

An Investigation into the Impact of COVID-19 on the Relationships Between Parents of Children Diagnosed with Cystic Fibrosis and the Cystic Fibrosis Multi-Disciplinary Team.

Steve Jones, Leanne Smith and Katie Ainsworth

*Corresponding author

Steve Jones,
Sheffield Children's Hospital NHSFT.

Received Date : May 14, 2024

Accepted Date : May 16, 2024

Published Date : June 16, 2024

ABSTRACT

The COVID-19 pandemic has led to a shift in Cystic Fibrosis (CF) clinical practice towards remote models. This study examines how changing working methods affect interactions between families of young people with CF and CF Multi-disciplinary Teams (MDT), as well as parents' opinions about working remotely. Inductive content analysis was used to analyze six semi-structured interviews with parents of young people receiving care at a regional UK CF specialist center. The results revealed three domains: interpersonal relationships, remote clinics, and CF in the context of COVID-19. The MDT and families' tight relationships were explored, along with the feasibility of distant clinics in the future.

Conclusions: Quality relationships between families and CF MDTs are crucial for improving continuing care. Remote working was allowed at COVID-19 and could be beneficial in the future.

Keywords: Cystic fibrosis, MDT, COVID-19, tele-health, psychology, qualitative.

INTRODUCTION

Cystic Fibrosis (CF) is a hereditary disorder that causes chronic health issues throughout life [1]. Individuals with cystic fibrosis receive continuous support to improve their health and longevity. Multidisciplinary Teams (MDT). MDTs often include doctors, specialist nurses, physiotherapists, dieticians, social workers, psychologists, and administrative staff. Routine screening in the UK leads to early diagnosis of cystic fibrosis

(CF) [4]. According to European recommendations [1], patients are rigorously evaluated every 6-8 weeks through clinic visits and annual evaluations. Additional medical intervention may need inpatient stays. Paediatric CF centers support young people and their families from diagnosis to transition to adult services between the ages of 16 and 18 year.

Previous studies indicate that medication adherence, which is essential for preserving health, is significantly influenced by the interaction with the CF MDT. Standing inside CF [5]. Consequently, a good relationship would be valued for improving the health condition of young people and their families as well as for the quantity of interactions they have with the CF MDT. New national and worldwide responses to COVID-19 have caused a change in health care models. People with cystic fibrosis (CF) are recognized to be more prone to respiratory infections, thus the UK urged them to wear shields to reduce their exposure COVID-19 [6]. This led to a significant change in the way families could communicate with their CF teams, primarily focusing on video and remote clinics instead of in-person interactions. Although research has indicated that remote clinics can be successful in other nations [7], this is not customary in the United Kingdom.

The purpose of the current study is to determine how families' interactions with the CF MDT have been affected by the modifications in working practices brought about by COVID-19 and what this would imply for standard CF care after COVID-19's acute phase. The writers don't have any preconceived notions about how this study would turn out.

METHOD

Semi-structured interviews were conducted to assess the influence of COVID-19 on family ties with a CF MDT. The NHS IRAS panel gave ethical clearance for this investigation (IRAS-284623).

The study team (SJ & LS) approached parents of young kids attending a Regional Paediatric CF center during normal clinic visits to invite them to participate in the study.

First-come, first-served basis. The sampling approach did not account for disease severity. If parents expressed interest, a study information sheet was sent via email. A week later,

participants received a follow-up contact to discuss their involvement. They had the option to withdraw or schedule an interview. Six parents gave their agreement to be included in the initial sample, which was chosen based on earlier research [5]. Participants came from a wide range of geographic locations. Before sending the verbatim transcripts to SJ and LS for examination, KA anonymized them. The method of analysis used was Inductive Content Analysis [8], as it has been utilized in this situation [5]. Before starting to find meaning units or codes within the text, SJ and LS read the transcripts to become fully immersed in the material. Meaning units are described as individual words or sentences that, depending on the context, have more than one thematic meaning. After finishing their examination of transcript number one, the writers independently created coding manuals that listed the themes they found in the text. After that, the writers talked about how to combine their coding manuals into a logical framework that is representative of the text and takes into consideration both major and minor ideas. The authors discussed their disagreements with one another. It was decided to use arbitration if a consensus could not be established, however this was not necessary. Once the main themes in the first coding manual were agreed upon, later transcripts were examined and added to in an iterative process until a final manual was created. Saturation of data

