Using eHealth to monitor idiopathic pulmonary fibrosis

Dr Marlies Wijsenbeek and Dr Karen Moor from the Erasmus Medical Centre are developing novel eHealth tools, in collaboration with patients, to enable home monitoring of patients with idiopathic pulmonary fibrosis (IPF). Patients are able to use the eHealth tool to find information about IPF, record their symptoms and conduct consultations via video or email. Furthermore, the patient can take regular real-time spirometry measurements which can be immediately assessed by healthcare providers. This alerts the patient and healthcare provider to changes in a patient's condition leading to potential treatment adjustments.

Idiopathic pulmonary fibrosis (IPF) is a devastating progressive lung disease with a median survival of only three to five years. IPF typically occurs more often in men than women and generally affects elderly patients, aged 50 years and above. IPF has a highly variable disease course. Some patients experience slow disease progression, whereas others suffer from a rapid decline in lung function. The incidence of IPF is steadily increasing and according to the British Lung Foundation, over 6,000 people are diagnosed with IPF every year in the UK. IPF is characterised by an accumulation of scar tissue (fibrosis), reducing lung elasticity which impacts oxygen uptake. The term 'idiopathic' means that the cause of fibrosis is unknown. However, it is thought that scar tissue accumulates due to lung damage from either acid reflux, viruses, or environmental factors such as breathing in certain kinds of dangerous dust. Furthermore, some patients may be more genetically prone to developing IPF when their lung is damaged.

Patients experience symptoms such as breathlessness, coughing and fatigue. These symptoms greatly lower the patient's quality of life, affecting even simple tasks such as going to the shops. Patients lose their independence and often have to rely on friends and family for support. Currently, there is no cure for IPF. In very rare cases, patients may be given a lung transplant. In general, patients are given medication and may also attend therapy to deal with their symptoms. For example, pulmonary rehabilitation consists of a specific exercise programme which helps the patient cope with feeling short of breath. There are two anti-fibrotic drugs which are specifically used to slow down lung scarring – pirfenidone and nintedanib. However, these drugs could have bothersome side-effects such as nausea, fatigue and diarrhoea.

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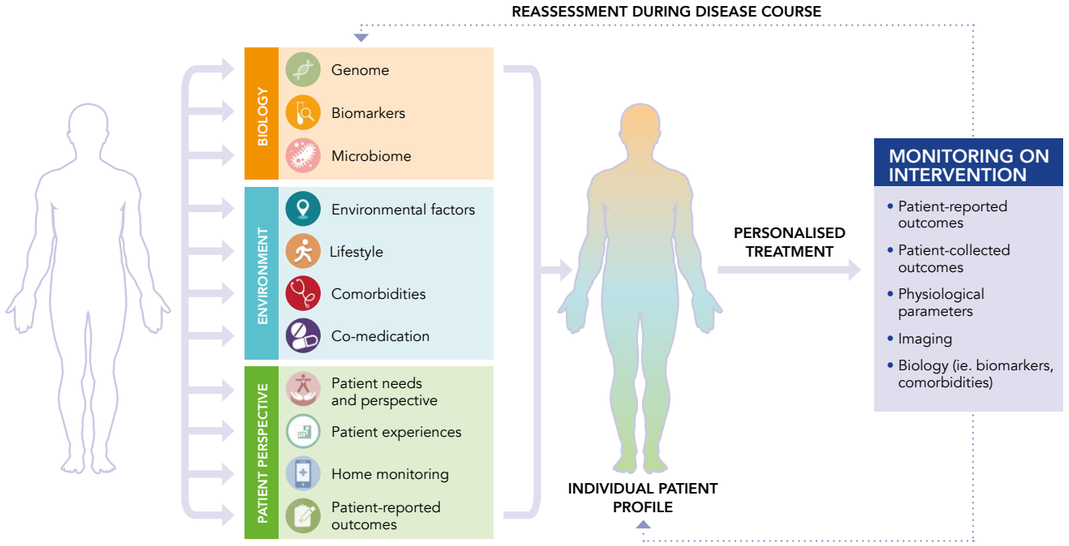
The uptake of oxygen via the lungs is key for good health. The scarring in IPF reduces the lung's elasticity and makes this process less effective.



