Title
Evaluation of Behavior Change in Patientswith Developmental Disabilities

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Curbside Consultation:

Evaluation of behavior change in patients with developmental disabilities

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Case Scenerio

A 19 year-old, non-verbal, autistic man was brought to the clinic by his mother. She requests medication to reduce episodes that include loud vocalizations, thrashing, and head-banging. These episodes usually occur in the car. At baseline, the man has difficulty with movement, characterized by decreased fine-motor control, impulsivity, and sudden darting away. His vision and hearing are normal. He often becomes overstimulated in busy environments. He has a partial complex seizure disorder for which he takes lamotrigine. How can I help this family?

Commentary [LH]

The physician's approach should emphasize physical, psychological and emotional safety for both patients and supporters, and help patients build a sense of control and empowerment. Coercive interventions, isolation, restraint, harsh or devaluing words, labeling, and focusing on what is "wrong" with the person can be harmful or trigger past trauma. These should be avoided. (1, 2) In addressing problem behaviors in people with developmental disabilities, is critical to understand the underlying reason, particularly if there is a change from baseline behavior or function. Medical causes should always be considered first.

Initial Approach [LH]

The physician should begin by clarifying the presenting circumstances by addressing the following questions:

1. How does the patient communicate best? [SH]

The first step is to communicate directly with your patient. With the patient's permission, information may also come from a variety of other sources. However, supporters may not recognize signs or symptoms or have accurate information. Being non-verbal is not the same thing as having nothing to say. All people communicate, but that capacity is often overlooked in people with limited speech, dysmorphic features, or cognitive disabilities. Some people communicate best through methods such as writing, typing, pointing to picture icons or letters, sign language, gestures, facial expressions, demonstrations, hand-leading, sounds, physical signs, or behaviors. Behavior such as darting off, self-injury, or aggression, can be a form of communicating distress. But behaviors can be misinterpreted when they are the result of adaptive, impulsive or involuntary movements rather than attempts to communicate.

Patients often come to appointments with supporters who, like interpreters and cultural brokers, can assist with communication. Information and videos that model how to work effectively with supporters can be found at: http://odpc.ucsf.edu/supported-health-care-decision-making. To assist you with understanding your patient's communication and support needs, you can encourage them to create a personalized accommodations report http://www.autismandhealth.org/ or health passport http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/FCIC_Health_Passport_Form_Typeable_English.pdf. Some people can complete these documents independently. Others can complete them with the assistance of a trusted supporter. Simple accommodations such as turning off fluorescent lights, maintaining a scent-free office, allowing extra time to respond, or using plain language and anatomy pictures or models can make a big difference in a patient's ability to participate in their own care. Other tips and strategies for working with non-traditional

communicators can be found on the website of the Office of Developmental Primary Care http://odpc.ucsf.edu. (3,4)

2. Is the behavior a change from the patient's baseline? [SH]

If the behavior is new, it may be due to a medical condition. If a behavior is not a change from baseline, it may simply be calming, adaptive or developmentally appropriate.

3. Has the caregiver's situation changed? [SH]

Sometimes behaviors aren't new, but there has been a change in the caregiver's ability to cope. For example, in the case, vocalizations and thrashing may have been manageable until the mother started a carpool or developed migraines.

Medical Evaluation [LH]

Undiagnosed or undertreated medical problems frequently cause changes in behavior. Simple problems such as constipation or rashes can be very distressing. Sensory processing and communication differences may make it challenging for people to localize or describe their distress. Common medical problems that contribute to behavior change are listed in Table 1. Do a comprehensive physical exam and review of systems. Consider a urinalysis and basic metabolic panel. Common problems can present in unusual ways. For example, head banging can be caused by hearing changes from ear wax. Reflux can present as insomnia. Patients may not exhibit typical pain behavior such as moaning, grimacing and touching the part that hurts. (5)

Non-medical causes of problem behavior [LH]

Non-medical causes of behavior should also be considered. A list of common non-medical causes of behavior change is found in Table 2.

Treatment approach

The goal of treatment is to address the cause of behavior rather than to suppress behaviors in the context of an untenable situation. In discussing these issues, the physician should presume competence and model positive, respectful communication. These attitudes decrease the anxiety people with disabilities often have from being underestimated, misunderstood or misrepresented.

Behaviors that are not harmful should be accepted and accommodated. If the problem is caregiver stress, that can be addressed with additional respite, education, referrals to service agencies, social support, mindfulness classes, or assistance with practical problem solving. (6) Medical treatment should target any identified, remediable medical conditions. Further treatment should help the patient and family manage non-medical conditions.

If the cause of the behavior cannot be determined, changing the social, physical or sensory environment can often resolve the issue. For example, in the case presented, the patient may be having an unrecognized sensory problem in the car such as sensitivity to bright sun. For some, fear of being exposed to a seizure trigger can make car rides stressful. Strobe-like flashes when driving past evenly spaced poles can sometimes trigger seizures. Experiment with different changes such as putting up window shields, trying another driver, reducing the number of people in the car; or playing favored music. (7)

The role of medication [LH]

Problem behavior such as aggression or self-injury is not a psychiatric diagnosis. However, mental health problems are common in people with developmental disabilities. With consent and appropriate diagnosis, medical treatment for psychiatric disability can be effective. The National Association for the Dually Diagnosed (http://thenad.org) has developed an adaptation of the Diagnostic and Statistical Manual for intellectual disability. (8) According to Canadian Consensus Guidelines, “In the absence of a robust diagnosis of psychotic illness, antipsychotic medications should not be regarded as routine treatments of problem behaviors in adults with developmental disabilities.” (9, 10)

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Table 1

Common Medical Causes of Behavior Change in people with developmental and intellectual disabilities

Cervical spine problems

Constipation

Dementia

Dental pain

Dysphagia

Gastroesophageal reflux

Joint, tendon or ligament injuries

Kidney stones

Medication side effects

Migraines

Occult fractures

Thyroid problems

Trauma including post-traumatic stress

Seizures

Urinary or biliary obstruction

Urinary tract infections

Unrecognized pain or discomfort (11)

Table 2

Common non-medical causes of behavior change

Abuse or other stressors
Boredom that leads to anxiety
Escape or avoidance of demands
Increase in arousal or self-stimulation
Means of accessing preferred activity or objects
Psychiatric disability
Pursuit of power and control
Sensory problem: hearing, vision, sensory integration
Substance abuse
Unmet need for social attention