

**Supporting adherence in adults with Cystic Fibrosis: a motivational interviewing intervention targeted by Prochaska & DiClemente stage of change evaluated by objective adherence measurement using the I-Neb**

**The start of a journey from rescue to prevention**

Study team

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## **Background**

Most people with Cystic Fibrosis (PWCF) die of respiratory failure and preventing death requires the multidisciplinary team (MDT) to enable PWCF to maintain lung function (FEV<sub>1</sub>) and weight (BMI) by supporting effective self-management in four areas : (1) Inhaled medication (nebulised antibiotics and mucolytics), (2) Weight maintenance, (3) Airway clearance and exercise and (4) Cystic Fibrosis related diabetes.

In the US CF registry, units consistently in the top quintile for FEV<sub>1</sub> and BMI were characterised by (1) High expectations. (2) Early aggressive intervention, (3) Patient and family engagement and (4) Limited use of rescue therapy. Arguably the most important characteristic of excellent units is in enabling the relationships that support family and patient engagement thus supporting adherence.

## **Adherence in CF is poor**

In CF sophisticated I-Neb nebulisers allow objective measurements of adherence to inhaled antibiotics and mucolytics and studies using these nebulisers have demonstrated median adherence rates in adults of only 36%<sup>1</sup>

## **Adherence in CF matters**

Briesacher used health maintenance organisation data to understand the impact of adherence to Tobramycin a nebulised antibiotic used alternate monthly in patients colonised with pseudomonas<sup>2</sup>. Patients taking the tobramycin as intended would take 6 courses per year. Patients collecting 4 or more courses of Tobramycin per year were 60% less likely to be admitted to hospital than those collecting only one. Regular inhaled antibiotics are a potent preventative treatment that avoids the need for rescue hospitalisation. Quittner showed that when Medicine Possession Ratio (MPR) is used to classify PWCF into those who collect >80% of their prescribed medication compared to those who collect <50% those collecting <50% have significantly greater healthcare costs that arise from hospital admission for rescue treatment<sup>3</sup>

## **Adherence interventions are weak**

A meta-analysis of interventions to support adherence found that though interventions to support adherence were broadly efficacious they were relatively weak with even the best interventions only increasing adherence by between 4 and 11 percent<sup>4</sup>. Horne concluded that a major reason for the poor performance of adherence interventions is that they are narrow in focus and characterised by a one size fits all approach<sup>5</sup>.

## **Effective adherence interventions are complex and require a clear conceptual framework**

The lack of potency of narrow, "one size fits all" adherence interventions highlights the importance of making a clear individual diagnosis of the problems leading to non-adherence and the need to develop a tailored

multifaceted response to those problems. Michie's behaviour wheel is a comprehensive generic behaviour change model that provides a suitable conceptual framework for the design of adherence interventions<sup>6</sup> Michie suggests that behaviour change requires motivation, capacity and opportunity and this maps well to Horne's understanding of adherence behaviour as unintentional non-adherence (can't adhere: a problem of capacity and opportunity) and intentional non-adherence (won't adhere: a problem of motivation)<sup>7</sup>.

### **Building an adherence intervention: the role of the MDT**

Non-adherence will often be multi-factorial with capacity and opportunity barriers overwhelming weak motivation. Clearly in this setting an effective intervention will both remove barriers and increase motivation. The MDT are well placed to develop a deep understanding of the patients' lives in order to support adherence with invaluable information coming from specialist nurse home visits.

### **Case history: Unintentional non-adherence**

A 26 year old woman, "Jean", who was a keen dancer, had well maintained lung function with an FEV<sub>1</sub> of 106%. When Jean had two children and went back to work her lung function steadily declined and fell to 65%. Consideration of Jean's daily routine by the MDT showed that a 25 minute break in the morning and afternoon at work would be feasible to allow Jean to do her nebulisers and physiotherapy. The team negotiated this with her employers and her lung function returned to 98%. This study will start to collect these interventions in a "toolkit" manual.

