Executive summary

Health Council of the Netherlands. ADHD: medication and society. The Hague: Health Council of the Netherlands, 2014; publication no. 2014/19

There is a widespread debate in social and political circles, and among professional practitioners, about the steady growth in the number of young people with mental health problems, including ADHD (Attention Deficit Hyperactivity Disorder). This growth is accompanied by an increasing demand for care or assistance, and by increasing medication use. Young people with symptoms of this kind encounter many problems in education and in the labour market. What are the underlying causes of this problem, and how can the tide be turned? The State Secretaries for Health, Welfare and Sport and for Social Affairs and Employment have submitted this broad-based question to the Health Council of the Netherlands. These government officials have requested two partial advisory reports from the Council: one on participation by young people with mental health problems in general, and one concerning the current level of knowledge in the field of ADHD. Both partial advisory reports were drawn up by a Health Council committee specially appointed for the purpose. The present advisory report concerns ADHD.

Social controversy

The debate about ADHD focuses primarily on the greatly increased use of medication to treat the disorder, especially methylphenidate (which is sold under a variety of brand names, including Ritalin). The question is, to what extent is this increased use medically justified? Critics claim that undesirable

medicalisation plays an important part in this: a problem is wrongly defined as a medical issue, then treated accordingly, for example through the use of medicinal products. The obvious course of action in such cases is demedicalisation – seeking solutions outside the medical domain. The Committee has determined that medicalisation (and demedicalisation) is a loaded term, with a wide range of interpretations and a range of normative elements. In this connection, it prefers to use the concept of "appropriate care".

The debate also touches on possible causes for the growth in the number of young people who, as a result of their ADHD, end up in the care circuit. The Committee calls attention to various social developments that have very likely paved the way for this growth. For instance, there is the increased pressure to perform. Children and young people whose performance is below average seem more likely to encounter performance problems. It also seems that the bandwidth of what is considered to be "normal" has narrowed, with less and less tolerance for any deviations from the mean. The same applies to active (and hyperactive), impulsive and inattentive behaviour. The health and education system has contributed to this growth through the introduction of financial incentives for schools, parents and those providing treatment that generated the requirement for a formal diagnosis.

Further analysis of increased demand for care

How prevalent is ADHD in children and adolescents, and is it becoming more common? The Committee has found that the answer to the first question depends on which diagnostic classification system is used, on the sources used in this context (experts, parents, children or teachers), and on the weighting assigned to diagnostic criteria (such as dysfunction) in epidemiological studies. Many studies make little or no allowance for dysfunction (the extent to which children experience difficulties at school and within the family). In such studies, those children who exhibit the characteristics of ADHD but who do not actually meet the criteria for a clinical diagnosis may also be included, thereby boosting prevalence. The Committee attaches great importance to the criterion of dysfunction. Accordingly, its estimate of average prevalence among children aged four to eighteen is lower than the average estimate (5%) derived from studies based on DSM criteria. Estimates based on ICD-10 (an alternative, less commonly used classification system) are also lower than the prevalence estimates based on DSM. Studies carried out in the Netherlands and elsewhere have not produced any evidence for an increase in the prevalence of ADHD.

Indeed, the Committee had not expected this to be the case, given that genetic factors and factors associated with the physical environment tend to remain more or less constant.

However, there has certainly been an increase in the number of prescriptions for methylphenidate. From 2003 to 2012, that number quadrupled among children aged four to eighteen. In 2013, nearly 4.5 percent of four to eighteen year olds were using methylphenidate. Furthermore, in 2011, general practitioners saw about twice as many children with ADHD-like problems as they did in 2002. With regard to specialist care in secondary healthcare, trend data has only been available since 2008. From then until 2011, the number of completed Diagnosis-Treatment-Combinations (DTCs) for ADHD in secondary healthcare increased by about a third. In short, while prevalence has remained more or less constant, there appears to have been substantial growth in the demand for care and for various other forms of support.

All of which raises the question of whether over-treatment is a factor here. The Committee feels that this conclusion cannot be drawn. On the one hand, the uptake of medication and care roughly correspond to the average prevalence estimate derived from DSM-based studies. On the other hand, prevalence estimates based on ICD-10 or on more robust DSM studies clearly tend to be lower. Moreover, formal diagnosis and medical management would not automatically benefit every single child who meets the rather subjective criteria for ADHD. The Committee is, therefore, concerned about the rapid growth in the number of prescriptions.

Treatment options assessed on the strength of the evidence

In assessing the effectiveness of treatment options, including medication, various psychosocial treatments, and dietary interventions, the Committee has examined both short-term and long-term outcomes. The first category includes the core symptoms of ADHD: inattention, hyperactivity and impulsivity. In addition to the effects on core symptoms, the Committee attaches great value to outcomes that reflect general performance, such as interactions within the family, interacting with peers, academic performance and quality of life. Long-term outcomes involve issues such as completing an educational programme, finding and keeping a job, and developing personal relationships. Where possible, the Committee has evaluated the effectiveness of various intervention using an effect-size format that is commonly used in the social sciences: small, medium or

large. A detailed justification is given in the advisory report's background document.

Medical management exerts the greatest effect on the core symptoms of ADHD in the short term. Such treatment is not without its problems, however. For instance, there are side effects such as insomnia, nervousness and headaches. In addition, the long-term safety of such treatment needs further study. Moreover, there is no conclusive evidence that it has beneficial effects on major associated outcome parameters, particularly school performance. There is a similar lack of evidence with regard to long-term efficacy. In the Committee's view, "appropriate care" does not necessarily mean that the (exclusive) use of medical management is indicated.

There is less evidence that mediation therapy (parent or teacher training) has effect on the core symptoms of ADHD. With regard to other outcome parameters, such as ODD (Oppositional Defiant Disorder) symptoms and social behaviour, the effectiveness of mediation therapy approaches that of medical management. A combination of both these interventions might make it possible to reduce the medication dose, with no loss of efficacy. It is not known whether or not mediation therapy delivers positive long-term outcomes.

Appropriate care in everyday practice

There is a lack of reliable data on how cases of ADHD in children and adolescents are identified, diagnosed and treated in everyday practice. What is clear is that these problems are often identified at school, but less is known about how referral takes place. In addition, little is known about compliance with existing ADHD guidelines, for example. Consequently, it is difficult to ascertain the extent to which the actual care provided is appropriate, in other words, does it provide the necessary support while avoiding the use of excessive measures. In the Committee's view, the development of integrated care programmes that involve a key role for general practice could offer a solution. Programmes of this kind have already been used in local projects.

How to proceed? Some recommendations

The Committee has identified quite a few gaps in our knowledge. It feels that further research is needed in each of these areas. The areas in question are:

- the everyday practice of care delivery and compliance with guidelines

- effects of social factors, including the effects of the upcoming overhaul of the youth care system
- the effectiveness of interventions to reduce problematic behaviour at school: what changes to the school environment could form the basis for intensive interventions for specific groups of children?

Citing its own advisory report on participation issues, the Committee emphasises that research into, and care for, children with ADHD should focus more on fostering their social participation. The demand for care formulated by these children and their parents requires this kind of perspective. Furthermore, the Committee recommends that an integrated care model be created and evaluated. This would focus less on ADHD criteria and more on whether the children in question are encountering problems. In this care model, collaboration between the various professional practitioners involved must be examined, as must the facilitating role that government can play in removing barriers to care delivery. Finally, the Committee also feels that it is important to invest in social initiatives, such as support networks for parents and information programmes for parents and teachers.