Self-management of COPD


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Self-management of COPD: A technology driven paradigm

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ABSTRACT
In this paper, we look at how the early detection of health decline in those with Chronic Obstructive Pulmonary Disease can lead to earlier provision of intervention advice. Current tools to support the self-management of Chronic Obstructive Pulmonary Disease provide alerts only when a problem has been encountered. It is suggested that continuous monitoring of a user’s health, behavior and contextual information when appropriate would provide the ability to detect health decline prior to a problem having occurred. Based on the review of the current body of work, important parameters for self-management have been identified; autonomy, methods of data transmission, and levels of intrusiveness. An autonomous context aware self-management tool is subsequently proposed. The approach aims to incorporate recent advances in mobile technology and overcome many of the limitations encountered in the solutions considered to date.

Categories and Subject Descriptors
D.3.3 [Computer Applications]: Life and medical sciences—Medical information systems

General Terms

Keywords
Chronic Obstructive Pulmonary Disease, Self-Management, Tele-Monitoring.

1. INTRODUCTION
A dramatic shift in population ageing is currently taking place. The global median age has been projected to increase from 37.3 years in 2000 to 47.7 years in 2050 [1]. This shift will have a profound impact in a number of areas, one such area being healthcare. Increased life expectancy raises the number of people at risk of developing chronic conditions which are more prevalent in older age groups [2]. This subsequently leads to an increased demand for healthcare provision and results in spiraling medical costs [3]. Self-management solutions realized through a technological infrastructure may be a means to alleviate this burden. In addition, it provides an opportunity to empower the patient with an increased level of control over their own healthcare [4].

By 2030 the World Health Organization (WHO) has predicted that Chronic Obstructive Pulmonary Disease (COPD) will affect over 64 million people and will be the third leading cause of death worldwide [5]. It is estimated that over 3 million people are currently affected by COPD in the UK with only 900,000 having been clinically diagnosed [6].

The economic impact of COPD is significant with respiratory disease consuming 6% of the European Union healthcare budget [7]. COPD accounts for over 50% of this cost totaling over 38.6 billion Euro [7]. As would be expected, costs associated with COPD dramatically increase as disease progression occurs. Economic hardship can also be found in those with COPD as they or their partner may no longer be able to work as the burden of care takes its toll [7][8]. Social burden can also be found in those with COPD when analyzing the total number of lost Disability Adjusted Life Years (DALY) [9]. In addition, COPD was ranked as the 11th leading cause of lost DALY in 2002 and has been predicted to be the 7th leading cause of lost DALY worldwide by 2030 [10].

There are a number of key indicators of COPD such as dyspnea, chronic cough and sputum production, however, the use of spirometry measurements is the only consistent and reliable method of detecting airflow obstruction. As such spirometry measurement is a prerequisite for a COPD diagnosis and in the determination of COPD severity (Table 1) [11]. It is important that each person is accurately assessed as this correlates directly with morbidity and mortality [12], however, it is interesting to
note that a poor severity rating does not necessarily correlate directly to a poor health related quality of life (HRQoL) [13] [14].

Table 1 Classification of severity of airflow limitation in COPD from the Global Initiative for Chronic Obstructive Lung Disease (GOLD) [15]

<table>
<thead>
<tr>
<th>Severity</th>
<th>Forced Expiratory Volume (FEV1) Reading</th>
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<tbody>
<tr>
<td>Mild</td>
<td>FEV ≥ 80% predicted</td>
</tr>
<tr>
<td>Moderate</td>
<td>50% ≤ FEV &lt; 80% predicted</td>
</tr>
<tr>
<td>Severe</td>
<td>30% ≤ FEV &lt; 50% predicted</td>
</tr>
<tr>
<td>Very severe</td>
<td>FEV &lt; 30% predicted</td>
</tr>
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</table>

Exacerbations are a common feature of COPD and are associated with an increase in symptoms such as nocturnal awakening, breathlessness and chronic cough or wheeze alongside a marked change in sputum production [16]. It has been asserted that early exacerbation treatment improves HRQoL and ensures timely recovery [17]. Delayed seeking of treatment, however, was noted to lower HRQoL, delay recovery time substantially and dramatically increase hospitalization risk [18]. Early detection of an oncoming exacerbation, together with appropriate intervention leads to the reduction in the severity of the exacerbation itself and the slowing of disease progression [18]. It has also been shown that pharmacologic therapies, pulmonary rehabilitation and smoking cessation all deliver significant benefit to people with COPD, however adherence and compliance with intervention and self-management techniques is poor [19] [20]. It is suggested in this paper that further research on improving patient adherence to therapy through the use of emerging mobile technology may result in fewer hospitalisations due to preventable COPD complications.