### **Intentional non-adherence: the importance of promoting discrepancy**

Non-adherence which is primarily Intentional (won't adhere) is more difficult. MI is helpful in supporting behaviour change in the face of ambivalence and resistance and is a crucial tool for an MDT seeking to improve adherence<sup>8</sup>. An important aspect of supporting change using MI is to help the patient perceive discrepancy between their current situation and a possible future situation that is both different and better. Posters that encompass the ethos of adherence and signpost its advantages can be used to prompt patients who are resistant to change to see that increased adherence might help the patient achieve their goals.

### **What we did**

#### **Aims**

The overall aim of this project was to pump prime a research program to increase the survival and quality of life of adult PWCF by supporting adherence to preventative therapy. We recognised that this would require a sustained change in the MDT approach to CF treatment by moving from an emphasis on rescue treatment to an emphasis on prevention. In achieving these aims we would be developing a complex intervention that would require us to work within the MRC complex interventions framework<sup>9</sup> with the recognition of the need to develop a conceptual framework to inform the work. At the beginning of the project we drew on Prochaska and DiClemente's stage of change model which fits well with ideas within motivational interviewing about promoting discrepancy and these ideas informed the poster work

outlined below. We were then able to develop our conceptual framework further as the grant proceeded as outlined below under “Pump priming”.

### **Objectives**

- 1) To equip staff in each discipline to become trainers in motivational interviewing:
  - (a) Specialist CF nurse (cascade to other specialist nurses and OPD staff),
  - (b) CF ward sister (cascade to ward staff),
  - (c) Specialist CF physiotherapist (cascade to other physiotherapists)
  - (d) Specialist dietician (cascade to dieticians)
  - (e) Unit psychologist (support for training across unit)
  - (f) Consultant CF doctor (cascade to doctors)
- (2) To enable other MDT staff to competently deliver MI
- (3) To use qualitative research to develop posters that encapsulate the concepts that help patients adhere to treatment.
- (4) To use the process of poster development to understand the factors that affect individual patient’s adherence behaviour.
- (5) To use a conceptual framework of behaviour change that integrates Michie’s generic behaviour wheel and Horne’s adherence specific intentional/non-intentional non-adherence model to develop interventions to support adherence.
- (6) To compare adherence to nebulised therapy at the beginning and the end of the intervention period using data from the I-neb nebuliser.

### **Results**

#### **Motivational Interviewing training**

The training was initially delivered by Dr Jeff Breckon from Sheffield Hallam University. This was linked to additional training cascaded within the team by a psychologist from Sheffield Teaching hospital. Unfortunately because of prolonged sickness absence this strand of training had to be modified but was picked up by the CF team psychologist and training is still ongoing using the Burdett funding with the final series planned for Spring 2014 in which Dr Jeff Breckon will work with team members to induct new CF MDT team members into MI and to consolidate skills. Training moved from conventional day seminars and educational sessions to review and scoring of clinical sessions to consolidate clinical skills. Formal training was supported by regular group sessions to inform practice and consolidate skills through reflection. Learning from this process has been shared with other CF teams through publications and presentations at the European Cystic Fibrosis conference<sup>10 11</sup>

#### **Posters Development**

The posters work was part funded by Respironics. This part of the work aimed to develop a social marketing strategy that encouraged people with CF to take nebulised antibiotics on the basis that this would keep them healthy. The Ethics ruling required the CF team to produce initial posters themes that were approved by ethics before being taken to patients. Posters were then refined during interviews with patients. The posters were then refined and produced professionally in partnership with Respironics. Posters are now in use in our clinic and in clinics around the UK and the work was presented at the European CF conference and a full paper is currently passing through the peer review process<sup>12</sup>.

## Pump Priming

We were able to refine our approach to adherence during the period of time supported by the grant. We measured our overall clinic median adherence and found it to be 45% which compared to the median adherence of 36% reported in the literature<sup>1</sup>.

In addition we reviewed the literature on barriers to adherence in CF and further refined our conceptual framework of adherence support<sup>13</sup> and this work informed the development of a £2 million NIHR program grant that was submitted using the Burdett grant as an important stepping stone. The NIHR programme grant to develop adherence interventions across the CF community has passed the first round and is currently under review.

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