Achieving and sustaining optimal management of children and adolescents with ADHD

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ADHD: easy to treat but hard to treat well
Most parents are reasonably satisfied with their child’s treatment

Q: Overall, how satisfied are you with your child’s current ADHD treatment? Please rate your level of satisfaction based on a scale of 1–7, where 1 is “not at all satisfied” and 7 is “extremely satisfied.”

Not at all satisfied 1 2 3 4 5 6 7

Extremely satisfied

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<tr>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>4%</td>
<td>4%</td>
<td>9%</td>
<td>15%</td>
<td>28%</td>
<td>25%</td>
<td>15%</td>
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</tbody>
</table>

Mean score = 5.0

Baseline: All qualified respondents whose child currently receives prescribed medication (n=350)

Survey conducted by Harris Interactive, with the support of Janssen-Cilag EMEA, a division of Janssen Pharmaceutica NV.
The same parents reported that their children with ADHD find the whole day challenging

Q: What time(s) of day does your child find challenging, if any?

Baseline: all qualified respondents (norms survey, n= 995; ADHD survey, n=910)

Survey conducted by Harris Interactive, with the support of Janssen-Cilag EMEA, a division of Janssen Pharmaceutica NV.
SNAP or ADHD IV Rating Scales

18 items (the DSM/ICD ADHD symptoms)
Each item scored 0 – 3
Easiest way to interpret is by using mean score per item
Add up all scores and divide by 18
Dundee CAMHS before development of ADHD care pathway

SNAP or ADHD IV Rating Scales

Baseline

In Treatment
MTA Study design

- Recruitment Screening Diagnosis
- Random Assignment
- 579 ADHD Subjects

14-m Treatment Stage
- Medication Only
  - 144 Subjects
- Psychosocial (Behavioral) Treatment Only
  - 144 Subjects
- Combined Medication and Psychosocial Treatment
  - 145 Subjects
- Assessment and Referral (Community Control)
  - No Treatment from Study; Assessed for 24 mo.
  - 146 Subjects

Follow-up After Treatment
- 10-m Follow-up
- 22-m Follow-up
- 36-m Follow-up

Month
0 14 24 36

Early Treatment (3 m)
Mid-treatment (9 m)
End Treatment (14 m)
Follow-up (24 m)
Follow-up (36 m)

Assessment Points

The MTA Cooperative Group. Arch Gen Psych 1999; 56:1073-86.
At the end of the 14 month trial:
- Medication alone better than Behavioural alone
- Medication alone better than Community Care (60% CC on medication)
- Combined Medication and Behavioural not much better than medication alone
- Behavioural as good as Community Care (60% CC on medication)
MTA ADHD Symptoms
Observational follow up – 36 months

Months Post Randomization

0 0.5 1 1.5 2 2.5

0 14 36
MTA ADHD SYMPTOMS
OBSERVATIONAL FOLLOW UP UP TO 8 YEARS

Mean daily doses for those on medication at 8 years in MPH equivalents
Comb = 20.2 mg, Med = 23.3 mg, Beh = 14.1 mg, CC = 17.6
Intensive medication management is more effective than ‘community care’ – treatment as usual - as long as it is continued.

No long-term sustained advantage of initial (14-month) medical management strategy over behavioral and community care from 36-months and beyond, once all subjects receive only treatment as usual.

Long-term follow-up reveals, for this treatment referred sample, sustained improvement but lack of normalization.

It is possible (but unproven) that SUSTAINED MTA Medication Strategy would show sustained differences from ‘treatment as usual’.

Self-selection does not explain lack of medication effects.

Sustained treatment benefits will likely require ongoing, high levels of quality medication management, youth engagement, and family support.

Future studies of outcomes must address comprehensive focus on life functioning rather than exclusive focus on symptoms.
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The Dundee ADHD Care Pathway

- Had to be both **clinically** and **cost** effective
- Needed to:
  - Reduce variability in the clinic through the use of a standardized approach to consultations with uniform protocols and standardized outcomes
  - Introduce a more standardized approach to titration
  - Continue with a standardized approach to ongoing follow up that allowed us to avoid the slippage seen in the MTA follow up
  - Use resources efficiently
- Aimed towards a modified version of the MTA MED protocol (“MTA light”)

At the end of the 14 month trial
Medication alone better than Community Care
(60% CC on medication)
Differences between MTA ‘medication protocol’ and ‘community care’

‘Medication’ group were:

• Treated with higher doses
• Had 3x daily dosing vs. 2x daily dosing
• Started treatment with intensive 28-day double blind titration trial
• Received more supportive counselling and reading materials
• Dosage adjustments informed by standardised outcome measures and teacher consultations

MTA Cooperative Group. Arch Gen Psych 1999; 56: 1073-86.
Differences between MTA “medication protocol” and Dundee Clinical Care

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Dundee ADHD titration protocol

• Start with a 4-week protocolled titration focusing on symptom reduction and optimising treatment

• MAXIMUM BENEFIT AT MINIMUM DOSE

• Almost always start with a stimulant
  • Choosing between MPH and amfetamine might as well be by the toss of a coin

Dundee ADHD titration protocol

• Delivered by nurses with medical backup (*floating doctor*)
• Fixed protocol with rigorous outcome measurements for continuing care
  • SNAP IV (clinician delivered)
  • SKAMP (teacher)
  • Height, weight, pulse and BP
  • Adverse Events (framed as ‘other symptoms’)  
  • Screen for ‘other problems’ and arrange treatment as required

SNAP or ADHD IV Rating Scales

Dundee CAMHS before development of ADHD care pathway

Baseline: 2.5
In Treatment: 1.6
SNAP or ADHD IV Rating Scales

Baseline: 2.5
End of titration: 0.7

Coghill & Seth 2015
Why did the medication and combined treatment groups slip back?

