





Clinical science

Experiences of systemic sclerosis patients with home monitoring of their pulmonary function: a qualitative study

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Abstract

Objective: To evaluate the experiences, perceived benefits and disadvantages of home monitoring of pulmonary function in SSc patients with interstitial lung disease (ILD).

Methods: Semistructured interviews were conducted among SSc-ILD patients who used the home monitoring application of pulmonary function for at least 3 months. In our program, patients are instructed to perform home spirometry weekly at fixed time points using a mobile application with results being directly visible for patients and physicians. Audiotapes of the interviews were transcribed verbatim and analysed using inductive thematic analysis after performing a member check.

Results: A total of 13 patients were interviewed, with a median age of 58 years (range 36–75) and a median experience with home monitoring of 12 months (range 3–12). We identified four major themes, including routine of telemonitoring, impact of telemonitoring, trust in telemonitoring and implementation in regular healthcare. Overall, patients found performing home spirometry to be feasible. Major perceived benefits of performing home spirometry are an increase in patient empowerment, better understanding of the disease course and a reduction in hospital visits, whereas identified disadvantages are an emotional burden of telemonitoring, heightened awareness of illness, doubts about its validity and the need for digital competencies. All patients expressed their willingness to continue, although some patients emphasized the need for face-to-face visits.

Conclusion: Telemonitoring of pulmonary function is accepted by SSc-ILD patients with the perceived benefits outweighing the disadvantages. Adopting a patient-centred strategy that considers individual factors and addresses concerns proactively is warranted to successfully implement home spirometry.

Lay Summary

What does this mean for patients?

In patients with systemic sclerosis (SSc), lung scarring (called pulmonary fibrosis) is an important organ complication that leads to reduced quality of life. It is the most frequent cause of SSc-related death. A group of experts in Europe recommend initiating treatment in patients with severe or progressing pulmonary fibrosis. Currently, it is difficult to measure lung function regularly to detect progressive disease, as there is variability in measurements and the course of the disease is unpredictable. Based on previous research, we predicted that measuring lung function at home might be an effective way to detect worsening lung function in a timely manner. Before implementing home lung function tests in regular healthcare, it is important to understand patients' views. Therefore, we evaluated the experiences of patients with SSc who have measured their lung function at home. We showed that, in general, patients find it acceptable to perform lung function tests at home, but that it might be accompanied by emotional burden. Adopting a patient-centred strategy that considers individual factors and addresses concerns in a proactive way is needed for successful implementation.

Keywords: systemic sclerosis, interstitial lung disease, telemonitoring pulmonary function, personalized medicine.

Rheumatology key messages

- Features of telemonitoring can be both advantageous and disadvantageous, warranting shared decision making for successful implementation.
- Our study shows that home spirometry might lead to an emotional burden in patients with systemic sclerosis.

Introduction

SSc is a heterogeneous autoimmune disease characterized by a triad of inflammation, vascular damage and fibrosis [1]. Different organs may be affected to a varying degree, causing

increased morbidity and mortality [2]. Interstitial lung disease associated with SSc (SSc-ILD) is an important complication that leads to reduced quality of life and represents the most frequent cause of disease-related mortality [3].

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SSc-ILD is characterized by an unpredictable disease course and occurs in the first 3–5 years after disease onset, with reported incidence rates of 30–50% [4–7]. Patients with SSc-ILD can be categorized based on their clinical presentation and the extent of their disease. Specifically, individuals with subclinical ILD have a confirmed ILD diagnosis through high-resolution CT (HRCT) scan but remain asymptomatic in terms of their ILD, in contrast to patients with clinical ILD [8]. To classify patients according to the extent of their disease, the Goh criteria are commonly employed. These criteria categorize patients as having extensive disease if they have either >30% disease involvement on HRCT or 10–30% disease involvement along with a forced vital capacity (FVC) \geq 70% [9]. All SSc-ILD patients can experience progressive disease, irrespective of their subset of ILD [8]. A recent study showed that the annual incidence of progressive ILD in patients with SSc is 30%, but that progressive periods and periods of stability and improvement alternate during the disease course [10]. Progressive SSc-ILD not only occurs in the early disease stage, but also in later stages, as patients with a disease duration >7 years have an annual incidence rate of progressive SSc-ILD of \approx 12–15%, comparable to that of patients in an early stage [11]. The European consensus statement recommends treating patients with progressive and/or severe ILD. Therefore, timely diagnosis of the onset of ILD and accurate monitoring of pulmonary function is crucial [12]. Current clinical practise is to monitor patients in an early disease stage with frequent in-hospital pulmonary function tests. Although FVC, one of the measured pulmonary function parameters, is an accepted clinical marker to monitor disease activity, it is a suboptimal way as it is hampered by variability in measurements and unpredictable disease course [5, 12, 13].

