Objectives: To assess the patients’ experiences with care provided by staff in CF centres, we developed a CF-specific questionnaire in 2009 [1]. After a pilot study [2], the revised form was used for a nationwide survey.

Methods: 90 CF centres in Germany were invited to participate. Centre staff collected patient consent forms and sent the patients’ addresses to the Picker Institute Germany. The 110 items had 3 to 6 response categories, which were dichotomised to “problem scores” (PS). The ideal score is 0%, indicating no problem.

Results: 56 CF centres took part in the survey and recruited 1642 adults with CF and 1205 parents. The response rates were 74% in each group. Factor analysis revealed 10 different factors covering 70% of the 110 items. Participants reported the best results for the factors “physiotherapists” (PS 86%) and “physician-patient relationship” (PS 9%). Factors with the highest problem scores were inpatient and outpatient “facilities and services”. Items with high PS were “not enough information on possible side effects of drugs” (PS 49%) and “inadequate support to meet other patients/families” (PS 46%). For each item and factor, the institutions received reports of their own results and the mean PS of all participating centres. The problem scores differed considerably between CF centres.

Conclusion: The CF-specific patient experience survey identified areas with higher and lower patient satisfaction. Centre staff can use the results to augment the quality of care.

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Reference(s)

WS6.6 A prospective multi centre study to examine the impact of home intravenous antibiotic treatment (H-IVAT) on carer well being

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Objectives: The UK CF registry states since 2007 over 40% of intravenous antibiotics administered to children in the UK were delivered by carer(s) at home (H-IVAT). Carer focus groups reflecting on the challenge of living with CF identified H-IVAT as the most challenging task they faced. This study was designed to examine this healthcare task and identify features that impact on carer well being.

Methods: This was a multi centre observational study of carers. At baseline carers completed a number of psychometric measures including the Beck Depression Inventory (BDI) and the Parenting Stress Index (PSI), and a bespoke RISK tool to assess H-IVAT. Phone diaries were collected at one regular care period and one time period when parents had the addition of H-IVAT to manage to assess the impact of H-IVAT on family’s daily life.

Results: 129 families from 30 different CF centres across the UK took part in the study, representing 22% of children who completed H-IVAT 2009−10. Use of a homecare company (F1,99 = 15.9 p < 0.001) and use of infusion device (F2,97 = 6.9, p < 0.005). Parenting stress from “isolation” (r = 0.57) and “carer poor health” (r = 0.58) associated with higher BDI scores, but not “use of homecare” or “infusion device”. Multivariate analysis found “use of homecare company”, “isolation” and “carer poor health” explained the variance in carer BDI scores (R2 = 0.44). Parents slept on average 74 minutes less during H-IVAT than the regular care period (t = 2.8, df = 18, p = 0.012).

Conclusion: Use of infusion devices and a homecare company associated with fewer depressive symptoms. On average carers sleep less during H-IVAT.