Cystic fibrosis: an example of research and practice
Plan

• Questions from earlier presentation
• Cystic Fibrosis
• Our work in CF:
  – Clinical practice, research, and a focus on adherence...
Questions?
Cystic Fibrosis (CF)

- Inherited (Autosomal recessive)
  - Commonest inherited life limiting condition in Caucasians (1/2500 affected births)
- Typically presents in childhood
Mutation

• Mutation in cystic fibrosis transmembrane regulator (CFTR)
  – Chloride blocked
  – Mucus builds up (e.g. in lungs)
  – Multisystemic consequences
Consequences

- Lungs prone to infection & damage
- Diabetes
- Poor weight gain
- Infertility
- Nb segregation
Consequences

• Prognosis improving
  – Before 1939, 85% died by age 2
  – Predicted survival 40 yrs for 1990 birth cohort
• But heavy disease burden
• And intrusive adherence regimen
  – Physiotherapy to keep lungs clear
  – Tablets with every meal
  – Antibiotics to keep lungs sterile
  – And more!
One Day’s Treatment!
Adherence

• A study of nebuliser use (for anti-biotics) in CF: < 40% adherence.
• No one taking all medications as prescribed.

CF in Norway

- Approx. 280 patients with CF in Norway
- About 60% over 18
What we do in Leeds

- Clinical services
- Research
- Our work on adherence
Clinical services

Adult regional unit

Paediatric regional unit

Brownlee brothers in Triathlon!
Clinical Services

• 2 psychologists in paediatric unit (1.5 wte)
• 2 psychologists in adult unit (1.2 wte)
• Reasons for referral?
  • Paediatric:
    – adherence, procedural distress (e.g. needles), parental anx/dep, pre-school behaviour problems (esp. feeding), child/adolescent anx/dep
  • Adult:
    – Psychological support (& trauma), anx/dep, OCD, adherence
Clinical Services

- Recent survey on anxiety and depression (TIDES study)
- Higher rates in parents
- Rates for adults with CF?
  - No higher than general population in Leeds (Latchford & Duff, 2013)
  - Because already receiving psychological support?
  - Individuals do become distressed; related to decline in health & serious consequences..
Clinical Services

• Currently screening patients and parents using depression and anxiety measures
• Also using routine, sessional measurement of outcome and therapeutic alliance
Research

Clinical Psychology Training Programme

Paediatric regional unit

Adult regional unit
Research

• Recent Clinical Psychology Trainee doctoral research in CF
  – Adherence beliefs of children and their parents
  – Experience of education and employment
  – Experience of young mothers with CF
  – Beliefs about new drug treatments
  – Decision making about risk of infection
Our work on adherence
Tackling adherence

• Individual referrals
• But too many patients: team needs to change practice
• How can we help the team change?

• Duff AJA; Latchford G. Adherence in cystic fibrosis; care teams need to change first. The Lancet Respiratory Medicine. 2014; 2 (9):683-685.
Training CF teams in Motivational Interviewing (MI)

1. Provide training in adherence:
   - Potential reasons for non-adherence (e.g. Rob Horne’s necessity/concerns framework)
   - Behaviour change techniques

2. Provide training in MI

3. Help team think about support and organisational change
The Necessity-Concerns Framework

NECESSITY
Do I need the medication?
Will it work?

CONCERNS
Will I get any adverse effects?
The change process

Beliefs, behaviours, etc.

Motivational Interviewing

Behaviour Change Techniques

The Decision

The Team
Support
Change in clinics etc
What is MI?

IN 5 MINUTES!
Motivational Interviewing: origins

• It began with alcohol, where the traditional treatment was...

• Confront the patient until they accept their illness
  – Assumption: unless the patient admitted they were an ‘alcoholic’, they would not get better

• What happened?
  – Patients denied the problem

• Conclusion?
  – Put down to “poor willpower”
Motivational Interviewing: the idea

- An alternative view from Bill Miller:
  - Motivation is not fixed – it goes up and down!
  - Motivation is a product of the situation
  - So confronting someone makes them more stubborn
  - Instead, motivational interviewing is designed to enhance motivation to change

- Worked with Steve Rollnick:
  - MI applied to many behaviours, including physical health
A definition of Motivational Interviewing

• A directive, client-centered counseling style for eliciting behaviour change by helping clients explore and resolve ambivalence

• Rollnick and Miller, 1995
Key ingredients

• Avoid confrontation
• Don’t impose change on patients
• Instead, help them to talk about their ambivalence and resolve it by choosing to change
• Readiness to change is not a trait, but a fluctuating product of interpersonal interaction
• Aim for a partnership, not expert/recipient
Key skills & principles

• Expressing empathy
• Reflective listening
• Respect client autonomy
The spirit of MI
(Rollnick and Miller, 1995)

- But also:

  “Motivational Interviewing is not a series of techniques for doing therapy but instead is a way of being with patients”

  *Bill Miller*
What’s it like?

• Jones, Latchford & Tober: client experiences of MI, an Interpersonal Process Recall study
What’s it like?

• Jones, Latchford & Tober: client experiences of MI

“She’s driving the conversation, very very subtly, that’s the trick… She’s allowing me to take the reigns of the conversation, but she’s steering it very gently, allowing me to get out what I need to.”
“She’s made us think about stuff I didn’t even know I was thinking.”
Does MI work?

• Extensive research base (> 100 trials)
  – E.g. some of the largest psychotherapy RCTs
    (Project MATCH, UKATT)

• 6 Meta analyses, most recent:

• Lundahl et al (2013) – 48 RCTs in health
# Does MI work?

<table>
<thead>
<tr>
<th>Group of comparison</th>
<th>Effect size (standard deviation)</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weak (Waiting list, treatment as usual, written materials)</td>
<td>0.28</td>
<td>0.22-0.34</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Strong (12-step program or cognitive behavioral therapy)</td>
<td>0.09</td>
<td>-0.01-0.18</td>
<td>0.080</td>
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</tbody>
</table>

- **Bigger effect when compared with a non-psychological intervention**
- **As effective, no better – as expected BUT quicker (3 or 4 sessions)**
Are teams using MI already?

• No

• Moran, Latchford and Bekker (2008): analysis of routine consultations in a diabetes clinic
  – Minimal to no use of MI style
  – Patient centred style: higher patient satisfaction & greater expression of views

• So if MI is to be used by teams, they need to be trained
Training health professionals in MI

• Difficult!
  – “No time”
  – Professionals sometimes think they are doing MI but are not
  – Therapist drift after training (Miller & Mount, 2001)
Training CF teams in MI 2011-12

- Established training package:
  - 2 sessions, three months apart
- Trained CF teams together in UK & Ireland
- Feedback from questionnaire & telephone interview
Training CF teams in MI 2011-12

- Positive feedback: teams like MI; believe it improves practice
- Barriers and facilitators:
  - Support after training
  - Changing team culture

Embedding MI in CF care

• Teams are very important in CF
• MI in context of support from team:
  – Training for staff
  – Supervision and peer support
  – Embed MI in clinic structure
• Current work: training adherence advocates/champions as resources for the team
Takk!
Noen Spørsmål?

[Image of a Lego model of the Norwegian flag with flowers below it]

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