Vision: The BCMJ is an independent and inclusive forum to communicate ideas, inspiring excellent health care in British Columbia.

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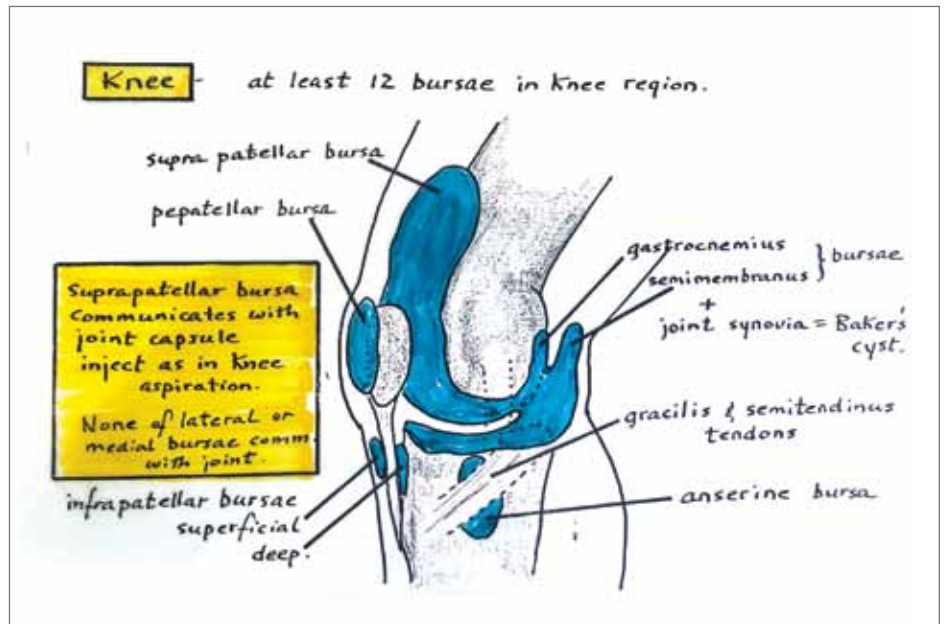
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One of the many line drawings the late Dr Daniel Froese made for teaching patients and students. His obituary begins on page 313.

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Does working part-time mean I've failed as a feminist?

I recently made the decision to work part-time in my clinical practice. The change allows me more space for my nonclinical work, like boards, volunteering, research, and teaching. It also gives my younger colleagues more time to grow their patient rosters and improves the attention I can give to my current patients. However, despite the (defensive and rambling) justification that I feel compelled to lead with, I feel uncomfortable admitting that the main impetus for stepping back from clinical work is, in truth, family.

When my husband and I were both working full-time, I now fully recognize that there were multiple days per week when my kids might not see either of us in the morning or at bedtime. We persevered this way while our kids were toddlers, coping day-to-day with two nannies, supportive grandparents, and millions, yes millions, of work-related Aeroplan miles. If we can say that any good came from COVID-19, for our family, it was the travel hiatus that kept us close for 2 years. But when travel and in-office work returned, I found myself increasingly sympathetic to my kids' tearful pleas to have the family together "like we used to be." They're old enough now to be aware of the differences in a so-called "post-COVID" time, having spent their formative early years in and out of lockdowns.

In his current job, my husband cannot work part-time; therefore, it makes sense for me to adjust my career at this stage in our life. So why do I feel like a failure for the feminist cause?

I suppose I should explain the use of the "F" word in this editorial. Feminism means different things to different people. It can be alienating and polarizing, particularly to those who associate all types of feminism with radical feminism, perceiving it as being overtly antipatriarchal and inherently

antimale. For a long time, I hesitated to use the "F" word because I did not fully understand the concept. However, as a gynecologist and women's health advocate, I have now become comfortable enough in my skin and my lived experience to call myself a feminist. I believe in equal treatment of all sexes, be it political, economic, or social.

Historically, a man's career and education have been prioritized over a woman's in relationships. This is just one contributor to the societal expectations and gender discrimination that mean women make 87 cents on the dollar compared with men.¹ (A gap that is worse for racialized women, newcomers, Indigenous women, women with disabilities, and trans women.¹) It may also underpin the "surgical sexism" described by Dr Chaikof and colleagues in the *Canadian Journal of Surgery*, who concluded that "the lower reimbursement of the surgical care of female patients than for similar care provided to male patients represents double discrimination against both female physicians and their female patients."²

I do worry about becoming a statistic, another example of, as Anne-Marie Slaughter wrote in a great article for *The Atlantic*, "why women still can't have it all."³ I feel like a feminism failure because I am consciously stepping back from my clinical work to do more of the home work, which we all know is unpaid and often unrecognized. I know there is no shame in homemaking; the shame is in the stereotype that it must be women who do it. I have also questioned the reality of part-time work. Many women remark that it becomes "full-time work for part-time pay."

**There is no shame
in homemaking;
the shame is in the
stereotype that it must
be women who do it.**

Had our situation been different, my husband might have been the one making the change. For now, I am satisfied with my choice, and I know that nothing is permanent. It may actually be my belief in feminism that allows me to make the proactive, independent choice to live more life with my family. Time is a nonrenewable resource, and Instagram constantly reminds me that 90% of the time you have with your kids is before they turn 18.

(Why do sentimental montages of strangers' kids get me every time?!)

As I tell my kids: fair does not always mean equal. I'm going to have to go with that for now. ■

—Caitlin Dunne, MD

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Getting further away from retirement, and loving it!

“So, Doc, . . . when are you planning to retire?”
 “I hope you’re not planning on retiring anytime soon.”

These are two comments/questions I hear more often these days. Some of my patients are getting increasingly anxious as they see more grey hair on my head (or maybe it’s that they are seeing less hair!). They also hear from the media and their social circles how challenging it is to find a family physician who is accepting new patients. Our medical office receives countless calls every day from people trying to find a family physician and asking if any of us are accepting new patients. As is the case with most family physicians, the answer is in the negative.

Our local division of family practice has successfully attached thousands of patients over the last few years and continues to do

so, despite a number of family physician retirements from our community in recent years. As with the rest of the province, we still have a long way to go. As the province launches its Health Connect Registry through HealthLinkBC, it will be interesting to see if the recent Longitudinal Family Physician Payment Model will have any effect on attachment numbers.

Back to the question that many of my patients are asking me. My original plan, earlier in my medical career, was to start thinking about retirement in my 60s and to spend more time with my friends and family. Well, stuff happens, or something like that, as the saying goes. Five years ago, as this journal was celebrating its 60th anniversary of publication, I made a difficult personal decision, which some people call the worst financial decision a person can make. However, you can’t put a price on

health and happiness, and my health and personal happiness have improved significantly since that decision. As a direct result of my decision, I have some financial obligations that continue for another 6.25 years, but who’s counting? I harbor no resentment about this. I just look forward to paying off my debts as anyone else would.

Additionally, I purchased my dream home a few months ago. This added significantly to my happiness and to my financial obligations for the foreseeable future. When my bank’s mortgage professional was assessing my qualifications for a new mortgage with a 25-year amortization, one of his questions was about my retirement plans. He was very polite and professional in his questioning: “So, Dr Chapman, we are approximately the same age, and I am easing into retirement this year. May I ask what your plans are for retirement?” My answer to him was that with my new mortgage in place, if my health allows (G-d willing), I plan to work well beyond my original 6.25-year retirement plan!

I love coming home from work each day to my new home; it feels like I am on a permanent vacation. Besides the financial obligations, I also love going to work each day. My work is now affording me my dream home. I have great partners and fantastic staff. My life partner is also a family physician, and she is another reason why I enjoy my work and my life.

The last time I opined on the topic of retirement was more than 11 years ago [*BCMJ* 2012;54:118-119]. In that editorial, I spoke about retiring in stages. The next stage of my retirement will be to retire from this esteemed Editorial Board (likely in late 2024). I have completed 15 years in this role, and now that term limits have been introduced, I have exceeded those limits. I also plan to

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A fond farewell to Dr Cindy Verchere and a warm welcome to Dr Sepehr Khorasani



Cindy Verchere, MD

Dr Cindy Verchere has served on the Editorial Board of the *BCMJ* for over 14 years. Although we wish her the best in retirement, she will be tremendously missed. Dr Verchere’s fondness for puns brought levity to our meetings, while her experience and sharp wit made her a valuable member of our team.

Simultaneously, we are pleased to announce the addition of Dr Sepehr Khorasani to the Editorial Board. Dr Khorasani is a general surgeon from Vancouver Island with subspecialty training in colorectal surgery. He has an interest in research and quality assurance and holds a master’s degree in clinical epidemiology and health care research from the University of Toronto.

Although bad medical puns are hard to stomach, as a final tip of the hat to Dr Verchere’s sharp wit, we hope you will indulge us in this attempt to be “humerus.” Q: What operation most commonly involves Lego? A: Pediatric plastic surgery.



Sepehr Khorasani, MD



In pursuit of equanimity

Many physicians I admire possess calmness, levelheadedness, and composure in difficult situations—a state of equanimity if you will—that I wish to emulate. Whereas I can get riled up or irritated when things aren't going well, they can take on an immeasurable amount of stress, work, or tasks with a countenance I don't always possess. It makes me wonder how they make it happen. Is it innate? Is it trained? Or do they choose this demeanor?

In health care, there seem to be innumerable overwhelming issues, everything from climate emergencies to ER closures, from wait times for specialist services to an ongoing lack of access to family physicians, along with a digital space that is complex and fraught with challenges. We see these issues firsthand in our local communities, we hear about them from colleagues, we read about them in the news, and I personally receive emails about them from doctors on a weekly basis. The multitude of ongoing and agonizing issues contributes to our individual and collective suffering. Some feel this pain more acutely than others, in part because of their circumstances or their response to the initial harm. We hurt when our patients hurt, we suffer because the system is suffering, and our hearts ache because our colleagues' hearts ache. I want to pursue how to mitigate, minimize, or eliminate this secondary suffering. Is equanimity the answer?

As the Buddha says, "In life, we can't always control the first arrow. However, the second arrow is our reaction to the first. The second arrow is optional." I came to

understand this parable through a conversation with a friend about health issues we each suffered this summer. She had an orthopaedic injury that forced her to be non-weight-bearing for weeks, while I experienced a diverticular abscess while working in a remote location. We were not lamenting the physical pain we endured but rather the emotional toil and the feeling of ineptness as we recovered. The first arrow represents an event that can cause pain—in our case the physical injury. The optional second arrow represents our reaction to the event; depending on how we choose to respond, it can bring as much pain and suffering as the first arrow or more. Undoubtedly, we usually find ourselves dealing with consequences from the second arrow more so than the first. What resonates with me is that minimizing suffering and pursuing equanimity is not about denying the initial pain but about finding composure in how to respond emotionally.

There are moments when I want to scream about the many issues impacting us, our colleagues, our profession, our patients, and our communities. Over the past several months, numerous friends and colleagues were affected by ER closures, rampant wildfires, and the inability to seek refuge from one or more overwhelming circumstances. Those are all first arrows, and each of them hurts. But I also know many of those individuals stepped up to support one another despite the difficult situations they were facing, whether by staying late to admit evacuated patients from the territories or by opening their homes to those who were displaced, and that is the second arrow. We

share a level of composure and a genuine desire to help one another, and we endeavor to do so with a level of equanimity. We know this is the right and good thing to do. Conceivably, it will also help lessen the suffering of the second arrow the next time we face a negative event and get hit with an arrow ourselves. ■

—Joshua Greggain, MD
Doctors of BC President

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Justice, rights, and unnecessary suffering

As physicians, we need to expand our circle of moral concern to include all people as well as animals we use for food, and to provide them some degree of political and legal standing.

Jan Hajek, MD

Ten years ago, I sat at a global health conference luncheon with an inspirational physician-leader and human rights champion. As they talked about the need for physicians to recognize and call out systemic injustice in the world, they chose the mayonnaise and ham sandwiches from the selection of food on offer. That struck me as odd and inconsistent.

I often think about that encounter. I admire that physician. What they were saying about human rights, principles of equity, and how we need to be careful to not overlook systemic injustices, especially those that may benefit us personally, was impactful. What also stood out was how we could then shrug off the plight of nonhuman animals as an entirely separate issue, one not worthy of serious consideration or attention.

The majority of physicians are advocates for human rights and take social justice issues seriously. Over 100 years ago, Dr Rudolf Virchow famously stated that “physicians are the natural attorneys of the poor, and social problems fall to a large extent within their jurisdiction.” Our concern for people faced with unjust oppression or systemic violence should naturally extend to nonhuman animals. In fact, there are

synergies, and there is evidence that caring about animals and promoting animal rights can actually help promote human rights, equity, and social justice.¹

Most physicians in Canada enjoy consuming meat, eggs, and milk products. These foods are an important part of many of our daily routines and may have been part of our families’ traditions and cultural identities for centuries. But, over the years, our uses of animals, our scientific understanding of animals’ cognitive and emotional capacities, and our knowledge of nutrition have evolved. This presents challenges we need to grapple with. Difficult social changes may be needed, and some aspects of our daily routines and traditions may need to be adjusted.

We shudder to think of the philosopher René Descartes theorizing that animals are just like machines, calmly nailing a dog’s feet to a board and dissecting it alive while it only *appeared* to be in pain.² We now cringe at the thought of someone being so callous. But while we would rightfully prosecute someone who mistreated a dog, we have normalized and justified relatively brutal industrial farming practices, which are generally exempt from current anticruelty laws.³

Most pigs and cows raised for food are subject to unnecessary suffering and have objectively miserable lives. On farms across Canada, castrating and hot iron branding a young cow without any pain control is still an acceptable practice.⁴ Female pigs can be kept in small crates most of their adult

lives.⁵ Most dairy cows live in stalls, are repeatedly impregnated, and have their calves taken away soon after birth to maximize the amount of milk extracted by milking machines.⁶

Our choices are not questions of necessity. There are alternative farming practices available. Nutritional science has even established that humans can thrive on well-planned plant-based diets.⁷ Yes, there are people in the world who still depend on raising animals like cows for their sustenance. There are also people who currently depend on the trade of endangered wild animals for their livelihood. We need to consider people’s individual situations and provide additional support to allow them to transition to safer and more compassionate livelihoods. But that is not the case for those of us living and working as physicians in Canada. Most of us do not eat meat or drink milk because of necessity.

Indigenous people’s leadership is crucial to protecting our planet. According to Judy Wilson, former Kúkpi7 (Chief) of the Neskonlith Indian Band, “Indigenous Peoples rely on hunting, fishing, and traditional foods and hold respect for the animals and all they harvest. Indigenous Peoples’ teachings are based on understandings that animals are our relatives and we are all connected. Large scale, industrialized animal farming and slaughterhouses are not the future for humanity as they are not sustainable and are inhumane to the animals whether they are for food sources or hides

Dr Hajek is an infectious diseases doctor based at Vancouver General Hospital and a clinical assistant professor of medicine at the University of British Columbia.

This article has been peer reviewed.

or the fur pelts” (J. Wilson, electronic communication, 21 April 2023).

There is room for different ethical views concerning the treatment of animals. However, these views must take into consideration the facts, and the facts are that domesticated animals like pigs and cows have complex cognitive and emotional lives, can establish sociable relations with humans, and objectively suffer on most farms when raised for food, and there are alternative farming practices and foods readily available.

As physicians, our promotion of human rights over the past several decades has been revolutionary and has meaningfully moved toward delegitimizing unjust structural hierarchies based on race, religion, and gender. However, insofar as these rights have sometimes been defined in stark contrast to animals (e.g., don't treat them like animals) there have been mixed consequences. Defining human rights based on a strict animal-human divide may lead to the unjust disregard of the rights and interests of animals. In contrast, acknowledging that animals are similar to humans (versus humans as similar to animals or superior to animals) could lead to less prejudicial attitudes toward other people.¹

As physicians, we need to expand our circle of moral concern to include not only all people, but also animals we use for food, like pigs and cows. And not only moral concern; we also need to provide some degree of political and legal standing. Notably, the US military no longer recognizes military working dogs as equipment, but more as personnel, which grants them some protections from abuse and slaughter when they are older and need to retire.⁸ Other animals could also be granted the right not to be treated as mere property.

Given pandemic risks and environmental impacts of animal agriculture, the issues of justice and rights for animals can also be framed as a matter of self-interest.⁹ Being compassionate and taking the welfare and interests of animals seriously will ultimately help us as well. It is also

entirely reasonable for physicians to advocate against the unnecessary suffering of animals on the basis of their individual rights and interests, along the lines of physicians advocating against the abuse of people on the basis of their individual rights and interests. These considerations can be manifest in some of our daily decisions and food choices. ■

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Continued from page 278

retire my pager this year. Although I still juggle 3 call schedules and am on call on average 4 times a month, my cellphone has made my pager obsolete. The pager has been useful when on call and in an area of poor cell reception, but its retirement is long overdue.

