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Standardizing Proper Medical Care for Individuals with Autism

For more than 50 years, doctors and researchers viewed autism solely as a neurodevelopmental disorder. In recent decades, however, we have begun to focus increasing attention on medical co-morbidities in autism spectrum disorders (ASD), including seizures, immune and metabolic dysfunction, gastrointestinal (GI) impairment, anxiety, and sleep disorders.

Countless studies and scientific surveys have documented medical comorbidities in people with ASD. In addition, more than half of individuals diagnosed with autism suffer from one or more medical issues.

Given the high prevalence rate of autism, it might be assumed that health-related government agencies, professional medical organizations, and insurance companies closely monitor the progress of research in autism, and that physicians are continually updated on best practice. Yet a standard of medical care for individuals with ASD has not been established. As a result, many of the medical problems of people with ASD go unnoticed and thus untreated.

What should medical care for individuals with ASD look like?

For patients with ASD to receive proper medical care, doctors and their clinical staffs must possess four types of knowledge:

- They need to be aware of the medical conditions commonly associated with autism.
- They need to know how to determine whether their patients with ASD have any of these comorbidities.
- They need to know which laboratory tests are required to evaluate specific problems.
- They need to be knowledgeable about appropriate treatments and should also know when to refer a patient to a specialist for further testing.

Here are steps we can take to foster each type of knowledge.

Awareness of common medical conditions. Currently, physicians have opportunities to learn about medical problems associated with autism, but this is optional. Given the high rate of autism, knowledge about common comorbidities in ASD should be mandatory for physicians to be in good standing in professional organizations such as the American Medical Association, the American Academy of Pediatrics, and the American Academy of Neurology.

The information physicians need is readily available to them. Several organizations host webinars on medical issues associated with autism, and some of them offer continuing medical education (CME) credit. ARI offers, in joint providership with the Cleveland Clinic, complimentary AMA PRA Category 1 Credit™ to physicians and the general public.

Parents can also play a role in educating physicians and medical staff by sharing links to informative, science-based websites as well as specific articles of interest.

Identification of medical problems.

Experts in the field of autism should work together to develop a standardized intake form to help doctors screen for possible medical conditions. This form could be completed by a care provider or a patient with ASD prior to a visit (using an online form) or at the doctor's office. The intake form should include questions regarding allergies, anxiety, GI problems, possible signs of seizures, sensory sensitivities, and sleep problems. Work is already in progress on this front; for example, a checklist designed to identify GI disorders was recently published by Kara Gross Margolis and her colleagues.

After reviewing the intake form, medical professionals should ask additional questions in order to avoid any misinterpretation as well as to learn more specifics about possible medical problems.

Physicians should also be aware that patients with ASD may not express any signs of discomfort or pain, or may react by engaging in a challenging behavior. Regarding the former, we have heard reports of individuals with ruptured eardrums or appendixes who gave no indication of any distress prior to, during, or after the rupture. Regarding the latter, medical conditions associated with behavior problems may include ear infections and ear-hitting, headaches and head banging, sinus infections and face-slapping, excessive scratching and rash, and sleep problems and stomachaches.

Laboratory testing and referral. If a physician suspects an underlying medical condition, he or she should know which laboratory tests to order. If the patient is referred to a specialist, the referring physician should be able to describe, at least to some degree, the procedures likely to be involved in the specialist's evaluation.

Furthermore, it would be ideal for the referring physician or medical staff to provide information about specialists, including the types of health insurance they accept and the amount of experience they have in examining individuals with ASD. Specialists with little

or no experience may need guidance from patients or care providers.

Care providers, for their part, should consider the use of social stories to reduce anxiety during medical tests and procedures.

Treatment. The medical protocol for patients with ASD should include only evidence-based treatments. This will prevent patients and caregivers from wasting precious time and financial resources on interventions that may sound reasonable in theory, but have no effect or could possibly lead to adverse effects.

Some physicians hesitate to prescribe certain treatments for which there is little or no research involving individuals with ASD, even when these treatments have been shown to be effective in treating the neurotypical population. Examples include treatments for constipation, allergies, GERD, rashes, and infections. In such cases, physicians should carefully weigh the costs and benefits of treatment.

Physicians should be mindful when prescribing treatments that may impact multiple biological systems, either directly or indirectly. For example, many psychiatric medications, such as antidepressants and anti-convulsants, can slow stool motility, and this could worsen an already constipated bowel. In addition, laxatives can lead to dehydration, which is already a problem among many individuals with ASD.

Furthermore, physicians have a responsibility to provide unbiased and accurate information to care providers and individuals with ASD who inquire about treatments that may not be included in a standard medical protocol. It would be advantageous, and could be part of the informed consent process, to make "white papers" available on all popular interventions, whether evidence-based or not.

What can be done now?

Given what we already know, it is disconcerting that many autistic individuals do not receive treatment for mild, moderate, or even severe medical issues.

There is no reason for the medical community to wait any longer to develop a comprehensive standard of care for autism. We do not need to know all the answers before such a protocol is written. It is safe to state that all medical care progresses over time.

If a standard medical protocol is agreed upon, then an important but delicate question would be, "Who will oversee the protocol?" All stakeholders in the autism community should have a say in answering this question.

Where there is a will, there's a way!