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## Polygenic risk scores, prediction of psychiatric disorders, and the health of all of us

The use of polygenic risk scores for psychiatric disorders raises an increasingly pressing question: given finite resources, how should a health-care system that aspires to advance precision medicine and population health view a new class of data that is of such uncertain meaning that it is currently of no apparent clinical value?<sup>2</sup>

Being uncertain, in the sense of highly probabilistic, hardly makes psychiatric polygenic risk scores unique. Even a pathogenic *BRCA* mutation is uncertain in the sense that it only indicates a high probability of disease. What is salient today is the much greater degree to which psychiatric polygenic risk scores are of uncertain meaning and thus below the threshold of clinical utility. Although for most people it appears that any negative psychological reactions of receiving uncertain genomic information are mild and transient,<sup>2</sup> some people do have negative reactions.<sup>3</sup>

Perhaps more surprising is that many people say they would derive personal utility or a sense of empowerment from receiving the information, regardless of clinical utility.<sup>4</sup> Furthermore, some have begun to argue that because uncertain genomic information is an ineradicable part of our lives, we should stop trying to vanquish uncertainty. Rather, we should begin to articulate a fully fledged ethics of uncertainty, which accepts the ineradicable uncertainty associated with such information.<sup>5</sup> Although these scholars do not advocate the return of all uncertain information, it would be easy for others to combine the ethics of uncertainty argument with the familiar observation that the cost of genomic information is falling to claim that health-care systems

should provide all the genomic information patients say they want.

Because health professionals cannot know how individuals will respond to uncertain genomic information that has no clinical utility, one option would be to provide an educational or a genetic counselling process for all potential recipients of psychiatric polygenic risk scores. Individuals could then decide whether such information has personal utility. This approach would agree with claims that patients have a right to their genomic information and that all information can empower—even if the patient does not truly appreciate what its effect could be. However, such an approach would be time consuming for clinicians and genetic counsellors, a limited and valuable resource.

A second option is for health-care institutions to refrain from generating or returning psychiatric polygenic risk scores. It might be acceptable to return such information in research settings, in which investigators are studying its effect on clinical decision making and psychosocial functioning. However, given that such uncertain information has the potential to create psychological distress and that health-care systems have neither the personnel nor financial resources to provide counselling to all who would need it, we recommend that not generating or returning psychiatric polygenic risk scores in clinical settings should be the rebuttable presumption.

We declare no competing interests.

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1 Martin AR, Daly MJ, Robinson EB, Hyman SE, Neale BM. Predicting polygenic risk of psychiatric disorders. *Biol Psychiatry* 2019; **86**: 97–109.

- 2 Wade CH. What is the psychosocial impact of providing genetic and genomic health information to individuals? An overview of systematic reviews. *Hastings Cent Rep* 2019; **49**: S88–96.
- 3 Werner-Lin A, Mccoyd JLM, Bernhardt BA. Actions and uncertainty: how prenatally diagnosed variants of uncertain significance become actionable. *Hastings Cent Rep* 2019; **49**: S61–71.
- 4 Wendler D, Emanuel E. The debate over research on stored biological samples: what do sources think? *Arch Intern Med* 2002; **162**: 1457–62.
- 5 Newson AJ, Leonard SJ, Hall A, Gaff CL. Known unknowns: building an ethics of uncertainty into genomic medicine. *BMC Med Genomics* 2016; **9**: 57.

## COVID-19: overcoming the challenges faced by individuals with autism and their families

While the infection rate of coronavirus disease 2019 (COVID-19) rises exponentially around the globe, individuals with autism spectrum disorder are being identified as part of a group at higher risk for complications from COVID-19.<sup>1</sup> Furthermore, autism spectrum disorder is often accompanied by anxiety, dyspraxia, learning disabilities, epilepsy, fragile X syndrome, Down syndrome, and immune system alterations. Individuals with autism can also have different types of behavioral challenges including deficits in social communication, attention-deficit hyperactivity disorder, irritability, and aggression. Such common comorbidities can present additional challenges for individuals to cope with during the COVID-19 pandemic, making it more difficult to receive needed therapies, practice physical distancing, and adjust to disrupted daily routines. We assert that individuals with autism are an important group who might require additional support during the COVID-19 outbreak and future public health emergencies.

A common feature of children on the autism spectrum is obsession with routine, and disruptions in routine

linked to COVID-19 might elicit major emotional and behavioural upheaval. Depending on the severity of the developmental disability that is associated with an autism diagnosis, children on the spectrum might have difficulty comprehending what is going on. Core features of successful educational programmes for children with autism include several hours per day of engaged instruction.<sup>2</sup> Because of the COVID-19 pandemic, many businesses providing care or specialised educational programmes have closed across the world, either voluntarily or because of mandates. These closures mean that individuals with autism spectrum disorder are receiving fewer, if any, crucial therapy hours (eg, speech therapy, behavioural therapy, and occupational therapy) and classroom time than they normally would. The effects of this pandemic present a profound change of routine for these individuals, which is a considerable challenge, both for them and for their caregivers.

