Telemedicine and Cystic Fibrosis: Do we still need face-to-face clinics?

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Educational Aims:

The reader will come to appreciate:

- **Standards of Care for paediatric cystic fibrosis**
- **The acute impact of the Covid-19 pandemic on healthcare delivery and the adaptations made by CF multidisciplinary teams.**
- **Advantages of non-hospital based monitoring for patients, families and clinical teams**
- **Concerns and limitations of remote care delivery**

Abstract

There has been growing interest in telemedicine for cystic fibrosis over recent years based largely on convenience for patients and/ or increasing the frequency of surveillance and early detection which, it is assumed, could improve treatment outcomes. During 2020, the covid-19 pandemic catalysed the pace of development of this field, as CF patients were presumed to be at high risk of infection. Most clinics adapted to digital platforms with provision of lung function monitoring and sample collection

systems. Here, we present the views of multidisciplinary team members at a large paediatric CF centre on what has worked well and what requires further optimisation in the future. In response to the question posed, 'Do we still need face to face clinics?' our answer is 'Yes, but not every time, and not for everyone'.

Keywords

Cystic Fibrosis, telemedicine, telehealth, home monitoring, remote care, lung function, spirometry, psychology, physiotherapy.

Introduction: What is telemedicine?

A report from 2007 found over 100 peer-reviewed definitions of telemedicine; the one adopted by the World Health Organisation is '*The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities'*[1].

Home monitoring/telemedicine is not new and has, in fact, been around in various guises since the 1960's. The medical specialty exploring this option first was nephrology as a way to monitor home dialysis patients[2]. The first evidence of telemedicine in lung health was in surveillance of respiratory illness in children in the 1970's[3]. In 1986 Finkelstein et al explored the feasibility of home measurement monitoring in people with cystic fibrosis (pwCF)[4]. They used paper diaries and provided stamped addressed envelopes for their return. Over 2 years they showed a diary completion rate of 75-80%, demonstrating that- at least in that era- advanced technology was not necessarily required for remote monitoring.

There is currently great interest in telemedicine and remote care delivery models for pwCF catalysed by the 2020 covid-19 pandemic. In this article, we compare standard care with newer approaches and take a multidisciplinary team look at pros and cons of more recent models. We highlight areas in which we consider further work is required.

The good(?) old days of hospital-based CF care

One of the major celebrated advances of the last few decades has been the delivery of standards-based, multi-disciplinary team (MDT) care led by tertiary CF centres (https://www.ecfs.eu/news/ecfs-standards-care-available-open-access). In some cases, centre care is shared with a local district-general hospital; in the UK, this is more common in paediatrics than in adult care. Patients attend routine out-patient clinic appointments at regular intervals: weight and height (if growing) are measured, spirometry performed (if old enough), sputum or cough swab for microbiological culture collected and clinical assessment is performed by members of an MDT including specialist medical, nursing, dietetic, physiotherapy staff. Most clinics are also able to provide psychology or social work support, albeit less frequently, and a growing number have specialist pharmacists. Additional expertise in gastrointestinal medicine, diabetes, rheumatology, pregnancy planning and care is available. Annually, a more extensive assessment is performed including a full blood workup, lung imaging and lung function testing. At certain annual assessments patients will undergo screening for CF-related diabetes (CFRD), ultrasound of liver and spleen, exercise testing and assessment of bone health. Between routine visits, additional contact may take the form of home or school visits, most commonly by nursing or physiotherapy staff, or may be triggered by patients reporting symptoms of concern, for example a pulmonary exacerbation (PEx). Admissions to hospital for intravenous (IV) antibiotics are largely 'as required' in most regions, although regular admissions have been standard in some countries in the past. Many clinics also facilitate IV antibiotics at home.

At all hospital attendances, strict measures are implemented to avoid potential cross-infection including no patient-to-patient contact and hard surface cleaning/ air exchange regimens between subjects in consulting/ in-patient rooms[5]. In many regions globally, data are entered into national and international patient registries; these have proven invaluable in quality improvement initiatives, addressing research questions and for pharmacovigilance.