From a work perspective, I am at the same stage now as I was when I wrote that editorial in 2012, although arguably I may be further away from retirement now! However, from a personal perspective, I am far happier in my life. ■

—David B. Chapman, MBChB

Correction: Shifting access to apps—availability through the College Library

The College Library article published in the September issue (*BCM J* 2023;65:264) has been revised online. The authors provided the following content postpublication:

- Essential Evidence Plus is available from the CMA until December 2023.
- The CMA's subscriptions to CPS and DynaMed were discontinued as of June 2023.
- The CMA Library is now a corporate library; the CMA will stop providing clinical tools and services as part of CMA membership as of December 2023. ■



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Robin Friedlander, MD, FRCPC, Aaron Ooi, MBChB, DipPaed, PGDipClinEd, FRACP

Autism today



Dr Robin Friedlander



Dr Aaron Ooi

Dr Friedlander is a child and adolescent psychiatrist in the Neuropsychiatry Clinic at BC Children's Hospital. He is also head of the Neurodevelopmental Disorders program and a clinical professor in the Department of Psychiatry at the University of British Columbia. Dr Ooi was a postgraduate fellow in the Neuropsychiatry Clinic at BC Children's Hospital and is a general pediatrician in the Department of Paediatrics at Rotorua Hospital, Rotorua, New Zealand.

This editorial has been peer reviewed.

Autism is an important neurodevelopmental condition that is usually evident in early childhood and is typically associated with significant impairment. Awareness of autism has grown exponentially over the past 20 years, with increased recognition of the condition, along with generous public funding for early intervention. Approximately 3% of children and youth in BC carry an autism diagnosis. Media interest in autism has focused primarily on children and adults with so-called high-functioning autism. Some of these individuals identify as neurodivergent and consider autism a difference to be embraced rather than a disease to be cured. However, a significant minority of children with autism are nonverbal or minimally verbal and have complex behavioral challenges. This theme issue focuses on this subgroup but also contains some information on funding for adults with autism.

The first article in this theme issue is an update and review of some of the current practices and controversies related to autism. The authors discuss the reasons for the increased diagnosis of autism over the past 30 years and review some common coexisting conditions. This is followed by a summary of the benefits and limitations of early intervention and treatment for aggressive behavior. The article concludes with information about accessing public funding and highlights the unmet needs of those children and youth who are most impaired. This article should be of interest to any physician in BC.

The second article presents an algorithm for assessing and managing irritability and aggression in children and youth with autism. The algorithm guides the clinician to rule out or treat medical, sleep, and psychiatric conditions; consider developmental, environmental, and psychosocial factors;

and implement behavioral interventions before considering a prescription for atypical antipsychotics such as risperidone and aripiprazole. This article will be of particular interest to pediatricians and psychiatrists, who are the physicians most likely to manage such children and youth.

The third article discusses the challenges inherent in the routine medical evaluation of children and youth with autism and related neurodevelopmental disorders due to behavioral complexity. Such evaluations frequently necessitate examinations under anesthesia; however, difficulties in coordinating care result in fragmented and traumatic service provision. This article presents the preliminary findings of a multipronged study in which the clinical records of a cohort of children who had an elective procedure under anesthesia at BC Children's Hospital were reviewed: 1 in 6 children were identified as having behavioral complexity, and missed opportunities were noted for child-/family-centred, trauma-informed, equitable access to care. Recommendations are provided for improving coordination of care when a child undergoes sedation to reduce trauma from repeated sedations and for improving equitable access. This article will be of interest to physicians such as pediatricians and anesthesiologists who are involved in the care of complex populations. ■

Robin Friedlander, MD, FRCPC, Francois Proulx, MD, FRCPC

Autism: Current practices and controversies

The medical profession and society should learn to celebrate neurodivergence and ensure that neurodivergent individuals receive the supports and accommodations they need to realize their full potential.

ABSTRACT: The *DSM-5* condition known as autism spectrum disorder is usually a lifelong diverse condition whose etiology is not fully elucidated. Over the past few decades, its prevalence has increased, and the relationship with other neurodevelopmental disorders has evolved. In BC, there is a well-defined process for making the diagnosis. Treatment interventions are available for both the core symptoms of autism in early childhood and comorbid conditions throughout the lifespan. Supports are available through provincial programs and the health care sector but may be difficult for families to access. We discuss the advocacy burden for the families whose children have the most complex needs and impairment.

Autism is a neurodevelopmental disorder that typically presents in early childhood and is characterized by impaired social communication and

restricted and repetitive patterns of behavior and interests. Although considered a specific disorder, autism is one of a number of neurodevelopmental disorders, with which it shares many aspects.¹ We review evolving aspects of diagnosing autism spectrum disorder in BC and in clinical practice, as informed by recent developments in the field. While we may touch on areas of evolving knowledge, it is beyond the scope of this article to provide a comprehensive review of more controversial aspects of autism.

Diagnosing autism

The gold standard for diagnosing autism involves obtaining a child's history by conducting a thorough diagnostic interview with the child and their parents and a mental status examination. Some jurisdictions, such as BC, have a prescribed diagnostic process, in part to standardize who may access limited therapeutic and support resources. The BC Autism Assessment Network (www.phsa.ca/our-services/programs-services/bc-autism-assessment-network) and its affiliated centres see children who have a query of autism and designate the required assessment process for the diagnosis to be recognized by the Ministry of Children and Family Development, and for these children to be allocated individualized funding for treatment intervention. The same process is followed by both publicly funded assessors in BC Autism Assessment Network centres and private fee-for-service assessors. There are long wait lists for assessments conducted by publicly funded developmental clinics in

BC (such as Sunny Hill Health Centre), but the wait list is often shorter for private fee-for-service assessors.

In addition to a history and mental status examination obtained by a trained clinician, a BC Autism Assessment Network assessment requires a semistructured interview with the parents—the Autism Diagnostic Interview—and a semistructured interaction with the child—the Autism Diagnostic Observation Schedule.²

DSM-5 diagnostic criteria for autism spectrum disorder³

- A. Persistent deficits in social communication and interaction across multiple contexts.
- B. Restricted, repetitive patterns of behavior, interests, or activities.
- C. Onset in the early developmental period (although may not be manifest until social demands exceed capacity).
- D. Causes significant impairment in functioning.
- E. Symptoms not better explained by intellectual disability/global developmental delay.

Autism today

Increasing prevalence, broadening phenotype, and relationship to other neurodevelopmental disorders

Experienced clinicians have traditionally been able to fairly quickly assess whether a child has autism. However, we are increasingly seeing children with autism diagnoses

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in whom the classic diagnostic features are not readily apparent. This is likely because the diagnostic boundaries of the behavioral phenotype that defines autism have broadened over the past 30 years, and there is now large variability in symptom types, onset, and degree of severity.^{1,4} Whereas it is true that the contemporary cohort of patients with autism may include fewer individuals with comorbid intellectual disability, data also indicate a secular trend toward less severe features of autism in subjects with this diagnosis.⁵

From the 1970s onward, the reported prevalence of autism has increased substantially. The condition was previously considered rare and affected less than 0.05% of the population, but by 2015, the prevalence was estimated as at least 1% in both children and adults.¹ In 2022, the proportion of children and youth in BC between the ages of 6 and 18 years with an autism diagnosis was 1 in 32 (3%).⁶ This rate is somewhat higher than that reported by the Public Health Agency of Canada, which noted that in 2019, 1 in 50 (2%) of Canadian children and youth aged 1 to 17 years were diagnosed with autism.⁷

The increased rate of diagnosis is controversial because there is no evidence that the autism phenotype, the symptoms on which the diagnostic criteria are based, is occurring with increased frequency. Lundström and colleagues followed more than 4000 children born in Sweden over a 10-year period, from 1993 to 2002, and found that the year-over-year prevalence of the autism phenotype was stable during that period.¹ In contrast, there was a significant increase in the prevalence of registered diagnoses of autism spectrum disorder in the Swedish national patient register.¹ Lundström and colleagues¹ postulated that this was due to three factors:

- There may have been an implicit broadening of potentially overlapping diagnostic criteria. The considerable overlap of symptoms between autism and other neurodevelopmental and psychiatric diagnoses may have contributed to the rapid rise in autism diagnoses in recent years.

- Increasing awareness of autism may have been associated with diagnostic substitution (e.g., the increased prevalence of autism diagnosis has corresponded, to an extent, with a parallel decrease in diagnosis of intellectual disability documented in the literature, but also, in our practice, of other psychiatric and neurodevelopmental disorders).

In 2022, the proportion of children and youth in BC between the ages of 6 and 18 years with an autism diagnosis was 1 in 32 (3%).

- Diagnosis and prevalence may be sensitive to funding and availability of therapeutic and support services. Dedicated funding and specific interventions for autism may have contributed to an increase in the likelihood of referral for diagnosis. Similar hypotheses have been made in the Canadian context.

Dr Anton Miller, a developmental pediatrician at Sunny Hill Health Centre, responded to Lundström's article with a letter to the *British Medical Journal*, noting that in BC, a substantial proportion of referred cases now consist of children aged 2 to 3 years for whom autism-related clinical observation of such things as social reciprocity and social communication may be mild, and whose low-level restricted and repetitive behaviors may be difficult to distinguish from those exhibited by typical children.⁸ Dr Miller also noted that for many of these children, it can remain clinically subjective whether to attribute impairment to symptoms of autism or to delays or impairment in language or executive functioning skills, which are frequently also present.

Indeed, in our respective practices, comparatively few children with autism present with autism traits in isolation. Most also experience other comorbid cognitive and mental health issues, such as intellectual disability, learning disorders, tics, anxiety,

and attention deficit hyperactivity disorder. This clinical presentation is sometimes called "autism plus" and often accounts for a large part of the impairment in children with autism.⁹ Due to the considerable overlap of symptoms between autism and other neurodevelopmental disorders, children diagnosed with autism frequently have concurrent neurodevelopmental and/or psychiatric disorders, such that comorbidity is the rule rather than the exception. Given the spectrum of severity in autism itself and the spectrum of comorbidities, patients with a diagnosis of autism have heterogeneous needs, including psychiatric needs. The broader recognition of autism continues to be associated with significant diagnostic overshadowing of other psychiatric comorbidities. A diagnosis of autism may not, for a particular patient and at a particular point in time in their life, be the primary source of psychiatric impairment.¹⁰

Ambiguous language

The term "high-functioning autism" does not have a consistently agreed upon definition but is generally used to refer to individuals with autism who are of average or above average intellectual functioning (such as patients with autism without intellectual disability). The term, as commonly used, does not refer to the severity of the autistic symptoms in a specific individual and may be misleading, because some patients with "high-functioning" autism may be substantially impaired in their functioning. In the past, such individuals may have been assigned a diagnosis of Asperger syndrome. However, studies have not been able to clearly distinguish Asperger syndrome from other forms of autism, and in the *DSM-5*, such individuals are classified as part of the autism spectrum.³

Also plagued with inconsistent definition, though less frequently used, is the phrase "low-functioning autism," which is generally assumed to mean that the affected individual has comorbid intellectual disability or may be nonverbal or minimally verbal. In a multisite study conducted in the US between 2000 and 2016, 27% of

8-year-old children with autism were assessed to have profound autism (defined as being nonverbal or minimally verbal or having an IQ < 50).¹¹ Children with profound autism are more likely to be born preterm or with low birth weight; to be female; to be from ethnic minority groups; to have lower socioeconomic status, a seizure disorder, and lower adaptive functioning scores; and to present with self-injurious behaviors.¹¹

Autism through the lifespan

In most cases, autism persists throughout the lifespan. One of the benefits of the increased awareness about autism is that a number of adults who were previously undiagnosed and misunderstood have recognized characteristics of autism in themselves. Having a label for their neurodivergence can be very helpful for these individuals. For example, Mary Doherty, an Irish physician, recognized in her mid-40s that she had autism, and in 2019 she founded Autistic Doctors International, a peer support and advocacy group.¹²

The increased media interest in autism has generally focused on milder forms of the disorder. However, individuals with more severe and less visible forms of autism may be more likely to have behavioral/mental health challenges and to require clinical attention (medical and psychiatric). In the US, families of individuals who are more impaired with autism have formed an advocacy group, the National Council on Severe Autism, to focus attention on those individuals with autism who, by virtue of any combination of cognitive and functional impairments, require continuous or near-continuous lifelong services.

Evolving knowledge

Etiology

Genetic factors play a consistently larger role than environmental factors in etiology.⁴ Approximately 85% of individuals with autism have idiopathic autism, whereas approximately 15% are diagnosed with syndromic or secondary autism.⁴ Well-documented causes of secondary autism include conditions such as tuberous sclerosis, fragile X

syndrome, and some congenital infections (e.g., rubella). In some cases, secondary autism may be associated with more severe behavioral problems than is idiopathic autism.

Gender and socioeconomic factors

In BC, approximately three times more males than females receive funding from the Ministry of Children and Family Development's Autism Funding Unit, despite a greater increase in the diagnosis of autism in girls in recent years.⁶

Studies from different countries have suggested that the prevalence of autism, especially in combination with intellectual disability, is higher among children of immigrant women. Such children are more likely to be diagnosed with autism at a younger age and to present with more severe traits of autism and associated intellectual disability than are children of non-immigrant women. Etiological factors associated with immigrant mothers could include vitamin D deficiency, socioeconomic disadvantage, and less access to medical care during the prenatal period.¹³

Autistic regression

Two forms of developmental regression are sometimes seen in pediatric patients with autism:

- Most children show symptoms of autism before 18 months of age. However, a subset of children with autism appear to have relatively normal development, followed by the appearance of autistic features in the second or third year of life. A case example is a child we treated who had relatively normal development until about the age of 2 or 3 years, when he started losing skills, became very quiet, and appeared reluctant to even to say his name until the age of 4 years. The onset of autism in such children is temporally correlated with public immunization schedules (the measles, mumps, and rubella vaccine in the second year of life). This may contribute to the erroneous but persistent belief that this vaccine could be the cause of the autism.

- In the 1960s and 1970s, it was first noted that some children with autism lose skills and develop behavioral symptoms in adolescence. In 2006, in a community-based sample in Ontario, Bradley and Bolton identified patients with autism who, in adolescence, developed complex psychiatric symptoms associated with loss of functioning.¹⁴ In the authors' experience, such regression and behavioral change can often be attributed to adolescent onset of comorbid psychiatric disorders, such as catatonia or mood disorders.¹⁴

Pathological demand avoidance

Pathological demand avoidance is a concept that recently emerged to describe a group of children who are driven to avoid everyday demands and expectations to an extreme extent.¹⁵ Such children are typically passive in their first year of life. As more is expected of them, the child becomes "actively passive" and strongly objects to normal demands in the family or school environment. The child seems to feel under intolerable pressure from normal expectations and, over time, develops strategies that allow avoidance of such expectations but may be experienced as disruptive or distressing by the family or school. Such children have a high rate of mood lability and anxiety. The behavior tends to persist into adulthood.¹⁵ It is hypothesized that underlying anxiety drives pathological demand avoidance. Symptoms can overlap with those of oppositional defiant disorder, which may also occur in children with autism and is often related to underlying attention deficit hyperactivity disorder, anxiety, or depression. In our clinical opinion, a diagnosis of pathological demand avoidance should not obscure consideration of treatable comorbid disorders, such as anxiety and attention deficit hyperactivity disorder.

Avoidant/restrictive food intake disorder

This is a new diagnostic category in the *DSM-5* and is characterized by avoiding or restricting food intake, without the body

image disturbance that would be seen in anorexia nervosa.³ Children with autism are often noted to be fussy and rigid eaters and may have extreme sensitivity to the appearance, texture, or taste of food. Avoidant/restrictive food intake disorder can be understood as a particularly severe form of food sensitivity in such children and would be diagnosed when the child has significant weight loss or faltering growth. Treatment may include behavioral desensitization.

Treatments and interventions for children with autism

Early intervention

For many years, autism was considered to be an intractable neurodevelopmental disorder with few effective treatment options. However, a few decades ago, quality university-led trials of psychosocial interventions in early childhood demonstrated positive changes in young children with autism.¹⁶

Historically, such early intervention focused on instructor-led high-intensity applied behavioral analysis and discrete trial training that relied on external rewards, based on principles of applied behavior analysis. Other validated early intervention models have emerged in parallel to applied behavior analysis, which focus on teaching parents to support the child in early communication and social interaction, sometimes with delivery intensity that is lower than was initially anticipated to be necessary for effectiveness. Early intervention can successfully teach the child practical skills for day-to-day living, such as asking for help, saying no, and improving emotional regulation, as well as the basic building blocks for future socially mediated learning, such as joint attention and imitation.¹⁷

As is often the case in many areas of medicine, the early enthusiasm of initial landmark efficacy studies has been dampened over the years by subsequent real-world effectiveness and observational data. It was initially believed that intensive early intervention during the preschool period would dramatically improve long-term outcomes for most children with autism.¹⁶ However,

a multisite Canadian study showed limited change in the trajectory of autism for most children diagnosed during the preschool years, even though all the children had received some degree of early intervention.¹⁸ In that study, Szatmari and colleagues followed 421 children with autism from diagnosis, at between 2 and 4 years of age, up to 6 years of age. Approximately 11% of the children improved in terms of autism severity and adaptive functioning. However,

Good-quality literature supports the benefits of modified cognitive-behavioral therapy in children and youth with autism and comorbid anxiety disorders.

90% continued to have severe symptoms of autism and showed little change in adaptive functioning at 6 years of age. The children who had improved the most were often those who presented with less severe symptoms at the time of diagnosis.

A follow-up study of the same cohort of Canadian children at 10 years of age showed that approximately 25% of the children displayed less severe symptoms of autism over time.¹⁹ The group that showed favorable symptom evolution over time tended to have lower autism severity and better cognitive, language, and adaptive living skills at the time of diagnosis.