A number of research projects have focused on the area of user monitoring and alert generation when a health problem has been detected in those with COPD [21][22]. Alerting when a problem has occurred is limited in its benefit, as a difficulty has already been encountered. It is therefore proposed that an unobstrusive system, monitoring a user's health, behavior and environment for undesirable changes can lead to the provision of timely advice, therefore enabling the user to change their lifestyle and prevent a problem from occurring. This notion of moving from reactive to a proactive monitoring situation is in line with many recent developments in the area of technology based solutions in support of long term chronic conditions.

The remainder of this paper is structured as follows. Section 2 provides a review of related work in the area of mobile self-management for COPD. Section 3 details identified areas for improvement and Section 4 presents the details of a proposed system taking into consideration the current challenges in this domain. Section 5 provides a summary.

2. RELATED WORK

Self-management in the context of COPD involves the provision of feedback of symptoms and educational content, enabling one, to take control and manage symptoms, medication and lifestyle choices so that HRQoL may be increased and the chronic condition controlled [23]. Self-management has proven to be effective in the management and control of COPD in a number of studies with intervention groups showing distinctly lower hospitalisation or emergency room visits than control groups. A systematic Cochrane review of 14 randomised trials from (January 1985 to January 2006) found that self-management was associated with lower hospitalisations alongside an improvement in health related quality of life for those with COPD [24]. Mobile device use in the self-management of COPD is a new approach with more work needed in this area [25].

A review was carried out to determine the state of the art techniques for the self-management of COPD. Google Scholar, PubMed and IEEE databases were searched utilizing a number of key terms (Table 2) whilst limiting the search to only papers written in English and published between 2010 to 2013.

Table 2 Key search terms used when reviewing of related work

<table>
<thead>
<tr>
<th>Search Terms</th>
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<tr>
<td>&quot;Chronic Obstructive Pulmonary Disease&quot; OR &quot;COPD&quot; AND &quot;Self-management&quot; AND &quot;Mobile&quot;</td>
</tr>
<tr>
<td>&quot;Chronic Obstructive Pulmonary Disease&quot; OR &quot;COPD&quot; AND &quot;mobile&quot;</td>
</tr>
<tr>
<td>&quot;Chronic Obstructive Pulmonary Disease&quot; OR &quot;COPD&quot; AND &quot;Self-management&quot; AND &quot;mhealth&quot;</td>
</tr>
<tr>
<td>&quot;Chronic Obstructive Pulmonary Disease&quot; OR &quot;COPD&quot; AND &quot;Self-management&quot; AND &quot;smart phone&quot;</td>
</tr>
<tr>
<td>&quot;Chronic Obstructive Pulmonary Disease&quot; OR &quot;COPD&quot; AND &quot;smart phone&quot;</td>
</tr>
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</table>

Google Scholar returned 2151 papers, PubMed / Medline returned 309 papers and IEEE returned 115 papers in total. From this group, the papers were further refined by title and abstract and 25 papers subsequently reviewed in full. From this seven key papers in the area where selected for more detailed consideration.

From the review it was apparent that tele-monitoring can be divided into two categories:(1) data is communicated to a clinician who decides upon a relevant course of action [26] [27] and (2) systems with intelligence that perform some aspect of data analysis autonomously, thus reducing the need for a clinician and providing timely advice and alerts to the patient [28] [29].

2.1 Non-Automated Systems

The review carried out yielded two projects that communicated information directly to the clinician for further analysis. ASTRI (ATS) [26] was created to investigate user acceptance of a tele-care system. Twenty-two people were included in the intervention group for this project alongside 18 controls. Sensors measuring respiratory rate, pulse and blood oxygen levels [26] were connected wirelessly through to a mobile device and from there to an online personal health database. Monitoring of the physiological parameters took place three times a day, Monday through to Friday by the community nurse who would take relevant action if it was determined that the user was in danger. It was noted that monitoring of recorded data was not supported over weekends or bank holidays [26]. User feedback indicated satisfaction with the system, however, it was stated that the addition of automated advice on healthcare would have been of benefit.

A second non-automated system AMICA [27] was developed to enable the early detection of an oncoming exacerbation. The system utilized a holistic approach to the management of COPD. AMICA recorded a number of physiological signals from each user including sound and ECG via a custom multifunctional sensor. Recorded sound and ECG signals had a number of biomarkers extracted prior to being uploaded to a remote
A further study [28] had the aim of understanding how tele-monitoring interventions backed by primary care impact upon recurring hospital admissions for those with COPD. The basis for this project was founded on the understanding that early exacerbation detection profoundly affects health related quality of life while also reducing the cost on the health system [18]. To determine the effect that tele-monitoring had, an intervention group recorded vital signs daily using a tele-monitoring kit provided while also completing a mobile-based questionnaire on perceived levels of health.

Recorded data was uploaded daily and reviewed by a health professional, the participant had direct contact with a clinical professional on a bi-weekly basis [28] and personalized alerts were triggered if recordings were found to be outside of a pre-defined range (Table 3).