The weaknesses in this conventional model relate largely to patient inconvenience and, for some, cost: many live a considerable distance from their centre, necessitating long journeys. The routine scheduling of visits means some will occur during periods of good health, rather than times perceived by a patient as 'greatest need'. Furthermore, the relative infrequency of visits means that a new infection or a slow decline in health could go undetected for up to several months, potentially reducing the chance of success once treatment is initiated. The number of MDT members seeing the patient, together with infection control measures, often mean that clinics run inefficiently, impacting both patients and staff. And despite best attempts, there remain some opportunities for cross-infection, for example when patients collect drugs from pharmacy, attend the radiology department or even whilst walking down corridors. Importantly, the adult CF population is expanding; many of the larger centres are already challenged by the size of their patient population, an issue which will increase over time.

Telemedicine for CF: a brave new world?

For all the reasons above, telemedicine or 'remote' care for CF has been considered for several years. However, it has recently become a major area of interest: of 74 titles recovered in PubMed (Dec 2020) with the term 'cystic fibrosis' and 'telemedicine or telehealth', 30% of them were published in 2020. The vast majority of these report work conducted in the pre-covid-19 era; the pandemic itself has triggered many more studies. Areas of focus have been: improved access to care in regions where travel is a barrier[6,7]; measuring/ improving adherence[8]; detecting and treating pulmonary exacerbations[9,10]; reducing chronic infection[11]; engagement in physio/ exercise[12,13];

nutrition[14]; mental health or several of the above[15]. The most recent systematic review in 2012[16] concluded 'There is insufficient evidence to reach a firm conclusion about the benefits of telehealth in people with CF, but it remains a promising area for future investigation.'

This evidence is certainly beginning to accrue at a pace. The delivery of healthcare generally faced major challenges during the covid-19 pandemic which hit large swathes of the globe in 2020. The rapid increase in numbers of patients admitted with severe SARSCoV-2 infection led many hospitals to close to routine, in-person care. Additionally, and along with other patients with severe and chronic diseases, pwCF were initially feared to be highly vulnerable to the infection; in the UK they were instructed to 'shield' at home and not leave the house for shopping, school etc. Most UK CF clinics therefore went completely virtual, implementing systems to support remote care. Details differed somewhat between centres, but the philosophy was similar, to provide a safe means of monitoring pwCF at home as much as possible. Within the paediatric department at the Royal Brompton Hospital we adopted the processes outlined in Table 1.

During the course of 2020, both in the UK (through the UK Medical Association and the CF Patient Registry) and Europe more widely through international registry-led surveys, considerable evidence began to provide reassurance about the frequency of infection in pwCF and, in particular, the relative lack of severe disease; the vast majority of people acquiring the infection in fact had mild or moderate disease[17,18]. Whilst reasons for this are currently unclear, the data did allow a certain relaxing of the strict shielding plans; children with CF were encouraged to return to school and by the summer, most adults were no longer being advised to strictly stay home. Some of our clinic visits have returned to in-person, although numbers are far fewer than previously, with personalised decisions being made. At the time of writing, the UK is experiencing a significant second wave of Covid-19 infection, nationwide lockdown and virtual assessment whenever possible. With a few exceptions however, children with CF are no longer considered in the highest-risk groups requiring to be shielded[18] and will mostly return to school once they open alongside their healthy peers.

Here, 12 months into the pandemic, we have collated feedback on telemedicine/ remote care from our paediatric CF MDT. We discuss what can be achieved and how this differs from previous standard practice. We highlight the benefits to the patient, family, clinical team and environment. We consider the similar, but subtly different scenario of research/ clinical trial visits. And finally, but crucially, we highlight weaknesses in the system and propose ways in which further work can help to address these once no longer driven by covid-related concerns alone.

What can we achieve with telemedicine?