The early childhood period provides many opportunities for growth and learning. Although it is generally accepted that early intervention is a benefit to young patients with autism, it has become apparent that the nature, specific target symptoms, and intensity of intervention must be tailored to the needs of each child and their family.

Psychotherapy

Psychotherapy may be helpful for children who are verbal and youth with comorbid anxiety, depression, obsessive-compulsive

disorder, or tic disorders. Good-quality literature supports the benefits of modified cognitive-behavioral therapy in children and youth with autism and comorbid anxiety disorders.²⁰ Modifications may include helping the child identify and label emotions and having greater involvement of the parents in the treatment. Modified cognitive-behavioral therapy for comorbid anxiety disorder involves graduated and sustained exposures to anxiety-provoking situations and positive reinforcement for exposing oneself to feared situations.²⁰ However, it can be difficult to find a clinical counselor or psychologist with skills in the area of anxiety disorders comorbid with autism.

Behavioral therapy for challenging behaviors

In many cases, challenging behaviors in patients with autism stem from a mixture of biological and environmental contributors, but the precise mix varies greatly between cases.

Even infrequent and sporadic aggressive or self-injurious behaviors can lead to substantial restrictions on an individual's access to school and the community. This may limit the child's access to important treatments and interventions. Challenging behaviors can result in injury to the child or family members. Such behaviors can result in families feeling anxious and unsafe and can reduce the quality of life. Families often learn to cope by restricting their lifestyle in anticipation of the next episode of challenging behavior. In severe cases, challenging behaviors may become a factor in a child having to live away from their family.

Challenging behaviors commonly result in, and are perpetuated by, reinforcement over time. Behavioral treatment may be needed to improve such behaviors; there is substantial literature on the effectiveness of such behavioral intervention in treating irritable/aggressive behavior in children with autism. The current approach to addressing problem behavior requires a functional behavior assessment, followed

by implementation of a function-based intervention. The goal is to reduce the rate and prevalence of problem behaviors while teaching functional, socially desired alternatives (e.g., if the function of the problem behavior is determined to be accessing attention, the functionally equivalent target behavior would yield access to attention; if it is escape from a difficult task, the task would be modified, or a break response would be taught).²¹

Parent management training uses parents as agents of behavioral change in the child to promote skill acquisition and generalization of the acquired skills to the home, the school, and various community settings. Common elements of parent management training include formal instruction in general principles of behavioral psychology and in specific management techniques, role-playing, homework assignments, teaching of play and social skills, and use of visual communication techniques. Parent management training can be supplemented with home visits and telephone consultation.

Psychotropic medications

Psychotropic medications used judiciously in line with a limited but increasing evidence base to address common psychiatric comorbidities, such as attention deficit hyperactivity disorder and anxiety disorders, can improve functioning in some children. Off-label use of psychotropic medications to address challenging behaviors is fraught with significant drawbacks and limitations but can become necessary in some cases. A companion article in this issue reviews the psychopharmacological treatment of irritability in autism (see page 291).

Alternative treatments

A number of open, nonplacebo, controlled studies published between 2010 and 2019 suggested there was significant improvement in challenging behaviors, sleep, and symptoms of anxiety in children and youth with autism who were treated with cannabis-derived products. The first randomized, double-blind, placebo-controlled trial was conducted in Israel.²² 150 children

and youths with autism who were 5 to 21 years of age were given either placebo, whole-plant cannabis extract, or cannabidiol. Improvement in challenging behavior was suggested for whole-plant cannabis but not for cannabidiol. One of the main adverse effects was somnolence. The authors were cautious in their conclusions, noting that evidence for efficacy was mixed and

Parent management training uses parents as agents of behavioral change in the child to promote skill acquisition and generalization of the acquired skills to the home, the school, and various community settings.

insufficient. In a 2019 policy statement, the American Academy of Child and Adolescent Psychiatry advised “against the use of medical marijuana or isolated cannabinoids for core symptoms or co-occurring emotional or behavioral problems in children and adolescents with autism spectrum disorder.”²³

A systematic review of 19 randomized controlled trials evaluated dietary supplements (such as digestive enzymes and vitamin B12) and variations of the gluten-/casein-free diet. The studies were small and short-term, and there was little evidence to support the use of nutritional supplements or dietary therapies for autism.²⁴

Government supports and psychiatric care

Funding

Children and youth. In BC, funding for treatment and community support for children and youth with autism is administered by the Ministry of Children and Family Development: Children and Youth with Support Needs. Funding for treatment interventions is individualized to each child

and is ultimately managed by the family, within the parameters set by the Ministry. Funding can be disbursed for certain devices or services provided by approved treatment providers who are contracted by families. In BC, children with autism who are under 6 years of age are allocated \$22 000/year. Between 6 and 18 years of age, children and youth with autism receive \$6000/year.

A diagnosis of autism also allows the school to receive additional funding from the Ministry of Education and Child Care, which may allow for the provision of 1:1 educational assistance, if needed. Personal communication with teachers in special education indicates that some are concerned that the increased focus on autism within the education system may have resulted in comparatively less funding and attention dedicated to children with specific learning disorders (neurodevelopmental disorders associated with specific impairment in reading, mathematics, or writing). Some patients with psychiatric diagnoses other than autism, including other neurodevelopmental disorders, can present with functional impairment equal to or greater than some children with autism but do not receive the level of funding available to children with autism. The Representative for Children and Youth of BC notes that there are “thousands of children with [fetal alcohol spectrum disorder], Down syndrome and a wide range of other neurocognitive developmental needs who receive little or no support from the Province of BC.”²⁵

Adults. Adults with autism may receive publicly funded community supports that are contracted to community agencies by Community Living British Columbia if they meet either of two eligible pathways:

- They have a concurrent diagnosis of intellectual disability (whose psychometric definition has classically consisted of cognitive and adaptive functioning at more than two standard deviations below the mean or lower on standardized psychometric assessment).
- Adults with autism, but without comorbid intellectual disability, may

still be eligible for Community Living British Columbia supports if their adaptive functioning is more than three standard deviations below the mean (a much narrower statistical definition), through the Personalized Supports Initiative.

Psychiatric care and behavioral therapy

Psychiatric care. Despite the high rates of psychiatric comorbidity in autism, Child and Youth Mental Health teams in the province may be reluctant to see such children because they already have large caseloads and may lack the skills to assist such complex children. It is difficult to access child psychiatrists in BC, although BC Children's Hospital has a Neuropsychiatry Clinic that can provide consultation for such children. In the Lower Mainland, youth 12 years of age and older (14 years of age and older elsewhere in the province) can be seen by their local Developmental Disabilities Mental Health Service team only if they have a comorbid diagnosis of intellectual disability. Most of the care of these children is provided by community physicians, particularly pediatricians. Community physicians, nurse practitioners, and mental health clinicians can obtain advice from a child psychiatrist regarding management of such children via the BC Children's Hospital Compass Mental Health program (<https://compassbc.ca>).

Behavioral therapy. In BC, behavioral consultants are available to families who have children with autism. However, the training and experience of behavioral consultants varies, and some may lack the expertise to provide evidence-based behavioral treatment for challenging behaviors such as aggression. If the behavioral problem is severe and more intensive behavioral treatment is required, the \$500 per month of individualized funding available to families of school-aged children may not be sufficient.

There is often an expectation that the family will implement the behavior therapy plan by themselves within their home

environment. This may not be realistic in some situations, such as when implementation of the plan is expected to cause an initial debilitating increase in challenging behaviors (the "extinction burst"), or in situations where a family's time and resources may be pulled in various directions. The competing priorities and needs of all family members, and the limitations on their time and resources, have to be balanced against caregiver burnout.

For families of children with significant behavioral challenges, there is a need to constantly advocate to receive the necessary enhanced supports and respite.

Supporting families

In clinical practice, the unmet support needs of the most behaviorally complex children with autism and their families are of particular concern. Many of these children and youth are relatively nonverbal and exhibit severe challenging behavior, aggression, or self-injury. Families of such children need respite. Whereas all families of children with autism receive limited funding to access respite care, the public funding for respite is the same for all families, irrespective of need. Finding a provider who can offer respite to the families of children with the most challenging behaviors can be very difficult because of safety concerns.

When the institutions in BC that historically housed individuals with neurodevelopmental disorders were closed in the 1980s and 1990s, the belief was that families would be able to access publicly funded supports in the community. However, respite for families has become progressively less available over time. One of us started working in the field in 1993, at which time families of children with neurodevelopmental disorders still had access to staffed respite homes where their child

could receive respite care on select days of the month.

For families of children with significant behavioral challenges, there is a need to constantly advocate to receive the necessary enhanced supports and respite. Even the most competent parents of such children will likely find the task of advocating with the Ministry of Children and Family Development both daunting and draining. This is even more so for parents from historically marginalized groups, such as parents with their own disabilities or immigrant families.

In our clinic, we recommend that families contact the Family Support Institute of BC (<https://familysupportbc.com>), which provides invaluable advice and assistance to parents and siblings regarding advocacy.

Meeting the needs of the most severely impaired patients

A minority of patients who have autism with severe and refractory challenging behaviors may use disproportionate amounts of emergency and inpatient medical and psychiatric care. The severe symptoms of this most significantly impaired group of patients can cause great distress in the patients themselves, in their families, and in their community care providers. It may impair the patients' ability to participate in school and their family's ability to work. Patients who have autism with severe and refractory psychiatric symptoms can benefit from specialized multidisciplinary residential assessment and treatment. Currently, the only option for this in BC is Community Living British Columbia's Provincial Assessment Centre, which serves youths 14 years of age and older and adults with a diagnosis of intellectual disability. However, the Provincial Assessment Centre has stopped accepting patients with a history of aggression, even though it is considered one of the strongest predictors of inpatient psychiatric care in youths with autism.²⁶

Case histories

Early intervention

A 4-year-old child recently diagnosed with autism presented to primary care

with challenging outbursts of anger and physical aggression. Such outbursts were in excess of what would be expected at his developmental stage and were the cause of a number of significant injuries that were sustained by his parents. Outbursts and physical aggression impaired the family as a whole: one parent had to leave their job and forgo part of the family's income, and various early childhood education settings had refused to care for the child due to his behavioral challenges. A primary care assessment did not reveal any cause of pain or discomfort that could be contributing to such outbursts in this child with impaired adaptive skills.

Concurrently with the child being referred to a preschool psychiatry clinic, the family used their individualized autism funding to contract a behavior analyst, a team of behavior interventionists, and a speech and language therapist. After 4 months of treatment intervention, the goal of which was to teach the child functional communication and more adaptive behavior scripts, the outbursts and physical aggression had decreased to such a degree that by the time the child was finally assessed at the early childhood psychiatry clinic, he was functioning well at home and in his new early childhood education centre (with educational assistance provided by their catchment's Supported Child Development team). Off-label use of psychotropic medications to control aggression and irritability was no longer a consideration.

Autism and attention deficit hyperactivity disorder

An 8-year-old boy had been asked to leave day care at 3 years of age because of hyperactivity, including jumping on tables and throwing objects. Autistic symptoms identified at the time included echolalia, spinning ribbons, hyperacusis, and missing social cues. He was diagnosed with autism at 5 years of age. Behavioral problems persisted, and at 8 years of age, he was refusing to do schoolwork and would bolt out of class, touch peers inappropriately,

and hit the bus driver and educational assistant. The parents were unable to find someone to provide respite care because of his significant challenging behaviors. In the consulting room, he was extremely wriggly and distractible and pulled at his mother's clothing to get her attention. Mood was overall good. Lisdexamfetamine, 30 mg daily, for treatment of comorbid attention

Most community pediatricians and family physicians, and indeed most physicians, in BC will encounter individuals with autism in their practice, be it as patients or co-workers or in their personal lives and families.

deficit hyperactivity disorder was helpful but wore off by noon. An increase in lisdexamfetamine to 60 mg daily led to a dramatic response, and behavior became manageable throughout the day.

Autism and social anxiety

A 16-year-old male was diagnosed with autism at 8 years of age when the school noted that he would not play with other children and talked to himself. He was overly self-aware and constantly compared himself to his peers. He would not use the washroom or eat in front of others at school. He avoided answering questions in class and was placed in a separate room with the educational assistant. He eventually refused to go to school altogether. He was seeing a counselor, but the psychotherapy was mostly supportive and did not consist of modified cognitive-behavioral therapy, which is the evidence-based treatment for anxiety. Treatment with 40 mg of fluoxetine daily was very helpful for the social anxiety and allowed the child to return to school with support.

Autism, intellectual disability, and obsessive-compulsive disorder

An 11-year-old boy had a history of prematurity and significant developmental delays (nonverbal until 6 years of age) and was diagnosed with autism at 2 years of age. He had a history of attention deficit hyperactivity disorder and complex tics. At 8 years of age, he started to exhibit severe behavioral outbursts related to rituals. A certain blanket had to be folded in a particular way and placed in a certain corner, he had to hold certain objects in a particular manner, and he repeatedly touched walls at a particular spot. Brushing his teeth became rigid and time-consuming because there had to be a particular amount of toothpaste on the toothbrush or he would need to start again. If saliva came out of his mouth when brushing his teeth, he would need to wipe his mouth a certain number of times. When getting dressed, his mother had to stand in a particular spot and not move while he adjusted his clothing. Showers took 60 to 90 minutes, and the soap had to be applied to his hands in a particular way.

Rituals would take more than 3 hours per day to perform, and he would need to persist at them until he was satisfied they were done correctly. He was diagnosed with comorbid obsessive-compulsive disorder and was treated with 50 mg of sertraline daily, which partially reduced the compulsions and outbursts. He could not tolerate a higher dose.

Conclusions

Autism exists across a spectrum of severity throughout the lifespan and with a constellation of comorbidities. Supports for patients and their families and treatments for challenging behaviors and comorbid conditions exist but may be difficult to access. Most community pediatricians and family physicians, and indeed most physicians, in BC will encounter individuals with autism in their practice, be it as patients or co-workers or in their personal lives and families. As a profession and as a society, we should learn to celebrate neurodivergence, while recognizing that impairment and

distress often exist and that supports and accommodations may be needed for such individuals to realize their full potential. ■

Competing interests

None declared.

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Evaluating and managing irritability and aggression in children and adolescents with autism spectrum disorder: An algorithm

Because the drivers of irritability and aggression in individuals with autism spectrum disorder can be multifactorial, they must be addressed in a stepwise manner or in parallel to identify treatable contributors and institute appropriate management.

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ABSTRACT: A range of maladaptive behaviors, including irritability and aggression, are often encountered in autism spectrum disorder. Challenges in complex clinical decision making and management exist, and off-label antipsychotic prescribing is increasing in Canada. A literature review of various treatments, limited to randomized controlled trials in the pediatric population, was used to develop an algorithm for evaluating and managing irritability and aggression in autism spectrum disorder within a Canadian context, which is supported by expert consensus. Holistic consideration of biomedical, psychiatric, psychosocial, environmental, and developmental factors that affect behavior is emphasized. The algorithm highlights the multifactorial contributors to irritability and aggression in autism spectrum disorder and reserves the use of antipsychotic medication for managing the most severe and refractory cases. A comprehensive evaluation of the drivers of behavior when addressing irritability and aggression in autism spectrum disorder is crucial to identify treatable contributors and institute appropriate management.

Autism spectrum disorder is a complex neurodevelopmental disorder that affects 1 in 32 children and youth in Canada.¹ It is characterized by impairments in social communication and

interaction and a pattern of repetitive or restricted activities, interests, or behaviors.² A wide range of maladaptive behaviors are commonly encountered, including irritability and aggression, with prevalence estimated at 25% to 68%.^{3,4} Irritability can be defined as a mood state characterized by easy annoyance, anger, and the manifestation of temper outbursts; aggression can be defined as intentional verbal or physical threats, attempts to inflict or infliction of bodily harm on another individual, or intentional destruction of property.^{5,6} We have excluded self-injurious behavior within the scope of these definitions for the purposes of this article. The causes for irritability and aggression are often multifactorial and can result from difficulties arising from autism spectrum disorder itself, including hypersensitivity to environmental triggers, communication difficulties, and excessive rigidity. Irritability and aggression can also be related to medical symptoms such as pain and discomfort or a symptom of several psychiatric conditions such as attention deficit hyperactivity disorder, anxiety disorders, and mood disorders.²

Based on positive clinical trials, the US Food and Drug Administration approved the atypical antipsychotics risperidone and aripiprazole for the treatment of “irritability,

including aggression, deliberate self-injury and temper tantrums” in the autism spectrum disorder population.^{7,8} In Canada, no antipsychotic medication is approved for this use. Despite this, off-label antipsychotic prescription rates in the pediatric population in Canada are increasing and present concerns given the known side effects of antipsychotic medications and paucity of data on long-term use and safety.⁹

A practice pathway designed to help pediatric primary care practitioners assess and manage irritability and problem behaviors in autism spectrum disorder and a systematic review and meta-analysis of pharmacological management have been published.^{10,11} However, to our knowledge, there are no published Canadian guidelines for an area in which frequent challenges exist with regard to decision making. Therefore, our aim was to offer a Canadian perspective that is tailored toward child and adolescent psychiatrists, pediatricians, and family physicians. We conducted a literature review, and, building on our clinical experience in a neuropsychiatry clinic at a quaternary centre, we obtained consensus to produce a clinically useful algorithm to guide decision making for behavioral complexity [Figure]. Frequently occurring and treatable comorbid conditions are also discussed, with emphasis on the complexity in psychiatric diagnoses and management. The algorithm highlights the multifactorial contributors to irritability and aggression in autism spectrum disorder and reserves the use of antipsychotic medication for managing the most severe and refractory cases.

