Managing "behaviours that challenge" - a paradigm shift?

by Karen McNeil MD CCFP FCFP

Literature from around the world makes us hopeful that a paradigm shift in the way we prescribe psychotropic medication for the management of behaviors that challenge* (BTC) in people with intellectual and developmental disabilities (IDD) is occurring.

"Behaviours that Challenge" is a new term to primary care. This new term refocuses the attention that is on the person exhibiting the behaviour and places it on the people experiencing the behaviour. This new concept operates from the premise that all behaviours are communication and the onus is on the observer to determine what the person with IDD is communicating.[1]

The literature reveals that the paradigm is shifting away from routine prescribing of antipsychotic medication for behaviours that challenge towards a comprehensive evaluation of behaviour, that includes environmental, health, mental health and trauma assessments. Only then, using medication as a last resort to keep the person and their family or caregivers safe.

One of the motivators for this shift is the recognition that people with developmental disability have increased morbidity and earlier mortality when compared to the general population.[2,3] The use of psychotropic medication contributes to this disparity; these medications can result in serious short- (arrhythmias, sudden death, tardive dyskinesia) and long-term (metabolic syndrome) side effects.

Other motivators include the scandals that have come to light in the last decade. These scandals demonstrate abuse of this population; one of the factors associated with the abuse is the use of chemical restraints.[4,5,6]

Research, experts, and guidelines all support not prescribing psychotropic medication without a robust psychiatric diagnosis. All advise that interventions other than medication are usually effective for managing behaviors. They encourage physicians to rule out health, emotional and environmental causes and only using psychotropic medication when the person or their caregivers are at risk of harm.[1,7,8]In the UK, primary care physicians, psychiatrists, nurses and pharmacists are taking a pledge to stop over-medication of people with learning disabilities.[9]

Current Practice:

The Atlas on the Care of Adults with Developmental Disabilities in Ontario[10]reports that 20% of people with IDD are on five or more medications and 20% are prescribed two types of antipsychotic drugs concurrently. With so much support for not using psychotropic medication for behaviour, why do we still see these prescribing practices?

Why are more patients with BTC not given a robust non-pharmacological approach: an environmental review and personalized supports, trauma informed care, and behavioral programming? The reason is evident; this kind of care would require an interprofessional team (e.g. occupational therapist (OT), behavioral therapist (BT), speech language pathologist (SLP), psychologists, and social worker (MSW)) available and accessible at the

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community level, collaborating with the primary care physician and having access to a psychiatrist and pharmacists familiar with patients with IDD. This specialized care is either not available or not abundant in most provinces. Pharmacological management on the other hand is readily available and relies only on the skill of the prescriber. This scenario puts the family physician in the middle of the mix.

The prescribing of antipsychotic medications because the patient, family or caregiver are in danger is all too common. This is understandable. Persons with IDD have many risks for escalating BTC: communication challenges; undiagnosed pain; hearing and vision deficits; sensory issues; high incidence of abuse and PTSD; lower socioeconomic status; unsuitable housing; and unemployment and / or isolation. In contrast, they have very little at the community level to mitigate these risks. As a result, the BTC or "communication" happens; without skills and supports to understand the message, their voices get louder and louder. I'm scared, I'm anxious, I'm angry, I'm in pain. These cries need to be understood and primary care providers need better alternatives to psychotropic medication.

Conclusion:

The use of antipsychotic medication to manage BTC persists because there are major gaps in the provision of care and services for persons with IDD. Most provinces do not have available, sustainable, evidence-based behavior programming at the community level, delivered by skilled interprofessional. It is not that the ask is unreasonable. Most, if not all patient populations with this level of complexity have interprofessional teams supporting them. The leap is that these services need to be community based, not in tertiary care. A change of this magnitude in the delivery of services is what is needed and called for, to make this dogged paradigm shift.

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