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Updated European guidelines for Tourette syndrome: and now use them!

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This focused issue of *European Child and Adolescent Psychiatry* contains fully updated guidelines for the assessment and treatment of Tourette syndrome, written by European experts. The articles provide very useful practical recommendations for optimal care of children and adolescents with a tic disorder, spanning assessment, [1] psychological interventions [2], pharmacological treatments [3], and deep brain stimulation [4]. Recommendations are not only based on evidence from clinical trials but also took clinical experience into account to fill the existing gaps of evidence. Uniquely, also a report on patients' perspectives on research and treatment is included, indicating the need for more research into better treatments and problems in the day-to-day lives of patients with Tourette syndrome [5].

European Child and Adolescent Psychiatry very much encourages other European expert groups to submit guideline papers for disorders in our field. Guidelines are an important prerequisite for delivering the best care to our patients. Empirical evidence has repeatedly shown that assessment and treatment in accordance with expert guidelines greatly benefits the outcome of clinical care [6]. A classic example is the Multimodal Treatment of Attention Deficit Hyperactivity Disorder (ADHD), [7] which showed that carefully crafted medication management according to guidelines is vastly superior to routine community care (even if that includes medication) as typically delivered in clinical practice.

Unfortunately, however, it is not the lack of clinical guidelines or existing gaps in the base of evidence underlying some recommendations, but rather the limited adherence to

available guidelines that forms the weakest link in delivering evidence-based care in clinical practice in the field of pediatric mental health care. A number of recently published studies have indeed highlighted subpar adherence to available guidelines. A study among mental health clinicians across Europe found that 46% of them were unaware of the existence of guidelines in their country for the treatment of severe behavioral problems in children, and of the ones who were aware, 37.6% did not use them in practice [8]. More than 40% of Dutch clinicians reported using ADHD guidelines only 'sometimes', or less [9]. Many clinicians indicated to deviate from these guidelines in their daily practice, which is most concerning with regard to parent training: as many as one-third of the clinicians only advised the use of parent training in a minority of the children with ADHD in their practice, whereas guidelines uniformly recommend parent training as preferred first-choice treatment for all children with ADHD. This practice clearly bears the risk of starting ADHD medication where this is not (yet) indicated.

A study from Germany that assessed patient records of 73 clinicians regarding their handling of ADHD in their daily practice found only moderate adherence to most mandatory guideline components [10]. Particularly disappointing were insufficient involvement of teachers and schools in the treatment process, limited implementation of psychoeducational methods, as well as a lack of careful examination of patients, including monitoring of treatment effects during titration trials. Insufficient ongoing monitoring of children on ADHD medication, particularly with regard to documenting heart rate, blood pressure, and weight were also found in an investigation of medical records of children with ADHD from Australia against indicators derived from guideline recommendations [11]. That study also reported that the intended treatment duration with ADHD medication and signals for stopping the medication were often not documented prior to prescription.

Strikingly, a documented ADHD diagnosis was absent in about one in 10 patients who were prescribed ADHD

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medication according to the results of an analysis of German claims data, including 18,703 children and adolescents aged with a first-time dispensation of ADHD medication in the period 2015–2017 [12]. This contrasts with German guideline recommendations that require a structured, comprehensive ADHD assessment prior to prescribing ADHD medication. Another finding of that study was that 2.6% of all first-time prescriptions concerned second-line ADHD medication (e.g., lisdexamfetamine, guanfacine, dexamfetamine). This is clearly not constituting rational pharmacotherapy, given the less favorable efficacy and safety picture of second-line ADHD medication compared to first-line options. Australian general practitioners were deviating from recommendations to use stimulants ahead of other ADHD medications in almost a quarter of cases [11].

Adherence to guidelines regarding other classes of psychotropic medication has also been found to be disappointing. In an assessment of medical records from the Netherlands for adherence to guideline recommendations for antipsychotic prescription off-label prescribed for behavioral problems in children and adolescents, we found that the recommended screening of contra-indications prior to prescription was very rarely adhered to (below 20% of cases) [13]. Moreover, the important guideline recommendation that antipsychotics for behavior problems should only be prescribed in combination with psychosocial interventions was met in a mere 37% of the reviewed medical records. Simultaneous use of multiple antipsychotics occurred in as many as 3.2% of cases, a clear violation of guidelines. Younger children were found to be most at risk of receiving suboptimal care, warranting special attention to this vulnerable group.

Clinical practice regarding the use of antidepressants in young people is also worrisome. Guidelines for the treatment of depression recommend to start with fluoxetine, as the evidence for its efficacy is strongest and the risk of suicidality lowest, and also recommend to use a low starting dose. However, an investigation of data from a Dutch pharmacy prescription database indicated that it was not fluoxetine, but paroxetine and citalopram that were the most commonly prescribed first-use antidepressants in minors [14]. Moreover, starting doses were guideline concordant in only 58% of the time for children, 31% for preteens, and 16% for teens. A Danish study found that less than a quarter of the parents were informed specifically about suicidality as possible adverse events of antidepressants [15].

How can better use of guideline commendations be reached? The studies that we reviewed offer some clear clues. Foremost, awareness of the very existence of guidelines should be increased [8]. For this to happen, guideline training should be an essential component of (continuing) education programs for both medical and non-medical professions. Another useful way to increase guideline use is

to improve the ease of applicability of these guidelines, for example, by developing an app with guideline-based decision trees or guideline checks embedded in electronic patient records [9]. Especially rational pharmacotherapy could be enhanced by incorporating a more standardized and mandatory documentation of the essential treatment steps in the medical record [13]. Other interventions to increase adherence to guidelines include provision of educational materials, performance of regular practice audits with feedback to individual clinicians, and raising awareness and limiting the role of marketing activities by pharmaceutical companies [14].

Adherence to guidelines is more likely when recommendations are specific and concrete and when few additional resources are required for implementation [14]. We do believe that the updated European guidelines for the assessment and treatment of Tourette syndrome meet these requirements. They have been written with practical applicability in mind. Included is a very useful clinical decision tree for the treatment of patients with Tourette syndrome based on shared clinician-patient decision making, outlining the various treatment steps that may be applied [16]. Obviously, we very much encourage applying our recommendations in clinical practice. Applicability for busy clinicians could be increased by making summary cards in the various European languages, which may also be used in continuous education programs. It is recommended to make such information available online, as part of websites that summarize recommended assessment and treatment steps for pediatric mental disorders. To enhance shared patient-clinician decision making, it will also be important to make psychoeducational information leaflets with recommended steps for assessment and treatment directed at children, their families, and schools, in co-operation with patient associations and to make sure these are also available online in all European countries.

At last, we are curious if the pandemic (i.e., not corona associated) phenomenon of “functional tics” [17] will ebb again or will be an elementary part of the next update of the European guidelines.

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