Algorithm

Comorbidities and links to maladaptive behavior

Patients with autism spectrum disorder often have one or more medical or psychiatric comorbidities and can present to clinicians with a complex interplay of symptoms, including maladaptive behaviors.^{10,12} A study of 58 adolescents with autism spectrum disorder who were admitted to a neurobehavioral unit for severe challenging behaviors suggested that 28% and

48% had a primary medical condition or non-autism spectrum disorder psychiatric condition, respectively, that accounted for decompensation.^{12,13} Such findings support the need for a comprehensive assessment when patients with autism spectrum disorder present with irritability and aggression,

The algorithm highlights the multifactorial contributors to irritability and aggression in autism spectrum disorder and reserves the use of antipsychotic medication for managing the most severe and refractory cases.

particularly in children who cannot communicate effectively. Identification of underlying comorbid conditions contributing to irritability and aggression permits specific and targeted treatments and may avoid the use of antipsychotics, which carry significant side effects. In contrast, behaviors associated with an unrecognized medical or psychiatric problem are unlikely to improve if the underlying driver of behavior is not addressed and may worsen with nontargeted treatments.

Medical comorbidities

Common medical comorbidities encountered in autism spectrum disorder include gastrointestinal dysfunction; feeding disorders; ear, nose, throat, or dental pathology; seizures; and side effects of medications that contribute to symptoms.¹³ Although it has been difficult to determine the frequency in which medical factors directly cause or exacerbate maladaptive behaviors, conventional clinical practice and consensus advocate that such potentially reversible causes should be addressed prior to or in parallel with specific treatment that is targeting behaviors.¹³ Gastrointestinal dysfunction (such as abdominal pain, gastroesophageal reflux

disease, constipation, diarrhea, or abdominal bloating), which occurs in 24% to 79% of the population with autism spectrum disorder, has been associated with behavioral issues.¹⁴ Recognizing that medical evaluations may be poorly tolerated in some children with autism spectrum disorder, it has been suggested that diagnostic trials of empiric therapy for gastroesophageal reflux or constipation may be undertaken to provide diagnostic clarity if supported by history.¹⁵ An evaluation of the ear, nose, throat, and dental health, alongside a medical systems review, is also warranted.^{10,13} The presence of seizures in patients with autism spectrum disorder, which has an estimated prevalence of 7% to 46%, is particularly significant, because many anticonvulsant medications such as levetiracetam and clobazam can also adversely affect behavior.^{16,17}

Sleep

Sleep disorders are common in autism spectrum disorder: the estimated prevalence is 50% to 80%.¹⁸ An association between sleep problems and aggression in autism spectrum disorder has been described.¹⁹ A comprehensive evaluation of sleep, including identification of issues related to sleep initiation, maintenance, and nighttime awakenings, is suggested. This should include a review of common causes of nighttime awakenings, such as poor sleep habits, primary sleep disorders (e.g., parasomnias, obstructive sleep apnea, restless legs syndrome), comorbid medical conditions (e.g., seizures, gastroesophageal reflux disease, enuresis), and psychiatric disorders (e.g., anxiety, mood disorders), which may warrant further subspecialist involvement.^{13,20}

In managing sleep disorders in patients with autism spectrum disorder, current recommendations focus on education and implementation of sleep hygiene and behavioral measures as first-line treatment; several resources are available to support this approach.^{20,21} Consideration of using melatonin (starting dose 1 mg at bedtime, with a maximum of 10 mg at bedtime) can be made as a second-line recommendation if sleep hygiene and behavioral measures are

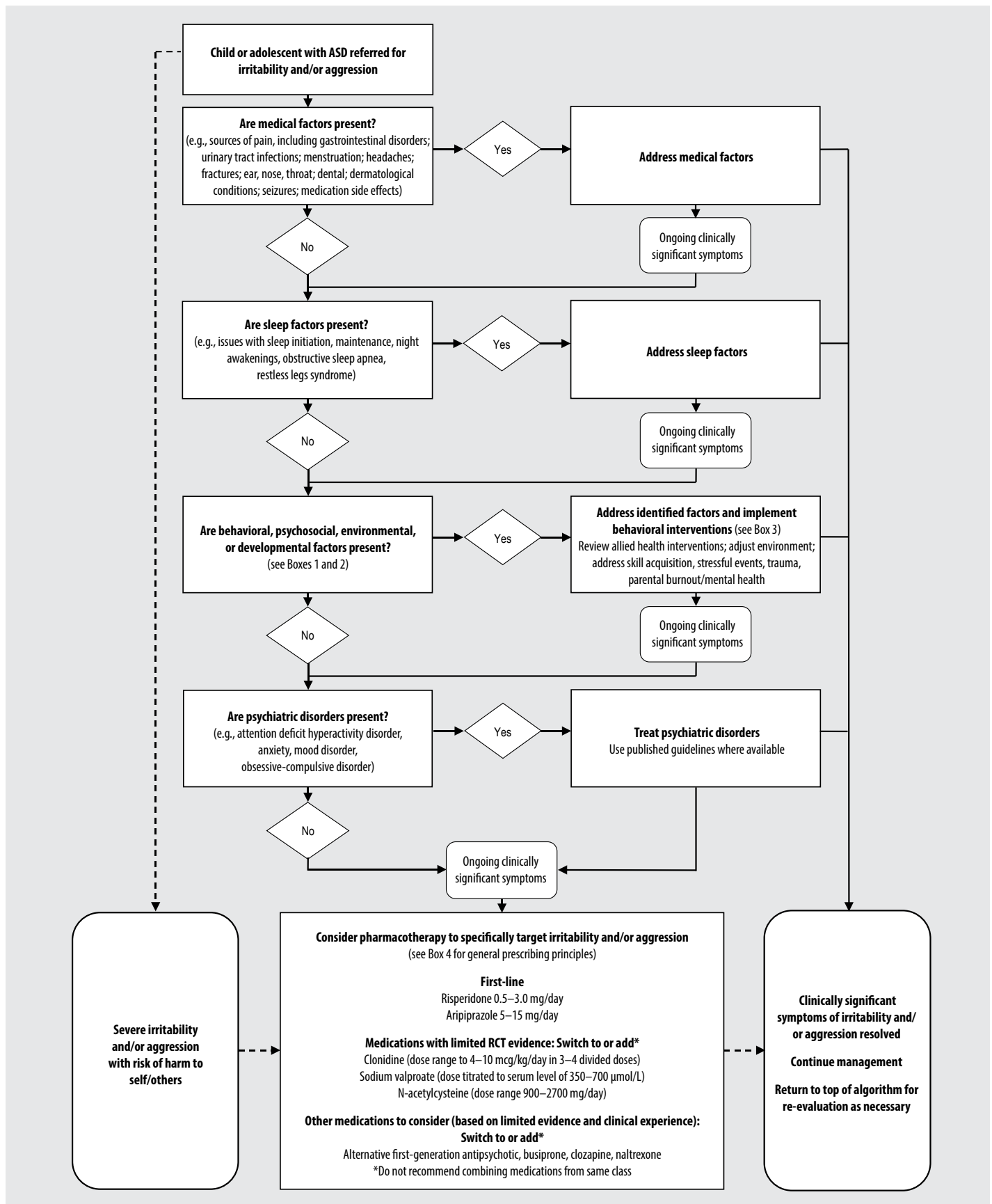


FIGURE. Algorithm for assessing and managing irritability and aggression in children and adolescents with autism spectrum disorder (ASD).

RCT = randomized controlled trial.

unsuccessful; a meta-analysis demonstrated increased sleep duration and reduced sleep onset latency but no effect on nighttime awakenings.²² Third-line treatments may include the use of clonidine, risperidone, or trazodone due to their sedative side effects. Nevertheless, given that there are limited robust data drawn primarily from open-label and observational studies, these medications should be used cautiously.^{23,24}

Behavioral, psychosocial, environmental, and developmental factors

In addition to a history of the behavior itself [Box 1], it is pertinent to explore such behaviors within their broader psychosocial, environmental, and developmental context when evaluating for irritability and aggression [Box 2]. In considering psychosocial factors, exploration into parent/caregiver strategies to manage the behavior (such as the ability to consistently implement a routine and the need for front-loading—i.e., preparation for changes ahead of time), their capacity, and adequacy of supports should also be addressed. Stressful events such as bullying and abuse should also be considered, given their increased risks compared with the general pediatric population.^{25,26} Developmental factors may include the need for an efficient and effective means of functional communication (e.g., specific communication strategies such as a picture exchange communication system or augmentative communication devices), given that behaviors may arise because of frustration resulting from the inability to communicate needs.²⁷ Play skills, the ability to self- or emotionally regulate, and the ability to wait are additional developmental factors that warrant attention [Box 2]. Several general preventive and environmental strategies can also be considered to aid aspects of behavioral management [Box 3].

Psychiatric comorbidities

A significant number of children and adolescents with autism spectrum disorder have at least one identifiable psychiatric comorbidity, which evidence suggests is linked to

irritability and maladaptive behaviors. The *Diagnostic and Statistical Manual for Mental Disorders*, fifth edition (*DSM-5-TR*), reports rates of psychiatric comorbidity in autism spectrum disorder as approximately 70%, including attention deficit hyperactivity disorder, anxiety disorders, mood disorders, and obsessive-compulsive disorder.² This suggests that psychiatric comorbidity is usually present in clinical populations and highlights the importance of looking for potentially modifiable psychiatric pathology in patients with autism spectrum disorder who present with irritability and aggression.

A significant number of children and adolescents with autism spectrum disorder have at least one identifiable psychiatric comorbidity.

Diagnostic evaluation and management of comorbid psychiatric conditions. Psychiatric comorbidities in autism spectrum disorder can be challenging to recognize and diagnose, particularly in the context of cognitive, language, or communication impairments and inherent difficulties in reporting emotional states. This subsequently necessitates reliance on parent/caregiver reports and clinician observations and is compounded by a lack of standardized tools for making psychiatric diagnoses in populations with autism spectrum disorder. Additional challenges can arise due to diagnostic overshadowing, whereby emotional and behavioral symptoms are frequently attributed to autism spectrum disorder itself—for example, when distinguishing overlapping symptoms such as social anxiety and social deficits or obsessive-compulsive disorder and repetitive stereotypical behaviors.²⁸

Several strategies can be used in differentiating diagnostic dilemmas and symptom overlap. A comprehensive history from multiple perspectives is paramount,

including the child, where possible, the parents/caregivers, and other key individuals, such as teachers. Emphasis should be placed on elucidating baseline behaviors and how current behaviors differ from baseline in relation to the child's level of functioning and their psychosocial, environmental, and developmental context [Boxes 1 and 2]. Particular attention to the history of the behavior itself, including the age of onset and variation in symptoms over time, is pertinent. For example, a 7-year-old boy with autism spectrum disorder who presents with a 1-month history of behavioral escalations in the morning before going to school in a new school environment, despite significant transition planning, may suggest an evolving anxiety disorder rather than symptoms attributed to autistic rigidity. Similarly, a 14-year-old boy with autism spectrum disorder and previous repetitive behaviors who presents with a 3-month history of increasing time spent per day performing new ritualistic and repetitive behaviors, and becoming aggressive whenever he is unable to perform such rituals, may suggest evolving obsessive-compulsive disorder. The examination should also include general observations and a mental status examination, ideally within a familiar environment, to watch for behaviors that may help provide diagnostic clarity. This may include observations of a child's ability to sit still, their reported mood or observed affect, and their speech.

Given the paucity of randomized controlled trials published to date that have reviewed psychotropic medications to treat comorbid psychiatric conditions in populations with autism spectrum disorder, guidelines and reviews have suggested adapting treatments based on evidence from the general pediatric population for treating psychiatric comorbidities in autism spectrum disorder.^{10,13} Careful attention should be paid to monitoring for side effects whenever psychiatric medication is prescribed.^{13,29} Psychiatric medication may also cause irritability or maladaptive behaviors, such as akathisia, with antipsychotic treatment and activation with antidepressant treatment.

BOX 1. Behavioral history.

What is the behavior and what is the context in which it occurs, what function might the behavior serve, or what is behind the behavior?

1. Tell me about the behavior that concerns you.
2. What does it look like, including topography, intensity, frequency, duration, and time trends (increasing, decreasing, or stable)?
3. What is the context in which the behavior occurs? Is there a predictable trigger (antecedents)? Things that make the behavior better/worse?
 - a. External setting events that might be related (e.g., home/school/community, specific activities, following specific instructions/demands, with specific people, time of day)?
 - b. Internal factors that might be related (e.g., mood, fatigue, hunger, boredom, frustration, pain, sensory aversions/seeking)?
4. What happens after the behavior (consequences)?
 - a. Does the behavior lead to avoidance or delay of a nonpreferred activity (i.e., escape motivated)?
 - b. Does the child gain access to something desirable (motivated by attention, either positive or negative; access to a preferred item or activity)?
5. What are the child's baseline behaviors? Does the behavior represent an escalation of baseline behaviors or an onset of new behaviors (if the latter, how is this different)?

BOX 3. General environmental/preventive strategies.

What can we do to provide increased support and prevent challenging behavior from occurring?

1. Is there a clear and predictable schedule that is displayed and referenced daily?
2. Is there sufficient structure and routine, minimizing the amount of stressful transitions?
3. Is there front-loading prior to activities and transitions (e.g., what is going to happen next, expectations for behavior and rewards/consequences)?
4. Is time externalized through the use of visual schedules and visual timers?
5. Are behavioral expectations made clear prior to activities and new contexts?
6. Are behavioral expectations realistic and developmentally appropriate? Do demands exceed skill/ability level (self-help, academics)?
7. Are expectations for behavior consistent across caregivers and settings?
8. Does the child have sufficient access to enjoyable/preferred activities throughout the day?
9. Is the child provided with choice throughout the day?
10. Are difficult/nonpreferred tasks interspersed with easy/preferred tasks?
11. Are appropriate/replacement behaviors rewarded quickly and consistently?
12. Have known sensory triggers been addressed (e.g., loud noises, tactile aversions)? Or has a similar sensory experience been created through an enriched environment (e.g., oral stimulation with appropriate oral motor toys)?

BOX 2. Behavioral, psychosocial, environmental, and developmental factors.

Behavioral, psychosocial, and environmental factors

1. Parents/caregivers
 - a. What strategies have been useful in managing behavior? What has not worked thus far?
 - b. How successful have you been in altering the environment to avoid known triggers?
 - c. Have rewards and incentives been tried?
 - i. Does the child like the reward?
 - ii. Is the reward tied specifically to the target behavior, or can the child access the reward in other situations?
 - iii. Has the reward been used consistently?
 - d. Are the parents/caregivers burned-out? Do they have access to sufficient respite services/other supports (e.g., extended family, support workers, church, professional support)?
 - e. Is there parental/caregiver mental illness that needs to be addressed?
2. Other systems/supports
 - a. Have stressful events, including bullying and abuse, been dealt with?
 - b. Is a behavior consultant involved? If yes, does the behavioral approach target the child's current challenging behaviors? Has the behavioral approach been changed or modified in the past year to adapt to the child's ongoing behavioral challenges?

Developmental factors and skill acquisition

What skill areas need to be addressed to help meet the needs of the child and make the challenging behavior redundant?

1. Do the parents/caregivers have a realistic understanding of the child's developmental level and trajectory (e.g., level of support child will likely require, expectations consistent with child's ability level)?
2. Communication
 - a. Does your child use an alternative/augmentative communication system?
 - b. If yes, where do they use it (school, home, community)?
 - c. If yes, can they use it independently (initiate without prompting/help)?
 - d. If yes, do you find it useful?
 - e. How does your child indicate:
 - i. That they want something (food item, activity, person).
 - ii. That they want a break or want to stop an activity.
 - iii. Choice (among multiple items).
 - iv. Yes/No.
3. Play
 - a. What does your child like to do when given free time? Do they have preferred activities?
 - b. Can your child play on their own? For how long?
 - c. Can your child play with other children without support?
4. Self-regulation/emotion regulation
 - a. How does your child let you know that they are upset (e.g., with words like "I'm angry," with behavior, by running away, by crying)?
 - b. How does your child self-soothe?
 - c. Are there strategies that help your child calm down when upset?
5. Wait
 - a. Can your child wait to obtain/delay obtaining an item or activity?
 - b. Are there strategies that help your child wait (e.g., a visual timer, distraction using an alternative activity, visual schedule indicating when they will access the item/activity, use of "when/then" instructions)?

Attention deficit hyperactivity disorder. The *DSM-5-TR* permits the diagnosis of comorbid attention deficit hyperactivity disorder in autism spectrum disorder.² Nevertheless, several challenges can exist in the diagnostic process for attention deficit hyperactivity disorder in the context of autism spectrum disorder, including the need to consider cognitive and developmental levels and the similarities in behavioral phenotypes to other common comorbid conditions such as anxiety.¹³ For example, a 10-year-old boy with an intellectual disability who is given tasks beyond his cognitive level without educational support and adaptations may present with behaviors such as inattention, hyperactivity, and aggression. Management in such instances should first be centred on psychoeducation and initiation of supports and accommodations rather than pharmacological therapy for attention deficit hyperactivity disorder.