We can assess much of the usual:

a) Just as easily

Most MDT members felt that the telehealth systems had allowed collection of the majority of the 'usual' information. Much of the interaction with parents/ carer and child was considered similar to what occurs face to face. The provision of equipment allowed measurement of weight, height and lung function[19]; when necessary, the latter could be performed 'in front of' the physiologists, who could guide on technique in real-time and view flow/volume loops. The lack of in-person contact was felt actually to be a benefit if the team member wished to demonstrate a technique. The medical team considered that often stable children require little more than history and cough/huff which can be done over video, the additional benefits of chest auscultation being relatively minor. Our CF nurse specialists reported that school 'visits' worked very well and could be 3-way, easily including teachers, parents and the CF team. The pharmacy team reported that recall of medicines was easier if parents were at home and could refer to their medicine cupboard as needed.

b) More frequently

One benefit identified by MDT members across disciplines was the availability of increased frequency of monitoring. Examples given were the repeating of spirometry after introduction of

mucolytics or a course of antibiotics; more frequent assessment of microbiology; weights could be checked more frequently in infants for whom there is some concern.

c) In a more timely fashion

Similarly, several team members identified timeliness as a major advantage:

- Clinical review could be actioned promptly in response to reported symptoms of a PEx
- Culture results from a sample submitted prior to review could guide appropriate treatment. In addition to potential short-term clinical benefits, it was also suggested that, over time, this could reduce the prevalence of antimicrobial resistance, if targeted antibiotics were prescribed as opposed to 'best guess'. Of course, this change could also be implemented were clinical encounters brought back to the hospital setting.
- Review could be provided soon after a new intervention (e.g. new inhaled medication) allowing adjustments as appropriate
- It was suggested that families' threshold for asking for help might be lower both because they would not have the inconvenience of an in-person visit, but also if they felt were not 'bothering' the team as much

d) In a more personalised way

Team members considered that the new system had the potential for them to focus on patients most in need, having a 'lighter touch' for those who were well. It was also flagged that it was easier to tailor the timing of virtual consults allowing children to attend a full day at school and seeing younger children earlier in the day. It was noted that two parents were more frequently present than was common at in-person clinics and that the small group of overseas patients we care for, were not disadvantaged, everyone being 'in the same boat'. Telemedicine may lend itself particularly well to psychological assessment and mental health support. In our own experience, when audited by our psychology service, all 27 participants responded positively to remote sessions,

citing flexibility of appointment and the opportunity to access timely support. Whilst needing further research, emerging pilot data published also suggests this may be met favourably by pwCF[20].

We can also do things we couldn't previously:

Several new opportunities afforded by telehealth were identified by team members:

- Physiotherapists:
    - 'We are able to actually see the patients' airway clearance equipment, which is not usually brought to clinic. We can assess their technique and see how clean equipment is, advising as needed.'
    - 'We may reach a wider demographic with our exercise programmes, which do not have the expense associated with gym membership/personal trainers. Patients don't need to travel and can exercise under our supervision in their own home, so there may be fewer perceived barriers. Privacy is also important for patients who are self-conscious about exercise/effects of exercise (coughing/sweating/expectorating etc)
    - Wearables, such as step count, heart rate and activity monitors are increasingly used, and could usefully be incorporated into exercise programmes
- Pharmacists:
    - 'Medicine reconciliation is more comprehensive; we are able to see medicines which families sometimes struggle to recall accurately in clinic. We can check expiry dates, and also identify non-adherence if large stocks are present.'

Enhanced convenience for the family and child

There was universal recognition that telemedicine systems saved time for families and reduced the costs and stresses associated with travel, parking etc. One of our families estimated costs of over £1,000 through travel to our centre and loss of earnings during the first year following their newborn's diagnosis. It was considered easier to be flexible with appointment timing, working

around the patient/ family's schedule. It was thought likely there was less waiting time, although this has not been formally assessed. Either way, the child able to entertain him or herself at home rather than being bored in the consulting room was a perceived advantage. The home-care team members reported that often families prepare for their visit by tidying the house etc; a virtual visit removes this pressure.

Benefits to patient safety & well-being

Despite our best efforts, attendance in a hospital setting poses some degree of infection risk; this is removed completely with virtual visits as is any chance of infection whilst travelling in. Although this was a particular issue during the covid-19 pandemic, crowded public transport in major cities increases the risk of viral infections at any time. Many people describe travelling long distances to clinic as physically exhausting, some of our young adults feeling 'wiped out' the next day. This is of course avoided with telehealth systems. Families or patients may feel more comfortable and relaxed in their own home and be happier to chat more openly; some have negative associations with hospitals which cause them additional stress.

