International Telehealth Toolbox for Physiotherapists working in Cystic Fibrosis: Bridging the gap between real world and virtual consultations.

Morrison, L. Hauser, J. Maguire, I. Button, B.

Introduction

Over the last decade Telehealth platforms and remote health care has become available worldwide. Telehealth had been used in Cystic Fibrosis (CF) care prior to COVID-19 however this had been limited to more remote regional areas out of necessity rather than preference with the common objective of connecting people with healthcare needs to their health care provider via the internet. [1-4].

In early 2020 the Covid19 pandemic triggered a worldwide need for Telehealth as regions went into lockdown with populations of people in quarantine or shielding. CF Centers with established Telehealth services seamlessly transitioned to managing patients at home. Others were required to set up services and educate people/persons with CF (pwCF) and health care providers on the technical and professional use of remote healthcare.

Healthcare providers must have the necessary resources and guidelines to continue to use clinical reasoning and uphold a duty of care whether they are delivering services via Telehealth or face to face. The safety recommendations and data security considerations highlighted in this document should be maintained throughout any of the reviews/treatments discussed.

The aim of this toolkit is to provide information on establishing and maintaining an effective Telehealth service and to provide resources to help inform choice of suitable outcome measures, assessment, and treatment delivery via Telehealth.

Setting up a CF Physiotherapy Telehealth Service

The service needs to mirror the face-to-face consultation as closely as possible. It needs to be safe, confidential, be equally accessible for all patients, easy to use, fit for purpose and effective. It needs to be flexible and agile in order to meet the specific clinical needs of the pwCF, thus ensuring the service is person centered.

Conducting Telehealth sessions should comply with professional codes of conduct and professional standards of practice.

Many of these factors will already have been considered if your CF service offers a multi-disciplinary team (MDT) Telehealth review, however they are essential when establishing Physiotherapy specific reviews.

Technology

Telehealth readiness assessments to ascertain the capacity and the capability of both the physiotherapy staff and the patients to engage in a Telehealth consultation should be undertaken.

Capacity, capability and data security:

- Is there adequate staffing within the CF Physiotherapy team to deliver the Telehealth service?
- Do staff and patients have access to the internet and the necessary devices and software licenses to facilitate this?

- Do staff and patients have the understanding and capability to use digital technology?

- Is digital poverty an issue for patients and families and does the choice of Telehealth platform account for this?

- Are there Instruction leaflets on the use of the Telehealth platform?
    - Do they comply with easy read guidelines?

- Your Telehealth service should align with local and national Telehealth service policies.

- Do the data storage terms and conditions of apps or company owned hospital portals comply with General Data Protection Regulations?
- Has a Data Protection Impact Assessment been completed and signed off by a designated Data Protection Officer within your organisation?

Remote Monitoring

When deciding to use remote monitoring it is useful to consider:

- Requirement of clinical measurements.
- recording and storage of measurements.
- if the data can be accessibility by patients and families.

Reliability of readings:
Home spirometry readings should be validated against trusted hospital equipment to ensure stability of recordings. Spirometry can be conducted with Physiotherapy guidance or independently which may also influence readings.

Expert Support:

- Support from IT colleagues, clinical engineers and biomedical scientists in your organisation to help provide, set up and address technical difficulties with remote monitoring equipment is invaluable.

Patient Safety.

Patient safety is paramount; therefore, it is important to ensure there are processes in place to identify and mitigate against and respond to any potential adverse events during a telehealth consultation.

In advance:

- If the pwCF is alone is there a buddy system in place- where an individual is paired with the pwCF and can assume responsibility for their welfare or safety.
- Have you ready access to the patient's address should you need to call emergency services?
- Have you an escalation policy in place which is in line with your organisation's risk and safety policy?
- Has the patient got the appropriate space at home to safely perform exercise, nebulisers, airway clearance and/or spirometry?

Before starting and during the session:

- Complete a short risk assessment before starting each session. We have included some guides and practical considerations for a safe and effective clinical consultation in appendices 1-4.

- Has the patient (and parent/guardian) given consent for the treatment session?

- Knowing the patient's current medical status and being able to pre-empt potential adverse events is important:
    - Is the patient stable or on treatment for an exacerbation? Do they de-saturate during airway clearance or on exercise- have they home oxygen in place?
    - Are you planning to perform lung function? Is there a risk of syncope?
    - Have they CF related diabetes- have they eaten, have they a glucometer and glucose on hand?
    - Have they liver complications and associated blood pressure issues?
    - Any previous adverse events during face-to-face sessions?
    - Can you see the patient clearly enough to assess any deterioration?

