

### CLASSIFICATION AND PREVALENCE

Attention deficit hyperactivity disorder (ADHD) is the name given to a condition characterised by inattention, hyperactivity, and impulsivity. Although there are many historical descriptions of these behaviours in children,<sup>1</sup> definitions of ADHD as a disease emerged in the 1980s, when the practice of classifying mental disorders became popular and the DSM-III and ICD-9 diagnostic systems shifted the scientific focus on mental illness from aetiological debates to finding practical and reliable disease descriptions.

The term ADHD, drawn from the DSM-III, was initially used only in North America. In Europe, the term 'hyperkinetic disorder' was used and was initially reserved only for the most severe cases. The broader definition afforded by the DSM eventually led to a corresponding rise in diagnosis rates in Europe, although they were still dwarfed by the much higher rates seen in the US. This historic diversion in practice has been partly explained by differing diagnostic criteria, but also by the power of the pharmaceutical industry, advocacy groups, and the internet.<sup>2</sup> A comprehensive 2015 meta-analysis included 175 ADHD prevalence studies and suggested an overall pooled estimate of 7.2%, although few included studies were from outside of Europe and North America.<sup>3</sup>

Prescribing rates are naturally closely linked to prevalence and have also received much attention. A 2016 study explored prescribing patterns of ADHD drugs in children in the UK using primary care records, finding a dramatic increase in use from 1992 until around 2008, with stable levels of use since then.<sup>4</sup> Indeed, ADHD drug use in children aged <16 years increased a staggering 34-fold overall in that 16-year period. The steadying of prevalence in 2008 coincides with an update of the National Institute for Health and Care Excellence (NICE) guideline that stipulated that 'drug treatment is not indicated as the first-line treatment for all school-age children and young people with ADHD'.<sup>5</sup>

### DIAGNOSTIC CHALLENGES

Diagnosis of ADHD can be challenging as one or more of the core symptoms can be missing and presentations are often linked to problems in education or with the justice system. As well as the

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overlay with antisocial behaviour, there may also be concurrent mental health issues, which can be difficult to disentangle. Adults, meanwhile, may have learned to compensate after years of untreated symptoms, adding an additional layer of complexity to the diagnostic process. It is not uncommon for adult patients to present to their GP querying whether they may have undiagnosed ADHD.<sup>6</sup> Indeed, with the DSM-5 including for the first time diagnostic criteria for diagnosing ADHD in adults,<sup>7</sup> ADHD is no longer a disease confined to childhood, and has acquired the status of a chronic condition that may encompass the patient's lifespan.

A key role of GPs is to conduct an initial assessment to determine the severity of the symptoms, and the impact on daily life. A discussion may then ensue about the merits of a referral to confirm a possible diagnosis. Following specialist assessment, GPs provide support for the patient and family, and can help with ongoing monitoring of problems between specialist review appointments.<sup>8</sup> As well as pharmacological treatments, group-based parent-training programmes are an important part of ADHD management, and psychological treatments are also a potential option. GPs work with mental health and paediatric teams, as well as teachers and social workers, to coordinate care in ADHD.

In light of the apparently subjective nature of ADHD diagnostic criteria and the wide variation in diagnostic rates in different parts of the world, there has been much debate about whether ADHD is being under- or overdiagnosed. This debate has taken place in both the medical and psychological communities, as well as in the public domain, notably through stories in the lay press. Perhaps unsurprisingly given the exceptionally high prevalence rates in the US, the anxiety about overdiagnosis has been particularly fervent in the US and

has had support from a number of media, celebrity, and political commentators. However, these concerns have also been voiced by clinicians and academics from across the world, including from within the UK. Shifting definitions and commercial influences have been suggested as important drivers of this overdiagnosis, and it has been noted that elevated medication costs, adverse events, and psychological harms are all potential consequences.<sup>9</sup> The argument for ADHD being underdiagnosed, meanwhile, has been less forceful and less public, arising primarily from groups within the psychiatric community.

Although ADHD medications should only be initiated in secondary care, GPs are the first point of contact for patients and families. They are both gatekeepers to specialist services and long-term prescribers of ADHD medications. Families visit specialist services at regular, defined intervals but tend to see their GPs during key moments of crisis. Given the public controversy about ADHD and, particularly, its drug treatments, it is important for GPs to be well equipped to effectively counsel families who are often making difficult decisions about whether to persist with treatments.

### SHARED DECISION MAKING

Shared decision making is one of the most important concepts in clinical medicine and is part of the essence of high-quality general practice.<sup>10</sup> It requires clinicians to acknowledge both their own values and the limitations of medical science. By ascertaining the values of patients and providing them with accessible and reliable information based on clinical evidence, treatment decisions can be taken jointly and GPs can provide care that is inclusive, balanced, and compassionate.

Research that describes the experiences of patients in particular groups or settings can help clinicians gain deeper insight into

the issues that matter most to patients and has the potential therefore to help them share decisions in a more effective way. The research used to gain these insights, though, typically employs qualitative methodologies and are therefore rarely referred to in clinical practice guidelines.

In a recently published systematic review,<sup>11</sup> 31 such studies that investigated medication taking in ADHD patients and their carers were synthesised. It highlighted a complex array of factors that contribute to decisions about whether to take medications, including acceptance of the diagnostic label, anticipated and actual side effects of medications, and the external influences of school, friends, and the media. Self-management was a particularly important theme and the decision-making process tended to evolve as child patients enter adulthood and move towards autonomy. A further key theme was the concept of 'trade-offs', as families described having to weigh up the numerous positive and negative consequences of medications on various aspects of their lives.

As well as providing a rich account of issues that may need discussion in consultations about ADHD prescriptions, this systematic review emphasises the importance of understanding patient experience when making treatment decisions.

## IMPLICATIONS FOR PRACTICE

Although clinical research provides us with invaluable information that helps guide treatment options, social science research can be equally helpful in highlighting the real-world complexity of being a clinician or patient.

The 2008 NICE guidance is under review and a draft recommendation is currently open for consultation.<sup>12</sup> The revised guidance — due for publication in 2018 — is much more explicit in outlining strategies for sharing decisions relating to ADHD management: there is more focus on involving families, more specific recommendations on conversations

around medication adherence, as well as proactive encouragement to discuss patient preferences around discontinuing or changing medication. The role of the GP remains one of supporting referral to specialist services for diagnosis and treatment, and to offer support, monitoring, and advice.

## CONCLUSION

In many ways, ADHD is a disease of the 21st century. It provides column inches, fierce debates, polarised opinions, celebrity activism, information overload, and, sadly, much confusion for patients and their families. It also demonstrates the role of the 21st-century clinician — to provide balanced and informed counsel and facilitate a shared decision-making process in all consultations. Clearly, specialist services will play an important part in deciding which patients are suitable for drug therapy, but, in their role as holistic and kind patient advocates, GPs can play a key role in helping families to make sense of diagnostic and treatment uncertainties, and make decisions that work best for them at that particular moment in their lives.

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