In the past decade, research has shown that home spirometry is feasible and reliable for most patients with ILD, leading to the hypothesis that in SSc-ILD, telemonitoring might be an effective approach for timely detection of progressive SSc-ILD [14]. After establishing the feasibility of home spirometry in SSc-ILD, we are currently investigating the validity of home spirometry in detecting progressive SSc-ILD in a prospective multicentre observational study called the DecreaSSc study.

In order to provide person-centred medicine, it is important to understand the experiences of patients with home monitoring of pulmonary function. A recent qualitative study, primarily involving patients with idiopathic pulmonary fibrosis (IPF) and a few with connective tissue-associated ILD, revealed numerous advantages of home spirometry but also highlighted potential risks to psychological well-being [15]. Given key differences in IPF and SSc-ILD in the natural disease course, these findings might not apply similarly for SSc-ILD patients. Whereas SSc-ILD is characterized by alternating periods of progressive disease and stabilized or improved pulmonary function, IPF typically lacks natural improvement and is characterized by progressive disease [16]. Therefore, it is important to investigate whether specific unmet needs are present with home spirometry in SSc-ILD patients. In this qualitative study we aimed to investigate patients' experiences, benefits and disadvantages of home monitoring the pulmonary function specifically in SSc-ILD.

Methods

Patient sampling

This qualitative study is part of an ongoing clinical prospective study (DecreaSSc study) to evaluate the validity of using home spirometry in detecting progressive SSc-ILD. In the DecreaSSc study, adult SSc-ILD patients with a disease duration \leq 5 years and a treatment duration of a maximum of 8 weeks are included and instructed to perform home spirometry once a week at a fixed time point. The results are collected via a mobile application and are directly visible for both patients and physicians. A relevant decline in the home measurement is confirmed with a hospital measurement and results in appropriate further steps. Patients who were unable to speak, read or write in Dutch, patients without a compatible device or patients with no internet or mobile network access were excluded from the DecreaSSc study.

The Institutional Review Board of the Radboud University Medical Center, Nijmegen concluded that the Dutch Medical Research Involving Human Subjects Act did not apply to this study. Informed consent was obtained prior to each interview. The Consolidated Criteria for Reporting Qualitative Research checklist was used to ensure complete and transparent reporting [17].

Data collection

For this qualitative study, patients were invited to participate via phone by the researcher conducting the interview if they had at least 3-months experience of home monitoring pulmonary function. Purposive sampling was applied using age, decline in pulmonary function in home measurements (i.e. FVC decline \geq 5%) and treatment for ILD to obtain a heterogeneous study population. Semistructured interviews were conducted face-to-face or via videocall (due to the COVID-19 pandemic) in Dutch by a female PhD student (A.V.) or a female fourth-year medical student (G.M.M.S.) between February 2022 and December 2022. One interview was conducted with each participant. The initial three interviews were conducted by the first investigator (A.V.), who is also the researcher responsible for enrolling the patients into the DecreaSSc study and providing ongoing guidance throughout the study. The first investigator was not involved in the treatment of the participants. The second investigator (G.M.M.S.) was unacquainted with the participants. Both interviewers received appropriate interview training preceding the study.

