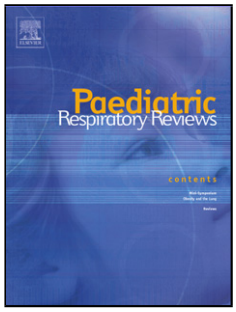

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Telemedicine is the way forward for the management of Cystic Fibrosis- The case against

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Summary

It is reasonable to suggest that Telemedicine could help in the management of chronic diseases by giving patients more flexibility to remain at home with opportunities to forward electronic data to healthcare professionals, reduce hospital emergency attendances and reduce overall costs. The reality, particularly in cystic fibrosis care, is this has not happened. There is concern that home-generated lung function data is of poor quality and virtually no studies show improved outcomes. The UK has a poor record in developing novel IT programmes and we need many more well designed clinical studies in Telemedicine before wading in with ill-conceived expensive plans just because the idea seems interesting

Keywords: Cystic fibrosis, telemedicine, limitations

The Debate

The concept of Telemedicine/TeleHealth Care (THC) has been around for nearly 20 years. It would be futile to say it has no place whatsoever in the future management of patients in the NHS but it is important to look at what it has achieved over that time, or indeed what it hasn't achieved, before pushing forward with new plans to expand its use. For the purposes of this debate I will mainly confine myself primarily with the evidence for THC in patients with chronic diseases particularly cystic fibrosis (CF).

On its website the Telehealthcare Services Association-TSA (the voice of technology enabled care) states that the early results of the WSD (Whole System Demonstrator) programme showed a 15% reduction in visits to A&E, a 20% reduction in emergency admissions and a 45% reduction in mortality rates (1). If such results could be transposed into the care of patients with CF I would have little argument against forging ahead with lots of THC CF programmes. Sadly, the facts are that, rather than showing clear patient benefit, the introduction of THC programmes into CF care has been difficult, expensive in time for patients and healthcare professionals (HCPs) and has also required significant additional training for HCPs. The programmes have not been universally embraced by patients and the greatest concern is that they have rarely shown any clinical usefulness (2).

General comments in favour of telemedicine have been that they are a convenient and more accessible way of managing patients, that they demonstrate healthcare cost savings and that they reduce unnecessary emergency room visits. They extend the accessibility of patients to their physicians and healthcare team, they extend and increase patient engagement and demonstrate better patient Quality of Life (3). I looked very hard for these outcomes within the CF medical literature but was disappointed not to find them.

General comments against the usefulness of telemedicine suggest it will only be available for a minority of patients and healthcare professionals and it will be expensive. There will be lack of bonding between HCPs and patients because of less direct clinic contact. In the care of patients with CF its use has been very limited and it has been questioned whether patients will regularly send lung function recordings electronically from their homes to the CF clinic staff and whether those recordings will be reliable and accurate in the absence of the presence of a supervising expert lung function technician to ensure optimal technique (4).

During the debate I reminded the audience that the NHS has not had a great track record for the development of electronic data capture over recent years. Connecting for Health was a massively ambitious programme to unify electronic NHS data (5). The programme was launched in 2002 and it commenced in earnest on 1 April 2005- a date worthy of note! It was finally abandoned as a total failure some 9 years later having cost 12.4 billion pounds (6)

In chronic conditions other than cystic fibrosis the outcomes have not been great. Hermens and colleagues investigated personalised coaching systems to support healthy behaviour. The result of the study showed that the protocol was feasible but there were many challenges if the outcomes were to be favourable in future studies (7). Tabak and co-workers in the Netherlands undertook a

pilot study to determine if the use of 3D accelerometer activity connected to a smartphone could increase physical activity at home in patients with COPD. No increase in activity was observed in the 34 patients during the time of the study (8).

Murgia and colleagues published studies in patients with CF in 2011 (9) and 2015 (10) and although the results were somewhat encouraging the authors highlighted the medico-legal aspects involved in telemedicine as well as the need for everyone to universally approve and implement agreed and consistent collaborative protocols in future THC studies if reliable long-term data is to be generated. There is little evidence from the medical literature that this has happened.

