Characterising the autistic spectrum and the implications for public health

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In this paper, we consider the statistical distribution of Autistic Spectrum Disorder (ASD) levels in the population and hypothesise that it follows an exponential distribution. We note that the diagnosis of ASD over the past decades has been made based on an ever-expanded view of what constitutes autism and indicate how the associated disproportionate increase in the number of individuals diagnosed with ASD is consistent with this exponential distribution characterisation. The shift in diagnostic boundaries for ASD and the characterisation of autism as a spectrum has led to a profoundly different statistical picture of the occurrence of autism in the population and has implications for public health policy. In particular, the wider recognition of ASD as a diagnosed mental health condition could lead to a concentration of limited resources for those on the milder end of the spectrum compared with those on the severe end. Certainly, the changing composition of sub-populations diagnosed with ASD needs to be analysed and interrogated so that a fair allocation of resources is made to the various spectrum mental health conditions.

Keywords. Autism spectrum; exponential distribution; autism score distribution; resource allocation.

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Autism was classified as a psychiatric condition in the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-4, 2000)[1,2] based on the following criteria:

Delays or abnormal functioning in at least one of the following areas, with onset prior to age three years:

(1) Qualitative impairment in social interaction,
(2) Qualitative impairment in communication language as used in social communication, OR
(3) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities.

Additionally, the diagnosis requires that these disturbances could not be better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

However, under the DSM-5 (2013),[3] Autistic disorder, Asperger Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) – a psychiatric disorder first defined in 1980 – were combined under a single diagnosis: Autism Spectrum Disorder (ASD). The criteria in the DSM-5 for diagnosing ASD include three key deficits in social communication and social interactions. In addition, the DSM-5 revised the symptoms that were required to make a diagnosis of ASD, combining the separate social and communication domains into a single social-communication domain and adding sensory symptoms as a diagnostic criterion.

It is of public interest to explore the effects of this shift in diagnostic criteria, if only to understand the likely implications for the cost and allocation of resources. In this paper, we put forward some models of the demographics of autism and examine the effects of shifting diagnostic boundaries.

Theoretical characterisation of the distribution of ASD

We hypothesise that the probability distribution of ASD within a given population, designated by the random variable X, can be closely approximated by the exponential distribution, defined below in (1).

The probability distribution function of the exponential distribution is expressed mathematically as:

$$\begin{aligned} f(x) &= \lambda e^{-\lambda x} && x \geq 0 \\ &= 0 && \text{otherwise} \end{aligned} \qquad (1)$$

This is generally written as $X \sim E(\lambda)$

The rationale behind this assumption is that the vast majority of the population has no (or undetectable) levels of autism, while an increasingly smaller proportion exhibits increasingly higher levels of autism. We depict the exponential distribution for three different values of λ using a hypothetical index score for autism. In theory, the exponential distribution would accommodate an infinite scale of measurement. However, in practice, a test score would be capped. For this example, we assume a maximum autism index of 100, where the absence of autism would have an

index value of zero and the maximum measurable level would have a value of 100.

We then consider three hypothetical threshold values indicating a score which would lead to a diagnosis of autism, to examine the effect of a shifting diagnostic boundary, given an underlying exponential distribution of autism in the population:

- Traditional (narrow spectrum autism) test: Score ≥50 (C_3)
- Broader spectrum test for autism: Score ≥40 (C_2)
- Extended spectrum test for autism: Score ≥30 (C_1)

An intriguing feature of ascribing an exponential-type distribution to ASD in the population is the flexibility of the distribution according to the parameter, λ. This parameter captures the degree of rarity of the condition in the population.

A higher λresults in a steeper decline in the distribution from non-autistic to autistic, indicating a relatively smaller proportion of autistic individuals in the population for any set of thresholds. In contrast, a lower λ produces a flatter distribution, implying a more even spread of ASD across the population and thus a relatively higher proportion of autistic individuals for any set of diagnostic thresholds.

Table 1 illustrates how different values of λ would produce different values for autistic proportions in the population for a given diagnostic threshold (Fig. 1). We consider three hypothetical thresholds (30, 40 and 50) for autistic categorisation.