- Medication lost effectiveness?

- Self-selection patients?

- Importance of carefully titrated pharmacological treatment with ongoing, high quality medication management, with strong youth engagement, and family support?

Why did the medication and combined treatment groups slip back?

• Medication lost effectiveness?

• Self-selection patients?

• Importance of carefully titrated pharmacological treatment with ongoing, high quality medication management, with strong youth engagement, and family support?

Monitoring ongoing care

- Use the same protocol as used in titration with the same outcome measurements for continuing care
  - SNAP IV (clinician delivered)
  - SKAMP (teacher)
  - Height, weight, pulse and BP
  - Adverse Events (framed as ‘other symptoms’)
  - Screen for ‘other problems’ and arrange treatment as required

Dundee ADHD Care Pathway: Around 900 patients within general CAMHS outpatient setting

**SNAP or ADHD IV Rating Scales**

- **Baseline**: 2.5
- **End of titration**: 0.7
- **Most recent visit**: 0.8

N = 120

Mean duration of treatment 43 months (1 – 119)
Mean dose of MPH 52 mg/day

Coghill & Seth 2015
Dundee ADHD Care Pathway: Around 900 patients within general CAMHS outpatient setting

SNAP or ADHD IV Rating Scales

- Baseline: 2.5
- End of titration: 0.7
- Most recent visit: 0.8
- MTA 8 year outcomes: 1.1

N = 120

Mean duration of treatment 43 months (1 – 119)
Mean dose of MPH 52 mg/day

Coghill & Seth 2015
Treatment effects don’t need to dwindle over time

Coghill D: unpublished data.
With such good outcomes why does it seem so hard to change routine clinical practice?

• I’m pretty sure you don’t need help to come up with reasons why this would be too hard in your clinical setting

• Our view was that it needed to shift thinking from problem finding to solution focused
Dundee Pathway: Rates of remission

Cut off scores for remission on the SNAP and ADHD-RS total score of <23 (mean item score <1.3)

Remission Rate pre-change 44%
Remission Rate post-change 67%

Coghill D: unpublished data.
Managing medication is only part of the package

• In our routine follow up appointments we still measured symptoms and tried to optimise outcomes.

• But we also sought to identify “other problems”
  • Structured prompts to ask about other mental health problems
  • Structured assessment of potential adverse effects of medication
  • Height weight and blood pressure charted against norms
  • Discussion about school functioning
  • Family relationships and functioning
  • Peer relationships and community activities

• Whilst some of these “other problems” could be managed during the review appointment time constraints often required additional appointments either with the core worker or as a specific “asked-to-see” appointment with another team member (e.g. a clinical psychologist, dietician, OT or physician)
Adverse effects of medication taken very seriously
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Not present</th>
<th>Present but not impairing</th>
<th>Present and impairing</th>
<th>Present and severely impairing</th>
<th>Write note ↓</th>
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</thead>
<tbody>
<tr>
<td>Insomnia or trouble sleeping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Nightmares</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Drowsiness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tr>
<tr>
<td>Nausea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Anorexia (Less hungry than other children)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Stomach-aches</td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
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<tr>
<td>Dizziness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Sad/unhappy</td>
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<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Prone to crying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Thoughts of self-harm</td>
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<td>2</td>
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<tr>
<td>Suicidal ideation</td>
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<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Euphoric/unusually happy</td>
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<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Anxious</td>
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<tr>
<td>Tics or nervous movements</td>
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<td>1</td>
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<tr>
<td>“Spaced-out” / “Zombie-like”</td>
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<tr>
<td>Less talkative than other children</td>
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<td>Less sociable than other children</td>
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<td>Other Symptoms</td>
<td>Visits</td>
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<tr>
<td>Insomnia or trouble sleeping</td>
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<tr>
<td>Anorexia / less hungry than</td>
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<td>③</td>
<td>③</td>
<td>③</td>
<td>③</td>
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<tr>
<td>other children</td>
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<td>②</td>
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</tr>
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</table>
Where to from here?

• Need to think about routinely measuring broader outcomes
  • Functional impairment and quality of life
  • Neurocognitive outcomes may also add some colour

• Application to conduct a pragmatic RCT vs treatment as usual in a real world setting

• Aim to identify predictors of outcome and ways to individualise treatment more effectively
Thank You!
Comparison of Performance on ADHD Quality of Care Indicators Practitioner Self-Report Versus Chart Review

• 188 practitioners from 50 US paediatric practices completed questionnaires
• 1,599 charts were reviewed

• Conclusion: Practitioners over report performance on quality of care indicators. These differences were large and consistent across ADHD diagnostic and treatment monitoring practices.
Assessing symptom outcome

<table>
<thead>
<tr>
<th>ADHD-RS-IV or SNAP-IV questionnaire score</th>
<th>(ii) Post-treatment monitoring</th>
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</thead>
<tbody>
<tr>
<td><strong>Total score (range 0–54)</strong></td>
<td><strong>Mean item total score</strong></td>
</tr>
<tr>
<td>0–18</td>
<td>≤ 1</td>
</tr>
<tr>
<td>19–26</td>
<td>&lt; 1.5</td>
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<tr>
<td>27–36</td>
<td>1.5–2</td>
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<tr>
<td>37–54</td>
<td>&gt; 2</td>
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</tbody>
</table>
What to do if response clinically inadequate after titration?

• Switch to the other stimulant if available

• May consider atomoxetine or α2 agonist where MPH is not tolerated or associated with significant safety issues
  • although this should not be automatic

• But if the non stimulants are the only alternative don’t forget that they are also effective medications