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Drug treatments in people with intellectual disability and challenging behaviour

Time to rethink?

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Do we still need to be reminded that the drug treatment of people with intellectual disability is often prolonged and not without dangers? We probably do. Drug treatment has been a mainstay for managing a common syndrome subsumed under the label “aggressive challenging behaviour” since chlorpromazine was first introduced for its treatment over 40 years ago.

We have no fundamental criticism of the transfer of a successful treatment for one disorder in general psychiatry to the same disorder in people who are intellectually disabled. However, challenging behaviour has no equivalent in general psychiatry, so there is no treatment to transfer. Challenging behaviour is the most common disturbance requiring intervention in intellectual disability services, but it does not have proper diagnostic status in standard psychiatric classifications.

Yet this does not inhibit the wholesale import of adult psychopharmacology into its management. Psychotropic medication in its many forms—mainly antipsychotics, sedatives and tranquillisers, antidepressants, and mood stabilisers—has seen extensive off-label prescribing for the past 50 years. Thus, a recent population based cohort study of 1023 adults with intellectual disabilities showed that 49.5% were taking some form of psychotropic drug, with 23.2% taking an antipsychotic despite only 4.4% having a psychotic disorder. This finding is replicated elsewhere. Antipsychotics are only part of the story; there is a similar high rate of prescription of other drugs such as antidepressants, anxiolytics, and mood stabilisers in this population.

This prescribing would not be a concern if adverse effects were few and easily corrected, but neither of these is true. The high levels of obesity, metabolic syndrome, and diabetes in this population are largely due to these drugs and predispose to premature mortality. National audits such as those carried out by the Prescribing Observatory for Mental Health suggest that more people with intellectual disability are being regularly checked for known and established side effects of antipsychotic medication in secondary care. But there is a lack of primary care data on whether people with intellectual disability prescribed psychotropic drugs receive similar care and are targeted as a higher risk group. Once these drugs are prescribed they far too often become part of long term management, reinforced by the nervousness of care staff with limited knowledge of psychopharmacology and reluctance of practitioners and carers to alter a treatment when it may be wrongly perceived as effective. Attempts to stop these drugs after people have been taking them for many months or years have had only limited success.

What is the evidence for the benefits of these drugs in the treatment of challenging behaviour? Virtually none. Almost all the evidence in favour comes from small trials conducted by drug companies. Yet it would be perverse if doctors continued to prescribe these drugs, knowing about their adverse effects, if they were entirely without efficacy, and many claim that they cannot care adequately for their patients without the option of drug treatment. We therefore need clear indications for drug treatment, as well as to develop a range of more effective psychosocial treatments, for which there is now increasing evidence, but there is still ground to cover.

In the interim, a key element is education of prescribers. This should highlight the need to assess adequately the cause of the aggressive symptoms rather than just taking the easy approach of attempting to suppress them. Additionally, until there is better evidence, drug treatment should be considered to be a trial, and hence quality processes to monitor the effectiveness, or lack of evidence, drug treatment should be considered to be a trial, and hence quality processes to monitor the effectiveness, or lack of effectiveness, of the drug intervention over time are essential. It is unlikely that the effects of drug treatment can be put down to the placebo effect alone, although this effect can be substantial in this population.

Good randomised trials, preferably not funded by the drug industry, are needed to show efficacy. At present there are no randomised trials with adequate numbers that can give definitive advice on the value of any drug group in this population. The main reasons for this are the difficulty that all researchers have...
in carrying out such trials with this very vulnerable population, the strong, and often very divergent, views of practitioners and carers about them participating at all,\(^1\) the limited expertise of research funders of research in vulnerable people, and the additional time and costs it incurs. Although other designs such as crossover trials have often been used in this population, they are not appropriate for a condition that is recurrent and often persists in the long term.

Drug treatment of challenging behaviour in people with intellectual disability should no longer be on the sidelines of evidence based medicine. If we are going to achieve parity of esteem for people with mental illness, we can no longer tolerate our ignorance on this subject. Quite apart from the deficiencies in evidence allowing dogma and opinion to rule, the cost of prescribing these drugs is enormous. If they truly are unnecessary, clinicians, pharmacists, service managers, and those who fund services for people with intellectual disability need to know, and soon.

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