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Telehealth after the pandemic: Will the inverse care law apply? (Commentary)[☆]

Rebecca J Calthorpe*, Alan R. Smyth

Division of Child Health, Obstetrics & Gynaecology, University of Nottingham, Queens Medical Centre, UK



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ABSTRACT

The COVID-19 pandemic has accelerated the use of telehealth within the cystic fibrosis (CF) community to deliver CF care. The article by Solomon and colleagues exploring the patient and family experiences of telehealth care delivery, as part of the CF chronic care model in the US, is therefore timely. In this commentary, we discuss how the US experience of telehealth care compares with reports from CF centres in other parts of the world. We highlight the potential challenges, including whether the inverse care law will apply in this new era of CF telehealth.

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1. Telehealth after the pandemic: will the inverse care law apply?

In January 2020, the World Health Organisation declared coronavirus a global health emergency [1] and countries around the world implemented national lockdowns and social distancing guidance to limit virus transmission. In many countries, even more rigorous restrictions were recommended for those deemed clinically extremely vulnerable – for example the “shielding” advised in the UK [2]. These measures disrupted routine clinical care for those with cystic fibrosis (CF) and necessitated a change in healthcare delivery.

Prior to the pandemic, CF care in North America, the UK, Europe and Australia has been conducted mainly through regular multidisciplinary team reviews, at least every 3 months [3]. There was a paucity of evidence for the use of telehealth in cystic fibrosis (CF) prior to the COVID-19 pandemic [4]. However, the pandemic has accelerated its use within the CF community and in person consultations have, in many cases, been replaced with telehealth interactions. Telehealth is the use of virtual technology and electronic devices to deliver healthcare remotely, with methods including video and telephone consultation, SMS services, health apps and the use of data from home devices such as nebulisers, spirometers, and blood glucose monitors. Telehealth has a number of synonyms, in-

cluding telemedicine, remote consultations and digital healthcare. The article by Solomon and colleagues is therefore timely. The authors present survey data on the use of telehealth consultations, from over 400 people with CF (pwCF) and parents of affected children, collected in the early stages of the pandemic. In parts of the world where patients can access CFTR modulator therapy, pwCF who feel better may feel less inclined to travel long distances and take time off work for clinic appointments. As and when pandemic restrictions are eased, it is therefore unlikely that CF care will return to “business as usual”. It is particularly important to understand what pwCF feel are the benefits and potential barriers of using telehealth for their clinical care in order to plan future services.

The survey shows that telehealth consultations were used by 81% of respondents; the majority of interactions via videocall. Respondents reported advantages of telehealth, including: saving time having to travel to clinic and not having to take time out from work or school. In the US and in many parts of the UK, Europe and Australia, centralisation of CF care means that patients often do not live in close proximity to their CF centre and have to travel long distances to receive specialised care. CF is associated with a high treatment burden and qualitative research has highlighted “digital appointments” as a way of mitigating this burden [5].

The authors demonstrated that the majority of patients were able to access a clinician, nurse and dietician at their reviews. However, less than half said their telehealth consultation included a physiotherapist, pharmacist, social worker or mental health professional. In a 2020 UK survey, CF teams reported that virtual clinics appeared fragmented and provided patients with more limited access to the full multidisciplinary team, compared to face to

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* Corresponding author: Dr Rebecca Calthorpe, Evidence Based Child Health Group, School of Medicine, E Floor East Block, Queens Medical Centre, Nottingham NG7 2UH, UK.

E-mail address: Rebecca.calthorpe@nottingham.ac.uk (R.J. Calthorpe).

face reviews (Connett G, personal communication). If the telehealth model is to be implemented beyond the pandemic, it is essential that it enables full engagement with the multidisciplinary team.

Telehealth may, of course, have unintended consequences. Not having to take time off school or work to attend appointments is reported as an advantage. However, paediatric consultations should engage both the parent and the child (or young person) – a principle which becomes increasingly important during transition to adult care. Solomon et al. do not report whether telehealth consultations took place during school hours (and were conducted with the parent alone) or whether arrangements were made to include the paediatric patient (e.g. virtual evening clinics).

The 2020 UK survey (Connett G, personal communication) suggests that the speed of implementation has raised challenges for the longer-term delivery of virtual CF care. Many CF centres reported a lack of IT infrastructure or funding available to fully support the delivery of services online. Clinical teams therefore report a mixed experience of telehealth. Access to home monitoring in many UK centres is not available and this was also reported by the survey respondents in Solomon study.

Solomon et al., describe disadvantages of telehealth, including: lack of respiratory samples for microbiology; no physical examination; and absence of spirometry. This was also experienced by large Canadian CF centre who saw a three-fold reduction in the number of respiratory samples received during the pandemic [6]. Mitigations might include a postal system for microbiology specimens and home spirometry (which has now been implemented in some UK CF centres) [7]. However, there have been concerns that home spirometry may systematically under-read [8]. Quality assurance of the patient's spirometry technique and proper maintenance of the equipment will be essential, if home spirometry becomes standard of care.

It is possible that remote consultation and the inability to perform physical examination might make it more difficult to identify non-adherence to treatment and safeguarding issues in children. This may be partly overcome by the assessment of adherence to nebulised therapy through data tracking nebulisers [9]. This has been implemented by some adult CF centres in the UK using the CFHealthHub online platform, which is accessible to both patients and clinicians. As well as recording adherence to nebulised therapy and spirometry, CFHealthHub includes online educational and behavioural change tools for pwCF to build knowledge, skills and confidence in managing their condition [10].

