inadequate monitoring of therapy due to non-attendance versus potential treatment breaks in HEMT.

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West Midlands Adult Cystic Fibrosis Centre experience of the effects of Kaftrio® on patients within the lung transplant programme

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Background: The effects of Kaftrio are known to have a positive impact on the health of people with CF. Clinical trials for Kaftrio have shown 10% increase in lung function. Lung transplant is an option for pwCF with advanced lung disease. We reviewed patients' response to Kaftrio on the lung transplant programme.
Aim: To evaluate the impact of Kaftrio on patients' health within our lung transplant programme.
Method: We assessed patients on both the active list and regular review with the transplant team. Objective measurements were: Lung function, weight, IV antibiotic courses, hospital admissions and transplant status. These were measured 1 year pre and post Kaftrio.
Results: Pre Kaftrio 7 patients were on the active list: mean FEV1 25%; weight 50.4 kg. Number of hospital admissions varied from 0–6 (total 21). IV antibiotic courses varied from 0–6 (Total 22). 1 year post Kaftrio 3 patients remained on the active list and 4 were placed on regular review. Mean FEV1 increased by 6.6% to 31.6%, weight increased to 66.1 kg. Number of hospital admissions varied from 0–2 (Total 6) with a total decrease of 15 admissions. IV antibiotic courses varied from 1–3 (total 9) with a total decrease of 13. Pre Kaftrio there was 21 patients under regular review. 1 patient was not eligible for Kaftrio. Mean FEV1 30.3%.and weight 57.6 kg. Number of hospital admissions varied from 0–6 (total 53). IV antibiotic courses varied from 1 –6 (total 64). 1 year Post Kaftrio 6 patients remained under regular review. 9 patients were discharged from the transplant programme. 1 patient was discharged but referred back. 5 patients DNA/ cancelled appointments. Mean FEV1 increased by 9.7% to 42% and weight increased to 66 kg. Hospital admissions varied from 1–5 (total 14) with a total decrease of 39 admissions. IV antibiotic courses varied from 0–4 (total 16) with a decrease of 48 IV antibiotic courses.
Conclusion: This study demonstrates the benefit of Kaftrio in pwCF with advanced lung disease.

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A qualitative study exploring parent's experience of the diagnosis of cystic fibrosis for their newborn baby

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Objectives: Cystic Fibrosis is often diagnosed during the first few weeks or months of a young person's life, occurring within the context of families adapting to parenthood, family identity development and nurturing of secure attachment. Having a new-born baby diagnosed with a chronic health condition adds to this time of transition. A literature search revealed sparse research into the lived experiences of parents during this time. Therefore, the current study sought to better understand the parental experience of having a new-born baby diagnosed with Cystic Fibrosis.
Methods: Parents of young people diagnosed with Cystic Fibrosis within the past 3 years were approached within Sheffield Children's Hospital to participate in a qualitative interview to discuss their experiences of diagnosis. Data from these interviews was analysed using Interpretative phenomenological analysis (IPA) to support understanding of the experience diagnosis.
Results: Four themes were reported: "re-writing parenthood", "importance of hope", "professionals' power", and "managing the changeable social world". Participants were acutely aware that their expectations of parenthood changed. Participants reported that 'hope' was an important feeling that professionals could offer in the first hours of contact which helped participants overcome the difficulties associated with a new diagnosis. Additionally, participants noted that the power professionals held throughout the process was daunting, but that through time, power starting to be equally shared. Participants were aware that the social world around them changed, as interactions with family, friends, work colleagues, strangers and CF peer support had the capacity to be damaging as well as supportive and protective.
Conclusions: Families' experiences around the time of diagnosis are significantly impacted by their experiences of chronic health and the interpersonal interactions with the medical team and those around them. Consideration of a families lived experience should be carefully considered to support them at this time and beyond.

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A qualitative study on awareness, attitudes, behaviors and social adaptation of mothers of children with cystic fibrosis

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Objectives: Cystic Fibrosis (CF) may affect the whole life of the family and social adaptation is very important for the management. Aim of this study is to evaluate awareness, attitudes, behaviors, and social adaptation of mothers of children with CF.
Methods: Our qualitative study was carried out in April 2022 with 11 mothers of children admitted to a CF center in İstanbul, Türkiye. For data collection a semi-structured question guide was applied using in-depth interview technique. Thematic analysis method was used in analysis of the data. The ethics committee approval was obtained.
Results: Most mothers noticed the disease in the presence of symptoms such as salty skin, frequent productive coughing, and fever attacks. Majority were not aware of the cause, some even thinking that it could be due to an accident or prolonged delivery. All parents adjusted their whole lives according to their children and their social life was limited after the diagnosis. They abided by hygienic rules, seldom spent time outside home, particularly avoided crowded areas.
While most mothers expressed that their family relations were strengthened, and they were supported psychosocially, some mothers could not get the understanding and support they expected. Many of the participants received professional psychological support to cope with this situation. The disease had a negative impact on the education life of children; in addition to that families had difficulties due to the economic burden of the treatment. Majority stated the Covid-19 pandemic did not affect them so much, since their life was already limited. Their advice for the parents of newly diagnosed children were to be strong.
Conclusion: CF affects the lives of families in many ways, especially psychosocially and economically. Despite all the difficulties, the mothers could cope with life and became somewhat resilient. Awareness of CF should be raised in society and psychosocial support should be provided to caregivers.

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Psychological study of the relationship between pain perception and fear, anxiety and quality of life in children with cystic fibrosis

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Objectives: The aim of this research was to investigate the relationship between fear of pain, pain perception, anxiety and QoL in cystic fibrosis children during care procedures. Recent advent of CFTR modulators induced a major advance in the disease, both at the somatic level and in terms of patients' quality of life (QOL). Indeed, by reducing the need for care, the presence of a CFTR modulator treatment could have an effect on pain perception, fear of pain, anxiety and QoL of patients.
Method: Children aged between 8 and 18 years, followed at the Centre de Ressource et de Compétence pour la Mucoviscidose of the Toulouse Hospital, will be included in this prospective study. First, participants answer at the Visual Analogue Scale (VAS) during venipuncture (VAS1), or respiratory physiotherapy (VAS 2). In a second time, the child version of the State Trait Anxiety Inventory (STAI-C), the Fear Of Pain Questionnaire