Communication

Designing Home Telecare: A Case Study in Monitoring Cystic Fibrosis

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ABSTRACT

The objective of this study was to investigate the feasibility of using home telecare for monitoring cystic fibrosis (CF). Five adolescents were asked to use a home telecare system during a routine hospital visit over one week. Frequency of use was measured from computer logs. Unacceptable measurements were identified by visual inspection. User impressions of home telecare and appropriateness of the system for managing CF was determined from observations of user interaction, survey and qualitative analysis.

Patients used the system to record lung function measurements without any supervision and indicated that the system was easy to learn and use. The role of home telecare in supporting collaborative self-management appeared to be well understood. Home telecare was seen as a supplement to standard care that would provide a link to the hospital between clinic visits. Participants indicated that feedback provided by the system and ongoing clinical support would determine long-term use and compliance with the monitoring protocol. Clinicians reported the usefulness of home telecare in maintaining a longitudinal record of their patient’s health that would supplement verbal description of symptoms and reduce time to treatment by increasing patient self-awareness of health status.

Home telecare may be a feasible intervention for monitoring CF. Feedback provided by the system must be presented in a format that is familiar and easily understood by users. Further system refinement and evaluation is required to determine patient compliance with their customized monitoring protocol prior to assessing impact on clinical outcomes.

INTRODUCTION

Innovations in information and communications technologies enable new models for healthcare delivery in the home. 1–4 Home telecare extends traditional diagnosis and patient management beyond the doctor’s clinic into the everyday environment. A continuum of care from the patient’s home, to the doctor’s surgery, to specialty services in hospitals, and to other service providers in the health sector can provide a more integrated approach to healthcare provision and disease management. However, many recent reviews of telemedicine have failed to find evidence to show the benefits of technology-enabled models to support home care. 5–7 Despite the significant volume of literature on telemedicine applications, high qual-

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ity studies based on quantitative or qualitative data are scarce.

The incompatibility of home telecare technology with the broader socio-technical environment within which it is placed may be a significant barrier to successful implementation and evaluation of clinical impact. It is increasingly being recognized that technology is not implemented and used in isolation of the broader socio-technical context, and that human and organizational issues should be taken into account during system design.\textsuperscript{8, 9}

We undertook to design a home telecare service to provide a communication link between patients and a hospital-based clinic for monitoring cystic fibrosis (CF). A systematic methodology was followed to carry out the design of this intervention involving the following stages:

Stage 1: Define problem and assess needs
Stage 2: Identify type of intervention
Stage 3: Develop a model of intervention
Stage 4: Assemble enabling technology
Stage 5: Conduct field tests to refine and implement home telecare
Stage 6: Evaluate clinical impact

An overview of the technical configuration resulting from Stage 4, as listed above, is given in Figure 1.\textsuperscript{10, 11} The intervention was designed to facilitate a communication link between patients at home and a hospital-based CF clinic. Home-based patients are connected to a central host via the Internet. A computer-based measurement module is required for the review and acquisition of clinical data from the patient’s home. A database server is a central repository where patient information and clinical data is stored. Clinicians and the CF Clinic also have access to the central host via the Internet. Up to date clinical data is available for review.

The prototype system was implemented as a subset of the Home Telecare System developed at the Biomedical Systems Laboratory, University of New South Wales.\textsuperscript{12} Each patient was provided with a PC-based measurement device (a spirometer connected to a laptop computer) interfaced to the RS-232 serial port. The user interface was customized to provide facilities for lung function measurement and a symptoms diary was implemented as part of the system’s questionnaire module. A screen shot of the patient interface (Home Client) for acquisition of lung function measurements is shown in Figure 2. This interface guides patients through the process of acquiring measurements and provides instant feedback at the end of the recording. The Clinicians Interface is web-based and shows a trends graph for lung function recordings (Fig. 3). Each point on this graph illustrates the selected parameters tracked over a selected time period. Details of the recordings used to extract these parameters may be viewed by selecting a given point on the graph.

The configuration facilitates data collection from the home and makes it available to clinicians for review. Data is transferred to the Central Host using TCP/IP via a standard telephone line. The Home Client was set up to automatically upload the data once a day. Confidentiality of medical records is maintained by implementing separate access levels in the web application. An authentication system is used to restrict access to patient records.

