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Virtual Paediatric Cystic Fibrosis Clinics in Response to the COVID-19 Pandemic and the Patient Experience

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The COVID-19 pandemic created unique challenges in the delivery of patient care across all medical subspecialties, including the paediatric cystic fibrosis (CF) service. For our tertiary centre looking after 125 children with CF and their families, we sought to utilise technology to deliver the same standard of care to our outpatients whilst minimising their COVID-19 exposure risk. In March 2020, we established virtual CF outpatient appointments, consisting of a consultant phone-call to parents, and subsequent contact with the different members of our multi-disciplinary team (MDT), including sub-specialist physiotherapy, dietetics, and psychology. Our unscheduled review system whereby parents can access a medical review at short notice in the case of an acute clinical concern, continued with COVID-19 precautions added.

We evaluated our patients' experiences of these virtual OPD's using an anonymous five-point online questionnaire that was emailed to each family during November 2020, with results compiled and analysed during February 2021. We achieved an overall response rate of 82/125 (65.6%). A total of 50/82 (61%) found it "easy" to maintain contact with the CF team during the pandemic, with only 7/82 (8.5%) describing it as either "somewhat difficult" or "difficult". In terms of virtual OPD satisfaction, 44/82 described themselves as "satisfied" (53.7%), with a further 23/82 (28.1%) "somewhat satisfied". Only 2/82 (2.4%) were "dissatisfied" with the virtual OPD's. A total of 66/82 (80.5%) respondents felt it would be either "helpful" or "somewhat helpful" to retain an element of the virtual OPD's going forward. In terms of likelihood to attend for a face-to-face medical review during the pandemic, the majority (53/82, 64.6%) said that the pandemic "had no real effect" on their likelihood of attending for an unscheduled medical review, with 14/82 (17.1%) describing it as having made them "much less likely" to attend. Only 3/82 (3.67%) said that the pandemic made them "more likely" to attend.

Virtual OPD's offer the prospect of further reducing infection risk for our CF patients. Current evidence suggests that children with CF experienced a reduction in pulmonary exacerbations during the pandemic, believed to be secondary to infection control measures such as social distancing[1]. The combined response of parents finding it "easy" to access our service and being generally "satisfied" with the OPD's suggests that they did not increase feelings of parental isolation and/or anxiety and could potentially reduce infection risk.

Whilst the majority of respondents (64.6%) felt that the pandemic had no real effect on their likelihood of attending for an in-person medical review (n=28), 89.3% of those for whom it did have an effect said that it made them less likely to attend. This suggests that for this subgroup the desire to avoid perceived infection risk by attending the hospital outweighed the desire for their child to be seen medically. This is consistent with international evidence indicating that a high proportion of parents of children with CF were concerned about COVID-19 exposure when attending the hospital[2]. This study is limited by being single centre and subject to self-reporting bias in the questionnaire.

In conclusion, our study demonstrates that our virtual OPD's were well received by parents of children with CF. A combined virtual and "face-to-face" system could be implemented as part of the recommended quarterly reviews for paediatric CF patients[3]. Whilst the majority of patients did not report that the pandemic impacted their likelihood of attending the hospital for review, for those who did the vast majority were less likely to attend.

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