Evaluation

Evaluation of Telehealth services are important in order to:

- ascertain their efficacy, safety and fit for purpose
- to create an evidence base to guide best practice and
- to inform further development of Telehealth services.

The use of electronic records can be useful in collating statistics about the uptake and usage of Telehealth services and monitor trends in the demographics and clinical profile of patients who engage with on-line services.

Co-designing patient experience surveys and involving patients in decisions regarding outcome measures used ensures that evaluation of the service will be relevant and meaningful for all users. (See Appendices 5 and 6).

Supporting People with CF and their families to engage with Telehealth Physiotherapy Services.

It is important to have a communication process to inform patients and their families about the option of attending Physiotherapy Telehealth services.

Being able to offer pwCF who use these services the option of a blended face-to-face, and Telehealth service allows more patient-centered care and the provision of more support for self-management. Physiotherapy is required from diagnosis, with the recommendation that babies diagnosed with CF through New Born Screening be seen initially more frequently than regular 2-3 monthly clinic reviews, with the frequency of reviews and treatment regimen tailored to the individual clinical, educational and social needs of the baby and their parents/guardians [5]. The option of providing more frequent follow up reviews via telehealth may help to reduce the stress of travelling distances to a CF centre with a small baby and therefore increase accessibility of the CF Physiotherapy Service to the family.

Transition in Cystic Fibrosis

The rationale for transition from paediatric to adult care in CF is multifactorial. Many developed countries in Europe and other parts of the world have more adults in their CF Centers than children [6,7].

Early adulthood in CF is associated with increased complexity of care as a result of maturation, a decline in health together with the burden caused by increased co-morbidities.

Transition 'readiness' should be flexible and based on the adolescent's chronological age, and physical and cognitive maturity [8]. Ideally, communication between the paediatric and adult services starts earlier in adolescence. The final handover of care usually occurs with the two multidisciplinary teams meeting with the young adult and their family with specific handovers. In the past this has usually been in face-to-face meetings at one of the health care sites This is usually accompanied with a written report and in the case of physiotherapy outlining the history, lung function, co-morbidities, exercise capacity tests, preferred airway clearance techniques, musculoskeletal issues and other relevant information.

Telehealth offers benefits for both MDT's, the young adult and their family. In some situations, centers are separated by distance historically making visits to the adult center less accessible. An outpatient clinic visit is arranged and the process of introducing the young adult to the members of the extended MDT occurs, with orientation to the physical environment and the initiation of working therapeutic relationships with each profession. The optimisation of airway clearance, exercise routines, education about the differences between the paediatric and adult healthcare setting and choices available together with attention to the importance of adherence to treatment starts and is the foundation for future management.

During Covid times Telehealth offered the opportunity for virtual 'get to know you' meetings as well as the actual handover. Presentation of clinical information and meeting with the team and family using break out rooms were all achievable via virtual meetings.

PHYSIOTHERAPY REVIEW/TREATMENT SESSIONS

As physiotherapy is implemented from diagnosis the management of different age groups necessitates modification. Provision of equipment and appropriate supportive literature should be provided in advance of any therapy session. As we move from paediatric care through transition and into adulthood the opportunity to access any online video demonstrations/resources should be encouraged. Signpost parents and young pwCF to these in advance of the session, e.g www.cfphysio.com, YouTube etc.

Dependent on caseload – a period of regular sessions can be organised to assist with adherence and support engagement with physiotherapy

- For a routine annual review of airway clearance/ inhalation therapy or spirometry ensure the patient has all their necessary devices with them at the time of review.
- If time is limited encourage the patient to complete any recommended/prescribed inhaled therapies prior to the Telehealth review to assist with secretion clearance.

- If there are any safety concerns or assistance required during the Telehealth session ensure a carer/parent is present, and/or ensure the buddy safety system has been set up, prior to the session commencing.
- If there are any concerns with the patient's respiratory status, ensure you have discussed with medical staff if Telehealth is still an appropriate platform to review the patient or if a face-to-face consultation is required.
- Ensure the patient has the relevant self-monitoring devices, and sputum pot or container for sampling.
- Complete the Telehealth checklist (refer to appendix 3) – this will also include the platform check for visual and sound quality.

AIRWAY CLEARANCE

Airway clearance techniques should be individualised and tailored to the pwCF, this reduces the likelihood of poor technique and therapeutic benefits will be optimised. More than one airway clearance technique may be required in clinical practice and patient preference should be considered to improve adherence.

