Evidence and belief in ADHD

Informed decisions on stimulants must be based on studies with good methodology

Attention deficit hyperactivity disorder (ADHD) generates controversy. Some believe that it does not exist, whereas others see the reluctance of clinicians to diagnose and treat it as denying effective health care to children.[1] Epidemiological studies show that 3-5% of children of school age may be classified as having attention deficit hyperactivity disorder.[2] No validated diagnostic test exists to confirm the clinical diagnosis.

It is a complex neurodevelopmental constellation of problems rather than a single disorder. The core symptoms are inattention, hyperactivity, and impulsivity. These are also, however, normal behavioural traits present in unaffected children. The extent to which each causes disability varies and should be seen within the context of a child's developmental level. For example, an active 3 year old, impulsive and frequently interrupting of others, differs from a disruptive, unfocused 8 year old who is unable to cope educationally. Yet both may display core symptoms. Also, it is important to establish that symptoms exist in various settings and are not better accounted for by another mental disorder.[2] Specialists should undertake this assessment.

The variability of treatment and concerns about overuse of stimulants has led to the writing of practice parameters,[3] clinical guidelines, and evidence based briefings[4] to support clinicians in achieving best practice. Prescriptions in the United Kingdom rose from 183 000 in 1991 to 1.58 million in 1995.[5] The use of stimulants varies worldwide—it is estimated to be 10 to 30 times as high in North America as in the United Kingdom.[6] Concern has been expressed about the rise in the use of psychoactive drugs, especially in preschool children in the United States.[7]

For parents and children, getting information about ADHD is a lottery that depends on which professional they see and what they read or gather from television and the internet.

What roles should the general practitioner, child psychiatrist, child psychologist, and paediatrician play? Szatmari suggests that our most important function is that of interpreting evidence.[8] Through dialogue with parents and children the risks and benefits of treatment may be considered along with the family's values and cultural background. Transparency is essential, and requires that clinicians are able adequately to interpret less than perfect evidence.

Two new studies add to the debate. The collaborative multimodal treatment study of children with ADHD is the largest, most rigorous randomised controlled trial in ADHD research thus far.[9] About 579 children aged 7 to 9.9 years with ADHD were assigned to four groups: medication management, intensive behavioural treatment, medication management plus intensive behavioural treatment, and standard community care. It showed significantly greater improvement among groups that were given medication. These results are in keeping with other studies examining drug treatment of ADHD with stimulants and confirm that these benefits continue during treatment.[10] Serious methodological issues have been raised,[11] however, including that of the evaluation of non-drug interventions.[6]

The systematic review from McMaster University[1] reviews 77 randomised controlled trials, including the collaborative multimodal treatment study, and also incorporates results from the systematic review by researchers at the University of British Columbia.[10] It concludes that stimulants are effective in the short term, are more effective than placebo, compare well with each other, and seem to be more effective than tricyclics and non-drug treatments.

The short term benefits of stimulants seem to continue into the longer term as long as they are taken, but evidence is limited in this area.[9] Little is known, for example, about outcomes such as educational achievement, employment, or social functioning.[1] Adverse reactions are usually dose related and no evidence exists of harmful long term effects of therapeutic use.[1]

Most importantly, the McMaster review highlights shortfalls in the published research. Many studies are small and do not adequately describe randomisation or blinding ,or account for withdrawals and dropouts.[1] Poor reporting of these basic methodological components limits our ability to assess the importance of published work, which is important to individual clinicians, systematic reviewers, and organisations (such as the National Institute of Clinical Excellence in England and Wales) that evaluate and summarise research. Many of the trials will have included these elements in their protocols and execution, yet they are absent from the final publication. Authors, peer reviewers, and editors should be encouraged to apply publication standards as recommended in the CONSORT (consolidation of the standards of reporting trials) statement.[12]

Stimulants should be prescribed judiciously and monitored carefully by specialists in close liaison with primary care physicians. Informed decision making by clinicians and parents will be aided by more attention to research methods and its improved reporting. The imminent report by the National Institute for Clinical Excellence on the use of methylphenidate in childhood hyperactivity will, we hope, assert this principle.

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Medical software's free future

Open collaboration over the internet is changing development methods

The government in the United Kingdom spent £7.1bn ($9.9bn) on information systems in 1998-9, of which £1bn was in health care. Yet information systems are difficult to commission, purchase, and evaluate, and the results not always good.[1]

As computer hardware becomes an ever cheaper commodity with ever increasing power, it is clear that software is the rate limiting step in system development. Software is slippery stuff: its possibilities seem almost limitless, but implementing a system competently is a difficult activity that commands premium rates of pay. A lot of its cost lies in planning, implementing, and monitoring and enforcing exchanges between the parties involved, who might be, for example, a hospital wanting to buy an information system and a system supplier. Such exchanges have high transaction costs.[2] The relationship between an information systems supplier and its clients has, according to transaction cost economists, the quality of "information impactedness": a state in which one of the parties to an exchange is much better informed than the other, and the other cannot achieve information parity, except at great cost.

Even when a system is successfully commissioned, the costs can remain high. Once a customer is "locked into" proprietary software, its makers can demand premium prices, safe in the knowledge that the client would find it even more expensive to change.[3]

It is such forces that have led to the rise of free software—most notably the GNU/Linux operating system, which is freely available for download from the internet.[4] (An operating system, such as Microsoft Windows, is the essential software that runs a computer's basic functions.) Free software differs from proprietary software in several important respects. Most importantly, its licence (the General Public License (GPL)) encourages free copying, distribution, and modification of the software.[5] There is only one catch: users must make any modifications that they make to the software available to others on the same basis that they received it. This virtuous cycle of development has, over the past decade, created a commonwealth of high quality software.

Free software facilitates the provision of common software components. As well as the saving on licence fees, it allows software engineers to concentrate on the important part of system development: customising components for the organisation that they serve.

There are other advantages. It is reliable and secure: source code can be inspected for bugs and security flaws before it is compiled for use. It can be maintained even if the developers who originally produced the software are no longer available. Many high quality components exist ready made, which allows new projects to build on the existing base of code; developers can spend their time creatively exploring new and unsolved problems rather than duplicating effort.[6]

Free software concepts make particular sense in medicine: although peer review has its problems, medical knowledge is becoming more open, not less,[7] and the idea of locking it up in proprietary systems is untenable. And professional staff should not invest time learning the user interface of proprietary systems that may change, be withdrawn, or be arbitrarily "upgraded" for commercial reasons. Much better instead to invest time on a system licensed under the General Public License that will always be free.

The European Union has already embraced open source: its fifth framework programme (which will fund 3.6bn Euros of research and development over the next 5-10 years) places a strong emphasis on projects which will yield open source software as one of the outputs.[8] Next week the NHS Information Authority hosts a seminar to consider the implications of the free software movement for its future strategy. If it chooses (as it should) to use and encourage open source development methods throughout the organisation, it will find a host of high quality programmes already under way across the world.[9] Leveraging this effort should reap rewards for managers, professionals, and patients alike.

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