The topic guide for the semistructured interviews was constructed based on evidence-based knowledge and clinical practice. To identify relevant topics, previous research about telemonitoring in chronic diseases was reviewed. The preliminary topic guide was discussed with two patient partners and pilot tested to obtain the final version (see Fig. 1). The interviews started with open-ended questions and the topic guide served as a guideline to steer the interview. Interviews were conducted until data saturation was reached, meaning that no new codes (i.e. meaningful items) were identified in the last two interviews. In addition, demographic and disease characteristics were gathered from medical records.

Data analysis

Interviews lasted 25–66 min and audiotapes were directly transcribed verbatim and summarized. Next, to increase internal validity, a member check was conducted, meaning the summary of the transcript was discussed with the participant

<p>Home monitoring program</p> <ul style="list-style-type: none"> • Breathing technique <ul style="list-style-type: none"> ▪ Use of the spirometer ▪ Frequency of measurements ▪ Fixed moment of performing the measurements • Application <ul style="list-style-type: none"> ▪ Reminders • Visualisation of own lung function <ul style="list-style-type: none"> ▪ interpretation of own lung function • Training and support during the study <p>Effects on patients</p> <ul style="list-style-type: none"> • Would you like to continue using home monitoring after the study has been finished? <ul style="list-style-type: none"> ▪ Pros and cons ▪ Recommendations to other patients ▪ Effect of decrease in hospital visits <p>Implementation in regular care</p> <ul style="list-style-type: none"> • Do you have any suggestions to improve home monitoring? • Undisclosed items

Figure 1. Overview of the topic guide used during the semistructured interviews

for feedback to ensure credibility of the data [18]. Subsequently, the interviews were analysed using inductive thematic analysis following the principles of grounded theory, including open coding, axial coding and selective coding in Atlas.ti version 23.1.1 (ATLAS.ti, Berlin, Germany) [18, 19]. The first step involved thoroughly reading the interviews multiple times to gain familiarity with the data. Thereafter, two researchers (A.V. and G.M.M.S.) labelled independent text fragments with meaningful content (open coding). Discrepancies in coding between the two researchers were carefully examined and discussed in order to achieve consensus. In cases where agreement could not be reached, a third investigator (C.H.M.E.) was consulted to provide additional input and help resolve the discrepancies. Once consensus was reached on the coding framework between the first two investigators (A.V. and G.M.M.S.), the interviews were coded by the second investigator (G.M.M.S.). To ensure accuracy and consistency, the codes were subsequently analysed and reviewed by the first investigator (A.V.). Any disagreements that arose during the review process were resolved through discussion as described above. The transcription of the interviews and analysis were performed in Dutch. The themes and citations were translated into English by the first author (A.V.).

After data saturation was reached, the codes were categorized (axial coding) and identified into themes and subthemes (selective coding) by the first investigator (A.V.). Next, the results of the selective coding were discussed with the senior investigator (C.H.M.E.) and thereafter with the whole research team, including the patient partners, to finalize the grouping.

Results

Participant characteristics

A total of 13 interviews were conducted, given that data saturation was reached at interview 11. None of the patients refused to participate or dropped out after giving informed consent. The baseline characteristics of patients are shown in Table 1. We interviewed eight female and five male patients,

of whom three showed a decline of >5% in FVC% predicted in the home measurements during the study.

In total, four major themes were identified, including routine of telemonitoring, impact of telemonitoring, trust in telemonitoring and implementation in regular healthcare (see Table 2 for themes and illustrative quotes). To address discrepancies in content coding, we organized a total of five meetings, each lasting 50–60 min.

Theme 1: Routine of telemonitoring

In Fig. 2, the home monitoring routine of patients is shown.

Measurements

Participants found it feasible to perform once a week home spirometry, although some preferred longer intervals during periods with stable pulmonary function. They advised against increasing the frequency of home monitoring, as they believed it could lead to heightened health awareness and potential challenges in incorporating regular home monitoring into their daily lives. Some participants struggled with the fixed timing for the measurements due to busy schedules, but the majority of patients found the time investment minimal. Some participants appreciated the repetition of reminders through e-mail, as it helped them to stay disciplined, while others suggested implementing a time-adjustable reminder feature within the application.

