Revolutionising Care: Unleashing the potential of digital health technology in the physiotherapy management for people with cystic fibrosis.

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Abstract

This viewpoint paper explores the dynamic intersection of physiotherapy and digital health technologies (DHTs) in enhancing the care of people with cystic fibrosis (pwCF), in the context of advancements such as highly effective modulator therapies (HEMTs) that are enhancing life expectancy and altering physiotherapy needs. The role of DHTs, including telehealth, surveillance, home monitoring, and activity promotion, has expanded, becoming crucial in overcoming geographical barriers and accelerated by the recent pandemic. Physiotherapy, integral to CF care since 1946, has shifted towards patient-centred approaches, emphasising exercise training and a physically active lifestyle. The reduction in inpatient admissions due to HEMTs has led to increased homecare and virtual consultations, and DHTs have revolutionised service delivery, offering flexibility, self-management, and personalised care options, however there is a need to comprehensively understand user experiences from both people with CF (pwCF) and physiotherapists. The paper highlights the essential exploration of user experiences to facilitate clinician adaptation to the digital requirements of modern clinical management, ensuring equitable care in the "Future Hospitals" arena. Identifying research gaps, the paper emphasises the need for a thorough evaluation of DHT utilisation in CF physiotherapy education, training, and self-monitoring, as well as the experiences of pwCF with virtual consultations, self-monitoring and remote interventions. Online group exercise platforms address historical challenges relating to infection control, but necessitate comprehensive evaluations of user experiences and preferences. Future-proofing DHTs within the physiotherapy management of CF demands a shift towards full integration, considering stakeholder opinions and addressing barriers. While DHTs have the potential to extend physiotherapy beyond the hospital, the paper stresses the importance of understanding user experiences, addressing digital poverty, and working towards more equitable healthcare access. A flexible approach in the 'future hospital' is advocated, emphasising the need for a nuanced understanding of user preferences and experiences to optimise the integration of DHTs in CF care.

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Revolutionising Care: Unleashing the potential of digital health technology in the physiotherapy management for people with cystic fibrosis.

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INTRODUCTION

Cystic fibrosis (CF) is a chronic, autosomal recessive, life-limiting multisystem disease, historically leading to respiratory failure and premature death (1). Chest physiotherapy (airway clearance techniques) to enhance secretion clearance has been a cornerstone of CF physiotherapy, with self-

and guided management being the focus of care as people with CF (pwCF) develop and their disease dictates different approaches. Advancements in clinical management of CF, including the introduction of highly effective modulator therapies (HEMTs), has positively impacted on life expectancy (1, 2). Consequently, physiotherapy management of CF and the specialist CF physiotherapist must adapt (3).

There is a growing body of evidence supporting examples where physiotherapy has benefited from DHTs, primarily existing in the management of musculoskeletal (4) or neurological issues (5, 6). Here, specific exercise, virtual reality and gaming have positively influenced rehabilitation, however this new innovative technology currently does not exist in CF physiotherapy management. DHTs have been utilised in CF for some time, particularly in areas of geographical diversity; with virtual consultation and monitoring therapies becoming increasingly commonplace (7). DHTs have been used in chipped nebulisers monitoring adherence to therapeutic regimes (8) and home spirometers, alongside other wearables and mobile applications (e.g. the Project Breathe patient-driven symptom reporting (9)). There has however, been limited research into evaluation of virtual physiotherapy interventions in CF, the implementation of DHTs and their effectiveness within the physiotherapy management for CF .

Virtual physiotherapy in CF could facilitate more than symptom monitoring, extending to simple exercise testing, remote physical activity, and exercise opportunities, as well as implementing measures to influence adherence and the prompt management of symptoms. Whilst virtual consultations may be more convenient for some pwCF and reduce risk of cross-infection, not all pwCF will benefit from reducing the frequency of in person consultations.

The changing role of physiotherapy within CF care

Physiotherapists, originally involved in CF care for chest clearance in 1946, now participate in a global clinical and research network; developing national and international clinical guidance and standards of care (3, 10-12) Whilst global standards of clinical care exist, there will be variation in implementation of these and DHTs, due to socio-economic factors, availability of infrastructure and accessibility in health care settings and beyond (13, 14). Irrespective of these challenges, an awareness of data storage, accessibility and safety of data is essential, and the physiotherapist must be mindful of these factors.

CF physiotherapy has progressed to a more active, patient-centred approach to clinical care (11, 12). This still includes airway clearance techniques and assessment of respiratory and non-respiratory manifestations (e.g. musculoskeletal, sinuses) and, with a rising prevalence of increased weight leading to obesity (15) and cardiovascular disease (16), an ever-increasing involvement in exercise

testing, training and physical active promotion. The reduction in inpatient admissions following HEMT has enabled an increase in homecare and virtual consultations, reducing reliance on hospital services, mitigating cross-infection risks, and reducing travel to hospital.

Virtual consultations, assess pwCF remotely, with mobile devices monitoring symptoms, assessing pulmonary function, and patient-reported outcomes, as well as promotion of physical activity (17, 18). These have been well received, but with variable compliance due to competing demands impacting on overall uptake (17). Several virtual platforms, some led by physiotherapists, offered education and training to pwCF and healthcare professionals, enabling widespread delivery of information and resources, with the potential for standardised data collection and optimised quality care (17, 19-22).