In this paper we report the results of a pilot study (Stage 5 of design) to investigate the feasibility of home telecare for monitoring CF. The objectives of the field trial are two-fold. The first is to assess use of the Home Telecare System in a field setting. The second is to obtain user impressions of home telecare and appropriateness of the system for managing CF.

FIG. 1. Overall architecture of home telecare system for managing CF. The central host supports the tasks of patients and clinicians.
MATERIALS AND METHODS

Setting and participants

Five patients, aged 10–14 years, participated in the pilot study. Since the home telecare service was modeled around the management of CF at a weekly hospital clinic, the pilot study was conducted in the same setting. Adolescents from the CF Clinic who were well enough to perform spirometry were invited to participate in the study. Parents were present during installation and were requested to be available for the interview. Two individuals declined to participate, citing a lack of interest.

The clinician group comprised two respiratory physicians. Additionally, a technician from the hospital respiratory laboratory served as an expert consultant to assess the validity of unsupervised lung function measurements acquired in this study.

Procedures

Patients were asked to use the Home Telecare System during their scheduled hospital stay for ongoing therapy. The study was carried out in parallel with routine treatments. A 3 L syringe was used to calibrate the device. Prior to installation the lung function measurements were validated against a hospital spirometer used as a gold standard. The system was deployed in a trial mode and no clinical interventions were based on the lung function measurements acquired during the study.

An information package was prepared for patients including participant information sheet,
consent form, and a system user manual. Following an initial introduction and training session, participants were asked to perform lung function measurements at least once a day. The symptoms diary, which was implemented as an online questionnaire, was also demonstrated. Help desk support was provided for the duration of the study.

Frequency of use was determined from automatically generated computer logs of system use. Observations of user interaction with the system were carried out one day after installation. The Home Client provided instant feedback about measurements to users (i.e., forced expiratory volume in one second (FEV₁) and forced vital capacity (FVC) at the end of each recording). At the end of their hospital stay (approximately 1 week), a structured interview was conducted to assess user impressions of home telecare and the appropriateness of the system for managing CF. Interviewees were asked to respond to a survey (Table 1) and were encouraged to elaborate on any views. Patients and their principal care giver, usually a parent, were asked to provide feedback about their experience of using the Home Telecare System. The survey was used to gather information about user perceptions of the technology; their concerns about the privacy and security of health information; usability, convenience, utility, potential effects on clinical process, and their overall impressions of the concept.

Two respiratory physicians and a respiratory laboratory technician were interviewed when a complete data set was available following patient assessments of the system. The system was demonstrated to clinicians and they were shown the online summary of patient results. Clinicians were asked to comment about utility of home telecare, appropriateness of the Home Telecare System, and requirements of the system for acquisition of valid lung function by unsupervised adolescents. Ethics approval for the study was obtained from the South Eastern Sydney Area Health Service Ethics Committee.

Analysis

Interviews were audio-taped and transcribed. Transcriptions were coded and analyzed using N-Vivo. Coding was based on the questions asked and on themes emerging from the interviews. This data was analyzed in combination with the questionnaire responses, computer logs, and usability assessment. The validity of unsupervised spirometry measurements was determined through visual analysis in consultation with a respiratory laboratory technician.

RESULTS

Use and usability of the Home Telecare System

The system was used by all five participants to perform lung function measurements. Between 9 and 19 lung functions (median 16) were attempted over a period of 5 to 9 days (Table 2). Since three efforts were required for each attempt, the total number of measurements ranged from 27 to 54 recordings (median 49). Four participants performed measurements more than once a day. This was in agreement with self-reported use where all participants reported doing the measurements at least once a day throughout the trial. More measurements were recorded on the first 2 days after installation when compared with use towards the end of the trial period. Participants also reported performing extra measurements to demonstrate for family and friends visiting them in hospital. A trend line of the lung function measurements (FEV₁ and FVC) recorded by participants is shown in Figure 3.

