Overmedication of people with intellectual disability

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BILD Restraint Reduction Network
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• Evidence of overuse of psychotropic drugs
• What happens when we reduce or discontinue antipsychotics used for behaviour that challenges?
• Influences on psychotropic prescribing
• Future directions to improve use of psychotropic drugs
Conflicts

- Research Fellowship funded by National Institute for Health Research
- Expert advisory group member NHS England STOMP monitoring study
- Working group member RCPsych Faculty of ID practice guidelines: psychotropic drug prescribing for people with ID

The views expressed are those of the author(s) and not necessarily those of UCL, the NHS, the NIHR or the Department of Health and Social Care
Longstanding concern related to over-use of psychotropic medication in ID services

Mainly related to use of antipsychotic drugs for challenging behaviour

Problematic for several reasons:
- Little evidence that they work
- Non-specific sedation
- Does not address underlying cause of behaviour that challenges
- Places emphasis on individual rather than environment and context
- Shifts focus from other interventions
- Exposes people to adverse drug side-effects
• Early research (1970s onwards) showed high rates of psychotropic use in institutions for people with ID

• Expected reduction with ‘de-instutionalisation’ did not occur (Nøttestad, 2003)

• Rates of prescribing may even increase after move to community living (Kelly, 2015)
Background

- Exposure of abuse at Winterbourne View put the care of people with ID high on the political agenda.
- Transforming Care authors highlighted “deep concerns about the overuse” of psychotropic drugs.
- But we had little representative contemporary data.

Need high-quality evidence for use of psychotropic drugs in adults with ID.
Using databases for health research

• Electronic Health Record gives opportunities for epidemiological research that did not previously exist ("big data")

• Several advantages
  • Data already exist (quick)
  • Representative (high participation rate)
  • Statistical power (large numbers)
  • No recruitment or direct participant contact (less expensive)

• Some disadvantages
  • Data collected for clinical care
  • Not able to validate the data (‘real world’ is messy)
Evidence of psychotropic overuse (Sheehan et al, 2015)

• We used a GP database to investigate rates of psychotropic prescribing

• We compared prescribing, rates of diagnosed mental illness, and behaviour that challenges in 33,016 adults with ID
Evidence of psychotropic overuse (Sheehan et al, 2015)
Evidence of psychotropic overuse (Sheehan et al, 2015)

- Associations with antipsychotic prescribing suggest off-label use

<table>
<thead>
<tr>
<th>Condition</th>
<th>Incidence rate ratio</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe mental illness</td>
<td>6.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Challenging behaviour</td>
<td>2.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Autism</td>
<td>1.8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Dementia</td>
<td>1.4</td>
<td>0.003</td>
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</tbody>
</table>
Evidence of psychotropic overuse (Glover et al, 2015)

- Public Health England study
  - 30,000-35,000 people with ID in England are taking a psychotropic medication when they do not have the health condition the medicines are for

Good evidence for need to improve psychotropic prescribing in people with ID
'Chemical cosh' scandal: Thousands of patients with no history of mental illness needlessly given cocktail of anti-psychotic drugs

Over-medication of people with learning disabilities infringes human rights

Fears that antipsychotic drugs being used as 'chemical cosh' in disability care
The STOMP programme

Stopping over medication of people with learning disabilities (STOMPLD)

Over-medication, and then lack of review, is a historic problem, but one that nobody knew the true scale of until recently.

It is estimated that on an average day in England, between 30,000 and 35,000 people with a learning disability are being prescribed powerful drugs, with serious potential side effects, without clinical justification and for too long. This is often despite evidence-based alternative interventions being available.

This inequality in care is unacceptable, and it is incumbent on clinicians and every other professional involved in an individual’s care to make sure they are acting in their patient’s best interest at all times.

We, the undersigned, representing professionals from across the NHS, therefore pledge to work together, and with people with a learning disability and their loved ones, to take real and measurable steps to stop over-medication.

We will each set out the actions our individual organisations will take towards this shared aim, and report regularly on the progress we have made – ensuring that we can be held to account.

Supported by the Challenging Behaviour Foundation
STOMP activity

- Awareness-raising, galvanizing and empowering stakeholders
- Includes people with ID, carers, statutory and third sector organisations
- Resources to promote appropriate medication use
- Dissemination and spread good practice
STOMP evaluation (NHS England, 2019)
STOMP evaluation (NHS England, 2019)

- Downward trend in overall prescribing since Q2 2016
- Equates to approx. 500 fewer adults with ID being prescribed antipsychotics
- But proportion without a recognised indication increased
• How easy is it to reduce or discontinue antipsychotic medication used for behavior in practice?
What does the research evidence say?

- Can be done in a substantial proportion of cases with:
  - Possible improvements in measures of physical health
  - Suggestion of improvements in adaptive or cognitive function and alertness

- But risks are:
  - Worsening of behaviour
  - Movement side-effects
  - Autonomic dysfunction

- Lots of gaps in evidence
Lack of research

- ANDREA-LD
- Funded by NIHR
- Full trial not possible due to problems with recruitment
- Need for focused support for practitioners, carers and patients, and alternative interventions in conjunction with medication reduction (McNamara et al, 2017)
Wider influences on antipsychotic prescribing

- Experience
- Beliefs about medication
- Confidence
- Skills
- Evidence
- Wider context
- Responsibility and balancing risks

Person with ID

Carers

Clinicians
Wider influences on antipsychotic prescribing

- Advocacy
- Restrictive interventions
- Working together

Core:
- Person with ID
- Carers
- Clinicians
- Services

Supporting factors:
- Philosophy of care
- 'Medical model'
- Proactive
- Availability of alternatives
- Inertia
- Crisis services
“Withdrawing medication requires a multidisciplinary approach, consideration of comorbidity, and the involvement of patients and their carers” (Shankar et al, 2019)
Unintended consequences of medication change

• Substitution of one psychotropic drug class for another (Maust et al, 2018; Donegan et al, 2017)

• Risk of under-treatment
Conclusions and future research

We know...

- Clearly a need to improve psychotropic prescribing to people with ID
- Publicity and activity but ?outcomes
- Prescribing is a reflection of a complex and inter-related system of multiple stakeholders

We need...

- Refine the model of influences on antipsychotic prescribing in people with ID and challenging behaviour
- Develop and test interventions to reduce anti-psychotics that recognise complexity and systems issues and offer an alternative
- High-level overview of prescribing nationally and think laterally for unintended consequences
Thank you

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