Self-monitoring, particularly spirometry, has been explored, with physiological data and symptom recognition proposing earlier identification of pulmonary exacerbation (9, 23-25). Self-monitoring, however, may be less accurate, leading to undetected worsening health status (23, 24). Despite suggestions that self-monitoring is well utilised (24, 26), uploading of digital data is poorly adhered to, and collecting data should be optimised based upon clinical usefulness (23). Cox et al. (27) highlighted in a systematic review, that > 50% of participants were non-compliant with data entry; with data upload considered burdensome, potentially intrusive and a barrier to sustainability. Exploration of opportunities for continuous monitoring or passive uploading of data [as occurs with some wearables (9)] may reduce the burden on pwCF and positively influence their use of devices. Improving accuracy of self-monitoring and symptom monitoring using DHTs may facilitate swifter directed access to relevant professionals providing individually tailored treatments, facilitating personalised discussion and, ultimately, leading to more user-driven outcomes [NCT04798014] (28, 29).

Following the introduction of HEMT, many clinical outcomes observed in pwCF with access have improved, such as fewer pulmonary exacerbations, improved lung function and exercise tolerance (30). The physiotherapists' role in exercise testing, training and promoting a physically active lifestyle is well researched (31-34), and remains central to the maintenance and optimisation of health in pwCF(12), however, there are no specific CF-related physical activity guidelines (35). Uptake and adherence to physical activity programmes in pwCF is poor (19), and this occurs irrespective of remote delivery (36). Physical activity is central to the CF physiotherapist's role; however, segregation requirements historically rendered group activities unachievable. Physical activity platforms have enabled physiotherapists to deliver online group exercise [23], both live and on-demand (20), and have been shown in other chronic illnesses to provide solutions to remotely

support physical activity, emotional wellbeing and improve quality of life (37). Online group activities allow pwCF to experience peer support (17, 20, 27), physiotherapy supervision, and education pertinent to their health (20, 38). Despite the anticipated positives of this, significant drop out and discontinuation in some centres has occurred. It is important to evaluate reasons for this and engage with pwCF to identify user opinion for future online physical activity provision.

The use of DHTs in the physiotherapy management of CF

Benefits of DHTs in CF care include reducing cross-infection (39) and enabling interprofessional team management in areas with diverse geographic distances (7). PwCF have responded positively to remote consultation, online exercise provision and monitoring [8, 12, 13].

Airway clearance quality has been shown to have a greater impact on respiratory function than quantity and frequency (40, 41). The integration of DHT using pressure sensors embedded in devices may influence physiotherapy assessment and treatment delivery. Using DHTs to guide, counsel and facilitate goal attainment may enable individualised physiotherapy care for pwCF, offering a flexible approach to modern management, enhancing adherence, and impacting on clinical outcomes important to pwCF. For example, the use of wearables and supportive messaging from physiotherapists demonstrated a prolonged and positive change in step count and exercise capacity in adults with CF (42). Assessment of data derived from virtual consultation and self- monitoring can guide assessment of what has worked well and what should perhaps be discontinued. This will include evaluation of digital literacy skills and acceptance by pwCF in using DHT to access their healthcare teams effectively and appropriately.

The role of telehealth for exercise testing has been shown in other diseases to offer a viable alternative to some in person testing (43) and requires further exploration in CF. To date exercise testing in pwCF has not been researched in a virtual capacity but could support centres with limited or no access to in house exercise testing facilities.

Can we future proof and optimise the use of DHTs within the physiotherapy management of CF?

DHTs are not yet fully integrated into CF management locally or globally (45) and often considered an “add-on”. Electronic patient records are widely used but have not fully replaced conventional written records for all consultations. Opinions of healthcare teams and pwCF are essential to strengthen implementation and sustainability of any future DHTs in routine care (24). Further research into barriers and facilitators for sustained use of DHTs will support long-term digital plans

(46, 47). Optimisation of current data uploading applications and platforms to ensure that they are clinically useful for both the user and the stakeholders must occur, including support for training and education when using DHT (45).

There are numerous frameworks (e.g. REAIM (48) and NASSS (49)) developed specifically identifying interacting influences dictating success or failure of a system (47, 50-52). Recent analysis of physical activity in pwCF (19) recognised that frameworks offer reasons for non-engagement, with respect to relevance and user satisfaction with interventions and associated technology. Future research should apply these frameworks, exploring how to improve uptake and use of DHT (53).

Implications of DHT should be considered, as changing one aspect may influence (positively or negatively) other areas of care (54), and introduction of DHTs in managing children and adolescents with CF will be significantly different to adults and those with multimorbidity's. Some pwCF are digital natives, growing up with an appreciation of DHTs, others have lower levels of digital literacy and trust in digital services and, consequently, uptake of opportunities to influence their health may be lower (55, 56). DHTs could negatively impact the "personal" feel of a consultation leaving pwCF feeling that they are no longer "known" to their clinical care team with respect to their wider societal issues (57).

Conclusion

DHTs present exciting potential for physiotherapy management in CF. Virtual consultations, online physiotherapy (including physical activity and exercise training) and remote monitoring may, however, not be desirable, available, or appropriate for everybody. We urgently need to understand the experience of early implementers, understand enablers of success and the needs of the CF community, to better inform equitable use. We must ensure this does not create a digital divide, as digital poverty continues to exist, impacting on digital and health literacy, utilisation, and practical application of DHT. We must ensure virtual consultations meet the requirements of those accessing them. To ensure "no-one is left behind" and optimise care for pwCF, we need to challenge the unsustainable 'one size fits all' approach. This involves a flexible infrastructure supporting the future physiotherapy management of pwCF, based on patient experience reported outcomes allowing refinement and delivery of an optimal service.

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Supplementary Files