Use of spirometer

Participants generally found the use of the home spirometer to be easy and straightforward, however, some participants experienced challenges with excessive saliva hindering optimal exhalation during repetitive measurements. Overall, participants did not find the required breathing technique to be burdensome. Some participants preferred the spontaneity of the hospital spirometry, as it was performed during a breathing cycle, while the home spirometry initiated abruptly.

Use of the application

Most participants found the application to be user friendly. The availability of two sign-in options (application and website) requiring separate passwords was perceived as confusing by some users. Some older participants struggled with the technology, which was also anticipated by younger participants.

Participants recommended streamlining the process of performing multiple measurements in succession by minimizing the number of repetitive steps in the application. Furthermore, participants suggested avoiding the use of sliders in the questionnaires, implementing a feature to indicate their inability to perform a weekly measurement and integrating an option to delete measurements.

Interpretation of results

Participants compared their measurements and analysed the trend of their pulmonary function. Some aimed to track trends, while others sought a comprehensive understanding of the findings.

Some participants wanted to receive immediate feedback on a detected decrease in their condition rather than waiting for the next consultation. Additionally, several participants also preferred to receive feedback even when their values fell within the range of normal, either through a visual

Table 1. Baseline characteristics of the interviewed patients

Participant	Gender	Age (years)	Disease duration (years)	FVC decline $\geq 5\%$	Immunosuppressive treatment	Experience with telemonitoring (months)
1	Female	37	2.5	Yes	Yes	9
2	Male	68	2.7	Yes	No	12
3	Female	69	1.2	No	No	12
4	Female	63	1.2	Yes	Yes	12
5	Male	58	2.6	No	No	12
6	Female	59	1.6	No	Yes	12
7	Female	48	3.17	No	No	12
8	Male	66	0.4	No	Yes	3
9	Male	57	0.9	No	Yes	6
10	Male	75	4.2	No	No	6
11	Female	36	1.3	No	No	12
12	Female	56	2.7	No	No	9
13	Female	57	0.1	No	Yes	12

None of the patients used antifibrotic treatment.

representation of the limits of normal values in the graph or through regularly scheduled feedback.

Motivation

Participants were motivated to perform home spirometry when they recognized the importance of home monitoring of pulmonary function, but motivation waned during periods with generally stable results and when combined with regular hospital pulmonary function tests. Some participants were reluctant to perform home spirometry because they doubted the reliability of the measurements. Technical issues, i.e. a malfunctioning application or difficulties in performing the test due to saliva overproduction, were also reported to be demotivating.

Theme 2: impact of telemonitoring

Emotional impact

Participants found it pleasant and reassuring to observe their weekly results through home spirometry, allowing them to detect ILD progression earlier and take appropriate actions. Participants noted that having knowledge about the limits of normal values would further enhance these feelings of reassurance.

The impact of performing home spirometry was linked to the course of FVC% predicted. Stable measurements provided reassurance, although the act of performing home spirometry itself could sometimes be stressful. Additionally, witnessing stable results in their home spirometry led to an increase in the participants' trust in their own health. Fluctuations in measurements within the range of normal evoked varying emotions. Participants who were able to filter out these fluctuations and concentrate on the overall trend perceived home spirometry as a valuable tool, while other participants experienced negative emotions such as stress, anxiety and insecurity with declining values. Furthermore, the uncertainty arising from a single decreased measurement was often unpleasant and confronting for participants, as it could potentially be attributed to suboptimal execution of the required technique for performing home spirometry. One patient had an extra scheduled hospital pulmonary function test during the study period due to a decrease in the home measurements. This patient appreciated the extra scheduled hospital visit and found it to be reassuring.

Weekly home spirometry was confrontational for some patients, as it heightened their awareness of illness, whereas

other patients did not experience this. Furthermore, regular monitoring at the hospital became less intimidating with prior knowledge about their pulmonary function.

Patient empowerment

Participants valued being in control and having the opportunity to regularly monitor their pulmonary function test without relying solely on hospital appointments. However, some participants stressed the importance of the physician taking the lead in evaluating the home spirometry measurements and effectively communicating the findings to the participant.

