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Death by Suicide Among People With Autism: Beyond Zebrafish

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Several recent population-based mortality studies have demonstrated extraordinarily high rates of death by suicide in autistic youth and adults. In this issue of *JAMA Network Open*, Kõlves et al[1] substantially move this work forward by narrowing the focus from overall mortality to specific data on suicide attempts and deaths and by analyzing targeted risk factors associated with age, sex, and the presence of other cooccurring psychiatric concerns. Using a Danish population-based sample of more than 6.5 million persons with observations over the course of 10 years, the authors report adjusted incidence rate ratios (aIRRs) more than 3 times higher among individuals with autism for both suicide attempts and deaths, with significantly higher rates compared with the general population across all age ranges, beginning from age 10 years. In particular, Kõlves et al[1] found devastating rates of suicide attempts for autistic girls and women (aIRR, 8.51) compared with boys and men (aIRR, 1.93) and for autistic individuals diagnosed with additional psychiatric conditions (aIRR, 9.27), particularly anxiety and affective disorders. These findings both clarify the roadmap for and emphasize the urgency of ongoing research into risk detection and prevention of suicide in autistic people.

Findings associated with sex differences and psychiatric conditions coalesce around several important themes. One is the issue of diagnostic overshadowing, described by Crane et al[2] and others, in which a clinician attuned to autism traits in their patient might overlook or confound signs of depression with autism, thus missing the opportunity to add important therapeutic elements to the treatment plan. The reverse likely happens even more frequently: clinicians used to diagnosing mood and anxiety disorders miss additional signs of autism. Even when correctly diagnosed, it may be challenging for autistic people to access evidence-based psychological treatments.[3] This is a critical failure because a growing body of research shows that many autistic youth and adults benefit from adapted therapies for a range of psychiatric concerns that more effectively integrate their unique strengths and difficulties into treatment. We note especially the common cooccurrence of autism alongside eating disorders, which may show expected symptoms but different underlying motivations, and with gender diversity, including elevated rates of gender dysphoria. Better understanding of autism-associated similarities and differences for symptom course and onset as well as therapeutic response is important for maximizing patient well-being.

Another important issue is the belief that autistic individuals should camouflage or mask their autistic traits to conform with societal expectations, for example by forcing themselves to make eye contact with others even when doing so is uncomfortable. It is essential to ask autistic people about the underlying motivations for their behaviors, which may be different than clinicians and caregivers assume. One helpful question about camouflaging is how much effort the person expends trying to perform as they think others require them to. Quantitative and qualitative research studies show that such camouflaging is exhausting and is associated with poor mental health, including suicidal thoughts and behavior. This has important implications for many interventions, including social skills training and behavioral therapies that aim to normalize appearance and behavior at the risk of exacerbating a disconnect between the true self and performing self, potentially increasing anxiety and decreasing self-esteem.

Understanding the downsides to camouflaging has ramifications for training and support models for autistic people that are often implicitly grounded in a deficit-based framework. This framework is challenged by what autistic scholar Damian Milton[4] has termed the double empathy problem, which recognizes that relational difficulties between autistic and nonautistic partners are a

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2-way street: although nonautistic people have the same challenges understanding autistic viewpoints as vice versa, the weight of societal expectations means that autistic people are disproportionately stigmatized and rejected. Increased acceptance of autistic youth and adults into schools, workplaces, and social groups cannot depend only on changing autistic people; greater awareness and flexibility is likewise needed for neurotypical partners.[5] More acceptance of neurodiversity will benefit everyone in society and may also lead to a decrease in feelings of rejection and suicidal thinking for autistic individuals.

Each of these issues seem to be compounded in autistic girls and women. In general, girls and women may be socialized to greater expectations for social interactions and skills, and indeed, rates of camouflaging seem to be higher in autistic girls and women than in boys and men. Overall, women with and without autism experience higher rates of depression, anxiety, and eating disorders than men. A recent study of women who report feeling overwhelmed in social situations, some diagnosed with autism and others with social anxiety disorder, found that the level of depression was more strongly associated with suicidal thoughts and behavior than the level of autism traits; thus, higher rates of depression in autistic girls and women could contribute to the higher rates of suicide compared with autistic boys and men.[6] Critically, diagnostic overshadowing is especially common in autistic girls and women for 2 main reasons. On the one hand, current diagnostic criteria for autism are based largely on profiles seen in young boys and do not adequately account for female-oriented presentations of autism. Conversely, increased camouflaging deflects diagnostic attention from possible autism traits, leaving autistic girls and women underdiagnosed and undersupported. Thus, girls and women are diagnosed with autism at later ages than boys and men, with many women getting their first diagnosis well into adulthood. Together, these factors may help explain the striking finding by Kõlves et al[1] that the rate of suicide attempts increased with the age at first diagnosis, with the highest age-based suicide rate in autism for individuals aged 30 to 39 years.

An important concern that could not be addressed with the Danish population data is that of nonsuicidal self-injury (NSSI). Prominent models of suicide risk emphasize the role of NSSI for overcoming instinctive aversion and building a tolerance for self-harm that increases the likelihood of death by suicide. NSSI is common in autism but is often assumed to be related to repetitive behaviors without suicidal intent, such as head banging to relieve stress. This assumption may be inaccurate and deadly, and careful investigation of intent to harm is required with autistic patients who are at risk of suicide.

Population studies such as that reported by Kõlves and colleagues[1] are especially useful for describing the critical research questions, outlining the way forward for individual-level investigations of the interplay between biological, cognitive, and social responses to stress and other negative emotions. The study of interactions between autism traits and transdiagnostic factors including emotion awareness (alexithymia) and intolerance of uncertainty—already well-known in other mental health conditions—may prove to be especially fruitful.[7] Unfortunately, to our knowledge, there have been few measurement tools for mental health status and suicide risk that have been validated for autistic youth or adults to date.[8]

Journalist and autistic self-advocate Sara Luterman has powerfully described funding discrepancies for basic vs applied research in autism mental health, noting that "millions of dollars go to genetically altered zebrafish and rats that groom too much, but hardly any to finding out why so many autistic adults attempt suicide."[9] Luterman believes, as do we, that basic and translational research in autism is crucial, but it is not enough. The sobering findings by Kõlves et al[1] intensify the urgency of funding agencies, health care systems, policy makers, and communities to dedicate more resources to the tragic, pervasive problem of intense mental health difficulties, suicidal thinking, and death by suicide in autistic youth and adults.

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Additional Information: This article uses the terms *autistic* as well as *people with autism* to acknowledge and respect both identity-first and person-first language.

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