Guidelines are available for the evaluation and pharmacotherapy of attention deficit hyperactivity disorder symptoms in autism spectrum disorder.^{30,31} The use of methylphenidate in populations with autism spectrum disorder has been explored in several randomized controlled trials; a meta-analysis noted it to be efficacious on the symptomatology of attention deficit hyperactivity disorder.³² Two randomized controlled trials have supported the use of atomoxetine in populations with autism spectrum disorder.^{33,34} Although Canadian manufacturer labeling advises against opening atomoxetine capsules, a formula for compounded atomoxetine suspension for children who are unable to swallow atomoxetine capsules has been published, and specialty compounding pharmacies may have other proprietary recipes available.³⁵ A randomized controlled trial showed guanfacine extended-release to be safe and effective for the reduction of hyperactivity, impulsivity, and distractibility symptoms in the autism spectrum disorder population, although use of this formulation requires the child to be able to swallow tablets whole.³⁶ Although limited evidence exists, our clinical experiences suggest that the use of clonidine

immediate-release in a carefully titrated manner is a useful adjunct or alternative and can be considered in cases where guanfacine extended-release tablets may not be an option.³⁷ An immediate-release guanfacine formulation is not available in Canada. Several randomized controlled trials support the efficacy of risperidone and aripiprazole

Current guideline recommendations centre on psychoeducation, modified cognitive-behavioral therapy, and pharmacological agents such as selective serotonin reuptake inhibitors used in anxiety in neurotypical populations.

on hyperactivity and impulsivity; nevertheless, these study populations were selected for irritability, and attention deficit hyperactivity disorder symptoms were not the primary outcomes for the studies.³⁸⁻⁴⁰ It is our clinical experience that treatment for attention deficit hyperactivity disorder should also be revisited if it is identified as a contributor to irritability and aggression following initiation of risperidone or aripiprazole because these medications may ameliorate stimulant-induced dysregulation, and subsequent improvements in behavior can sometimes be observed in such cases, which will eventually permit weaning of the antipsychotic [Figure].

Anxiety disorders. Anxiety disorders are highly comorbid with autism spectrum disorder. Clinical recommendations on assessing anxiety in pediatric populations with autism spectrum disorder have been published.⁴¹ The complexity of delineating core autism spectrum disorder symptoms from those of anxiety has been recognized. For

example, repetitive behaviors that improve with front-loading and transition planning may suggest an autism spectrum disorder phenotype, compared with repetitive behaviors associated with anxiety that continue to escalate despite using such an approach.

Several open trials and randomized controlled trials have used cognitive-behavioral therapy for anxiety in youth with high-functioning autism spectrum disorder, and a recent meta-analysis found a moderate treatment effect size for that therapy.^{42,43} To our knowledge, no randomized controlled trials have examined the use of pharmacotherapy for anxiety disorders in children and adolescents with autism spectrum disorder. Nevertheless, current guideline recommendations centre on psychoeducation, modified cognitive-behavioral therapy, and pharmacological agents such as selective serotonin reuptake inhibitors used in anxiety in neurotypical populations.⁴¹

Mood disorders. Current guidelines drawn from the general pediatric population suggest screening for depression in patients older than 12 years of age.⁴⁴ While symptoms of depressed mood and guilt are frequently cited in neurotypical populations with depression, challenges in expressing complex emotions in patients with autism spectrum disorder often necessitate reliance on parent/caregiver reports or observed behaviors by others.⁴⁵ Symptoms of social withdrawal and a flattened affect that can present in autism spectrum disorder can often be confused with symptoms of depression, thereby necessitating a comprehensive history in relation to the time course and the nature of other core symptoms of a mood disorder, such as anhedonia or sleep or appetite disturbances. Specifically, in nonverbal populations, less-typical presentations of depression in autism spectrum disorder may be observed, including increased irritability, aggression, self-injury, crying, repetitive behaviors, a sad or miserable facial appearance, or regressive behavior.^{45,46}

In terms of treatment options, a recent systematic review highlighted the paucity of data in evaluating the efficacy of

psychosocial interventions and pharmacological therapy in populations with depression and autism spectrum disorder.⁴⁷ Nevertheless, current expert opinion and recommendations centre on supportive therapy, cognitive-behavioral therapy, and pharmacological therapy with selective serotonin reuptake inhibitors based on general pediatric population data.¹³

Obsessive-compulsive disorder. Comorbid obsessive-compulsive disorder should also be considered in individuals with autism spectrum disorder who present with an escalation of restricted and repetitive behaviors or the development of new-onset ritualistic behaviors after the preschool period, given its potential for treatment. By definition, obsessive-compulsive disorder involves obsessions (recurrent, unwanted, and intrusive thoughts or urges) that are usually followed by compulsions (behaviors that are performed to ameliorate the anxiety arising from an obsession).⁴⁸ Difficulties in language skills may add to the complexity of obtaining an obsessive-compulsive disorder diagnosis. In contrast to the stereotyped, restricted, and repetitive behaviors seen in autism spectrum disorder, which are often pleasurable to the individual, compulsions in obsessive-compulsive disorder are often egodystonic and perceived as distressing or anxiety-provoking. Qualitatively, in evaluating the nature of the repetitive behaviors to help distinguish both diagnoses, checking, excessive cleaning, and repetitive behaviors to protect against harm have been determined to be more common in neurotypical children with obsessive-compulsive disorder and relatively uncommon in populations with autism spectrum disorder.⁴⁹

Treatment approaches include cognitive-behavioral therapy (including exposure/response prevention), which has been shown to be efficacious for obsessive-compulsive disorder in youth with autism spectrum disorder, although an adapted program may be required depending on the individual's language and cognition level.⁵⁰ Empiric treatment of obsessive-compulsive disorder based on

evidence in the general pediatric population is recommended, given the paucity of literature on this topic. One randomized controlled trial showed significantly greater reductions in obsessive-compulsive disorder symptoms and repetitive behaviors with the use of fluoxetine compared with placebo in children with autism spectrum disorder and comorbid obsessive-compulsive disorder, while a systematic review that evaluated pharmacological therapies for obsessive-compulsive disorder in populations with autism spectrum disorder suggested that fluvoxamine and risperidone were likely efficacious.^{51,52}

Treatment of irritability and aggression

Behavioral and psychosocial interventions. There is a considerable body of literature on the assessment and intervention of challenging behavior based on the principles of learning and behavioral theory.^{53,54} Several modalities of intervention have been proposed, including applied behavior analytic interventions, developmental relationship-focused interventions, naturalistic developmental behavioral interventions, and parent-mediated training.¹³ We discuss applied behavior analytic theory, which most evidence-based treatment models are based on.

According to this theory, all behavior serves a function.⁵⁵ The function can be analyzed by operationalizing the behavior in question (e.g., hitting the table with an open hand) and gaining clarification of the antecedents and consequences of the behavior. Antecedents refer to factors that influence the behavior in advance, including environmental factors (e.g., specific people, activities, setting, time of day, specific instructions/demands) and internal variables (e.g., boredom, stress, anxiety, pain, hunger, fatigue, sensory experiences). Consequences broadly refer to outcomes that follow the behavior (e.g., access to desired items or social attention, escape from the situation).

Understanding the antecedent-behavior-consequence relationship (e.g., the caregiver instructs the child to clean up their toys, the

child hits the table with an open hand, and the caregiver says, "Okay, you have 10 more minutes") can help elucidate the particular function(s) of behavior. Behavior often serves one of four functions: (1) to obtain social attention, (2) to obtain access to desirable items or activities, (3) to avoid or escape an undesirable demand or situation, or (4) to obtain sensory stimulation.^{56,57} There are several direct and indirect assessment methods, including experimental functional analysis, for gathering information on the function of behavior and contingencies surrounding the behavior [Boxes 1 and 2].^{58,59} A referral to a board-certified behavior analyst may be warranted to better understand the function of behavior and support related intervention plans.

The intervention plan should always target the function of behavior. When intervention plans do not adequately address function, challenging behavior is likely to continue or be replaced with new behavior. For example, a child with autism spectrum disorder who responds with aggression due to frustration at being unable to communicate demands is unlikely to improve with an intervention plan that teaches social skills until a consistent plan is developed to address the child's communication needs. Similarly, if escape from an activity does not occur when the child flips the table, they may attempt aggression toward others.

Based on applied behavior analytic theory, a well-designed intervention plan targets problem behavior by manipulating the antecedent and consequent variables that strengthen or weaken the behavior. Three categories of behavioral interventions are often used: (1) prevent: manipulate antecedent and environmental variables (e.g., identify triggers and prevent the behavior from occurring), (2) teach: use instructional strategies focused on teaching skills and behaviors that serve as effective replacements for the challenging behavior (e.g., asking for help, asking for a break, requesting play time), and (3) reinforce: adjust the consequences with an emphasis on positive reinforcement of more appropriate behaviors.^{53,60}

Antecedent-based strategies often include altering or eliminating the demand that triggers the behavior altogether or temporarily, enriching the environment to make it more engaging, providing a similar sensory experience, and reducing overall stress levels. For example, boredom is a commonly observed contributing factor to behavioral escalations. Instructional strategies that focus on addressing skill deficits that commonly contribute to challenging behavior, such as a lack of communication, play, and independent life skills, would be beneficial [Boxes 2 and 3]. There is strong evidence of the relationship between challenging behavior and poor communication skills.^{61,62} Even when an alternative, augmentative communication strategy is in place, further clarification is warranted to determine its effectiveness.

There are two broad categories of consequence-based interventions. First, reinforcement-based interventions encourage desirable behavior by providing attention, access, escape, and rewards for more appropriate replacement behaviors or physically incompatible behaviors (e.g., hands on lap versus hitting others). In such scenarios, it is imperative that the replacement behavior is rewarded more quickly and consistently than the challenging behavior (e.g., if the child asks for a break during a challenging activity, they are given a break immediately versus engaging in aggressive behavior). Second, extinction-based interventions include planned ignoring or withdrawal of a reinforcer following the challenging behavior (e.g., a parent/caregiver selectively ignores repetitive questioning if the function of the behavior is thought to be social attention).⁵⁹

Medications for irritability and aggression

Numerous medication trials that have examined potential agents for treating irritability and aggression in autism spectrum disorder have been published, including recent meta-analyses and a systematic review.^{11,63,64} We review commonly used medications, which can be considered alongside

BOX 4. General prescribing principles.

1. Obtain informed consent.
2. Identify specific target(s) of treatment (e.g., irritability, aggression, anxiety, mood).
3. Use an objective measure/tool to monitor treatment (e.g., Likert scale, rating scale).
4. Start medications at a low dose; use the lowest effective dose.
5. Make one change at a time, and consider a wider context during which changes are made (e.g., environmental triggers or significant life transitions happening at the same time, which may contribute to behavioral escalations).
6. Discontinue treatments that are ineffective.
7. Monitor closely for side effects, using guidelines where applicable (e.g., Canadian Alliance for Monitoring Effectiveness and Safety of Antipsychotics in Children).
8. Avoid polypharmacy as much as possible.
9. Consider treatment discontinuation or reduction in dose after 6–12 months.

general prescribing principles [Box 4]. Recommendations for pharmacologic management of acute agitation in children and youth have been published in BC but are beyond the scope of this article.⁶⁵

Risperidone and aripiprazole. The efficacy of risperidone in improving irritability has been demonstrated in several short-term, randomized, placebo-controlled trials.^{38,39,66-68} Intermediate-term follow-up studies have suggested sustained gains with ongoing risperidone treatment over a 6-month period and an increased risk of relapse when switched to placebo under blinded conditions.^{69,70} Longer-term data under blinded conditions are lacking, although a naturalistic follow-up study with a mean follow-up of 21 months suggested there were sustained benefits.⁷¹ A meta-analysis showed a large effect size ($d = 0.9$) and a number needed to treat of two patients for risperidone with typical doses (1–2 mg/day) over the short term (4–8 weeks).¹¹

The efficacy of aripiprazole has also been demonstrated in randomized controlled trials, and a subsequent meta-analysis demonstrated improvements in Aberrant Behavior Checklist – Irritability Subscale (ABC-I) scores compared with placebo.⁷²⁻⁷⁴ A maintenance study performed on patients 6 to 17 years of age who had autism spectrum disorder and responded to aripiprazole treatment over 16 weeks failed to show statistically

significant differences in time to relapse for placebo or aripiprazole, although a post hoc analysis suggested a number needed to treat of six patients to prevent one relapse.⁷⁵

A double-blind randomized trial that compared risperidone and aripiprazole over 8 weeks in 59 children and adolescents with autism spectrum disorder indicated that both interventions resulted in significant improvements in the primary outcome measure of change in ABC-I scores, and safety and efficacy were not significantly different among treatment arms.⁷⁶ A further trial in 2019 that compared risperidone and aripiprazole demonstrated improvement in ABC-I subscale scores, with statistically significant improvement greatest in the risperidone compared with the aripiprazole group at 3 and 6 weeks.⁷⁷

Adverse effects with risperidone included somnolence, increased appetite, weight gain, hyperprolactinemia, and enuresis.^{38,39,69-71} Only one study evaluated metabolic parameters beyond weight: increases in insulin levels and insulin resistance were associated with risperidone treatment in the short term, although at 6 months, an open-label follow-up study showed no change in these parameters but an increase in triglycerides.^{68,70} Variable rates of extrapyramidal side effects are reported (mostly akathisia), with rates as high as 16%.⁶⁸

Adverse effects of aripiprazole include sedation, weight gain, vomiting, increased appetite, akathisia, nasopharyngitis, and

upper respiratory tract infections.^{40,72,73,75,78} Changes in QTc interval appear to be minimal, and prolactin levels appear to be either unchanged or possibly reduced with treatment.^{72,73,79} Results on changes to metabolic parameters in the longer term are inconclusive.^{40,75,77} Extrapyramidal side effects are reported at rates of 14% to 23%.^{40,72,73,75}

The Canadian Alliance for Monitoring Effectiveness and Safety of Antipsychotics in Children has published guidelines and practice recommendations for monitoring antipsychotic use in children.⁸⁰ They include suggested physical examination procedures and laboratory testing as part of routine monitoring, which we generally advocate to be completed in this population and coordinated opportunistically with other procedures (e.g., dental examinations) that require sedation, if necessary.

Other antipsychotics. The use of other antipsychotics for managing irritability and aggression in autism spectrum disorder has also been explored. A randomized controlled trial (n = 150) of the atypical antipsychotic lurasidone failed to show a significant difference compared with placebo in the short-term treatment of irritability in children with autism spectrum disorder.⁸¹ A small pilot randomized controlled trial examined the use of olanzapine in 11 children and adolescents with autism spectrum disorder over 8 weeks and showed statistically significant improvement over placebo on the Clinical Global Impression – Improvement scale but not on other irritability or aggression scales, and patients in the olanzapine treatment group demonstrated significant weight gain.⁸² Another randomized controlled trial compared risperidone with haloperidol in 30 children and adolescents with autism spectrum disorder over 12 weeks; both interventions demonstrated a significant reduction in Aberrant Behavior Checklist (ABC) total scores (subscales not reported), risperidone showed numerically greater reductions than haloperidol, and haloperidol showed a significant increase in extrapyramidal side effects.⁸³ Although several published case

reports, case series, and open-label trials have examined the use of other typical and atypical antipsychotics in this patient population, to our knowledge, no other randomized controlled trials have been published.

Anticonvulsants. Two randomized controlled trials examined the use of sodium valproate for treating irritability and aggression in autism spectrum disorder but showed inconsistent results. One study compared the use of sodium valproate with placebo over 9 weeks in 30 children and adolescents (6 to 20 years of age) with any pervasive developmental disorder who were selected for aggression; there was no statistically significant improvement compared with placebo in primary (ABC-I) outcomes.⁸⁴ The other study examined the use of valproate over 12 weeks in 27 children and adolescents (5 to 17 years of age) with autism spectrum disorder who were selected for irritability and aggression; there were significant improvements of a moderate effect size on ABC-I scores, with 63% of the valproate patients deemed responders compared with 9% in the placebo group.⁸⁵

A small randomized controlled trial in 28 children with autism spectrum disorder that examined the use of lamotrigine for a wide range of symptoms showed no significant effects on any of the outcome measures, including ABC score.⁸⁶ Another small randomized controlled trial in 20 patients with autism spectrum disorder that examined the use of levetiracetam for behavioral problems showed no significant effects on outcome measures.⁸⁷

Novel approaches and augmentation studies. A small randomized controlled trial of clonidine and two randomized controlled trials of the glutamatergic agent N-acetylcysteine in children demonstrated a modest reduction in ABC-I scores compared with placebo.^{37,88,89} Several other small randomized controlled trials that examined alternative agents such as buspirone for the management of irritability associated with autism spectrum disorder have been published; however, methodological

challenges limit interpretation, which is beyond the scope of this article.⁹⁰ There have also been case reports that have suggested possible efficacy of clozapine and naltrexone in treating the most severe aggression in the population of patients with autism spectrum disorder who are refractory to other medications.^{91,92}

Conclusions

The presentation of irritability and aggression in individuals with autism spectrum disorder is common and warrants a multimodal, systematic, and comprehensive approach in delineating the drivers for such behaviors. It is important to recognize that the drivers can be multifactorial, which warrants addressing them in a stepwise manner or in parallel. We present our algorithm with a focus on psychiatric comorbidities, as well as a review of recent literature to guide decision making and management in this population. ■

Competing interests

None declared.