- Ask the patient to demonstrate their usual airway clearance regimen. Provide coaching or helpful support if the technique does not sound or look effective, or if the patient is reporting difficulty completing the technique.
- If pressure monitoring for any of the airway clearance devices require review the appropriate equipment can be mailed out in advance.
- When introducing a new treatment you may consider demonstrating the technique yourself, or you can encourage the patient to refer to instructional videos e.g www.cfphysio.com.
- Discuss with the patient the technique and possible contraindications or adverse events that may occur.
- Use this opportunity to explore barriers and enablers to adherence and support the patient to develop strategies to improve adherence and effectiveness of treatment as needed.
- Always discuss incorporating techniques into day-to-day routines, the timing recommended with inhalation therapies and/or exercise, and the instructions for use and cleaning.
- During a respiratory exacerbation the patient may present more unwell than in a routine clinic or annual physiotherapy review which will require closer clinical monitoring.

INHALATION THERAPY

- Demonstrate of their inhalation therapy may be in combination with an airway clearance device.
- Use this opportunity to discuss adherence, technique (including breathing strategies, posture, mouthpiece placement) and provide any coaching as required.
- Discuss with the patient the cleaning and maintenance of the equipment.
- Record details of the inhalation therapy equipment and if any replacement equipment is required.

HOME SPIROMETRY

- Spirometry via Telehealth should only be performed by an appropriately qualified health care professional. Familiarity with the technique and equipment is essential for both Physiotherapist and pwCF /carers.
- Enlist guidance of local or national guidelines when completing spirometry

Musculoskeletal (MSK)

Telehealth has been a useful tool to triage and address many MSK issues that would otherwise not have been managed during the pandemic as non-essential services were reduced. Some pwCF develop MSK problems in response to increased or decreased activity and overuse injuries whilst others experience longstanding postural complaints. Specialist CF physiotherapists can use Telehealth to address these issues as they arise, however if they are persistent or complex refer to specialised MSK physiotherapists for appropriate management is recommended.

Delivery of exercise sessions; individual and group.

Exercise is recognised as integral to the management of pwCF and opportunities for delivering activity-based therapies using virtual technology have been identified [9]. Integration of exercise and physical activity into everyday routines optimises the promotion of adherence and self-management [10]. Additionally, social media has been beneficial in the delivery of exercise and physical activity promotion in the adult CF population [11], and physical activity guidance is promoted internationally [12,13].

Participants should be directed to the activities most suited to their level of ability, disease progression and personal physical activity interest. A background knowledge of relevant medical history is required and should include measures of exercise tolerance collated during annual review, e.g diagnoses of diabetes, exercise induced bronchospasm and requirement for supplementary oxygen if appropriate.

Telehealth and virtual consultations mean we can offer group sessions for pwCF. This was previously prohibited due to cross infection implications.

Risk of adverse events or deterioration in the client's condition

In considering virtual / online exercise, physiotherapists need to consider the consequences of an adverse event or deterioration in the pwCF's condition. This should involve contingency planning and risk mitigation prior to the activity.

For example;

- Diabetic hypoglycaemia - ensure blood sugars are taken prior to activity and are in the safe zone (this is considered to be between 4-7mmol/l) and fast acting glucose is available should it be required during an activity.
- Oxygen use for activity- should be fully functioning and the opportunity to increase the flow rate is available.

Documentation

When documenting participation in exercise the Physiotherapist should note the description of activities undertaken, the duration and type of exercise in the warmup/ body of class/ cool down. If using music, identify the tempo of the music as this dictates the cadence of any activity. If a participant is less able (for example where a flare of arthropathy may limit use of weight bearing through hands) modification of exercises should be offered to enable the participant to continue where possible.

Implementation of the "Buddy system" should be in place if the pwCF is exercising alone. Mobile phone numbers should be available, and phones turned on so that alternative communication is available in case of technical failure or delay.

The number of participants who can be safely monitored in a virtual class should be carefully considered. This may depend on the type of activity, the age of the participants and the degree of disease severity. In some instances, <6 individuals can be monitored by a single therapist with >6 necessitating 2 therapists.

Online activities can be suitable for all ages however the duration and type of activity should be tailored to the needs of that specific group. When engaging children and young people in online activities the consent (and on occasion presence) of their parent or carer is required.

Future Directions

The respiratory presentation for pwCF is changing as a consequence of the introduction of CFTR modulator therapy, with many pwCF reporting decreased sputum burden, decreased hospital admissions, improved respiratory health outcomes and a strong desire to reduce their burden of care. CFTR modulator therapy, improved specialised care, and improving life expectancy, is compelling clinicians to review current methods of service delivery, not only to improve efficiencies for the healthcare system but to continually optimise quality of care and health outcomes. Telehealth may provide one option for alternative models of care and whilst may not be suitable for all it should be considered as an option in any CF services moving into the future.