Participants found the interface highly usable. They did not have any trouble navigating the screens and reported that the instructions were clear and easy to follow (one strongly agreed, four agreed). This was confirmed by observations of their interaction with the system on the second day of the study. Participants did not require any extensive training and they were able to learn the tasks after one demonstration. Although computer experience was not specified as a selection criterion, all participants used computers at home and school. School assignments, web surfing, chatting with friends, and games were reported as the main reasons for using computers. This is also supported by all participants’ neutral response (neither agree or disagree) to the question: "Do you think the Home Telecare System is useful?"
<table>
<thead>
<tr>
<th>Table 1. Survey Items Used to Assess the Home Telecare Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Perception of information technology</strong></td>
</tr>
<tr>
<td>I think that computers and the Internet can play an important role in managing my health. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>I think that the home telecare system can play an important role in managing my health. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td><strong>Privacy &amp; security of health records</strong></td>
</tr>
<tr>
<td>I feel comfortable with having my health information collected and sent to my doctor by the computer. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>The use of the home telecare technology threatens the confidentiality of my health information. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td><strong>Usability</strong></td>
</tr>
<tr>
<td>I find the home telecare system easy to use. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>The instructions on the computer screen are clear and easy to follow. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>I find the computer screen easy to use. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>I would prefer a nurse or community health worker to take my measurements for me. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>How would you rate the appearance of the home clinical workstation unit? [five options, “very good” to “poor”]</td>
</tr>
<tr>
<td>How would you rate the appearance of the computer screens? [five options, “very good” to “poor”]</td>
</tr>
<tr>
<td><strong>Utility</strong></td>
</tr>
<tr>
<td>I liked the feedback that the home telecare system gave me about my condition. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>The home telecare system would give me more control over managing my health. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>The monitoring provided by the home telecare system would give me extra peace of mind. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td><strong>Use</strong></td>
</tr>
<tr>
<td>How often did you use the home telecare system? [five options e.g. more than once a day; once a day; several times a week; once a week; never]</td>
</tr>
<tr>
<td>Have you ever taken any extra measurements that were not scheduled? [three options e.g. never; once; several times]</td>
</tr>
<tr>
<td><strong>Convenience</strong></td>
</tr>
<tr>
<td>Would using the home telecare system interfere with your other activities? [yes/no]</td>
</tr>
<tr>
<td>The equipment would be intrusive to my home environment. [five options, “very good” to “poor”]</td>
</tr>
<tr>
<td><strong>Overall impressions</strong></td>
</tr>
<tr>
<td>Overall, how do you rate the home telecare system? [five options, “very good” to “poor”]</td>
</tr>
<tr>
<td>I enjoy using the home telecare system. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>Using the home telecare system has made me more comfortable with computers. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>The home telecare system would help me to better manage my condition. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>The home telecare system would help my doctor to better manage my condition. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>Overall, I am satisfied with my home telecare system. [five options, “strongly agree” to “strongly disagree”]</td>
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<tr>
<td>I would like to continue to use the home telecare system on a regular basis. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>I would recommend the home telecare system to my friends. [five options, “strongly agree” to “strongly disagree”]</td>
</tr>
<tr>
<td>How could we improve the home telecare system? Please give details of any changes that could be made to make the home telecare system more useful for you.</td>
</tr>
<tr>
<td><strong>Training, technical support</strong></td>
</tr>
<tr>
<td>How would you describe the technical support that you are receiving? [five options, “very good” to “poor”]</td>
</tr>
<tr>
<td>Is the home telecare system working without any problems? [three options, e.g., no problems, occasional problems, frequent problems]</td>
</tr>
<tr>
<td>Have there been any technical problems with any of the following? [six options e.g. none, occasional, several, many, not working at all, did not use]</td>
</tr>
<tr>
<td>Lung function unit, Questionnaires</td>
</tr>
<tr>
<td>If yes, please tell us about the problems you have had.</td>
</tr>
<tr>
<td>How would you describe the training that you received at the start of this study? [five options, “very good” to “poor”]</td>
</tr>
</tbody>
</table>
tionnaire statement, “Using the Home Telecare System has made me more comfortable with computers”.

After initial training the system was used without any assistance. Participants did not report any technical problems in the interviews and no calls were received at the help desk. However, a technical problem resulted in the corruption of records of one participant during synchronization with the server and it was not deemed appropriate to repeat the measurements. Except for verification of system use and lung function technique, almost all requirements of the trial were satisfied, a usability assessment was completed and the participant was interviewed.