As mentioned above, a λ of 0.05 gives a flattish exponential distribution for autism, indicating a relatively high proportion of autism in the population (22.3%, 13.5% and 8.2%) according to the three diagnostic threshold values (≥30, ≥40 and ≥50). Note that, in this case, around three times as many individuals would be categorised as autistic in the *extended* spectrum compared with the *traditional* spectrum.

A λ value of 0.1 gives a steeper distribution, with lower proportions of autism in the population, for the three threshold values (proportions of 5.0%, 1.8% and 0.7%). However, note that in this case, extending the spectrum to a value of 30 (or more) would increase the categorisation of autism by close to a factor of seven, relative to the traditional categorisation.

In turn, a λ of 0.15 gives an even steeper distribution, with lower proportions of autism for the three threshold values (viz., proportions of 1.1%, 0.2% and 0.1%). In this case, the effect of shifting the boundary from C3 to C1 has a more dramatic effect in that it would increase the categorisation of autism by a factor of 10.

Thus, an increase in the value of λ lowers the diagnostic threshold for autism categorisation, leading to a more significant increase in the proportion of diagnoses. In other words, the rarer the ASD condition in the underlying population, the sharper the increase in diagnoses of ASD that will result from lowering the diagnostic threshold.

Statistical cross-validation of estimates of ASD in the population

The estimates of autism in the population have changed markedly over time (Table 2). Several factors contribute to these changes. Scoring procedures have changed, leading to altered diagnostic thresholds and, as the notion of 'being on the autism spectrum' has become well-established as a psychiatric diagnosis, leading to greater numbers of people being tested for ASD. In a systematic review of the worldwide prevalence of autism, Zeidan *et al.*[4] concluded that changes in prevalence '…reflect changes in the definition of autism and differences in methodology and contexts of prevalence studies'. Yet, there is no conclusive evidence that the actual (true) prevalence of autism has changed.

Let us assume that the true incidence of autism has not changed over the period considered and is consistently described by an exponential distribution with some constant lambda. We explore reported figures on the prevalence of autism to demonstrate that a slight broadening of the spectrum (i.e., lowering of the diagnostic threshold) can be responsible for a mushrooming of autistic diagnoses. Lowering the threshold could be an effect of using different, more sensitive testing procedures.

We use the historical estimates obtained from the Centers for Disease Control, as listed in Table 2, for the years 2000 to 2020, in two-year intervals. For the year 2000, which serves as our baseline measure, we set a hypothetical ASD instrument cut-off value of 50. Then, assuming a stable exponential distribution for ASD we can calculate the value of λ consistent with the estimated ASD of 0.67% for 2000. This estimated value for λ is 0.1002.

Then, assuming that the exponential distribution with λ equal to 0.1002 is stable over the period of consideration until 2020, we estimate the implied ASD instrument cut-off values. These estimated cut-off values are presented in Table 1 for the years 2002 to 2020 in two-year intervals.

These numbers indicate the extent to which a downward drift in ASD cut-off values (as a consequence of increasingly sensitive testing procedures), results in an apparent commensurate increase in the percentage of measured ASD in the population.

The distribution of ASD and the distribution of the instrument scores

We have argued that the actual prevalence of ASD in the population is distributed according to an exponential distribution. In fact, we would generalise this argument to suggest that it is natural to characterise the prevalence of any spectrum medical condition in the population as exponential, particularly when the norm is the absence of such a condition. However, although

Table 1. Proportion classified with autistic spectrum disorder

	Different diagnostic thresholds for ASD		
Value of **λ**	Extended ≥30 (C1)	Broader ≥40 (C2)	Traditional ≥ 50 (C3)
0.05	22.3%	13.5%	8.2%
0.1	5.0%	1.8%	0.7%
0.15	1.1%	0.2%	0.1%

ASD = Autism spectrum disorder; C1 = Extended spectrum test for autism - score ≥30; C2 = Broader spectrum test for autism - score ≥40; C3 = Traditional (narrow spectrum) autism test - score ≥50.