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Examinations under anesthesia for children and youth with behavioral complexity

Medical evaluations of children with behavioral complexity should be coordinated to minimize the trauma of repeat sedations and to identify situations that lead to inequitable care.

ABSTRACT

Background: In British Columbia, a significant proportion of children with neurodevelopmental disorders are unable to access recommended medical investigations/assessments due to behavioral complexity such as aggression and self-injury; consequently, examinations/investigations under anesthesia are often required. However, difficulties in coordination result in fragmented and traumatic service provision.

Methods: Within a larger quality improvement project, an initial chart review of patients aged 2 to 18 years who underwent anesthesia at BC Children's Hospital was conducted to describe the current state of sedation in children with behavioral complexity. Patients were identified from the operating room slate for a randomly selected week in January 2021.

Results: Seventeen percent of patients (31/185) who accessed the operating room during the review period met the criteria for behavioral complexity. Of these, 16% received an add-on procedure in the operating room. Fifty-two percent of patients had not had any blood work done for at least 1 year before the date of their procedure.

Conclusions: It was impossible to efficiently characterize all missed opportunities to conduct physical examinations and medical assessments of children with behavioral complexity who are seen at BC Children's Hospital for sedated procedures, which highlights significant gaps in care optimization for these patients.

Background

Children and youth with autism spectrum disorder and other neurodevelopmental disorders often have associated behavioral complexity. We use the term behavioral complexity to align with the current pediatric understanding of “children with medical complexity,” which includes aggression, irritability, bolting, and self-injurious behaviors. This definition identifies the need for individualized approaches and acknowledges the unique care needs of this population, which frequently includes multiple medical and psychiatric comorbidities, associated intellectual impairment, challenges in communication, and polypharmacy.

Patients with neurodevelopmental disorders often have higher rates of comorbidities and thus require more frequent inpatient, outpatient, and emergency department visits and complex pharmacological management than patients without these disorders.¹⁻³ In these populations, routine physical examinations, laboratory investigations, and medical imaging are often integral to understanding the etiology of behavioral issues, determining appropriate treatment pathways, conducting routine health surveillance, and monitoring for side effects of medications. Nevertheless, access to such evaluations can be challenging due to the potential for behavioral escalations, which necessitates that assessments and investigations be performed under anesthesia.^{4,5} Unique challenges and considerations also exist when using sedation in these populations, which necessitates the use of flexible approaches whereby primary planned procedures (such as a dental assessment) may require additional secondary assessments and are completed opportunistically to reduce the need for repeat sedations.^{6,7}

Challenges in ensuring equitable access to care in populations with neurodevelopmental disorders and behavioral complexity have been documented.⁸ Children with these disorders and behavioral complexity are more likely to have difficulties in obtaining referrals, despite their greater needs, or to have delayed or missed investigations.^{3,9}

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In a recent provincial survey conducted in British Columbia, 36/48 (75%) and 19/50 (38%) of families of children with self-injurious behaviors reported being unable to access physician-recommended assessments and investigations, respectively, due to behavioral complexity (Richardson A. Identifying gaps in care: Perspectives from caregivers of children with intellectual impairment and self-injurious behaviours [under review]). The medical environment, for example, can be a source of distress for children with autism spectrum disorder due to difficulties with transitions and changes in routines, sensory sensitivities, and challenges in communication, which result in the inability to verbally articulate emotion, pain, and distress or to comprehend necessary procedures.^{6,10,11} Studies based on parent-as-proxy reports have also reported that children with autism spectrum disorder experience three times as many specific fears of medical consultations and physical examinations as children without the disorder and more anxiety about medical procedures than age-matched peers.^{12,13}

These factors present a unique set of challenges when striving to provide routine care that is trauma informed and have impacts on the child, their family, and health care providers.¹⁴ The increased health care needs of children with neurodevelopmental disorders place a greater burden of care on parents and caregivers to coordinate, attend, and prepare for repeat visits, which is compounded by the psychological and social challenges encountered when accessing care.^{2,3,7} Current systems in BC rely on parent/caregiver advocacy and their awareness of outstanding examinations and investigations to bring this to the attention of the surgical or anesthetic team when planning for a primary procedure under anesthesia. Our experience suggests that this results in many missed opportunities due to the lack of a centralized and formalized pathway. The fragmented communication and information technology systems between community and hospital providers also contribute to challenges in obtaining simple but necessary assessments. Moreover, when such

tests are missed opportunistically, repeat sedation and anesthesia are required—a system that is inefficient and additionally traumatic and stressful for children and their families.⁷

Our project, embedded within a larger quality improvement initiative, arose from the commitment of a group of physicians and health care providers who work with children with severe behavioral complexity at BC Children's Hospital (BCCH), a pediatric quaternary care centre in BC. This working group of providers included clinicians and representatives from administration; operations; general pediatrics (community- and hospital-based); neuropsychiatry; anesthesiology; dentistry; ophthalmology; ear, nose, and throat; medical genetics; complex care; child life; laboratory; radiology; and family immunization clinics. The project aimed to streamline and optimize examinations under anesthesia for children with neurodevelopmental disorders and behavioral complexity to improve clinical outcomes and efficiency and reduce the physical and psychological trauma currently experienced and associated with these procedures. A multipronged approach was used to establish the current state of coordination of examinations under anesthesia for children with behavioral complexity at BCCH, which, at present, is largely unknown. This included: (1) a 1-week retrospective review of electronic and paper charts to generate a snapshot of the current state at BCCH, (2) a subsequent 2-month extended chart review to build on the initial scoping review, (3) structured interviews with families of children with behavioral complexity who have recently had sedation, (4) structured interviews with service providers involved in coordinating sedation for children with behavioral complexity, and (5) the generation of a patient journey map that amalgamated information obtained from these sources. The results presented are the first step in establishing the current state of examinations under anesthesia and focus on the initial 1-week retrospective chart review component of the initiative.

Methods

The clinical records of all patients aged 2 to 18 years who had behavioral complexity and underwent an elective procedure under anesthesia within a randomly selected week in January 2021 were identified from the operating room slate. Inclusion criteria were defined as an indication of behavioral complexity from the slate based on the presence of a labeling “tag” used by the surgical service to indicate potential extra considerations needed for the patient. All patients with any of the following tags were included: autism, behavior, developmental delay, cerebral palsy, needle phobia, Down syndrome, purple dot (concern for violence), and Canuck Place (hospice) alert, and those who had a completed screening BALANCE tool for behavioral complexity (a tool used to formulate an individualized care plan for children with challenging behaviors). Patients were excluded if they were under 2 years of age or if there was no evidence of behavioral complexity on review of their clinical records.

The following data were collected:

- The patient's demographics (age, sex, ethnicity, postal code), current diagnoses, developmental or functional level (Gross Motor Function Classification System level where available, verbal/nonverbal), current medications, and specialties involved in ongoing care.
- Whether premedication was given (at home or in hospital) prior to entering the operating room.
- Operating room procedural-related information: nature of primary and secondary procedures; specialties involved; and time (1) from entering the operating room to the start time of the first procedure (duration of induction), (2) from the start time of the first procedure to the end time of the last procedure (duration of procedure), and (3) into and out of the anesthetic care unit (duration of anesthetic care unit admission).
- The nature of other procedures completed in the operating room or anesthetic care unit (e.g., physical examination, growth

parameters, laboratory or radiological investigations, ECG).

- Immunization status (up-to-date; if not, whether opportunistic immunizations were administered). Sources of information included the patient’s electronic record (PowerChart and CareConnect) and paper charts, and data were entered into an Excel spreadsheet for analysis with descriptive statistics. Consultation with the University of British Columbia Children’s and Women’s Research Ethics Board indicated that ethics approval was not required because this was a quality improvement initiative.

Results

In total, 185 patients were seen in the operating room for elective procedures from 11 to 15 January 2021. Multiple stakeholders confirmed that this week was reflective of a typical week in the operating room. Thirty-five (19%) of these patients met the inclusion criteria and had behavioral complexity according to tags on the operating room slate; however, based on a review of

the patients’ electronic charts, four patients were excluded from the study. As a result, the electronic and paper charts, including intraoperative records, of 31 patients were reviewed [Figure].

Demographics

The mean age of the children included in the review was 9.1 years [Table 1]. Females comprised 52% of the group. Thirty-nine percent of patients lived 50 km or more from BCCH. Although every effort was made to collect data on self-identified ethnicity, this information was not available due to a lack of documentation across all three data sources.

Diagnoses and comorbidities

The most common diagnoses were autism spectrum disorder (58%), global developmental delay or intellectual disability (52%), and attention deficit hyperactivity disorder (22%) [Table 1]. All six patients (19%) who had cerebral palsy were noted to have a Gross Motor Function Classification System score of 3 or higher. Almost one-third

of patients with behavioral complexity were unable to communicate verbally (32%).

An average of three specialties were involved in the care of each patient. The most common specialties were general/developmental pediatrics; orthopaedics; ophthalmology; dentistry; neurology; cardiology; respiratory; ears, nose, and throat; and neuropsychiatry [Table 1]. Other specialties involved in the care of these children were medical genetics, biochemical diseases, pediatric surgery, neurosurgery, plastic surgery, urology, oncology, hematology, endocrinology, gastroenterology, immunology, dermatology, rheumatology, Eating Disorder Clinic, and orthodontics.

Each child was taking an average of 2.5 regular medications; one-third of the group was taking more than 3.0 (range = 0 to 15) [Table 1].

Perioperative- and procedural-related information

The most common specialties involved in the procedures performed during the week evaluated were orthopaedic surgery (25%),

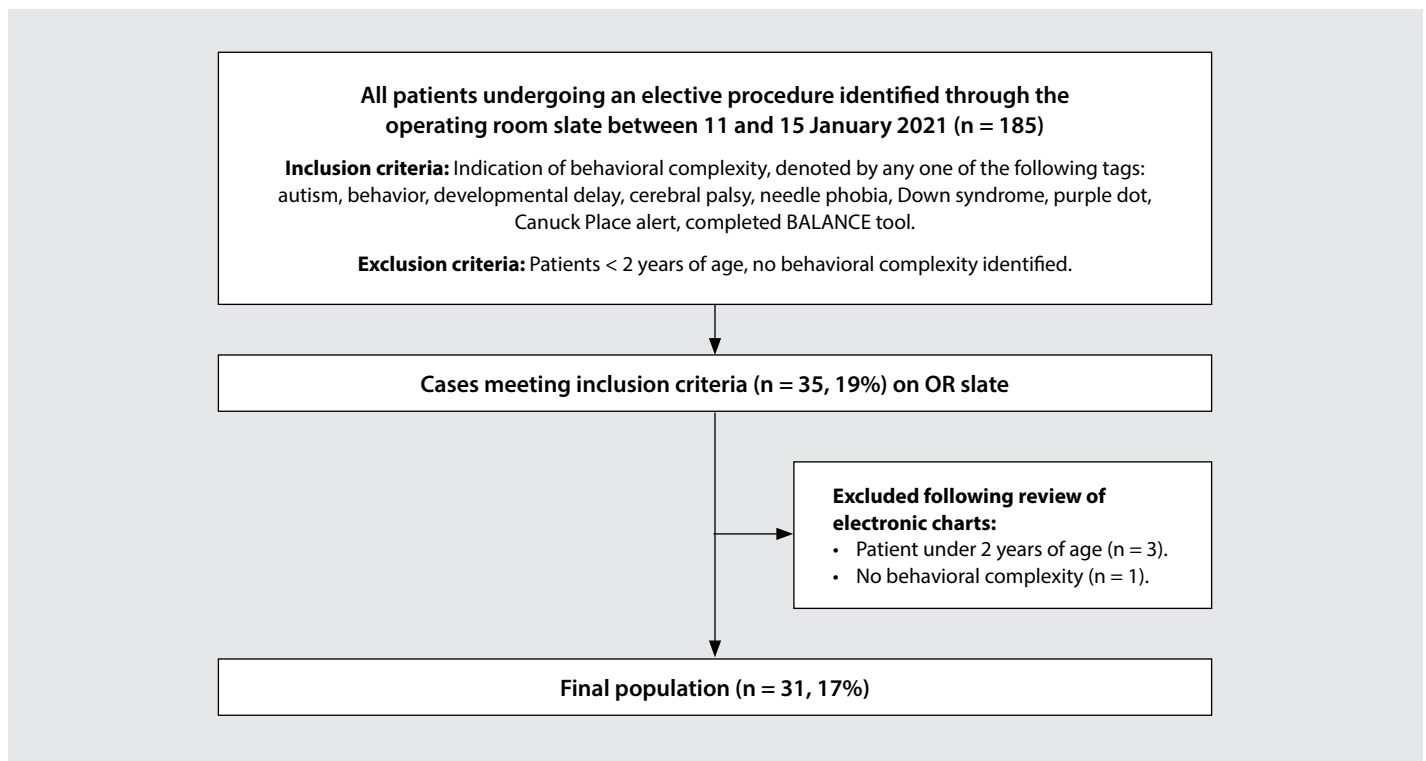


FIGURE. Population sample for examination under anesthesia project.

dentistry (23%), plastic surgery (11%), and radiology (9%), followed by general surgery, ophthalmology, and cardiology (6% each) and ear, nose, and throat surgery; plastic surgery; neurosurgery; psychiatry; gastroenterology; and dermatology (3% each) [Table 2]. Thirty-nine percent (n = 12/31) of children received premedication while in hospital; the number who received premedication at home could not be determined due to a lack of documentation. The average duration of induction (between entry into the operating room and induction of anesthesia) was 26 minutes (range = 7 to 86 minutes), the average duration of procedure was 87 minutes (range = 8 to 451 minutes), and the average duration of admission to the anesthetic care unit was 86 minutes (range = 5 to 204 minutes) [Table 2].

Intraoperatively, 16% of patients received an add-on procedure, the most common being ear, nose, and throat (n = 3); ophthalmology (n = 1); and a lumbar puncture (n = 1). In the anesthesia care unit, additional examinations and procedures were completed for seven patients (23%) and included imaging (n = 6), blood work (n = 1), and an echocardiogram (n = 1).

A comprehensive review of each patient's clinical records was undertaken to determine whether there were any outstanding examinations or investigations to be completed. In two cases, tests had been requested, but there was no record of them being completed to date or at the time of anesthesia. This information was obtained only after conducting an in-depth review of all previous documentation across all three sources for each patient, which took a significant amount of time (approximately 2 hours per patient chart).

Screening and surveillance blood work was completed for 39% of patients while under anesthesia. Fifty-two percent (n = 16) of patients had not had any blood work done for at least 1 year before the date of their procedure [Table 2]. Fifty-two percent (n = 16) of patients had up-to-date immunizations; the immunization status of the other 48% could not be determined from their clinical record. There is no indication that

TABLE 1. Patient demographics and clinical characteristics.

Patient demographics	n	%
Total number of patients	31	—
Female	16	52
Male	15	48
Mean age (years)	9.1	—
Distance from BC Children's Hospital		
< 50 km	19	61
50–100 km	7	23
>100 km	5	16
Clinical characteristics	n	%
Most common diagnoses		
Autism spectrum disorder	18	58
Global developmental delay/intellectual disability	16	52
Communication issues (nonverbal)	10	32
Attention deficit hyperactivity disorder	7	22
Orthopaedic issues	8	26
Cerebral palsy	6	19
Dental caries	6	19
Anxiety	2	6
Down syndrome	2	6
Visual impairment	2	6
Most common specialties involved in care		
Pediatrics (general/developmental)	21	68
Orthopaedics	13	42
Ophthalmology	9	29
Dentistry	8	26
Neurology	7	23
Cardiology	7	23
Respirology	5	16
Ear, nose, and throat	5	16
Neuropsychiatry	3	10
Most common medications prescribed		
Antiepileptics/mood stabilizers	7	23
Benzodiazepines	5	16
Alpha agonists	4	13
Stimulants	3	10
Sleep aids	3	10
Asthma medications	3	10
Antireflux medications (e.g., omeprazole)	3	10
Nutritional medications (e.g., vitamin D, iron)	3	10
Endocrine medications (e.g., thyroxine, desmopressin)	3	10
Selective serotonin reuptake inhibitors/serotonin and norepinephrine reuptake inhibitors	2	6
Pain medications	2	6
Diuretics	2	6
Antipsychotics	1	3
Antihypertensives	1	3

any of the 31 patients received opportunistic immunizations in the operating room.