Participants reported the ease of being able to perform lung function measurements without any supervision (all five agreed that the lung function unit was easy to use). The validity of measurements is effort dependent, thus lung function is usually measured under supervision of a laboratory technician. The patients were generally familiar with spirometry from having to perform these measurements on every visit to the clinic. They did not require assistance or prefer a nurse or community health worker to take the measurements for them. All participants disagreed with both statements about requiring assistance (two strongly disagreed and three disagreed) and preference for a nurse or community health worker to supervise recording of lung function (four strongly disagreed and one disagreed). Ambiguity in one of the screen instructions was identified. One patient reported discomfort at having to perform three successive blows without an interval between consecutive efforts.

Not all measurements recorded by participants were valid lung function records (Table 2). Errors in measurement were classified as either being performed with an acceptable or poor technique (Fig. 4). Participants mistakenly inhaled through the mouth-piece, either before or after the required exhalation. Poor efforts and false starts were largely responsible for the remaining measurement errors. Unsupervised valid recordings of lung function are illustrated in Figure 5.

There was some interest in an on-screen incentive. A boat race corresponding to the three consecutive blows was available in the user interface as an incentive scheme for younger participants. This feature was only selected by the younger participants, as most were interested in seeing the on-screen flow-volume curve. Parents of younger participants suggested that an on-screen incentive scheme that would coach the user through each of the three lung function measurements, similar to a computer game, would increase the likelihood of the system being used.

Participants reported that the system was convenient to use. Time required to perform the measurements was not seen as a barrier for home monitoring. All participants disagreed with the statement that taking measurements was time consuming (four disagreed and one strongly disagreed). Use of the Home Telecare System was not seen as something that would interfere with their other activities. Home monitoring was perceived as something that could

<table>
<thead>
<tr>
<th>Patient</th>
<th>Days</th>
<th>Total efforts</th>
<th>Inhaling through mouth piece (%)</th>
<th>Poor effort (%)</th>
<th>False starts (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5</td>
<td>45</td>
<td>12 (26.7)</td>
<td>20 (44.4)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td>2*</td>
<td>9</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>54</td>
<td>1 (2.2)</td>
<td>7 (15.6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>4</td>
<td>7</td>
<td>57</td>
<td>0 (0)</td>
<td>8 (17.8)</td>
<td>11 (24.4)</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
<td>27</td>
<td>2 (4.4)</td>
<td>6 (13.3)</td>
<td>2 (4.4)</td>
</tr>
</tbody>
</table>

Table 2. Usage Summary of the Home Telecare System

*Records corrupted due to technical problem.
be easily integrated into a daily therapeutic regime that would typically comprise physiotherapy, use of a nebulizer, and medications. Participants reported that the measurements were easy to perform and did not take up much time and that they would be willing to perform the measurements once a day. Participants indicated that technical problems with computers would increase frustration and may be a barrier if adequate support was not available. In this respect interviewees reported the general user frustration with computers and the time required to fix them. An interest in online CF specific health information was also expressed. However, its usefulness was seen as being dependent on ease of access. Therefore, ease of use and access were seen as barriers for use of computer based support for managing CF.

Overall, the Home Telecare System was perceived to be easy to use (four agreed and one strongly agreed). The computer screens received a good rating (three good and two average) and the home clinical workstation unit received an adequate rating. The system was reported as being: PI: “Good, nice and easy to read, easy to navigate.”

FIG. 4. Examples of some errors in performing spirometry measurements unsupervised.
Patient impressions of the concept and system

Participants had favorable impressions of the home telecare model. The Home Telecare System received good ratings (two very good, three good) and participants indicated that they were satisfied, and enjoyed using the system (all five agreed with both items).

They indicated that computers and the Internet could potentially play an important role in chronic disease management. (two strongly agreed, three agreed). The system was perceived as being relevant to the management of CF. Responses to the statement “... the Home Telecare System can play an important role in managing my health,” ranged from strongly agree (one) to neither agree or disagree (one), two agreed with the statement. Their neutral response was based on reasoning that the role played by the system would be dependent on the support and feedback available from clinicians. Participants did not report searching on the Web for information specific to CF. Physicians and the CF Clinic were reported as the main source of health information.

The role of home telecare in supporting collaborative self-management appeared to be understood well. This was evident from participants’ comments about the ability of home telecare to provide a link to the hospital, whereby the families could modify treatments based on feedback from the hospital.

The interviewees did not express any major concerns about breaches to privacy and the security of health records on the Internet. All participants felt comfortable about having their information sent to their doctor on the Internet. They did not think that the home telecare technology threatened the confidentiality of their health information since home monitoring data did not contain any sensitive information. A comparison with personal financial information like bank balances and credit card details was made to point out the difference. Even so, parents were generally satisfied to know that their child’s health records were secure and access was restricted. All participants expressed an interest in using the system on a more regular basis and reported that they would recommend it to their friends.