Furthermore, performing home spirometry offered participants a better understanding of their disease course and reduced their fear of progression. Despite the potential confrontations associated with home monitoring, certain participants found that the gained disease insight made it worthwhile. Some participants found performing weekly measurements to be less crucial as they acquired a deeper understanding of their disease course.

Theme 3: trust in telemonitoring

Confidence in measurements

Several participants trusted home measurements as much as hospital measurements, while others had more trust in hospital measurements due to the standardized procedures and equipment used in the hospital setting. It was mentioned that home monitoring is subjective, as factors like fatigue, time constraints or not performing at one's best could lead to worse results. Moreover, for some participants the absence of external motivation diminished trust in home spirometry. One patient found that regularly performing home spirometry provided a better overview of the trend than the hospital measurements, which are typically conducted at longer intervals. Therefore, few participants had more trust in the home measurements. One participant found home monitoring incomplete due to the absence of diffusing capacity of the lungs for carbon monoxide. Lastly, participants expressed their appreciation for the opportunity to schedule an additional check-up at the hospital when they developed progressive ILD.

Theme 4: implementation

Continuing home monitoring

All participants expressed their interest in continuing home monitoring of pulmonary function. A few participants with stable disease did not see immediate value but were willing to

Table 2. Overview of themes and subthemes

Theme	Subtheme	Illustrative quotation
Routine of telemonitoring	Measurements	Participant 12: 'It only takes 5 min, however, including signing in and answering questionnaires it may be 10 min. But that is all, so it really is a little effort'. Participant 10: 'Performing weekly a measurement is possible, but once every two weeks would also be okay'.
	Usage of spirometer	Participant 11: 'I never had problems with performing home spirometry as a consequence of malfunctioning of the spirometer or bad Bluetooth connection with the spirometer. So in general it is going quite well'. Participant 2: 'During the hospital measurement, you first always breathe calmly, and then they tell you to deeply inhale and immediately exhale hard. This method gives more calmness in your breathing cycle. Now you have to inhale and exhale in the spirometer exactly at the right time'. Participant 8: 'The first time I need to perform, everything goes well. The second and third time, however, I perform not so good, e.g. 27% instead of 87%, because I am hindered by saliva'.
	Use of the application	Participant 6: 'The application itself is very straightforward. It is really easy to find your data and everything works rapidly. So I am very positive about that'. Participant 5: 'It might be useful to enable to unsubscribe for a measurement. So that you can announce that you are not able to perform a measurement due to lack of time or illness'. Participant 1: 'It depends on how good you are with mobile phones and more. I can imagine that elderly need more assistance'.
	Interpretation of results	Participant 7: 'It was good that we could see the measurements back, but I don't want to know all the details. If there is something wrong, I will be notified during a regular check-up'. Participant 13: 'I rewatch my measurements frequently to compare the results with a few months or 6 months ago. I then consider why a decrease has occurred'.
	Motivation	Participant 5: 'The home monitoring, you must be willing to do it. I think it is wise to take advantage of it, especially when you are concerned with your own health'. Participant 1: 'If I would like to continue home monitoring, it should yield something for me. Then there really has to be a reason for me to do it'.
Impact of telemonitoring	Emotional impact	Participant 2: 'You might feel it goes well, but when this is also confirmed by numbers it feels reassuring'. Participant 3: 'Because I sometimes had a week, which you of course also saw in the home monitoring, that I had lower values. And then I thought, this is not nice, but the week afterward it was then again good'. Participant 1: 'Every week you are confronted with the fact that you are ill and then you also have to do something with it'.
	Patient empowerment	Participant 12: 'I liked to participate, because you want to know what your situation is and how it is developing'. Participant 7: 'The doctor should be in the lead and communicate that with me'.
Trust in telemonitoring	Confidence in measurements	Participant 1: 'If, for example, I had to perform home spirometry, but actually did not have time or motivation, and I did perform at my best, than the results were also lower. That made me question the results of home monitoring'. Participant 12: 'I think weekly measurements give a better overview than a one-time measurement once a 3 months'.
Implementation	Continuing home monitoring	Participant 5: 'Continuing home monitoring depends on my well-being for me. I am doing very well at the moment, which makes it easier to stop. However, when this turns around, it is pleasant to know where you stand using home monitoring'. Participant 13: 'Performing home monitoring for years would provide me insight in my health status and a feeling of control, which I would appreciate'.
	Hospital visits	Participant 4: 'In case of a stable health situation, I think a reduction in hospital visits is a good call'. Participant 13: 'No, I would like to receive guidance in the hospital and also appreciate the hospital measurements more'.
	Recommendations for home monitoring	Participant 6: 'I would really recommend it as part of regular healthcare'. Participant 7: 'Especially for the young generation and people living far away from the hospital, home monitoring is very interesting'.