This diagram illustrates the numerous elements involved in personalised treatment, as well as the reassessments and adjustments needed.

A personalised approach to IPF requires frequent monitoring due to the highly variable nature of IPF and the variation in response to therapy by different patients. Dr Wijsenbeek and Dr Moor from the Erasmus Medical Centre were inspired by the possibility of using eHealth tools to monitor the patient more frequently at home with a low burden for the patients. They aimed to investigate whether this could improve patient quality of life.

PERSONALISED MEDICINE

Lately, there has been increasing interest in the use of personalised medicine to treat and monitor disease in IPF. Until now, personalised medicine has mainly focused on understanding the molecular mechanisms underpinning IPF. Little is understood about the influence of interactions between environmental, molecular and genetic mechanisms and how biological factors affect disease progression and influence the effectiveness of different treatment options. Improving our knowledge of these mechanisms could lead to the identification of specific biomarkers which could be used to develop targeted therapy.

However, Dr Wijsenbeek and Dr Moor believe that patient factors, such as lifestyle, comorbidities, preferences and experiences should also play a role in personalised medicine. Patient engagement is also an important aspect. For example, it is vital to assess the perspectives of patients before treatment. In randomised controlled trials, medication may show beneficial results at a group level. However, for some individuals, certain drugs may prove ineffective or the side effects may outweigh the benefits of treatment. Currently, over-use and under-use of medication is fairly common in IPF. However, this may not be the case if the patient's preferences are considered. These preferences may alter as the disease progresses, so personalised treatment plans must be regularly evaluated.

Dr Wijsenbeek and Dr Moor recognise the importance of personalising treatment for IPF, taking into consideration the patient's perspective, physiology and lifestyle. They believe that eHealth could contribute to personalised medicine by allowing for frequent home monitoring, evaluation of treatment response and potential treatment adjustments. In fact, a previous study in IPF showed that home-based measurements predicted disease decline better than less frequent hospital-based measurements of lung function. Moreover, home monitoring could be invaluable for IPF patients as they often struggle to attend frequent hospital visits due to reduced motility and breathlessness. As a result, the team developed an award-winning eHealth tool for patients to improve their understanding of their health and become actively involved in managing their disease.

eHealth involves the use of information and communication technologies to exchange health-related data between the patient and healthcare provider.

eHEALTH AND HOME MONITORING

eHealth involves the use of information and communication technologies to exchange health-related data between the patient and healthcare provider. Dr Wijsenbeek and Dr Moor developed a novel eHealth tool, IPF Online, in collaboration with patients. This innovative eHealth tool won two Dutch prizes - the Patient Participation Prize in 2018 and the Lung Foundation public prize in 2016. IPF Online has many features for patients to utilise including: an information library, the possibility for

econsultations and video consultations, information about medication and possible side-effects, an area for patients to fill in their symptoms and possible side-effects they may be experiencing and other patient-reported outcomes, such as quality-of-life questionnaires. Patient-reported outcomes are reports of the patient's quality of life, health or functional status that come directly from the patient, without, for example, interpretation by clinicians.

IPF Online is integrated with real-time wireless spirometry. This is a simple test used to monitor lung conditions using a spirometer to measure how much air is breathed out in one forced breath (forced vital capacity or FVC). Interestingly, the team believed that a major challenge would be patient engagement as many elderly people could possibly be hesitant using online tools. However, the majority of IPF patients who were asked to participate wanted to use IPF Online. By using IPF Online, the patient can gain insight into their own health condition and become involved in the management of their disease. The team performed multiple studies to determine the feasibility of the home monitoring programme/eHealth tool and patient satisfaction.

