We Have to Pay More Attention to Autistic Teens At Risk for Depression

Behavioral Health

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As more evidence emerges that autistic adolescents are at higher risk of depression and suicide, it's our job as clinicians and researchers to find ways to better identify youth at risk to connect them with support they need.

In a new study published in Academic Pediatrics, our team found that some recently implemented measures have been effective, but we offer suggestions below for further improvement to specifically support the needs of autistic youth.

Autistic Teens Are More Likely to Report Depression Symptoms

At Children's Hospital of Philadelphia (CHOP), all adolescents (ages 12 and older) should be screened for depression and suicide during their yearly well-child visits. Before meeting with their pediatricians, teens are asked to report any symptom they have experienced over the last two weeks that might indicate possible depression or suicide risk such as sadness, concentration problems, sleeping issues and thinking about death.

To understand how this screening is working for autistic youth, our team compared autistic and non-autistic teens who came in for a well-child visit between November 2017 and January 2019. We looked at which adolescents completed a screen and who screened positive for depression or suicide risk.

We found that autistic adolescents are less likely to be screened than their non-autistic peers. While approximately 79% of non-autistic adolescents had at least one completed screening during the study period, only 67% of autistic adolescents did, with lower screening rates for autistic individuals with other co-occurring neurodevelopmental conditions.

But when they were screened, autistic adolescents were more likely to report depression symptoms and suicidality.

Overall, the vast majority of children are participating in screening, but these findings suggest that there are opportunities to better meet the needs of autistic youth through ongoing education of clinicians, health system quality improvement initiatives, and health insurance design and reimbursement policy.

What do clinicians need to better support these teens?

Clinicians who provide care for autistic youth should have access to ongoing education that focuses on these patients' heightened risk for depression and suicide. Depression may present differently for autistic youth, so additional attention to the many possible signs and symptoms should be emphasized. These could include worsened aggression and self-injury, increased repetitive behaviors, withdrawal from activities, and new focused interests with sadder themes.

Autistic adolescents with variable cognitive and verbal abilities might have different indicators of depression. Non-verbal autistic youth might present with increased crying and toileting accidents. Autistic youth with more advanced language and communication skills might express sadness, decreased engagement in pleasurable activities and sleeping problems.

Families should also be informed of these possible signs and symptoms and should be active participants in the screening and diagnostic process.

After initial signs of possible depression or suicide risk are identified, children should be fully evaluated. Providers should not delay additional assessment, referrals and treatment when needed. There are evidence-based treatments that can be effective for autistic youth, but we need a well-trained mental health workforce that can address the unique needs of these teens to provide the continuum of care.

How can health systems adapt to improve screening practices?

In addition to improving access to mental health care for all children, health systems should continue to focus on closing the gaps in care between autistic and non-autistic adolescents.

Quality improvement initiatives can increase screening among autistic adolescents to improve depression and suicide risk identification. These efforts should be guided by scientific evidence and conducted in collaboration with self- and family advocates. Health systems can also apply strategies from successful autism-friendly health care initiatives, such as flexibility in routine practices and physical spaces, to depression and suicide screening.

At CHOP, patients complete the depression screen electronically on a tablet before the visit. However, educating autistic youth on the importance of screening, and then giving them options about how and when to complete the screening questionnaires may be helpful.

Autistic adolescents might prefer to complete the screening if administered verbally as an interview, may appreciate a private space with less sensory stimuli and distractions to complete a paper-based or electronic questionnaire, or some youth and families may rely more on support from caregivers in answering screening questions. Staff should use appropriate communication styles to match the patients' needs (e.g., use of concrete plain language and non-verbal communication tools such as pictures) to help introduce and support screening.

Additionally, it might be helpful to expand screening to other clinical and non-clinical settings where autistic individuals are frequently seen and cared for such as the emergency department, subspeciality clinics, schools and therapy centers.

How could policy play a role?

Our findings also highlight the importance of insurance coverage, and variation between public and commercial coverage, in successfully screening for adolescent depression. Medicaid-insured teens were more likely to have a completed screen compared to privately insured adolescents. This might reflect differences in reimbursement policy or incentivization for routine screenings by different insurance plans. Ensuring coverage of and adequate reimbursement for screening may help boost screening completion. It is also important to ensure coverage for other preventative and intervention services that may reduce youth's risk of depression and suicide.

While most children are being screened as part of routine primary care, additional efforts to meet the needs of autistic youth can ensure that this population’s mental health is recognized, addressed and supported. Successful screening and identification of depression and suicidality might be the first and the most important step to save a life or change it forever.

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