10. Delivery of Care

332* Validation of the treatment satisfaction questionnaire for medication (TSQM) in cystic fibrosis (CF)

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Objectives: To assess the measurement properties of the TSQM, a 14-item questionnaire measuring 4 dimensions related to treatment satisfaction (Effectiveness; Side-effects; Convenience; Global satisfaction) in CF.

Methods: The TSQM is a generic treatment satisfaction instrument validated in several chronic diseases but not used before in CF. It was included in the EAGER study, a randomized open-label clinical trial comparing a nebulized and a dry powder device for inhaled tobramycin in a CF population aged 6 years and above. The two treatment arms (N = 553) were pooled together to conduct psychometric analyses. Construct validity was assessed using confirmatory factor analysis (CFA) and multi-trait analysis. Cronbach's α were calculated to assess internal consistency reliability. Differential item functioning between responders who were assisted by a relative (patients below 12 years of age) and those who were not was sought for using logistic regression.

Results: The quality of completion of the 14 TSQM items was excellent since all had less than 2% missing data. The CFA goodness-of-fit of the 4-dimension structure met commonly used standards (e.g. Goodness of Fit index = 0.92). In the multitrait analysis, all items met the convergent validity criterion and all but one met the discriminant validity. All Cronbach's α were above 0.86, indicating very good reliability for all 4 dimensions. No item showed differential functioning related to mode of administration (alone vs. with the assistance of a relative).

Conclusion: The TSQM showed excellent measurement properties that strongly support the use of this instrument to assess patient satisfaction with inhaled CF treatments.

333 FEV₁ presented as graphs, does this improve understanding of respiratory function and improve treatment adherence?

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Respiratory function is an indicator of disease progression in patients with CF. Education is essential when involving patients in their treatment.

Objective: to consider patient understanding of respiratory function tests (RFT's) when given information graphically and if this would impact on their adherence to treatment.

Method: 26 CF patients (12 male) completed a questionnaire evaluating understanding of their RFT's (specifically FEV₁). Following presentation of their FEV₁ trend over the previous year as numbers and graphs, the questionnaire was repeated. 100% of patients wanted information on respiratory function. 88% of patients rated importance of RFT's as greater than 70% on a visual analogue scale. 50% of patients felt they knew their FEV₁ measurement. 76% correctly identified their FEV₁ with 19% correctly identifying their trend following presentation of the graph suggesting greater understanding of information given. When greater understanding of data occurred, 65% reported to prefer graphs as compared to numbers, 50% of patients consider that their adherence to therapies would increase. 27% were unsure if additional information would alter their behaviour. Patients identifying respiratory function as low in importance also experienced the lowest FEV₁. Education is essential when motivating patients.

Conclusion: Respiratory function can be preserved with adherence to airway clearance, exercise and nebulisers if we optimise education. In line with patient choice respiratory function data will be given in the desired format at clinic. Presentation of respiratory data, in numbers or graphs can influence treatment behaviour, may improve adherence and effect quality of life.

334^{*} Attitudes and barriers to the implementation of new E-health strategies in cystic fibrosis (CF)

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Opportunities for better healthcare have arisen because of advances in technology. Barriers and entrenched beliefs may impede the implementation of strategies in E-health.

Aim: To identify staff and patient barriers to implementation and use of new E-health applications.

Methodology: Thematic analysis of focus groups (patients n = 5, staff n = 5) identified five themes (1) current usage, (2) barriers, (3) attitudes, (4) benefits and (5) current systems. A staff and patient survey was developed based on the five domains. Individual's responses were scored from 0-10 on a Likert scale (5 = indeterminate response).

Results: A total of 267 participants (130 patients, mean age 32.87 ± 10.49 years (50.0% males) and 137 staff, mean age = 32.25 ± 10.51 years (33.7% males) completed the survey. Perceived barriers to E-health effectiveness are shown in table 1. Perceived benefits of technology are shown in table 2. Participants (54% staff, 68% patients) are more comfortable with a password-protected electronic health record compared to the current paper-based system.

Conclusion: (1) Training, security and funding issues must be addressed, (2) Change management strategy required – policy development

Table 1: Top 5 identified barriers to the implementation of E-health strategies

Barriers	Patients (Mean±SD)	Staff (Mean±SD)	p Value	
Funding	7.48±2.60	5.76±2.99	< 0.01	
Privacy/security concerns	$7.48{\pm}2.62$	$3.55{\pm}2.48$	< 0.01	
Lack of training/support	7.11±2.63	4.69±2.70	< 0.01	
Age of computer	6.46±3.02	5.50 ± 3.11	< 0.05	
Slow/inadequate internet access	6.15±3.05	5.53±3.04	NS	

Table 2: Benefits of SMS, videoconferencing and telemedicine reminders				
	Patient	Staff		
SMS appointment reminders beneficial to patients	7.87±2.93	7.24±2.50	NS	
Video conferencing beneficial to me	$5.55 {\pm} 2.86$	$5.80{\pm}2.69$	NS	
SMS medication reminders beneficial to me	$5.99{\pm}2.97$	$6.00{\pm}2.86$	NS	

335 Improving patient satisfaction by using PICC for intravenous antibiotic therapy

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Introduction: Since January 2010 pediatric CF patients requiring intravenous (iv) antibiotic therapy are offered a Peripherally Inserted Central Catheter (PICC) instead of a venflon. One year after introduction the procedure was evaluated.

Methods: PICC insertion occurs ultrasound guided using the Modified Seldinger technique. Some patients received oxazepam prior to the procedure; subcutaneous lidocain was given as a local analgetic. Demographic data of all CF patients receiving a PICC and complications were prospectively registered in a database. We contacted all patients after discharge to evaluate complications and patient satisfaction.

Results: PICC insertion was attempted in 49 patients. In 2 cases insertion of PICC was unsuccessful, both in the 1st trimester after start of the project. 9 CF patients received a PICC during two or more treatment periods. Median age of patients 13 years (range 6–18). Median duration of PICC presence was 17 days (range 2–51). One patient had a swollen arm, without any evidence for thrombosis on radiological examination; one PICC was occluded and damaged, after an attempt to resolve occlusion. No infections were seen, nor proven thrombosis. Patient satisfaction was high, mainly based on reduced stress compared to repeatedly inserted venflons in the past and less mobility restrictions. All patients would prefer a PICC in the future.

Conclusion: PICCs are useful alternatives for iv treatment of CF patients. Success rates are high, complication rate is low and patient satisfaction increased since introduction. This supports continuation of our PICC team.