The team weighed up the benefits of in-person communication and video links, most concluding that the current need for face masks or visors is a major inhibitor of rapport; although in the UK these measures have been adopted during the pandemic only, in many other regions of the world, masks are standard. It would be of interest to survey patients' attitudes in this area.

The final benefits on well-being identified were those of 'empowerment and ownership' as the patient or family takes more of an active role in monitoring their disease, e.g. with home spirometry. As above, patient views on this would be informative.

Impact on team communication and efficiencies

Our approach is an online MDT meeting ahead of each clinic at which we discuss patients attending and flag issues requiring attention; electronic patient files and lab results can be easily accessed in

real time and shared with the whole group. The Attend Anywhere (ATA) dashboard allows us to see which patients are waiting (and for how long) and for team members to join calls either individually or together as deemed most appropriate. Team members can also message each other during the course of the clinic. Impacts on communication and efficiency were reported in both positive and negative directions by the team:

- Many felt that communication was easier, better and more efficient in real-time within the team
- It was also mentioned that ATA provides a unique opportunity to link more closely with shared care clinical teams, members of whom can join the call. This not only aids communication but also provides an opportunity for sharing of expertise and joint decision-making
- Those team members usually based in the community had efficiency savings on travel time
- The psychology team felt their availability was improved; the removal of a need to defer note-making until after a face-to-face session was a major component of this.
- Medical trainees however flagged that a lack of in-person time with a more senior clinician could be a disadvantage to their training; the threshold for placing a call for a clinical query may be different than an informal chat in a clinic corridor
- Most team members felt the system did not necessarily cut down on their workload

Environmental impacts

One of the very few benefits of the covid-19 pandemic has been the impact on the environment and urban pollution[21]. Clearly, patients not travelling into the hospital and community teams not driving to patients' homes will produce environmental benefits. Ultimately, should telemedicine become more commonplace in the longer term, we may require smaller hospital spaces and lower energy bills. It is hoped that personal protective equipment, which will undoubtedly remain to some extent, could be made more environmentally friendly with less wastage than there is currently[22].

What are the downsides and remaining concerns over telehealth for this population?

Whilst it was completely appropriate that the urgent need during 2020 drove the rapid roll out of new processes, it does not follow that widespread adoption should continue without critical focus on areas which could be improved or require evidence to support them. Our team has identified a number of problem areas; there are almost certainly more:

a) *Engagement and communication*

- Will engagement be similar for patients in least and greatest need? Although the majority of people have access to a home computer or smart technology, this is not universal. Likewise, some patients and families may respond better than others to the required shifts in responsibility and need to proactively monitor e.g. performing and uploading lung function. People who have struggled previously to adhere to therapies may find this form of management particularly challenging. There are already socioeconomic impacts in CF outcomes[23]; care needs to be taken to ensure digital and telehealth systems do not exacerbate these equity issues further.
- Conducting in-person consultations with an interpreter for parents who do not speak the local language sufficiently well is already a challenge; in our (thankfully, limited) experience to date, this challenge is greatly exacerbated by a 3-way video/ phone call.
- There is a concern that attention on maintaining good health has been accentuated by fear during the pandemic. We need to ensure that attendance and monitoring do not decline once this acute phase has abated and that neither care teams nor patients become complacent.
- Where is the child? On a number of occasions parents have 'attended' our video clinic whilst their child has been out of the home at school, or even in the playground. It is essential, for fulfilling a duty of care, that clinical teams see the patient, and communicate directly with them when age appropriate.

b) What might we miss?