Utility of home telecare for CF management

Home telecare was perceived as being useful for management of CF. Participants thought that the system could help them and their doctor to better manage their condition. All participants agreed with both survey statements regarding the utility of the home telecare system. The merit of the system was seen in the quantitative measure of health status provided by lung function. Since lung function is only measured at monthly clinic visits in the existing therapeutic regimen, participants reported that their self-assessment was based on symptoms like cough, loss of energy, as well as changes in overall manner. The ability to quantitatively track changes for downward trends was perceived to be of value (P2–P4).
P2: “I think it’s an excellent way particularly with lung function because it plays such an important role in CF management. So I think it’s a great idea.”

P3: “. . . so it would make you much more aware of what’s going on, well and truly. And if you can get the figures [so that] you can compare with last week or yesterday . . . ”

P4: “That I would understand quicker and so normally she’s around such and such percentage and if she’s dropped then you know that there is a significant difference.”

Lung function measurements were also seen as something that would enable better explanation of symptoms for remote consultations via the telephone (P5).

P5: “Yeah we come down [to the clinic] every month and that’s really good and we still need to keep doing that. But there’s been times in between when I felt that she’s been unwell and I ring him up and I’m asking him what should I be doing and she’s been doing this and he’s got a lot of questions . . . whereas I think if he had something that he could look at . . . as well as talking to me on the phone it could give him a more accurate picture.”

Home telecare was also seen as an additional channel for communication between the home and hospital. Participants felt that the system would provide a link to the hospital between clinic visits. They did not think that the monitoring would reduce the number of clinic visits and felt that it would be a good add on and a quantitative measure would enable them to track a deteriorating condition sooner thereby reducing the time to treatment. Not having to wait until the clinic for an assessment of ongoing health was seen as an advantage, as evident by the following statements:

P6: “. . . I do wonder that if you had this sort of system going at home you could perhaps get onto those sort of situations quicker if you thought that there was a change in her condition.”

P7: “. . . so they might be able to say you need to be doing something now, rather than waiting a week or two.”

Participants also indicated that instant availability of monitoring results would enable them to adjust their physiotherapy accordingly.

P8: “Probably would, if you knew sort of that your lung function was say deteriorating, yeah you would sort of up the physio or do something quicker and would be a bit more aggressive with the care probably. Um . . . and if you saw you were getting better, well then, you could work out when to ease back a bit.”

The convenience offered by the system was also appreciated. The distance to the hospital and the time between clinic visits were mentioned as some barriers to accessing care. The system was considered important for:

P9: “. . . anybody who lives substantial distance from the hospital, where it’s not an easy task to be in and out to the doctor all the time.”

Parents felt that that using home telecare would increase their child’s sense of responsibility, as this was something that they could control and perform themselves. It could also improve compliance with existing therapy. Moreover, the computer system would enable adolescents to integrate their healthcare as an interest. It would also increase awareness and involvement of other family members in treatment. As far as the intrusiveness of the Home Telecare System was concerned, the system was perceived as something that would have more of a positive than negative effect. All participants disagreed with the statement about the equipment being intrusive with their home environment.

Although obtaining feedback and being able to understand the measurements were cited by all participants as an important factor determining utility and by extension use of the system, response to the questionnaire item regarding on-screen feedback was mixed (three neutral and two disagreed). Direct feedback to patients was not implemented in this stage of the design, patients and their carers were provided with printouts of their measurements. The on-screen feedback (FEV1 and FVC) was in the form of raw measurements which were not
expressed as a percentage of standard reference values. The neutral response was from participants who were not able to interpret their measurements. This group requested additional training in the use of the system and interpretation of results. The unsuitability of the on-screen format was pointed out by participants who were able to interpret their measurements. Due to familiarity with the format used by the hospital there was a preference for presentation of results in the same format. Although the parameters presented by the system (FEV1 and FVC) were relevant they were not presented in the most appropriate format. The following comments were made:

P10: “If you get the information back straight away, yes I would, but if you just did it and sent the information away, then there wouldn’t be any need for it.”