<table>
<thead>
<tr>
<th>Table 3 Pre-defined ranges at which an alert would be issued if reached [28]</th>
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<tr>
<td>Tele-monitored parameters</td>
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<tr>
<td>Respiratory-rate</td>
</tr>
<tr>
<td>Heart-rate</td>
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<tr>
<td>Systolic blood pressure</td>
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<tr>
<td>Oxygen saturation</td>
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<tr>
<td>Temperature</td>
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<tr>
<td>Weight</td>
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<tr>
<td>Qualitative questionnaire</td>
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The eCAALYX Project aimed to monitor user's health status by recording vital signs over a longitudinal period of time to detect changes in their condition and subsequently the progression of COPD. Similar to Chronious an educational module providing participants with general information on self-management and lifestyle changes to adopt was provided [29]. The eCAALYX system utilizes two individual methods of monitoring: a mobile body worn system alongside a home based system comprising of multiple sensors integrated into the user's environment.

Unique to eCALLYX a smart garment embedded with multiple sensors was used for the mobile monitoring system with physiological data such as respiration and skin temperature recorded [29]. The home-based monitoring system was integrated with the user's TV providing a platform for viewing recorded vital signs and historical recorded data [29]. The set top box connected to the TV also enabled input of questionnaire data alongside the provision of educational content and teleconference calls to the clinician when necessary [29]. eCAALYX is unique compared to other reviewed systems [28] [29] as it is the first system to provide direct feedback to the end user. Feedback of this nature may be empowering for the participant therefore encouraging life style change compliance and aiding in motivation. Feedback from
participants, however, was not positive. Nine volunteers evaluated the system for a total of 28 days and found aspects of the system “difficult to use” and garments to be “uncomfortable”.

2.2.2 Full Automation
One autonomous system [32] is currently under development aiming to provide computer aided self-management assistance and education while also enabling the detection of an oncoming exacerbation. The system aims to ensure that any event changes are detected, relevant people alerted and the condition monitored.

The main computational component within this system is a smart mobile device [32]. The mobile device is powerful enough to carry out all processing and communication required and removes the need for a dedicated computer system, thus reducing unnecessary technology and ensuring the system is unobtrusive unlike eCALLYX. A number of sensors are used to record vital sign information similar to each of the other projects evaluated and similarly a questionnaire on the mobile device is used to record relevant information related to the user's health [32]. What makes this system unique, however, is the integration of a “disease-specific probabilistic model". This Bayesian network was developed from expert knowledge [32]. An initial evaluation of the system was completed successfully with 5 participants from a lung rehabilitation program [32]. It was established that an exacerbation could in fact be detected autonomously ‘as it was occurring’, using the probabilistic model on the mobile device. This is a step forward in the development of autonomous self-management devices and paves the way for future work in this area. Researchers intend to work on earlier detection of an oncoming exacerbation and subsequently offer relevant advice to patients helping them better self-manage their condition [32].

Table 4 provides an overview on physiological data recorded in the projects reviewed. Table 5 presents a comparison between projects reviewed and the proposed COPD self-management system presented in this paper.

3.3 Future Developments
The Smart 3 Holistic Self-Management [33] project aims to create a self-management system for those with COPD, however, the proposed approach will identify how technology can be best utilized for self-management and rehabilitation. Smart 3 will be built upon a previously successful project entitled Smart 2 [34]. Smart 2 successfully utilized technology, intervention and educational information to support users with long term chronic conditions such as chronic heart failure and stroke achieve behavioral and lifestyle changes. Smart 3 builds on this project ensuring those with COPD self-manage their condition through a combination of personal and intervention advice on holistic self-management techniques. This aims to ensure a better quality of life for each individual user.

3. LIMITATIONS ENCOUNTERED
While reviewing the related work, a number of limitations were encountered. These can be overcome and a more comprehensive system developed that will improve upon current mobile based self-management systems for COPD.

3.1 Autonomy
The projects reviewed do not have a set methodology for providing the end user with feedback on the vital sign readings, it was found these readings were sent to the clinician who would then review and if necessary offer intervention information. This is a missed opportunity to help end users self-manage their condition effectively. Providing end users with feedback on recorded data may provide them with a better understanding of
their condition thus providing the necessary incentive required to manage their lifestyle accordingly. A number of systems reviewed only supported the transmission of intervention information and the display of self-management and motivational information when the clinician determined it necessary. An autonomous system that assessed recorded biomarkers against a number of pre-set guidelines may provide a superior system that could subsequently cut down on the clinician’s workload.

Similarly, community nurses involved in the review of transmitted data in systems such as [26] have indicated that they would welcome easy to read reports and charts detailing recorded vital signs as it is difficult and time consuming to review raw data. The generation of this information would alleviate such problems. It is also reasonable to assume that historical data in a graphical form would be of interest and benefit to the end-user.