- Certain types of assessment will continue to require physical examination: organomegaly or faecal loading, nasal polyps, chest wheezing or crackles are not possible to assess remotely. Digital stethoscopes are being developed[24], so technology may advance in this area. The teaching of physiotherapy and airway clearance techniques optimally requires a 'look, listen and feel' in-person approach.
- Home spirometers use different technology than bench top clinic devices. Multiple reports suggest that results may be discrepant due to these technical differences[25,26]; Over-reading could allow clinical decline to be undetected, whereas under-reading could increase anxiety and lead to unnecessary treatment. Benchmarking of home and clinic devices with same-day measurements would go some way to mitigate this. There may also be under-blowing when performance is unsupervised; this could be avoided by supervision over video link by physiology staff.
- Spirometry is poorly sensitive in early lung disease[27]; as the CF community enjoys better health on highly-effective modulator therapies, this will become an issue for more pwCF. More sensitive methods are available, in particular multibreath washout and certain forms of imaging; however, these require hospital attendance and are likely to do so for some time.
- Similarly, people unable to expectorate sputum currently rely on culture from cough or throat swabs; these lack sensitivity/ specificity for bacterial pathogens and are unsuitable for fungal or mycobacterial culture[28]. Sputum induction can be performed with good yield[29], although requires close collaboration with physio teams and is time consuming; whether this can be safely and effectively rolled out to patients' homes is unknown. Failure to detect lower airway infection in a timely manner may lead to poorer outcomes. Conversely, new systems allowing point-of-care, home monitoring for infection could be highly beneficial; several approaches to this are being researched.

- Commencement of new therapies may be delayed if 'challenge testing' is normally required; examples are nebulised agents which may cause bronchoconstriction or any drug re-start in a child with a previous suspected adverse reaction
- There have been team concerns around discussions of sensitive issues, for example breaking bad news or talking through fertility/ contraception with a teenager. Team members may find this more difficult when they are not with the patient or parent and are less able to read non-verbal cues; conversely, the fear of being over-heard may inhibit the person speaking from home. Concerns that 'lock-down' increased the risk for women and children experiencing domestic violence have been widely reported[30]; paediatric healthcare teams provide a major role in safeguarding, which may be more challenging if digital health becomes more common.
- The team all agreed that building a digital rapport is much easier if there is already an existing real-life relationship, and much more difficult with new patients/ families.
- The medicolegal implications of missed diagnoses or mistakes are not yet well tested; whilst there may be a lower bar for such issues during a global pandemic, later expectations will likely (and should) be higher.

c) Technology and manpower

- Technical failures sometimes occur, reducing the utility of a video conference or data upload; systems need to be sufficiently robust with time built into sessions to minimise the impact of this.
- There is the additional concern during nursing/psychology consultations in the context of risk and what may happen if a patient were to disclose information about risk to themselves or others and then is not contactable via telephone. To manage this the psychology team described preparing for their sessions with a rough 'script', allowing expectations and boundaries to be outlined and to explain what might happen if the call were to drop. An added difficulty is receiving questionnaires back from families, where in clinics these would

be handed in there is now a requirement to create electronic versions and email them to families, adding to burden for families and staff, increasing the time spent on each patient.

- All recognised that provision of telehealth services is a time-consuming process, generating a large amount of administrative work. Hopefully, automated systems will be developed in due course, for example allowing tracking of submitted samples. The health economics of these processes requires assessment.
- Delivery of services via telehealth will still require infrastructure and resource i.e. dedicated, IT-equipped areas for virtual clinics

d) Will outcomes be equally good?

- Finally, and of great importance, the current improvements in quality of life and health status pwCF are experiencing have arisen due to established patterns of care. We anticipate further improvements in the coming decades. Whether this excellence can be maintained with a move to telehealth is unexplored. The impact on physical health and psychological well-being require assessment.

The impacts on clinical research

- Much of what has been said above is equally relevant to clinical research. Whilst many institutions' research projects were halted at the height of the pandemic, alternative approaches were adopted to keep some going. In CF this was particularly crucial with clinical trials: some patients were getting access to drugs they could not have received through their clinic, the stopping of which would have been detrimental to their health. Many similar strategies to those described above were put in place, with admirable speed. As these were unprecedented and, in many cases, iterative, amended protocols required multiple approaches for new patient/ parent consent, which should be an area for improvement in the future.