PILOT STUDY

Ten IPF patients from the Erasmus Medical Centre were involved in the pilot study with home spirometry. Patients were asked to test IPF online for one month using a tablet. During this time patients performed daily home spirometry and online patient-reported outcomes at baseline and after four weeks. The spirometry data is transmitted real-time and is directly available for analysis by both patients and healthcare providers. Additionally, automated email alerts are sent if the patient reports troublesome side-effects or if the FVC declines by >10% for three consecutive days.

IPF patients found real-time spirometry very useful and would recommend it to others.

Overall, the results revealed that home spirometry highly correlated with hospital spirometry, showing that home spirometry is a reliable test. Furthermore, 80% of patients considered daily spirometry easy and 90% thought that the process was not burdensome at all. All patients found real-time spirometry very useful and would recommend it to other IPF sufferers.

Patients and hospital staff in the study group did identify several potential issues with home monitoring and spirometry and recommendations were made. For example, a handheld spirometer may be difficult for patients to use. Therefore, the team suggested that patients should be provided with clear training before they start the programme. Furthermore, some patients had no internet access. To tackle this issue, these patients could be supplied with a 4G SIM card to guarantee internet access. Patients who had never used the internet before were able to use the tablet with ease and perform spirometry due to the simple design. Additionally, some patients may not comply with taking measurements daily. In these situations, patients could be sent email reminders.

A limitation of the pilot study is that it was performed at a single centre with a relatively small sample size. Although this was effective at highlighting reliability, patient satisfaction and identifying potential barriers, a larger scale, multi-centre study is needed to see whether it improves patients' quality of life in the long term. The study team is currently addressing this by performing a multi-centre randomised clinical trial with three other centres in the Netherlands. The team is following patients for six months to investigate whether the home monitoring programme/eHealth tool improves quality of life compared to standard care.

FUTURE PERSPECTIVES

Dr Wijsenbeek and Dr Moor, in collaboration with patients and healthcare staff, have designed a novel eHealth tool that enables personalised, individually-tailored therapy. Patients can understand their own condition and have a say in managing their own disease. Furthermore, by performing real-time spirometry measurements, which are immediately available to health care providers, changes in condition are quickly identified and the right treatment can be given. eHealth tools could revolutionise how we treat chronic, long-term conditions. In the future, eHealth tools could be integrated in clinical practice to truly embrace personalised medicine.

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Patients can see a daily overview of their lung function results (FVC) in IPF Online. Healthcare providers can also see these results and receive an alert if FVC declines >10% for three consecutive days.

Behind the Research

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Research Objectives

Drs Wijsenbeek and Moor evaluated a new home monitoring programme with real-time wireless home spirometry in idiopathic pulmonary fibrosis.

Detail

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Bio

Marlies Wijsenbeek is a pulmonary physician and associate professor at the Erasmus MC in Rotterdam. She is chair of the Erasmus MC multidisciplinary interstitial lung disease center (ILD) centre, secretary of the Idiopathic Pulmonary Pneumonia Group of the European Respiratory Society and the Dutch National ILD section, and board member of the Netherlands Respiratory Society. Her research interests include eHealth and other patient-centred outcome measures in interstitial lung diseases, and new therapies in IPF and sarcoidosis.

Karen Moor is a PhD candidate at the Respiratory Department of the Erasmus MC in Rotterdam. The aim of her research is to improve clinical outcome measures and quality of life for patients with IPF, with a special focus on the development and use of eHealth tools.

Funding

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Collaborators

Currently a randomised controlled trial is being carried out together with the hospitals Zuyderland MC, St. Antonius hospital and OLVG in the Netherlands.

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Personal Response

How could eHealth tools, such as IPF Online, improve patients' quality of life in the long term?

" eHealth tools enable frequent monitoring at home at a low burden for patients. This is especially important in a chronic progressive disease such as IPF, which has a huge impact on patient quality of life and a high symptom burden. Our home monitoring programme IPF Online has the potential to improve quality of life through patient engagement, better medication use, low-threshold communication, stimulation of self-management and earlier detection of disease deterioration. "

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