continue if it reduced hospital visits or in case of disease progression. One participant, who initially dropped out due to heightened awareness of illness, expressed a willingness to continue with reduced frequency of home measurements (once every 2 weeks) to decrease hospital visits.

Hospital visits

Participants had mixed feelings about reducing the frequency of hospital visits. Some valued the potential reduction, considering travel distances and the inconvenience of hospital visits. However, some participants felt the current frequency

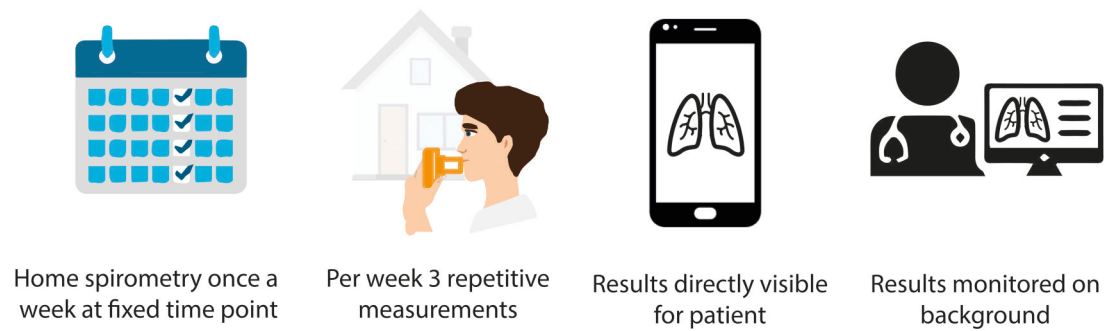


Figure 2. Routine of home monitoring

of face-to-face contact should remain the same, as they considered these consultations important and sometimes also trusted the hospital measurements more. The need for physical appointments to monitor other disease features or during unstable phases was mentioned as well.

Recommendations for home monitoring

Participants advocated to implement home monitoring of pulmonary function in healthcare and would recommend it to other participants, particularly younger individuals and those residing far from the hospital.

Discussion

This is the first qualitative study providing an in-depth analysis about the experiences of patients monitoring their pulmonary function with home spirometry in SSc-ILD. Our results indicate that, in general, all our patients are willing to perform home spirometry, despite some patients who experienced disadvantages with being telemonitored. Major reported benefits of performing home spirometry are an increase in patient empowerment, a better understanding of disease course and a reduction in hospital visits, whereas identified disadvantages are an emotional burden of telemonitoring, doubts about its validity and the need for digital competencies.

Features and aspects perceived as advantageous are increased patient empowerment, weekly update on the course of pulmonary function and a reduction of hospital visits, although for some patients these might be disadvantageous depending on individual preferences and circumstances. This is further exemplified by a patient who initially dropped out due to emotional distress but yet is willing to continue home spirometry if it leads to a reduction in hospital visits. These findings indicate that telemonitoring possibilities should be tailored to patients' characteristics, preferences and disease stage, aligning with the 2022 EULAR points to consider for remote care [20]. The personalization of a home spirometry program should focus, at a minimum, on the intensity of guidance, feedback about measurements and the frequency of face-to-face consultations. In sum, consultations about expectations, benefits and disadvantages preceding initiating home monitoring ensures that telemonitoring can be implemented effectively, hypothetically leading to improved patient outcomes and enhanced management of SSc-ILD.