RESULTS

The themes fall into three categories: interpersonal relationships, remote clinics, and CF in COVID-19 contexts. Table 1 contains quotes that illustrate each secondary theme. Participants reported long-lasting interactions with the CF team that began shortly after childbirth and continued throughout their child's life. Relationships between parents and children evolve with time, with more child engagement as they get older. Ruptures in the connection were observed, but they were resolved through talk. The staff team's continuity over time reduced repetition during consultations and increased familiarity. This Paediatric CF service had not previously used remote working or tele-health clinics, thus the current scenario provided an opportunity to discuss these options with parents. The Remote working offers significant time and expense benefits, particularly for individuals who must travel longer distances. Reducing disturbance to everyday routines is a significant advantage, especially when compared to missing entire school days for clinics. The inability of physicians to physically check patients was identified as a major drawback of remote clinics. This raised concerns among parents who lacked confidence that their child's health was fully assessed.

DISCUSSION

The COVID-19 pandemic has significantly impacted health service delivery, particularly for CF patients and families. There was a shift from face-to-face clinics to remote work. This study examined the influence of this adjustment on the relationship between a Paediatric CF MDT and their parents. The CF MDT has a unique interaction with patients that lasts from diagnosis to transition to adult services, with ongoing contact every 6-8 weeks [1]. Parents reported that their connection has evolved with time, with the young person becoming more involved in their own care. A recurring element that surfaced was the significance of a mutually trustworthy relationship in enabling efficient healthcare. It seemed that trust and clinician integrity, deference, apparent skill, concern, consolation, and friendship. These themes emphasize the value of accessibility and availability as well as the interpersonal skills necessary to support improved patient care in such a long-term partnership. Since telehealth clinics and remote working have not historically been commonplace in this pediatric CF service, the current circumstance offered a natural chance to talk about it with parents. The most benefits of working remotely were related to time and money savings, particularly for individuals who had longer travel distances to cover. One advantage that was mentioned again and again was the reduction in disruption to everyday routines, particularly when it came to not having to miss entire school days for a clinic. The inability of physicians to conduct in-person patient examinations was perceived as the primary drawback of remote clinics, raising concerns among parents who believed that clinicians had not fully grasped their child's medical condition.

REFERENCES

1. Karem E, Conway S, Elbron S, Heijerman H. Standards of care for patients with cystic fibrosis: A European consensus. *Journal of Cystic Fibrosis*. 2005;4(1):7-26.
2. The CF Trust. Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK. 2016. Retrieved online on 23/10/20 from: <https://www.cysticfibrosis.org.uk/media/documents/the-work-we-do/care/consensus-docs/with-new-address/cystic-fibrosis-trust-standards-of-care.ashx?la=en>
3. Mahadeva R, Webb K, Westerbeek RC, Carroll NR, Dodd ME, Bilton D, Lomas DA. Clinical outcome in relation to care in centres specializing in cystic fibrosis: cross sectional study. *BMJ*. 1998;316:1771-5.
4. Schluter DK, Southern KW, Dryden C, Diggle P, Taylor Robinson D. Impact of newborn screening on

outcomes and social inequalities in cystic fibrosis: A UK CF registry-based study. *Thorax*. 2020;75(2):123-31.

5. Jones S, Babiker N, Gardner E, Royle J, Curley R, Hoo ZH, Wildman MJ. Promoting adherence to nebulized therapy in cystic fibrosis: poster development and a qualitative exploration of adherence. *Patient Preference and Adherence*. 2015;9:1109-20.
6. The CF Trust. Statement on how people with cystic fibrosis and their families can help minimise their risk of COVID-19. 2020 Retrieved online on 23/10/20 from: <https://www.cysticfibrosis.org.uk/news/uk-cf-medical-associationsstatement-on-coronavirus>.
7. Wood J, Mulrennan S, Hill K, Cecins N, Morey S, Jenkins S. Telehealth clinics increase access to care for adults with cystic fibrosis living in rural and remote Western Australia. *Journal of Telemedicine and Telecare*. 2017;23(7):673-9.
8. Zhang Y, Wildemuth BM. Qualitative analysis of content. In: Wildemuth BM, editor. *Applications of Social Research Methods to Questions in Information and Library Science*. Westport, CT: Libraries Unlimited; 2009:308-19.