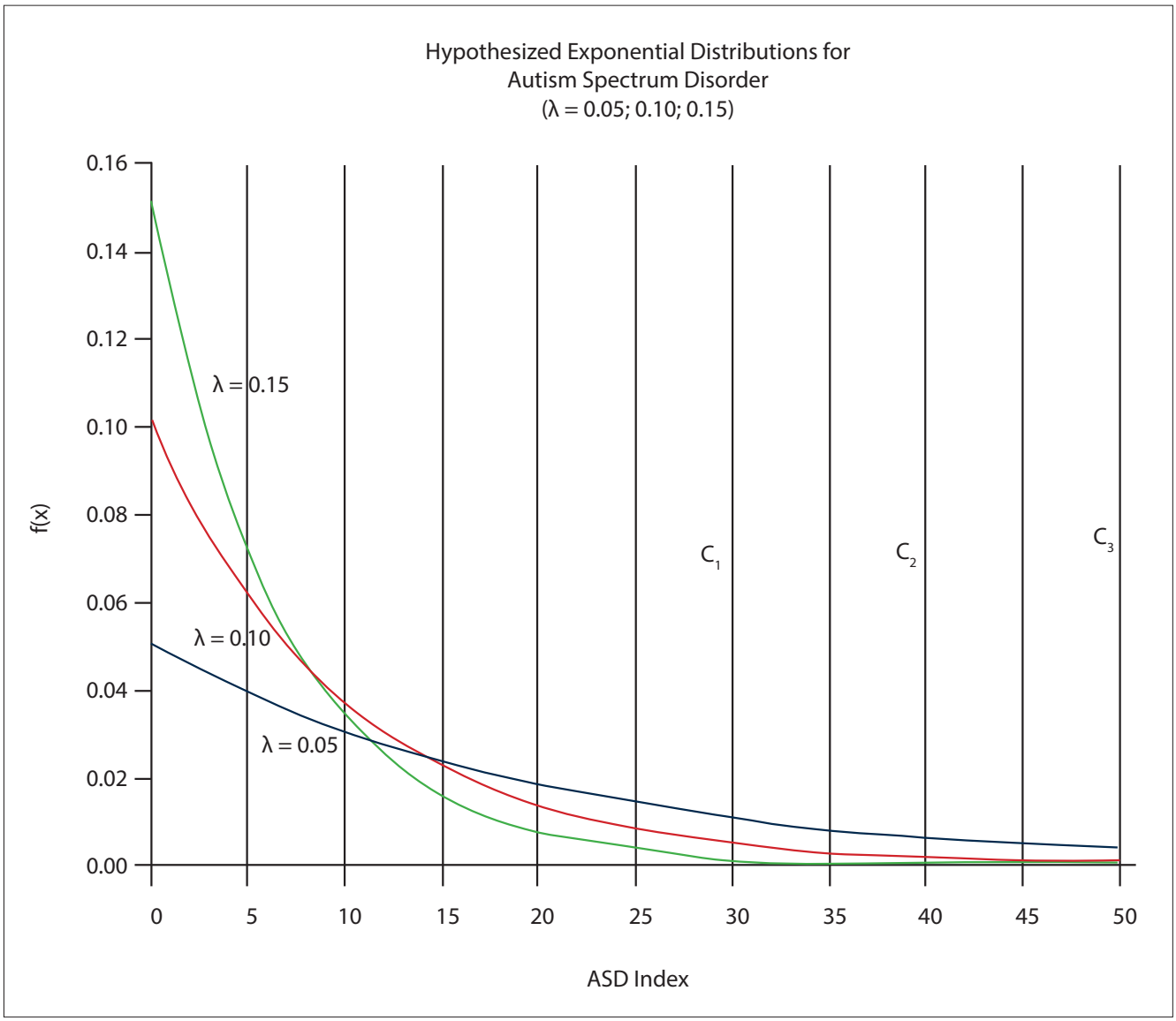

Fig. 1. Hypothesised exponential distributions for autism spectrum disorder.

Table 2. Relationship between the historical estimates of ASD prevalence, the Exponential distribution (λ) and the ASD instrument cut-off

Year	Estimated prevalence of ASD	Diagnostic threshold (Implied)	Exponential λ (× 100)
2000	1/150	50.0 (hypothetical)	10.02 (calculated)*
2002	1/150	50.0 (calculated)	10.02 (assumed)
2004	1/125	48.2 (calculated)	10.02 (assumed)
2006	1/110	47.0 (calculated)	10.02 (assumed)
2008	1/88	44.7 (calculated)	10.02 (assumed)
2010	1/68	42.1 (calculated)	10.02 (assumed)
2012	1/69	42.3 (calculated)	10.02 (assumed)
2014	1/59	40.7 (calculated)	10.02 (assumed)
2016	1/54	39.8 (calculated)	10.02 (assumed)
2018	1/44	37.8 (calculated)	10.02 (assumed)
2020	1/36	35.8 (calculated)	10.02 (assumed)