Discussion

Although we had no preconceptions about rates of behavioral complexity in children who accessed the BCCH operating room, we were surprised to find that approximately 20% of patients who received scheduled sedations at BCCH had pronounced behavioral complexity (which required some accommodation). Several studies have explored the prevalence of diagnoses such as autism spectrum disorder in patients who access care that requires anesthesia, as well as the incidence of postoperative maladaptive behaviors.¹⁵⁻¹⁷ A retrospective chart review of outcomes in dental procedures at a dental surgical centre reported that 12% of patients had a diagnosis of autism spectrum disorder, and 18% were diagnosed with developmental delay (global developmental delay/intellectual disability).¹⁷ In our study, 10% of children who underwent an elective procedure had a diagnosis of autism spectrum disorder, and 9% were diagnosed with global developmental delay/intellectual disability. In contrast, a retrospective review by Swartz and colleagues indicated that 1 in 74 cases (1.35%) of anesthetic use occurred in patients with autism spectrum disorder, although this result was extrapolated from the number of anesthetic procedures conducted (251 of 18 568 procedures).¹⁸ To our knowledge, our study is the first to attempt to determine the rates of behavioral complexity and to identify them preoperatively, although we recognize that complex behavior in the setting of neurodevelopmental disorders often crosses diagnostic boundaries and is not restricted solely to specific diagnoses.

Patient demographics

In this study, almost 40% of families traveled 50 km or more to BCCH. Inequitable access to care due to geographical isolation has been well documented.¹⁹⁻²¹ A recent systematic review highlighted the existence of socioeconomic and ethnic disparities in autism diagnosis and indicated

TABLE 2. Perioperative-related patient information for children and youth with neurodevelopmental disorders and behavioral complexity who underwent elective anesthesia.

Perioperative-related patient information	n	%
Primary perioperative specialties		
Orthopaedic surgery	9	25
Dentistry	8	23
Plastic surgery	4	11
Radiology	3	9
General surgery	2	6
Ophthalmology	2	6
Cardiology	2	6
Ear, nose, and throat surgery; plastic surgery; neurosurgery; psychiatry; gastroenterology; dermatology	1 each	3 each
Duration of induction*		
< 15 min	10	32
15–30 min	12	39
> 30 min	9	29
Duration of anesthetic care unit admission†		
< 30 min	11	35
30–60 min	11	35
> 60 min	9	29
Time since last blood work		
< 6 months	11	35
6–12 months	4	13
13–24 months	5	16
> 24 months	11	35

*mean = 26 minutes (range 7–86 minutes)
 †mean = 86 minutes (range 5–204 minutes)

that children from low-income families and ethnic minority groups had less access to acute care and specialized educational and community services compared with higher-income and Caucasian families.²² Parents of children with neurodevelopmental disorders are also less likely to be employed than parents of children with no health limitations, which adds to the time and financial impacts of travel to access care.²³ We suggest that a streamlined process that is aimed at reducing the need for multiple sedations at BCCH could be shared with tertiary centres, which would reduce the travel requirements for families that are already impacted by inequitable access. Due to the limitations of the retrospective nature of this review, we made every effort to collect data on self-identified ethnicity. However, the lack of routine

recording of such data in patient records limited our analyses; thus, this is an identified gap in equity research.

Degree of medical complexity

The degree of medical complexity in our population of patients was significant, as evidenced by their comorbidities, the number of subspecialties involved in their care, and their polypharmacy. The contributions of medical and psychiatric comorbidities to maladaptive behaviors in children with neurodevelopmental disorders such as autism spectrum disorder have been well documented. Current recommendations highlight the need for comprehensive evaluation of these children, which includes gastrointestinal; neurological; psychiatric; sleep; ear, nose, and throat; ophthalmological; dental; genetic; and metabolic disorders.²⁴⁻²⁷ In a

study of adolescents and adults with autism, Medication Regimen Complexity Index scores (a risk assessment tool for identifying patients on potentially problematic medication regimens) were significantly higher for patients with comorbid seizures, intellectual disability, and a history of aggressive behavior than children without these comorbidities.²⁸ The common classes of medications taken by children in our study were comparable to those in a study by Saqr and colleagues,²⁸ which included antiepileptics, benzodiazepines, stimulants, selective serotonin reuptake inhibitors/serotonin and norepinephrine reuptake inhibitors, and antipsychotics. Our results suggest that one-third of the children in our study were taking more than three medications. Jones and colleagues found that more than half the adults with autism in their study were taking four or more medications.²⁹

Perioperative- and procedural-related findings

A previous study reported that 34% of children with autism spectrum disorder required premedications when they were incorporated into an individualized perioperative management plan.¹⁸ In contrast, Arnold and colleagues reported that 85% of children with autism who underwent dental procedures under anesthesia received premedication; however, this high rate was likely attributable to a standard of care in the institution, given that 92% of children without autism were also offered premedication.¹⁷ In our study, 39% of children received premedication; this was likely driven by current processes in which decisions regarding premedication are based on each anesthesiologist's discretion. Furthermore, the average time to induction in our study was 25 minutes (range up to 86 minutes), compared with the allocated standard time to induction at BCCH of 15 minutes. This is likely suggestive of a complex induction process that is attributable to a range of factors when compared with neurotypical patients, and a reasonable assumption is that this may be related to the patient's behavioral complexity. Literature on the time

for induction of anesthesia in children with behavioral complexity is limited; however, a survey of procedural sedation programs in the US indicated that 28% allotted extra time for this population, and 33% reported scheduling these children as the first sedation of the day.³⁰ In addition to considering the need for premedications as part of a standardized approach, our preliminary

Children with autism spectrum disorder experience three times as many specific fears of medical consultations and physical examinations as children without the disorder.

findings suggest that it may be necessary to allocate extra time for induction in patients who are identified perioperatively to have behavioral complexity.

In reviewing the patients' clinical records, we tried to determine whether each child had outstanding required examinations or investigations that could have been added opportunistically during the anesthetic procedure. Although this was noted in two cases, this information was obtained only after an in-depth review of all previous documentation for each patient was conducted and required a significant amount of time, which would be difficult to perform as part of routine care. Ultimately, it was impossible to determine effectively and efficiently whether each child had outstanding tests that should have been performed while under sedation or what is required by other specialties involved in the care of the patient when providers attempt to maximize the number of procedures to be completed under one sedation. This finding highlights the challenges in care coordination for health care providers in attempting to determine outstanding evaluations from a patient's clinical records and is compounded by current systems that place the onus of advocacy and care coordination primarily

on the parent/caregiver, who is often already stretched in capacity.

Children with behavioral complexity currently experience inequitable access to care.³¹ Given that this patient population is seldom able to access routine and medically necessary or recommended procedures, optimizing planned sedations may present an opportunity to improve this inequity gap. We examined routine and medically necessary information, rather than exceptional investigations, that could improve care. More than 50% of the children in our study who had behavioral complexity and were seen in the operating room had not obtained blood work for at least 1 year prior to the date of their procedure. Guidelines on the usage of antiepileptics such as sodium valproate, psychostimulants, alpha-2 adrenergic agonists, and antipsychotics require routine monitoring, including physical examinations and surveillance blood work; this may have been a missed opportunity within the operating room for a proportion of our patients.^{32,33} Also, it was not possible to determine whether children seen in the operating room were up-to-date on their vaccinations and whether they received additional vaccines while under anesthesia due to a lack of documentation in their clinical record. This may have been another missed opportunity in health promotion, particularly given the challenges with providing immunizations for children with severe behavioral complexity.

Implications of results

The impact of an anesthetic on family and physician burnout is substantial. Participating in and witnessing sedation in a child who does not comprehend what is being done to them is a source of trauma, both physical and emotional, for all involved.³⁴ Parents have highlighted the direct impacts of being involved in such procedures, including behavioral escalations that incrementally worsen with repeated attempts to sedate the child.²⁴ Establishing a trauma-informed pathway would be pertinent when delivering health care to such populations. Furthermore, repeat

sedations due to missed opportunities result in inefficient use of limited health care resources, given that any procedures that require sedation result in longer hospital visits and increased costs.³⁵ While current systems capture the degree of complexity of the child based on their diagnosis, we argue that complexity should also be captured through an additional functional lens, given that common behavioral phenotypes span diagnoses; this presents an opportunity for future research, particularly in considering analyses from an economical perspective.

Study limitations and future directions

We note several limitations in our study. Our study population was drawn from operating room slates and, therefore, would not have captured a significant proportion of behaviorally complex children who require assessment and investigations but have not been actively scheduled for a procedure in the operating room. We anticipate that this may be better evaluated through our other data sources that are being used for this quality improvement project, including qualitative interviews with parents, caregivers, and providers (such as physicians, surgeons, allied health team members, and administrators). Our preliminary results are also limited in their generalizability, given that we examined only 1 week of operating room slates. Nevertheless, this week was chosen at random, and multiple stakeholders confirmed that it was representative of a typical week in the operating room at BCCH.

This study is the first step in a larger, multipronged, quality improvement project that is examining how to improve the coordination of examinations under anesthesia for children with behavioral complexity. Our preliminary chart review highlights an unmet need for access to routine care, with 1 in 6 children seen in the operating room at BCCH being identified as having behavioral complexity. The next phases of the project involve establishing the current state of coordinating examinations under anesthesia and optimizing current approaches, with data drawn from qualitative interviews

with families of children with neurodevelopmental disorders and behavioral complexity who have recently received sedation, and with providers such as physicians and administrative staff involved in coordinating examinations under anesthesia. A 2-month extended chart review that will build on this initial scoping exercise is also currently underway. Amalgamation of the data from these four sources will permit the development of a detailed patient journey map to comprehensively characterize the current pathway to receiving coordinated examinations under anesthesia and the facilitators and barriers involved. This will ultimately inform the development of a streamlined regional approach to examinations under anesthesia at BCCH in a patient-centred and trauma-informed manner that will be individualized to each patient and also draws from recommendations in the literature.

Emerging approaches that incorporate practical aspects for consideration within the perioperative setting that are tailored to populations with autism spectrum disorder and behavioral complexity have recently been published.³⁶⁻³⁹ A pilot study that used a protocol for enhanced perioperative management of children with autism spectrum disorder and incorporated a multidisciplinary approach contributed to positive anesthesia induction experiences,

with positive feedback obtained from both parents and health care providers.³⁸ This involved practical components such as separate quiet rooms as opposed to waiting rooms, child life support for the patient and family, and individualized sedation plans. Our aim is to implement a similar process at BCCH that incorporates sensitivity to the specific behavioral needs of patients with neurodevelopmental disorders and ways to minimize negative experiences. We also suggest that the clustering of care be considered by all clinicians involved with children and youth who have behavioral complexity. By coordinating multiple assessments, investigations, and opportunistic interventions under one sedation, efficiency and quality of care can be improved, and the need for repeat traumatic sedations and clinical risk can be reduced. Drawing from our current experiences, we propose that the examinations and investigations listed in the **Box** be coordinated when a child with behavioral complexity presents for sedation or examination under anesthesia. Ultimately, this study provides the first steps to doing so by establishing the absence of current coordination and missed opportunities for coordinated sedations. Our findings highlight a significant gap in equity research and an increased need to define children with behavioral complexity as an equity-deserving population.

BOX. Recommended assessments, investigations, and interventions to consider for children with behavioral complexity and neurodevelopmental disorders, to be coordinated under a single sedation/examination under anesthesia.

Assessments, investigations, and opportunistic interventions

- Growth parameters (weight, height, head circumference).
- Vital signs (including heart rate and blood pressure).
- Physical examination (including dysmorphology, skin/neurocutaneous stigmata, cardiovascular, respiratory, abdominal, neurological, and joint examinations).
- Dental examination.
- Ear, nose, and throat examination.
- Ophthalmological examination.
- Laboratory investigations (including genetic testing; screening for associated medical conditions, where relevant; and monitoring/surveillance of adverse effects of pharmacological agents).
- Radiological investigations (including X-rays, ultrasound, CT, and MRI).
- Electrocardiogram.
- Electroencephalography (dependent on modality and nature of sedation).
- Opportunistic immunizations (including routine scheduled, COVID-19, and influenza immunizations).

Conclusions

Further research must be conducted to characterize missed opportunities for children with neurodevelopmental disorder behavioral complexity who are seen at BCCH for sedated procedures, given that current systems are ineffective in efficiently determining outstanding evaluations for these children. Changes need to be implemented to create a system wherein medical evaluations for these children can be coordinated to minimize the trauma of repeat sedations, as well as missed opportunities that lead to inequitable care. The results of this study confirm that children with behavioral complexity make up a significant proportion of children seen in the operating room at BCCH on a weekly basis and highlight a need to prioritize optimization of care, not only for patients and families, but also for providers involved in coordinating sedations, to improve clinical outcomes and efficiency of current systems. ■

Competing interests

None declared.

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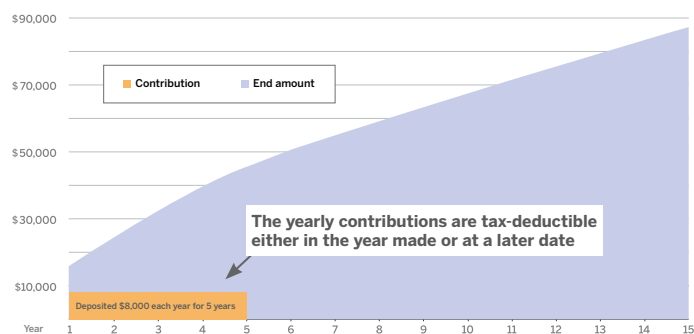
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² Chan, Kenneth. "BC housing market on 2024 rebound trajectory: forecast". Daily Hive [Vancouver], July 25, 2023.

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The origins of WorkSafeBC: What it means for you and your patients

Modern workers' compensation systems are complex, and physicians who treat injured workers often have questions on how to best help their patients. Being familiar with the history and mandate of WorkSafeBC, British Columbia's workers' compensation board, may further physicians' ability to help their patients with work-related injuries, diseases, and illnesses.

The pursuit of just compensation

Although there is evidence of compensation systems elsewhere in the world dating as far back as 2050 BC,¹ workers' compensation systems have existed in Canada only since the early 1900s. Before then, if a worker was injured on the job, they often received no compensation and risked permanent loss of their livelihood.

In 1910, the Ontario government commissioned Sir William Meredith to make recommendations on how to establish a workers' compensation system in Ontario. The Meredith Report subsequently formed the basis for workers' compensation systems in all provinces and territories in Canada. Sir Meredith noted the laws of the time were "entirely inadequate" to provide "just compensation" for injured workers.² If a worker was injured and wanted to be compensated, they had to sue their employer in court—a costly proposition for both workers and employers.

In what is referred to as the "historic compromise," a trade-off of rights, Sir Meredith proposed a no-fault compensation

system in which workers would be compensated for a reduction in their earnings if they became ill or injured due to their work. In exchange, employers would be freed from legal liability and the costs of defending court cases. Employers would fund the system by paying insurance premiums.

**You can make a
difference by starting
the conversation about
clinical and vocational
recovery early.**

Some additional features were added when BC's Workmen's Compensation Act came into effect in 1917. (The name was later changed to the Workers Compensation Act.) In a document known as the Pineo Report, a committee that advised on the scope of the original Act noted, "Laws which provide for the taxing of industry to furnish compensation for the victims of industrial accidents irrespective of fault are commendable and desirable, but laws which

will prevent the happening of such accidents are of more vital importance."³ This is how WorkSafeBC became the occupational health and safety regulator, with a mandate to prevent work-related injury and illness, in addition to being a compensation board.

WorkSafeBC's mandate today

The Workers Compensation Act has been amended many times, most recently in 2022. Today, WorkSafeBC's mandate is to:

- Promote the prevention of workplace injury, illness, and disease.
- Rehabilitate those who are injured and provide timely return to work.
- Provide fair compensation to replace workers' loss of wages while recovering from injuries.
- Ensure sound financial management for a viable workers' compensation system.⁴

WorkSafeBC's mandate on rehabilitation and timely return to work allows us to provide substantive assistance to help your patients who are injured workers achieve those goals. As workers look to their physicians for medical expertise, we value physicians' role in helping these patients reach

Continued on page 314

4th Annual WorkSafeBC-NAOEM Joint Conference for Primary Care and Occupational Medicine Practitioners

Join us for the hybrid 4th annual WorkSafeBC–Northwest Association of Occupational and Environmental Medicine Joint Conference for Primary Care and Occupational Medicine Practitioners. It will be held on Saturday, 28 October, in Victoria, BC, and is accredited for 6.75 Mainpro+/MOC Section 1 credits.

Learn more and register at <https://ubccpd.ca/learn/learning-activities/course?eventtemplate=525-4th-annual-worksafebcnaoem-joint-conference-for-community-physicians>.

This article is the opinion of WorkSafeBC and has not been peer reviewed by the BCMJ Editorial Board.