P11: “If they had a database back here that we were sending back the information . . . . Aw yeah . . . incredible, benefit to them and us, they can reconcile the data and give their diagnosis. They could ring me up and say that ought to come in because his lung function is going down. So the advantages of it would be very good.”

P12: “. . . if you’re going to do it at home there needs to be a home level understanding.”

P13: “Well I . . . see . . . the numbers on this were slightly different . . . they were the same numbers but they didn’t have them in percentages. I would have liked to see them . . . because I’m used to seeing her . . . whether she gets 70%, 80% or 90%, I would’ve liked the percentage on there because I understand that a little bit better.”

The symptoms diary was barely used. Participants felt that the questions were fairly basic and were not specific enough to their particular condition.

Clinician feedback

Clinicians agreed that home telecare would be useful for monitoring CF. The Home Telecare System would provide a longitudinal record of their patient’s health. The advantage of quantitative measurements that would supplement the verbal description of symptoms was highlighted. Clinicians indicated that home lung function measurements would have a positive effect on their patients. It would reduce time to treatment by increasing self-awareness, irrespective of whether they could interpret measurements expressed as percentages of reference values. Home telecare would be useful in teaching patients to interpret their percentage values. Lung function performed on the home telecare system would also have a therapeutic effect and would increase compliance with other therapy.

Electronic measurements and the visual interface were seen as advantages of the Home Telecare System. The integration of lung function acquisition with the visual interface and the longitudinal record were compared with a monitoring system that employed a peak flow meter and written diary. Clinicians noted that being able to see and do the measurements was much better. The usefulness of the home telecare in monitoring home intravenous (IV) therapy in CF and asthma was also indicated. A common symptoms diary was not seen as being very useful because of variations in severity of CF.

Clinicians were not surprised at the number of errors in recording lung function measurements. Stating that validity of measurements is dependent on effort, the clinicians recommended employment of a better on-screen incentive in the acquisition of lung function. The incentive should provide personal and population reference values as part of the user interface. This was seen as a method to reduce errors resulting from poor efforts and false starts. They agreed that training and improved screen instruction would reduce errors resulting from confusion with the technique.

DISCUSSION

Main findings and implications

This pilot study assessed the feasibility of using a Home Telecare System to support management of CF. Participants used the system to record lung function measurements unsupervised and reported that it was easy to learn and use. Most had underestimated the time and effort required to complete the measurements.
but indicated that the home telecare intervention could be easily integrated into their daily therapy. Time required to complete the monitoring task and convenience of using the system were important considerations for continued use. Feedback provided by the system and interpretation of clinical measurements were perceived to be crucial for acceptance and routine use of home telecare. Participants highlighted the need for presentation of results as percentages of population reference values, a format that was familiar and better understood. In other words, instead of expressing FEV1 as liters, it would be expressed as a percentage of predicted values for height and sex. This indicates a need to modify the user interface and retest feasibility prior to further evaluation of home telecare for monitoring CF.

Provision of a facility for home lung function measurements with reporting both to the clinician and patient was perceived to be of value. The role of home telecare in supporting collaborative self-management appeared to be well understood with the qualification that ongoing clinical support would be necessary to sustain such a model. Participants indicated that monitoring lung function at home would reduce the time to treatment thus it would be possible to quantitatively track health status to prevent further deterioration of their health. In this regard home telecare was perceived as a supplement to standard care that would provide a link to the hospital between clinic visits. These findings indicate that home telecare may be a feasible intervention to support remote monitoring of CF.

A large proportion of lung function measurement errors could be attributed to participants’ lack of familiarity with the procedure for recording lung function on the Home Telecare System. The technique for this system is similar to that of a peak flow meter; deep inhalation followed by a single exhalation through the mouthpiece. Since all participants regularly performed hospital measurements they were well trained in the technique required by the spirometer in the respiratory laboratory. Recording a lung function on that device firstly involved normal breathing to record tidal volume, then a deep inhalation and exhalation, followed by a final inhalation. Despite the initial training and second day observation, confusion with the recording technique was responsible for the large number of errors in the recordings of one participant. Although the other four participants were also initially confused with the recording technique, the training during installation was sufficient to clarify the procedure. In particular, the same breathing technique was required with our system but the requirement was to connect to the mouthpiece to breathe out and disconnect before breathing in. This was essentially a training issue and would require the trainer to make a clearer distinction between the Home Telecare System’s and the hospital spirometer. Clearer on-screen instructions may also be helpful in reducing some of the errors. Some errors were due to a screen instruction which asked users to “please blow now,” on completion of the first and second blows. This instruction would have been conveyed more clearly by, “The system is now ready. You can blow when you are comfortable.”