ASD = autism spectrum disorder.
*Calculated assuming a cut-off of 50.

we depict the actual prevalence of autism across the population using the exponential distribution, one would expect the distribution of actual diagnostic *test scores* for any specific level of autism to be normally distributed. This distribution would account for natural variation as well as the imprecision of the test instrument. When we conduct an ASD test on 100 randomly selected individuals with the same level of ASD (e.g., a score of 30), then the Central Limit Theorem indicates that the test score distribution will tend towards normality (Bell-shaped), around a mean of 30, as the sample size increases.[5]

This distribution captures the expected variability of scores around the true underlying ASD level of 30. We assume that the test

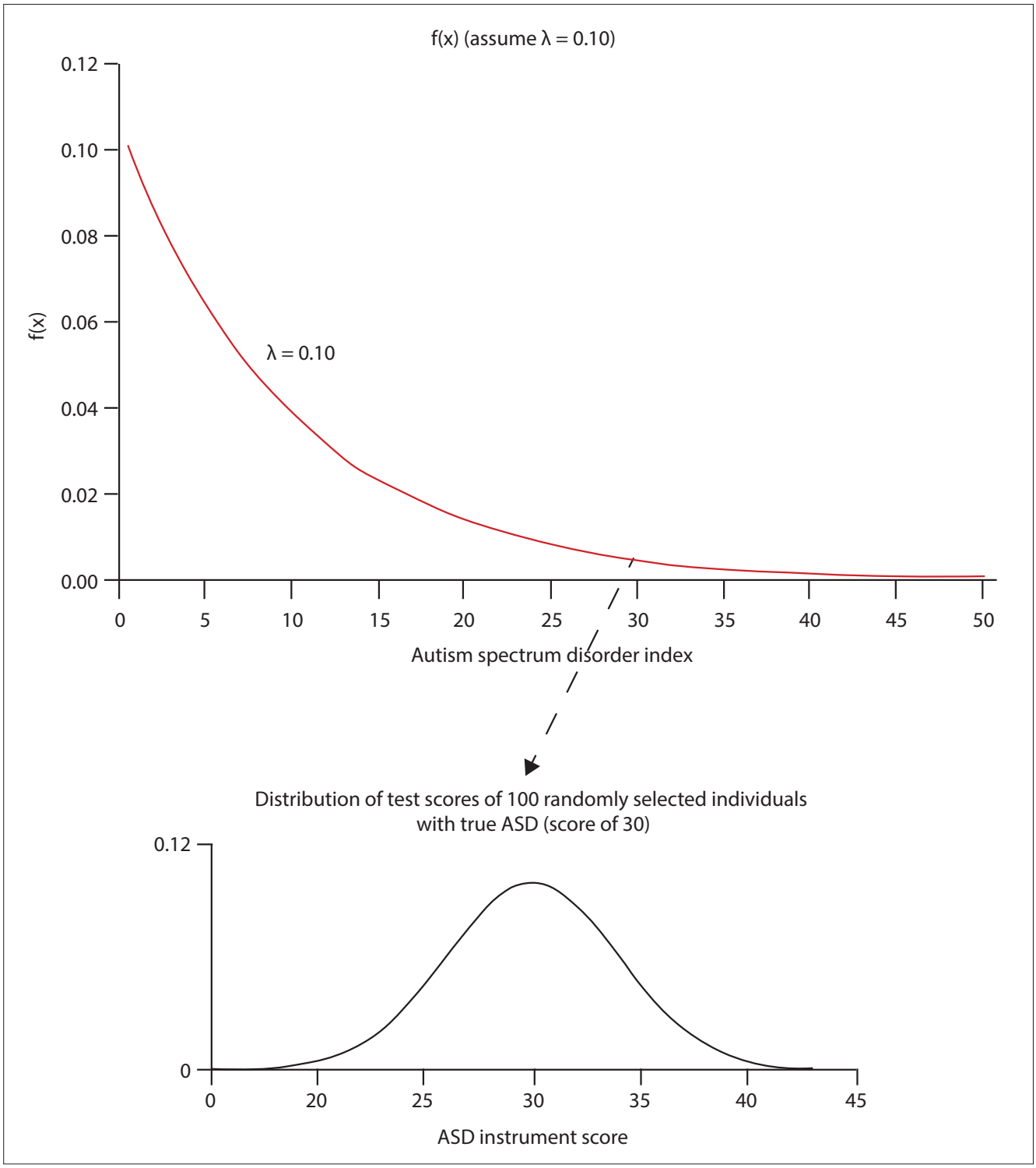

Fig. 2. Bell-shaped distribution of test scores of 100 individuals with the same true level of autism. [ASD = autism spectrum disorder].