Advantages including reduction in; risk of cross infection, PPE consumables and cleaning requirements. Enhanced clinical space availability, improved attendance to appointments, and improved ability to deliver novel approaches in CF care (e.g group sessions) are all possibilities through Telehealth. The significant reduction in cost not only to the hospital, but also the person/family with CF in respect to time and travel costs are invaluable. Joint sessions with shared care centers should consider the use of Telehealth to improve access and equitable specialised care/support for all. The use of Telehealth reviews in the transition process between adult and paediatric teams and the pwCF; and the use of Telehealth sessions for a family with a newly diagnosed infant with CF may reduce the stress of this diagnosis/process and improve access to all resources and members of the multi-disciplinary team.

Barriers to Telehealth should be discussed at an executive level within units to determine if these can be overcome and a Telehealth service can be implemented. Please see appendix 10 for additional resources.

It is only the beginning of this journey and with limited research in the field, centers implementing Telehealth into their routine care will need to develop rigorous methods to evaluate safety and effectiveness to ensure care remains optimal. Telehealth should be considered as an option for all persons with CF, with the possibility of hybrid models of care offering a combination of face-to-face reviews, and Telehealth reviews being the way of the future.

Declaration of competing interest- the authors have no competing interests in the publication of this work.

REFERENCES

1. Lenney W. Paediatr Respir Rev. 2018 Mar;26:22-23. doi: 10.1016/j.prrv.2017.03.005. Epub 2017 Mar 14.PMID: 28366680 Review. Telemedicine is the way forward for the management of cystic fibrosis- the case against.
2. Cox NS, Alison JA, Rasekaba T, Holland AE.J Telemed Telecare. 2012 Mar;18(2):72-8. doi: 10.1258/jtt.2011.110705. Epub 2011 Dec 23.PMID: 22198961 Review. Telehealth in cystic fibrosis: Telehealth in cystic fibrosis: a systematic review.
3. List R, Compton M, Soper M, Bruschwein H, Gettle L, Bailey M, Starheim E, Kalmanek J, Somerville L, Albon D.Telemed J E Health. 2020 Sep 14. doi: 10.1089/tmj.2020.0247. Online ahead of print.PMID: 32924854. Preserving Multidisciplinary care model and patient safety during reopening of ambulatory cystic fibrosis care for nonurgent care: A hybrid Telehealth model.
4. Calthorpe RJ, Smith S, Gathercole K, Smyth AR.Thorax. 2020 Jan;75(1):72-77. doi: 10.1136/thoraxjnl-2019-213233. Epub 2019 Oct 8.PMID: 31594802 Free article. Review. Using digital technology for home monitoring, adherence and self-management in cystic fibrosis: a state-of-the-art review.
5. ECFS Standards of Care: Framework for the Cystic Fibrosis Centre. Conway et al 2014. Journal of CF 13(2014)S3-S22.
6. European CF Society Patient Registry Annual Data Report 2017. Available at: https://www.ecfs.eu/sites/default/files/general-content-images/working-groups/ecfs-patient-registry/ECFSPR_Report2017_v1.3.pdf (Last accessed December 2020).
7. Cystic Fibrosis Foundation Patient Registry 2019 Annual Data Report Bethesda, Maryland ©2020 Cystic Fibrosis Foundation Available at: https://www.cff.org/Research/Researcher-Resources/Patient-Registry/2019-Patient-Registry-Annual-Data-Report.pdf (Last accessed December 2020);
8. Tuchman LK & Schwartz M. A US retrospective analysis suggests that transition leads to a less rapid decline in lung function Pediatrics. 2013;132(5):847–53.
9. Cox NS, Alison JA, Rasekaba T, Holland AE.J Telemed Telecare. 2012 Mar;18(2):72-8. doi: 10.1258/jtt.2011.110705. Epub 2011 Dec 23.PMID: 22198961 Review. Telehealth in cystic fibrosis: Telehealth in cystic fibrosis: a systematic review.
10. Calthorpe RJ, Smith S, Gathercole K, Smyth AR.Thorax. 2020 Jan;75(1):72-77. doi: 10.1136/thoraxjnl-2019-213233. Epub 2019 Oct 8.PMID: 31594802 Free

article. Review. Using digital technology for home monitoring, adherence and self-management in cystic fibrosis: a state-of-the-art review.
11. Smith A, Gouick L WSo5 30 day challenge- using social media to support adult CF patients to exercise in the adult CF service Dundee. JoCF 2015.
12. https://kidshealth.org/en/parents/fitness-6-12.html
13. Swisher A, Hebestreit H, Mejia-Downs A, Lowman JD, Gruber W, Nippins M, Alison J, Schneiderman J. (2015). Exercise and habitual physical activity for people with cystic fibrosis: Expert consensus. Evidence-based guide for advising patients. Cardiopulm Phys Ther J.