Our study shows that telemonitoring pulmonary function might be experienced as burdensome by some patients [21–24], which is in line with previous research [14, 15]. Interestingly, the same home monitoring application used in

the DecreaSSc study has been previously evaluated in patients with IPF, sarcoidosis and SSc, with results showing that the vast majority of patients positively evaluated home spirometry and none of the patients found home spirometry to be burdensome [21–24]. This discrepancy could be explained by the prognostic uncertainty associated with SSc, the longer duration of our study (previous studies lasted 3–6 months) or the method of evaluation (survey *vs* in-depth interviews). In our study, the emotional burden experienced by patients was mainly due to the heightened awareness of their illness and challenges involved in interpreting fluctuating measurements. The uncertainty associated with interpreting the results could be overcome with (written) instructions on how to interpret the results, providing limits of normal values and regular feedback via phone or (automated) feedback loops. Thus the emotional burden of home spirometry should not be ignored during consultations and can be substantially reduced by implementation of timely (automated) feedback loops and tailored guidance.

Before integrating home spirometry into the standard healthcare protocol for SSc-ILD patients, several critical steps must be taken. First, it is imperative to establish the validity of home spirometry in effectively detecting progressive SSc-ILD. Second, conducting a comprehensive cost-effectiveness study is essential to assess its feasibility. We hypothesize that home spirometry has the potential to yield significant cost savings for both the healthcare system and society at large. Home spirometry offers the possibility of reducing the frequency of hospital visits and the need for hospital-based pulmonary function tests. This could result in substantial savings in medical expenses. Furthermore, home spirometry holds the potential to contribute to the early detection of disease progression, facilitating prompt initiation of treatment. This, in turn, could lead to decreased productivity loss and reduced societal costs. In conclusion, the integration of home spirometry into the routine care of SSc-ILD patients holds great promise, but before implementation, validation of its effectiveness in detecting progressive disease is crucial.

The major strength of our study is the qualitative study design, allowing identification of new factors associated with home spirometry (e.g. emotional burden). Furthermore, the involvement of the patient's partners during the entire study was of added value to conduct proper interviews as well as analyse and interpret the results. A limitation is that moderator acceptance bias could have occurred, considering that the first few interviews were conducted by the researcher (A.V.), who included the patients in the telemonitoring program. However, given that the majority of the interviews were conducted by a researcher unfamiliar with the patients, we

believe that all different views have been collected in our study. As no treating physicians were involved in assessing the home measurements, no qualitative data are available concerning the experience of physicians. Given that this study focused on (almost) treatment-naïve SSc-ILD patients with a short disease duration, the results cannot be extrapolated to patients with more-established disease, as in the early stages more prognostic uncertainty exists. Furthermore, the inclusion criteria might have resulted in a positive selection bias, considering that patients were only eligible for this qualitative study after 3 months use of home spirometry. However, we did include two patients, who dropped out after 3 months, thereby still being able to collect experiences of patients who prematurely ended the study. Another limitation is that patients used telemonitoring as an add-on to regular health-care, which only allows us to hypothesize how blended care would be experienced by SSc-ILD patients. It is therefore important to continuously evaluate the experiences of the home monitoring program to further optimize telemonitoring of pulmonary function in SSc-ILD.

In conclusion, our study shows that telemonitoring of pulmonary function is in general accepted by SSc-ILD patients and highlights the significance of adopting a patient-centred strategy that considers individual factors and addresses concerns proactively, including the emotional burden due to telemonitoring.

Data availability

The datasets are available from the corresponding author upon reasonable request.

Authors' contributions

A.V., M.C.V., C.H.M.E. contributed to study conceptualization; A.V., G.M.M.S., C.H.M.E. to data curation; A.V., M.C.V., C.H.M.E. to formal analysis; M.C.V. to funding acquisition; A.V., G.M.M.S., C.H.M.E. to investigation; A.V., M.C.V., G.M.M.S., C.H.M.E. to methodology; AV to project administration; M.C.V., C.H.M.E. to supervision; A.V. to visualization; A.V. to writing the original draft; and all authors reviewing and editing the final draft.

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