Seniors' anxiety: Underdiagnosed and undertreated

Although complaints about anxiety are common among older persons, late-life anxiety disorders have been underestimated. Older persons tend to emphasize their physical complaints and are less likely to report psychiatric symptoms.¹ This article focuses on generalized anxiety disorder, which is characterized by chronic uncontrollable worry that interferes with functioning and is accompanied by restlessness and disturbed sleep.² However, it's important to also consider conditions such as social anxiety disorder, specific phobias (e.g., fear of falling), panic disorders, and posttraumatic stress disorder.³

Prevalence of anxiety disorders in later life varies significantly based on different methodologies and may not fully capture the nature of anxiety in older people, especially among ethnic and racial minority groups. Overall, anxiety disorders are more common in later life than depression, with estimated rates ranging from 1.2% to 7.3% for 6- and 12-month prevalence respectively, and up to 11% for lifetime prevalence.⁴ Using MSP billing data, anxiety codes account for only 0.6% of family practice and 1.5% of psychiatry billings for individuals 60 years of age and older, signaling that anxiety is not usually billed as a primary diagnosis for physician visits, possibly reflecting underdiagnosis or a secondary diagnosis.⁵

Physicians, especially frontline primary care providers, need to recognize the prevalence of anxiety, as many people go their entire lives normalizing it without seeking help. Treating anxiety can be life-changing,

making it crucial for overall well-being. Physicians should be aware of red flags such as new panic attacks in older adults, which are less common later in life, and should rule out other medical causes that can cause or mimic anxiety (e.g., paroxysmal atrial fibrillation, hyperthyroidism, tumor).⁶

Anxiety disorders in older adults are associated with increased physical disability, poorer quality of life, higher use of health services, greater risk of depression, cognitive impairment, and dementia.⁴ Older adult worries usually relate to later-life issues such as health care costs, loss of loved ones, retirement, caregiving responsibilities, and end-of-life planning.⁴

When nonmedication options are ineffective or not feasible, the first-selected pharmacotherapy is selective serotonin reuptake inhibitors or serotonin-norepinephrine reuptake inhibitors. Despite the specific risks, which are higher in the elderly, like syndrome of inappropriate antidiuretic hormone secretion, falls, and bleeds, use of these medications, as well as pregabalin, can be beneficial in certain cases to improve

quality of life and function. As per the classic geriatric adage, start low and go slow, but "go" is key, as medications need to be titrated to useful doses to be effective.⁶ The risk-benefit ratio of benzodiazepine pharmacotherapy in elderly patients is not favorable.⁷ Also, reduce dosage of or discontinue potentially anxiety-inducing medications while monitoring for suicidal ideation and symptom change.⁷

COVID-19 has disrupted the lives of many BC seniors with increased social isolation, contributing to anxiety. However, relying on social prescribing alone is insufficient to address this issue. Creating genuine social connections in the community is crucial to combat anxiety in seniors, but this falls beyond the scope of this article. The first step is recognizing and treating anxiety in seniors to help them thrive. National Seniors Day is 1 October! I encourage readers to share their strategies to combat seniors' anxiety. ■

—Eileen M. Wong, MD, CCFP, FCFP
Council on Health Promotion Member

Continued on page 314

This article is the opinion of the authors and not necessarily the Council on Health Promotion or Doctors of BC. This article has not been peer reviewed by the BCMJ Editorial Board.

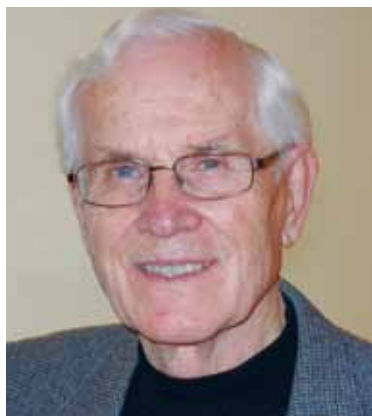
Resources for seniors' anxiety:

- Anxiety Canada's website (www.anxietycanada.com) and free MindShift CBT app (www.anxietycanada.com/resources/mindshift-cbt)
- CBT Skills Groups program for BC patients (<https://cbtskills.ca/physicians>)
- Mindful:
 - "How to shift direction when you feel stuck" (www.mindful.org/how-to-shift-direction-when-you-feel-stuck)
 - "Stressing Out? S.T.O.P." (stop, take, observe, proceed), creating space in the day to come down from a worried mind (www.mindful.org/stressing-out-stop) and video (www.youtube.com/watch?v=EiuTpeu5xQc)
- *Australian Family Physician*, "Acceptance and commitment therapy: Pathways for general practitioners" (www.racgp.org.au/afp/2012/september/acceptance-and-commitment-therapy)
- *Gerontologist*, "Self-compassionate aging: A systematic review" (<https://self-compassion.org/wp-content/uploads/2019/09/Brown2018.pdf>)
- American Association for Geriatric Psychiatry, "Anxiety and older adults: Overcoming worry and fear" (www.aagponline.org/patient-article/anxiety-and-older-adults-overcoming-worry-and-fear)
- Canadian Coalition for Seniors' Mental Health, "Anxiety in older adults" (<https://ccsmh.ca/projects/anxiety>)

Obituaries

We welcome original tributes of less than

700 words; we may edit them for clarity and length. Obituaries may be emailed to journal@doctorsofbc.ca. Include birth and death dates, full name and name deceased was best known by, key hospital and professional affiliations, relevant biographical data, and a high-resolution head-and-shoulders photo.



Dr Daniel Froese

1926–2022

Dr Daniel Froese, 96, passed away gently, quietly on 25 December 2022, in the presence of Margaret, his wife of 70 years, along with family and attending staff at the Waterford seniors' residence, Tsawwassen.

Daniel came from a German Mennonite family that emigrated from Russia. He was born near Swift Current, Saskatchewan, where the family (including 10 children) initially settled; a few years later they moved to Abbotsford, where Daniel finished school.

An excellent student, Daniel showed an interest in learning and teaching, so he attended the Mennonite Educational Institute of Abbotsford. It was not a degree-granting institution or college, but here he was invited to teach science to his fellow students, without any teacher's certificate. He was interested in studying art but, following this teaching experience, favored science. He completed a BSc at the University of British Columbia and was admitted to the then new UBC School of Medicine in 1953 (UBC's third graduating class). He was recognized as a focused, bright student, humble, committed, considerate, friendly,

and respectful of others. Upon graduation, he fulfilled his rotating internship at Vancouver General Hospital and joined a friend and fellow medical student as partners in family practice and geriatrics until his retirement at age 88 (57 years later).

Daniel dearly loved his wife, Margaret, and their family of four boys and treasured his wide circle of friends. His interests included sporting activities—ball games, skiing, fishing, hockey, and cross-country bicycling—as well as picnics and camping. He made time for his artistic talents of sketching, painting, photography, woodworking, music, and singing. His home, thanks to the dynamic Margaret, was usually crowded with people at Halloween, Christmas, Victoria Day, and Canada Day, and always welcoming of their children's friends to join the clamorous parties. Daniel, Margaret, and family took a year away, traveling across Canada and the US in a motorhome for the

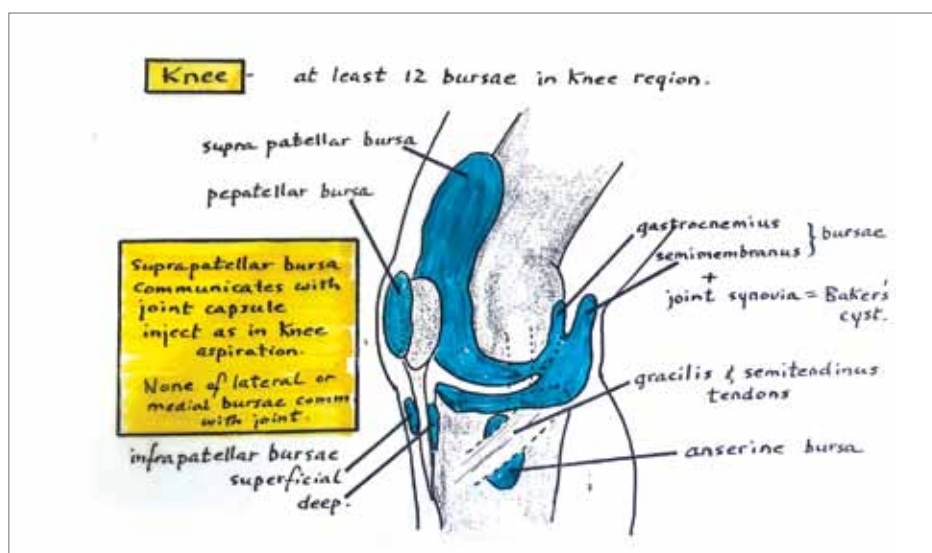


FIGURE 1. Dr Froese's line drawing of an injection procedure.



FIGURE 2. Dr Froese's line drawing of an idea for a symbol to engrave on the Canadian loonie to symbolize the Canadian West.

OBITUARIES

sake of everyone's broader education; the children's formal schooling continued by correspondence.

As a person, Daniel was steady, gentle, kind, generous, humble, faithful, attentive, empathetic, and considerate. He was also detailed, patient, caring, understanding, knowledgeable, and thorough, and he had a fine sense of humor. The sum of these characteristics, though, added up to sometimes being unaware of the clock or the passage of time.

As a family doctor, Daniel was adored by both adults and children. His reassuring attentiveness and kindness, and his maturity in handling ill, worried people, are now often missing from the busy profession of medicine. The fact that he took

time to deal with people meant that others would be waiting, but just the same, he was a favorite.

Daniel was a natural educator. Teaching, personal contact, communicating, and educating are a necessary part of a good physician's life and work. Daniel was awarded and accelerated in his career to associate clinical professor in the UBC Department of Family Practice. He mentored many students and family medicine residents and used his skills and experience to explain, demonstrate, and satisfy his patients' questions and concerns. He used these same skills in dealing with family, friends, and foes—if he had any.

To illustrate how thorough he could be, included is a line drawing of an injection procedure [Figure 1]. Over the years he

built a catalogue of such drawings that he used to teach patients and students, accompanied by a session on anatomy, indications, and expected results. His art went further afield when he submitted a drawing [Figure 2], that he thought would be a perfect symbol engraved on the Canadian loonie to symbolize the Canadian West.

Daniel Froese—BSc, MD, FRCFP, associate professor—was one terrific person, family man, teacher, exemplary physician, and model family doctor/geriatrician. He worked hard, played hard, and lived life to the fullest. To say he will be missed is almost trite. We need more like him in our health care system. ■

—Nis Schmidt, MD
Vancouver

COHP

Continued from page 312

Acknowledgments

The author would like to thank Ms Karen Gilbert, occupational therapist, Providence Health Care, and Dr Paul Blackburn, geriatric psychiatrist, Vancouver Coastal Health, for providing resources and content for this article.

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WORKSAFEBC

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functional goals so they can participate in the activities that give life meaning, including work. You can make a difference by starting the conversation about clinical and vocational recovery early, underscoring the importance of them staying in touch with their workplace, and discussing what they are able to do.

If you have questions about how WorkSafeBC can support a patient's vocational recovery, contact us using the RACE service (phone or app) or request a callback on the Physician's Report (Form 8/11). ■

—Tung Siu, MD, CCFP

Medical Advisor, Medical Services,
WorkSafeBC

—Celina Dunn, MD, CCFP

Manager, Medical Services, WorkSafeBC


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Kloshe Tillicum (good relations) move at the speed of trust

Why is it important for public health and health care providers to build trust with Indigenous patients and communities? This question came to the forefront due to the health impacts, stress, and inequality exacerbated by the COVID-19 pandemic. Importantly, the uptake of COVID-related public health measures required trust in both public health guidance and health care providers. However, in April 2020, a provincial survey of over 3000 participants assessing COVID misinformation in BC found that only 31% of Indigenous respondents trusted pandemic guidance from public health leaders, compared with 66% of white respondents. Further, Indigenous respondents were nearly twice as likely to report misinformation on treatments for COVID compared with white respondents (59% vs 37%). Ongoing legacies of colonization and the Indian Act, anti-Indigenous racism in the health care system,¹ and the shameful history of Indian hospitals² serve as fundamental sources of mistrust for Indigenous people in Canada today.

To get to the heart of this question, we launched Kloshe Tillicum (“good relations” in Chinook jargon): creating trustworthy and culturally meaningful public health guidance to address COVID-19, a Canadian Institutes of Health Research-funded collaboration between Indigenous and settler researchers from Chee Mamuk, an Indigenous-led health program within the BCCDC, and Simon Fraser University’s Faculty of Health Science. Between 2020 and 2022 we conducted nine focus groups

with 53 Indigenous individuals in urban and rural locations across BC to hear about their experiences during the COVID pandemic.

Trust emerged as a key theme. Overall mistrust toward the health care system was a common refrain shared by Indigenous participants. Approaches that emphasized building relationships, listening, and collaboration were preferred:

“I feel like I’ve seen some really forceful approaches and people being quite aggressive about it, making these kinds of things mandatory, and I’ve been with other health care professionals who were actually quite compassionate and understanding and had a very gentle approach that felt safe for me. So I think it’s like—when I think of trusting something, it’s like how safe do I feel with this person or with this information? That really makes a huge difference for me.”

Participants shared that community leaders stepped up during the pandemic as a trusted source of information amid rapidly evolving public health guidance and rampant misinformation spread by social media platforms like Facebook. Remote communities reported having limited access to doctors and health resources, making their trusted point person critical. Serving in this role was a double-edged sword: the community trusted their guidance and adopted their recommendations, yet that person faced extreme levels of pressure daily to get the guidance right for their Elders, children, and neighbors.

Kloshe Tillicum begin by recognizing why building trust is essential in health. Collectively we have a poor track record in Canada when it comes to Indigenous people, and as health care providers, we have a history of past and current harm to surmount. However, we have an opportunity ahead of us to build trust through new ways of working together. A recent meta-analysis observed

that trust toward health care providers has a direct correlation with health outcomes.³ Trust is built by taking time to build relationships, understand fear and concerns, and acknowledge the social realities that may influence adherence to public health guidelines and treatment recommendations (for example, affordability of medication, transportation to appointments, and access to life necessities like food and housing).⁴ We can better support the critical role of trusted leaders in Indigenous communities by providing accessible and culturally relevant information to share among their networks. Lastly, we can all commit to walking our own journeys of reconciliation, as modeled through the anti-Indigenous racism work and the dismantling of white supremacy being led within the Office of the Provincial Health Officer.⁵ ■

—Kloshe Tillicum Research Team: Chee Mamuk BCCDC, Simon Fraser University

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This article is the opinion of the BC Centre for Disease Control and has not been peer reviewed by the BCMJ Editorial Board.

Reflections on the importance of a name

Renaming the Powell River Division of Family Practice and opportunities for further action.

David May, MD, CCFP

What power does a name hold? Is it just an abstract construct, or is the process of naming an object or place important? Does a name hold power beyond the printed or spoken word?

I live, work, and play in qathet, on the traditional lands of the Tla'amin people. The name “qathet” was gifted to the then Powell River Regional District by Tla'amin Elders in 2017. The name translates loosely as “coming together” or “working together” in ʔayʔajuθəm (Ayajuthem), the language of the Tla'amin Nation. The area is beautiful and diverse, and there is an oral record of thousands of names describing the local environment and landscape since time immemorial. Many of those names have also been recorded in print.¹

qathet Regional District surrounds the city of Powell River, which was named after Israel Powell in 1955, and therein lies the problem. Powell (who never set foot in the area named after him) served as superintendent of the newly formed Department of Indian Affairs for the Province of British Columbia from 1872 to 1879.^{1,2} He was instrumental in both banning the potlatch and setting up Indian residential schools. In his words, “Patlatches’ [sic], no doubt, not only retard civilizing influences, but encourage idleness among the less worthy members of a tribe, and will, I trust, by wise administration become obsolete in time.”³

Dr May is past chair and current physician lead of the qathet Division of Family Practice.

This article has been peer reviewed.

In June 2021, Tla'amin Nation He-gus (Chief) John Hackett wrote a letter to the mayor and council of the City of Powell River requesting the city commit to change its name as part of its commitment to reconciliation.⁴ A member of the Tla'amin Nation wrote about place names before colonization and how they illustrate a “deep connection to land and [reflect] the area’s cultural significance. It is important to consider the histories of place names, appreciating where they come from, what they mean, and what they can teach us about our environment. . . . [R]enaming holds the potential to acknowledge Indigenous history, celebrate Indigenous resilience and move forward together in a spirit of reconciliation.”⁵

This request stirred up strong emotions in the city, but the municipality has not yet granted the request.

Among the 94 Calls to Action of the Truth and Reconciliation Commission are clear calls to action for leaders in health care.⁶ On 1 June 2019, Doctors of BC announced it had signed a declaration of commitment on cultural safety and humility in health services.⁷

The then named Powell River Division of Family Practice faced a problem. It was clear we needed to change our name, but as a not-for-profit society, any name change had to be voted on by members. In the initial request for a name change, the Tla'amin Nation had stated, “A referendum has no place in this process. Having the dominant culture decide whether the harms done to Tla'amin people and our rights outweigh

their attachment to colonialism is a classic strategy to maintain the status quo.”⁸ The danger then was that any vote that did not show a strong majority for a name change could be both hurtful and regressive.

The Division, therefore, embarked on an extensive period of education for its members. Among other activities, we discussed the *In Plain Sight* report,⁸ which details evidence of systemic racism in health care.⁹ After this education period, the membership voted 97% in favor of the name change, and on 28 June 2022 we officially became the qathet Division of Family Practice.

My own journey of cultural safety and humility is sometimes clumsy, awkward, and difficult, but I consider this name change to be one of the high points so far. My challenge to other divisions of family practice and health organizations is this: look at your name and how it originated, contact the local First Nation(s) on whose land you work and ask them what they think about the name, and reflect on your declaration of cultural safety and humility and how your name might be part of that. Names are important, but our actions are even more important. ■

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Preconception and Pregnancy**

Dr. Sawyer Huget-Penner

➤ **Donor Sperm, Donor Egg &
Surrogacy**

Dr. David Smithson

➤ **Digital Literacy and Internet Safety
for Parents and Those Who Work
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*Brandon Laur, CEO & Instructor of
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➤ **Ozempic Uses and Safety in the
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Dr. Sandra Cortina

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