- Future protocols could be designed to adopt the 'Study within a Trial (SWAT)' approach endorsed by the National Institute of Health Research, to formally assess home monitoring[31].
- Incorporation of some remote aspects to research studies may have beneficial impacts on recruitment and retention as convenience for participants is prioritised, but this will clearly be crucially dependent on the phase of a study and the perceived risk: benefit ratio. The monitoring for and data collection of adverse events is a major component of clinical studies, particularly those involving an intervention; this can be more challenging when patients are not seen in person.
- Additional benefits of a hybrid approach may include the easier retention of electronic (rather than paper) documents, the huge number of which will be familiar to anyone involved in research, particularly that of a commercial nature. Whilst 'remote' monitoring visits can be undertaken, it is important to bear in mind the very substantial workload that may fall to a research team in preparing for these, in our group at least, much more than for an in-person visit. The build-up of drug in pharmacy when monitors do not attend in-person to perform reconciliation and drug repatriation is also a challenge.

Conclusions

The RBHT paediatric CF MDT are largely positive about our experience of moving to a telehealth system; this exercise did generate several valuable take home points, which are highlighted in Table 2. There are undoubted advantages for patient and family convenience and for avoiding infection, both during the current pandemic and more generally. Systems being used need to be well understood and trusted. Novel technology in the form of wearables or point-of-care infection diagnostics may have future utility. The impacts of transitioning to virtual or hybrid systems outside the emergency of a clinical pandemic should be assessed on patients, parents and clinical team members (physical and psychological). In answer to the question we were challenged to address in

this article, '***Do we still need face-to-face clinics***?' our answer would be '***Yes, but not every time, and not for everyone***.'

Future Directions for Research

- **Building a prospective, objective evidence base for home monitoring, assessing the ability of data to detect clinical decline such as pulmonary exacerbations and the impact on patients' health and mental well-being**
- **Accurately determining the delivery costs of telehealth/ home monitoring to establishing a health economic model**

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Conflicts of interest

Prof. Jane Davies has performed clinical trial leadership roles, educational and/ or advisory activities for the following: Abbvie, Algipharma AS, Bayer AG, Boehringer Ingelheim Pharma GmbH & Co. KG, Eloxx, Enterprise, Galapagos NV, ImevaX GmbH, Ionis, Nivalis Therapeutics, Inc., Novartis, ProQR Therapeutics III B.V., Proteostasis Therapeutics, INC., Pulmocide Raptor Pharmaceuticals, Inc, Vertex Pharmaceuticals. The other authors have no disclosures of interest.

Table 1. Systems implemented by the Royal Brompton Hospital Paediatric CF Service during the covid-19 pandemic

- Conducted appointments via phone (initially) or video (currently with AttendAnywhere)
- Supplied hand-held spirometers capable of automatic uploads (partially funded through the National Health Service). Details of this are provided in an accompanying manuscript ref)
- Provided additional monitoring devices such as weighing scales (prioritising infants) and stadiometers.
- Provided kits to collect and post back airway samples for microbiology: sputum pots or throat/ cough swabs
- Blood testing systems: simple finger-prick testing for sugar, continuous blood glucose monitoring devices where indicated. Although less suitable for paediatric sampling, our adult colleagues have facilitated larger volume blood sample collection for liver function via, for example, Thriva kits. Finger-prick samples may also be suitable for therapeutic drug monitoring.
- Acute medicines were provided directly from the specialist centre to pwCF at home using post or courier. A dedicated CF pharmacy team rapidly expanded its support activities including the adoption of independent prescribing roles.

Table 2: Take home points:

- Optimal telehealth approaches will not be 'one-size-fits-all' but will work best if personalised and tailored to pwCF's needs and preferences. Patient/ family feedback is essential.
- Rapport ideally needs building first by face-to-face contact if possible

- We should not assume telehealth will be cheaper on personnel time, and should design robust health economic assessment systems.
- Teams must have confidence in what's being measured/ collected at home, with a prospective, objective evidence base.
- There is a clinical imperative to prospectively assess long terms outcomes on physical and mental health.
- We should not forget impacts on team members: trainees' education and personal contact (with patients and between colleagues; this is what attracted many of us to paediatric specialities in the first place).
- The medicolegal implications of mistakes, especially outside the context of a pandemic, are as yet, incompletely tested.
- Telehealth or hybrid systems would lend themselves well to adoption into clinical research protocols, but should be rigorously assessed.

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