Some caution is needed in interpreting the data provided by Solomon et al. The authors acknowledge that the survey may be subject to sampling bias: respondents might be more enthusiastic about telehealth (or in some cases may have had memorably bad experiences) compared to non-respondents. The survey reports that, although 65% of respondents felt that telehealth services were of equal or higher quality than face to face appointments, most of these positive respondents answered, “about the same”. Indeed, 35% of respondents found the quality of consultation was worse. A previous survey, completed prior to the pandemic, demonstrated that technology is being used by a subset of the CF community to aid treatment management. Health professionals tended to be more enthusiastic about the technology than pwCF [11]. Indeed, Solomon et al. also describe a level of uncertainty in the CF community as to whether mainly in person, online or a combination of the two modalities was most appropriate. Telehealth may not be suitable for all pwCF [11].

The future of telehealth implementation in CF is both exciting and challenging. The CF community should be proud of the speed with which telehealth has been applied to CF care, its acceptability to the patients and families and the resilience this allowed in the

face of the pandemic. The inverse care law states “that the availability of good medical care tends to vary inversely with the need of the population served” [12]. Telehealth has the potential to offer easier access to CF care to those who are socially and economically disadvantaged by avoiding the expense of travelling to the CF centre and unpaid time off work. However some families may lack internet access, a suitable digital device or a private space at home to undertake a digital consultation. The new era of CF care will undoubtedly involve greater use of telehealth and it will be critical to ensure the inverse care law does not prevent the digitally excluded from accessing high quality care from their CF centre.

Declaration of Competing Interest

R.C has no conflicts of interest. Outside the submitted work, A.S reports grants from Vertex and reports speaker honoraria and expenses from TEVA and Vertex. A.S reports membership of the US CF Foundation therapeutic development network data safety monitoring board. A.R. Smyth has a patent “Alkyl quinolones as biomarkers of *Pseudomonas aeruginosa* infection and uses thereof” issued.

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References

- [1] World Health Organisation. Statement on the second meeting of the international health regulations (2005) emergency committee regarding the outbreak of novel coronavirus (2019-nCoV). 2020. Available from: [https://www.who.int/news/item/30-01-2020-statement-on-the-second-meeting-of-the-international-health-regulations-\(2005\)-emergency-committee-regarding-the-outbreak-of-novel-coronavirus-\(2019-ncov\)](https://www.who.int/news/item/30-01-2020-statement-on-the-second-meeting-of-the-international-health-regulations-(2005)-emergency-committee-regarding-the-outbreak-of-novel-coronavirus-(2019-ncov)).
- [2] Public Health England. Guidance on protecting people who are clinically extremely vulnerable from COVID-19. 2021. Available from: [https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#:~:text=%E2%80%A2%20solid%20organ%20transplant%20recipients,pulmonary%20disease%20\(COPD\)](https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#:~:text=%E2%80%A2%20solid%20organ%20transplant%20recipients,pulmonary%20disease%20(COPD)).
- [3] Castellani C, Duff AJ, Bell SC, Heijerman HG, Munck A, Ratjen F, et al. ECFS best practice guidelines: the 2018 revision. *J Cyst Fibros* 2018;17(2):153–78.
- [4] Calthorpe RJ, Smith S, Gathercole K, Smyth AR. Using digital technology for home monitoring, adherence and self-management in cystic fibrosis: a state-of-the-art review. *Thorax* 2020;75(1):72.
- [5] Davies G, Rowbotham NJ, Smith S, Elliot ZC, Gathercole K, Rayner O, et al. Characterising burden of treatment in cystic fibrosis to identify priority areas for clinical trials. *J Cyst Fibros* 2020;19(3):499–502.
- [6] Franciosi AN, Wilcox PG, Quon BS. Cystic fibrosis respiratory microbiology monitoring during a global pandemic: lessons learned from a shift to telehealth. *Ann Am Thorac Soc* 2021.
- [7] Dixon E, Dick K, Olsson S, Jones D, Mattock H, Bentley S, et al. Telemedicine and cystic fibrosis: Do we still need face-to-face clinics? *Paediatr Respir Rev* 2021.
- [8] Gerzon FLGR, Jöbsis Q, Bannier MAGE, Winkens B, Dompeling E. Discrepancy between lung function measurements at home and in the hospital in children with asthma and cf. *J Clin Med* 2020;9(6):1617.
- [9] Hind D, Drabble SJ, Arden MA, Mandefield L, Waterhouse S, Maguire C, et al. Supporting medication adherence for adults with cystic fibrosis: a randomised feasibility study. *BMC Pulm Med* 2019;19(1):77.
- [10] National Institute for Health and Care Excellence. CFHealthHub for managing cystic fibrosis during the COVID-19 pandemic (MIB219). 2020. Available from: <https://www.nice.org.uk/advice/mib219/resources/cfhealthhub-for-managing-cystic-fibrosis-during-the-covid19-pandemic-pdf-2285965459946437>.
- [11] Calthorpe RJ, Smith SJ, Rowbotham NJ, Leighton PA, Davies G, Daniels T, et al. What effective ways of motivation, support and technologies help people with cystic fibrosis improve and sustain adherence to treatment? *BMJ Open Respir Res* 2020;7(1):e000601.
- [12] Hart JT. The inverse care law. *Lancet* 1971;1(7696):405–12.