From 2006-2014 I was the Medical Director of the West Midlands Medicines for Children's Research Network (WMMCRN) and had a number of meetings with our 'Children and Young People's Advisory Committee'. This was an extraordinary group of young people aged 9-17 years who truly advised us on what issues they felt were important to consider and progress in relation to children's medical research. We were often surprised by their comments but they were always clear and extremely helpful to us. I remember a full day's meeting with them about smart phones, Apps and telemedicine usage. They were very much against Apps as they slowed down their phones and didn't want to be reminded of their illnesses. If they felt reminders intruded into their lives they would 'switch them off'. They also explained that in many schools the teachers confiscate the pupils' phones on arrival in the morning and they are not given back to them until school closes in the afternoon. I wonder how many companies and individuals developing THC programmes for young people have taken the time to speak with those expected to use them and what type of responses they have received. There is an implicit understanding that anything developed with an IT component will be well received by the younger generation with eager enthusiasm. That is not my experience from my cystic fibrosis and young people's contacts within the West Midlands over the last 10 years.

The television programme 'In The Night Garden' broadcast on the CBeebies channel has been an outstanding success. The programme was designed by the same team that produced 'The Teletubbies'. Most members of the audience were familiar with some of the characters such as Iggle Piggle, Upsy Daisy, Makka Pakka and the Pontipines. What they were surprised about, however, was the amount of research which went into the programme's development. Families were videoed watching the programme over an 18 month period to determine the child and the family responses. The developers wanted to ensure they created a safe haven for the child before bedtime as well as portraying sounds produced during the development of speech. The programme was modified as a result of the detailed research findings. No such detailed research is evident in the medical literature about THC. It has just been assumed that 'it is a good thing' and will enhance future patient care. According to NHS Research, however, THC is now one of the favoured areas for funding support. Is there a possibility that millions of pounds will be wasted on THC projects and many hours of HCP time will be devoted to this theme without the appropriate background knowledge and customer support? THC is an inadequately researched theme which is now being targeted by the NHS as a major way forward. Have similar NHS targets ever been shown to be effective?

My personal belief is I still think there is no true replacement for direct patient contact, a belief that was reinforced by Amy, one of my patients with cystic fibrosis who has given me permission to tell you about her today. Amy was a model patient whom I looked after from a very young age. She and

her family never missed appointments but just as she was entering puberty in 2009 she decided she had had enough treatment and decided to stop everything so she could be normal like all her school friends. She began arguing with her parents, wouldn't listen to anyone and within three months her lung function had fallen from within the normal range to 40% expected for her age and height. She became very unwell and required intravenous antibiotics, intensive physiotherapy and a prolonged hospital admission. As she improved she recognised what had happened and at school wrote a wonderful essay about 'The day that changed me'. Amy and her parents have given their permission for all to access the website and read Amy's thoughts (11) from 2009. The reason I have included this is that I am sure that THC systems or the like would have had zero impact on Amy's decision at the time. In the end it was the personal contact and close support from all the CF team which eventually made Amy restart her medications. She is now a wonderful young person pursuing her ambition of becoming a performer on stage and we all wish her well in the future. She is now cared for by our adult CF team.

Claims that THC helps to 'Train the brain' and offer better vision in the future are overoptimistic and not founded on scientific principles. There is no regulatory body overseeing the development of new Apps so their quality is often unproven. The statement seen in association with an App-'Medically approved' is meaningless. How many Apps have references attached to enable a rigorous scientific analysis of its contents? Should THC become part of the jurisdiction of the Prescription Medicines Code of Practice Authority (PMCPA), the Medicines and Healthcare Regulatory Agency (MHRA) or the Department of Health (DoH)? Is this a time for caution and reflection or should we go forward as my colleague suggests developing more and more THC programmes just because we can?

The decision in the debate is yours but I would suggest that in these times of financial hardship and uncertain futures we should be cautious and I recommend you reject the motion that THC is the way forward in the management of patients with cystic fibrosis.

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