With professional and social support reduced because of these circumstances, parents and caregivers will almost certainly encounter an increased frequency and severity of challenging behaviour in individuals with autism spectrum disorder. Parents of children on the autism spectrum are likely to have personal challenges, including working from home or loss of employment, and could become overwhelmed with the demands of looking after their children without the daily support of specialists. If available and when possible, we encourage families to seek out timely, high quality behavioural therapy, speech and language therapy, and medical services via telehealth for their relatives with autism spectrum disorder. Because many individuals with autism show an affinity for electronics, telehealth might be an effective tool for teaching and therapy, with the proper support in place to enhance accessibility. Although more research is needed, clinical trials

and systematic reviews have shown telehealth interventions to result in promising, modest improvements in learning under the circumstances of limited access to in-person services.<sup>3</sup> We advocate for additional research in this area to develop telehealth services geared specifically towards people with autism, which could target everything from tele-diagnostics to tele-therapy and tele-support for families.

There is definitely a need for home-based COVID-19 testing for those with autism spectrum disorder. If an individual with autism becomes ill and presents to the clinic or emergency department, difficulty in maintaining physical distance might increase their risk of infection and the risk of infecting others. Some people with autism might not understand why they need to wear a mask and even resist wearing one or attempt to remove the mask of their caregivers. Compliance will be an issue if these individuals require specialised care such as oxygen or respiratory support. Allowing caregivers to remain with individuals with autism spectrum disorder while they receive health services will facilitate better patient-centred and family-centred care. Although this suggestion is inconsistent with many policies now in place in health-care facilities, both health-care providers and individuals with autism might benefit substantially if the risk of disruptive behaviour can be reduced. Currently, many hospitals have limited the number of visitors to zero in an attempt to curb viral transmission. The environment in emergency departments can impede care for children with autism and their parents. For example, waiting rooms have been described by parents as overwhelming for children on the autism spectrum, especially when a child comes to the emergency department during peak times. The pace and intensity of the emergency department can be very distressing for a child with autism.<sup>4</sup> Parent surveys about their emergency

department experience indicated that “openness to considering the child’s autism-specific care needs” was appreciated.<sup>5</sup> Challenges faced also included a paucity of staff knowledge about autism spectrum disorder, lengthy wait times, insufficient engagement of parents in case planning, and heightened sensory concerns for the child as a result of the environmental stimulation at the emergency department.<sup>4,5</sup> To combat these challenges, parents or caregivers can help individuals with autism to discuss their symptoms with the health-care worker and provide context for the patient’s behaviours, needs, and communications. To this end, we strongly recommend hospitals and other health-care settings make exceptions that allow caregivers to stay with individuals with autism for the entirety of the visit or hospital stay. Proactive prevention such as handwashing, temperature checks, symptom triage, and providing multiple facial masks (individuals with autism spectrum disorder can lose or damage them) to each patient and their caregiver might mitigate transmission.

Although hopefully a rare occurrence, the likelihood exists that the parents and guardians of children with autism could become infected and require hospitalisation, or even die. Children’s hospitals, social service systems, foster care systems, and guardian ad litem services should develop policies, plans, and clearly defined processes to address the acute needs of children left without a guardian under these circumstances. Parents should also be encouraged to develop legal documents related to guardianship that include multiple alternatives in case the designated guardian also becomes incapacitated and unable to provide care and support.

The number of adults with autism seeking out support and health-care services will probably also increase, and these individuals might also benefit

from the aforementioned measures. Although some adults on the autism spectrum are high functioning and mask their symptoms well, others with more severe symptoms remain at the cognitive level of young children. This population also requires the support of a family caregiver or chaperone in the hospital and the adjustment of COVID-19-specific rules to their needs. In some adults with autism, the cognitive level of understanding might not match chronological age, and health-care providers might need to adapt their approach to better help these individuals.

With the additional support needed for this population, individuals with autism and their parents or guardians might find themselves anxious and frustrated. Heavy patient caseloads and insufficient numbers of staff who are trained to help individuals with autism are commonplace in

virtually every health-care system, and especially so during this COVID-19 pandemic. As medical providers, we should do our very best to avoid any unintentional discrimination. We must try to ensure that our more vulnerable patients receive the same standard of care afforded to neurotypical patients.

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- 1 Chow N, Fleming-Dutra K, Gierke R, et al. Preliminary estimates of the prevalence of selected underlying health conditions among patients with Coronavirus disease 2019—United States, February 12–March 28, 2020. *MMWR Morb Mortal Wkly Rep* 2020; **69**: 382–86.
- 2 Lai MC, Lombardo MV, Baron-Cohen S. Autism. *Lancet* 2014; **383**: 896–910.
- 3 Ferguson J, Craig EA, Dounavi K. Telehealth as a model for providing behaviour analytic interventions to individuals with autism spectrum disorder: a systematic review. *J Autism Dev Disord* 2019; **49**: 582–616.
- 4 Postorino V, Kerns CM, Vivanti G, Bradshaw J, Siracusano M, Mazzone L. Anxiety disorders and obsessive-compulsive disorder in individuals with autism spectrum disorder. *Curr Psychiatry Rep* 2017; **19**: 92.
- 5 Nicholas DB, Muskat B, Zwaigenbaum L, et al. Patient- and family-centered care in the emergency department for children with autism. *Pediatrics* 2020; **145** (suppl 1): S93–98.