The present study provided an opportunity to employ a combination of qualitative and quantitative methods to investigate the feasibility of home telecare. We involved users in the testing process and recorded their impressions of the prototype system so that their views about what is planned, how the service is delivered, and their feedback about usability issues can be incorporated into the design prior to implementation. A home trial with a comparative group conducted over a longer duration is required to assess the clinical impact and effectiveness of home telecare for monitoring CF.

Limitations of this study

The hospital setting provided a well-controlled environment for achieving the objectives of this pilot study. The concept of home telecare was demonstrated and system usability was assessed with a representative sample of users. Even though the idea of having a personal device and novelty of the concept was responsible for the initial interest in the system, the duration of the trial was sufficient to assess true perceptions of the system. The underlying aim was to identify usability issues that would prevent effective use of the system. Even though compliance with the once-a-day mea-
measurement was good, a home trial conducted over a longer duration is required to assess patient compliance with their customized monitoring protocol. This would also facilitate demonstration of home telecare in a home environment. Nevertheless, hospital testing is a necessary step to elicit views and refine the intervention prior to deployment in a routine clinical setting.

As this study focused on the use and usability of the system, the accuracy of the spirometer was not extensively validated. A 3 L syringe was used to calibrate the device. Prior to installation the lung function measurements were validated against the hospital spirometer used as a gold standard. Although this was sufficient for this stage of the design, a full validation against American Thoracic Society (ATS) recommendations is required for future home trials.13

Comparison with the existing literature

Very little comparative data is available as the effectiveness of using electronic diaries to monitor lung function in CF has not been investigated extensively. The only home monitoring program reported in the literature was implemented at the University of Minnesota, Cystic Fibrosis Centre between 1986 and 1992.14,15 In this program, written diaries of lung function, body weight, breathing rate, and pulse were sent weekly to the CF clinic for updating. At 2 years this program achieved a 75–80% response rate among 111 patients. Vital capacity measurements made at home were closely correlated with laboratory measurements of forced vital capacity. A follow-up study showed that the home monitoring did not have any negative impact on patient health status over a 4-year period. However participants’ impressions about the usefulness of monitoring for self-management were not assessed and no follow-up studies are reported in the literature.

We found many errors associated with the performance of unsupervised spirometry measurements. These results are in agreement with investigations of electronic diaries to monitor lung function in patients with asthma which report many difficulties in obtaining valid unsupervised spirometry measurements in children and adolescents. Pelkonen and colleagues found that 23% of home measurements acquired with a computerized spirometer did not meet ATS criteria for reproducibility partially attributed to unacceptable technique.16 Mortimer and colleagues showed that an improved visual interface and quality control software produced acceptable data in 62% of sessions.17 Future revisions of the Home Telecare System will include a biosignal processing module that will automatically flag recordings that could be categorized as relating to poor technique or poor effort.

In our study, participants reported that ongoing clinical support would be crucial in maintaining compliance and long-term sustainability of a home telecare model for managing CF. This is in agreement with investigations in asthma which report compliance with monitoring to be a major limitation to implementing a home monitoring intervention. For example, Wensley and Silverman reported that a steady reduction in the validity of electronic lung function data over 16-weeks was largely due to reduced compliance after 4-weeks.18

CONCLUSIONS

Home telecare is feasible for remote monitoring of CF. Patients used the system to record lung function measurements without any supervision and indicated that the system was easy to learn and use. Clinicians reported the usefulness of home telecare in maintaining a longitudinal record of their patient’s health.

ACKNOWLEDGMENTS

The pilot study was supported by the Australian Cystic Fibrosis Research Trust. The authors wish to thank the participants who gave their time to take part in the study; Dr. John Morton for his interest in this project and for supporting the field trial. In particular, we would like to acknowledge the assistance of Ms. Alyson Boynton in testing the spirometry system.
CONFLICT OF INTEREST

The Home Telecare System was developed by researchers at the Biomedical Systems Laboratory and the Centre for Health Informatics at UNSW, and the University and some of the authors could benefit from commercial exploitation of the Home Telecare System or its technologies.

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