is unbiased so the larger the number of tests, the closer the average test score will get to 30 (Fig. 2).

Discussion

How shifting diagnostic boundaries impact public health concerns

We have demonstrated that even if the distribution of autism has remained unchanged and the acknowledged increase in the rate of testing for ASD is ignored, the expanded definition of autism, combined with an exponentially distributed underlying condition, would have led to a sharp rise in autism diagnoses in the population. Data from the USA has indicated that the pattern of increasing prevalence figures is consistent with expanding diagnostic boundaries. This inflation will have happened at the milder end of the spectrum, leading to a fundamentally different picture of the population diagnosed with autism. Prior to this view of autism as a spectrum, individuals who were diagnosed with autism were likely to be on the extreme of the autism spectrum, if not statistical outliers.[6,7] Given the limited resources available – such as schools for learners with autism, psychiatric professionals, educational support and care facilities – this is likely to reduce the resources available to support those on the more severe end of the spectrum. In South Africa (SA), comparatively little research on autism has been conducted compared with the USA. The existing studies mainly focus on the severe under-resourcing of mental health facilities for SA children, with autism-related services being particularly affected.[8-10]

A major worldwide public health concern, which may have particular resonance in an SA context, is the need to thoroughly investigate and accurately characterise the changing composition of sub-populations diagnosed with mental health conditions. This is essential for adequate planning and fair allocation of resources. We believe that assuming a normal distribution for these sub-populations is incorrect and could lead to serious misconceptions and inadequate support, particularly for those at the most vulnerable end of the spectrum.

In addition, there is a risk that increased diagnoses of mental health conditions may inevitably lead to increased prescribing of medications, partly because there is an expectation that a diagnosis requires treatment. If, as we have postulated, a slight shifting of the diagnostic boundary leads to significantly larger proportions of the population being diagnosed with a mental health condition, it should be investigated to what extent the treatment of 'newly admitted' members of the spectrum is appropriate and whether medication, where prescribed, leads unambiguously to positive outcomes.

Finally, it may be of interest to interrogate whether characterising autism as a spectrum is in fact useful.[11] Are there advantages in clustering together what appear to be extremely different manifestations of a mental health condition? Receiving a diagnosis may provide comfort to recipients, this could explain why the broadening of the spectrum has been welcomed by some patients and their families. This is acknowledged by science philosopher, Hacking,[5] who described the 'looping effect', whereby labelling a condition changes the patient's self-perception, their behaviour and ultimately the presenting symptoms themselves, potentially leading to further blurring of the boundaries within the loosely defined autism spectrum. Furthermore, if, as we suggest, the ballooning of the mild end of the spectrum has potentially relegated the more severe end to statistical outliers, it raises the question of whether autism might be better characterised as a set of separate conditions.

In this paper, we put forward a view on how the distribution of a mental health condition characterised as a spectrum should be modelled. This raises important questions about diagnostic boundaries, their impact on treatment and the allocation of public health resources.

Limitations of the study

This study hypothesises an exponential distribution for the occurrence of ASD across the population. Data is available from sites in the United States which indicate that the observed increasing proportion of those diagnosed with ASD is consistent with a concomitant increase in autistic threshold. The United States data set is by far the most detailed and expansive data on ASD available. Thus, the paper relies on this particular data set to support its conclusions. Other countries might exhibit different ASD proportions.

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Data availability statement. Data source: The data can be accessed via the Centers for Disease Control website: https://www.cdc.gov/autism/data-research/?CDC_AAref_Val=https://www.cdc.gov/ncbddd/autism/data.html (accessed 29 July 2024). Any restrictions or additional information regarding data access can be discussed with the corresponding author.

Conflicts of interest. None.

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