

398* Quality of Care and Quality of Life: Patient/Healthcare Perspectives

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Background: Patients with CF need attention, financial resources and energy for their daily, time consuming therapies to maintain an optimal health status. Our goal as healthcare providers (HP) is to offer the best care. This results in a heavy burden for the patients which impairs the quality of life (QoL) and may lead to poor adherence. The ultimate goal should be to propose a true balance between quality of care (QoC) and QoL. The QoC in CF is measured by outcome variables that include morbidity, mortality, FEV₁ and BMI. Over the last decade, the patient's perspective on QoL was included as well. Patients grade the effect of the disease on their daily life, and include their subjective assessment of respiratory status, physical activity, eating, body image, social status and the emotional effects of CF.

Aim: To investigate the differences in perception of quality of life and quality of care between HP and patients/parents in our CF center.

Method: QoL and QoC were assessed by an anonymous questionnaire that included 46 questions, completed by 13 HP, 24 patients >18 years and 29 parents of children <18 years.

Results: No significant differences between the perceptions of HP and the patients on QoC were detected. Significant differences were observed in QoL, i.e., subjective perception, daily activities, treatment burden and coping.

Despite the original assumption that patients perceived their QoL much lower than expected by the HP, this study showed the opposite.

Conclusions: Patients and parents perceive the chronic illness in a "healthier" light than the medical staff. Therefore healthcare providers should take the patient's perception into consideration and recommend the best care when developing treatment regimens.

400 Cystic Fibrosis Questionnaire Reference Data in a healthy, Dutch population 6–20 yrs

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Background: Optimizing Quality of Life (QoL) is considered an important goal in the management of patients with a chronic disease. The Cystic Fibrosis (CF) specific questionnaire (CFQ) has been developed as a tool to monitor QoL in CF patients.

The objective interpretation of the results of the CFQ is restricted by the lack of reference data from a healthy population. The aim of this study was to collect these reference data.

Subjects and Methods: A cross-sectional study was done. The CFQ was completed by 491 healthy children and adolescents by multi-staging (age groups: 6–11, 12–13 and ≥ 14 yrs). Inclusion criteria: not having a chronic disease and not visiting a paediatrician. Specific disease-related questions were omitted.

Results: In the healthy population an average score was seen per domain between 80–90 on a scale from 0–100. Lower scores were reported in the domains Emotional State and Vitality in all age groups. The domain Body Image scored significantly lower in the age group ≥ 14 yrs. Boys ≥ 14 yrs. showed higher scores in the domains Emotional State, Physical, Eating and Health Perception. No relationships were found between education or socioeconomic status and CFQ scores.

Conclusion: Mean CFQ scores in the healthy population are not constant across the ages; this should be considered when interpreting the CFQ scores in CF patients. Trends in generic domains can not only be explained by having CF as there's also a trend visible in the different healthy age groups. These CFQ reference data are unique and provide objective criteria to define abnormal versus normal CFQ scores in CF patients.

399 Patient satisfaction survey of the annual review service at a regional adult cystic fibrosis (CF) centre

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Introduction: The annual review is a detailed holistic assessment of the patients treatment, condition and knowledge. It is recognised as an integral element in the management of CF which identifies areas where treatment and care could be improved. At our centre the annual review service has developed over the past eight years.

Aim: To evaluate the patients views and satisfaction of the current annual review service.

Method: Over a three month period patients attending the out patient clinic were invited to complete an anonymous satisfaction questionnaire.

Results: 86 patients completed the questionnaire. 91%(78) understood the purpose of the annual review. 88%(76) had been offered an annual review in the previous 12 months of which 73%(60) attended. 57 patients reported the annual review to be beneficial. The benefits reported include improved understanding of progress or decline of their health, discussion of new treatments available and the opportunity to discuss issues that may not be addressed in a routine clinic appointment e.g. contraception and fertility. 23 patients did not attend for annual review. The reasons given for not attending included not understanding the reason for the annual review, unsuitable date and time, unable to take time off from work/college, additional travel costs and insufficient car parking facilities. 27 patients recorded that they had not received a copy of their annual review report.

Conclusion: Overall patients were satisfied with the current annual review service. In order to improve attendance we are currently addressing car parking costs, developing a patient information leaflet and improving feedback to patients.

401 To tell or not to tell – Young people's experiences of disclosure

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Introduction: A qualitative PhD study examining transition to adulthood for young people with CF.

Method: In-depth semi-structured interviews were conducted with 8 male and 10 female CF patients aged 16–21 years. The study has been conducted and analysed using Grounded Theory.

Results: Disclosure to peers was problematic for many of the young people and they displayed a range of disclosing patterns. For some disclosure was a spontaneous event whilst for others it occurred only after very careful consideration.

The issue of trust was often pertinent in decisions of disclosure and the young people made a clear distinction between acquaintances and friends. They were more willing to disclose to those considered to be friends as friends were deemed to be trustworthy.

Disclosure to potential partners was a particular concern. Many of the young people found explaining their condition both difficult and embarrassing and worried that doing so may hinder the possibility of a relationship. The young people expressed a desire for health care professionals to provide greater information on and discussion of this issue.

Discussion: Findings highlight that decisions of disclosure for young people with CF are both complex and dynamic. They also demonstrate the need for health care professionals to address wider aspects of transition beyond those directly linked to health care.