Furthermore, it was noted that certain projects relied on clinical professionals to monitor data on a daily basis, determining if vital signs were within the pre-set safe ranges. Participants involved in [26] were unable to receive tele-care at the weekend or on bank holidays as the community nurse was unavailable, further demonstrating the need for an automated system.

One of the benefits of mobile health is the processing capability such devices contain, carrying out automation and subsequently reducing clinician workload [32]. If data analysis was to be carried out on the mobile device, the end user could be provided with immediate feedback on their condition.

3.2 Data Transmission

It was observed in [27] that transmission of data occurred via a device located at the patient’s home. It can be assumed that transmission of monitoring data cannot take place if the user is not in the home. This restriction may impact on the duration of time the participant can be away from their home, thus limiting their movement. Alternatively, users would forego the transmission of physiological data that would have taken place had they been at home.

A secondary limitation encountered regards the transmission methods used for the transfer of recorded data. GPRS is utilized for data transmission in [28]. Utilising cellular transmission of data ensures the user is no longer restricted to staying in the house, however, if the user was to be in a rural area with limited network signal, it may still be difficult or impossible to transmit recorded data and receive relevant self-management or essential intervention techniques consistently.

In [29] a separate issue was encountered concerning the upload of data from the home unit. For this particular project, data uploads took on average 3.5 hours. Clearly this is unacceptable for the transmission of vital sign data, particularly if that data was to reveal a serious problem oncoming or having occurred.

3.3 Intrusiveness

It was established that certain systems over complicate the process of managing COPD to the degree that it may be off-putting to potential participants. Tele-care should be unobtrusive with technology deployed discretely within the environment. For instance, questionnaire information can be accomplished through a smart mobile device. The technology employed for management of chronic conditions such as COPD should be directed to the background[35].

On the contrary, participants in [26] had requested that the addition of a blood pressure monitor would be of benefit. This project, however, contained minimal technology in comparison to [29]. A compromise somewhere between these projects may provide the best solution.

It is also suggested that much of the manual data entry completed by the end users may not be necessary. The use of sensors to take readings and then request users to manually enter the results may lead to discrepancies. It is also conceivable that users may under report problems so as to not cause unnecessary concern to others. The use of sensors that automatically transmit data would remove such an issue.

3.4 Technology

Many of the projects reviewed utilized PDA devices as the mobile technology to be provided to the end user. Modern Smart phone devices contain many onboard sensors making the phone more than just a means of providing data. Onboard sensors such as GPS, gyroscope, accelerometers, and light sensors, enable the mobile device to play a larger role in the data collection process. Application programming interfaces (APIs) are available that allow the direct connection and analysis of external sensors through to the mobile device. It is proposed that the use of a modern smart phone device enables a more adaptable system to be developed that is no longer as restricted as was previously the case with PDAs.

3.5 Parameters for COPD Self-management

A number of limitations were encountered while reviewing the current body of work contributing to the area of self-management for those with COPD. It was found that each research project had a number of properties that were of benefit to the end user. Each project however, also had aspects that could have been improved upon. It is hypothesized that the creation of a system merging many of the beneficial properties while removing the poorer aspects of the projects would be of benefit. Future projects should take into account the following:

Autonomy; enabling intervention and self-management advice to be provided to the end user, removing the need for a clinician to evaluate data regularly. This will also allow for users to have educational or self-management information provided to them at optimal times.

Improved data transmission allowing data to be updated over 3G/4G or Wi-Fi should be implemented. Users should not be restricted in this regard. If no transmission method is available, data should be buffered until such a time that it is available.

Finally, solutions should be discreet and unobtrusive. Solutions should not overwhelm or intimidate the end user but still provide a comprehensive health overview.

4. PROPOSED SOLUTION

The proposed solution is a mobile-based self-management tool that will allow the unobtrusive monitoring of a user’s health condition over a prolonged period of time. The system will enable the detection of minor changes in health condition, thus allowing for intervention or educational material to be provided when required autonomously. It is proposed that these detections could lead to earlier non-pharmaceutical interventions leading to a reduction in disease progression and complications in those suffering from COPD. Figure 1 provides an overview of the proposed self-management approach.
The system architecture depicted in Figure 1 can be broken into a number of key areas that help to clarify how the system operates. All physiological, environmental or user inputted data (Figure 3) will initially pass through the context awareness/tele monitoring module. All data will be stored in a local database. Following this, a process will take place to determine if the user is currently in a state of health decline; to determine this, a number of algorithms will evaluate the recorded data. If it is determined the user is not in decline, no further action will be taken, and the data collection will continue. If the user is however deemed to be in decline, pre-defined rules based on recorded vital signs will determine if immediate medical help is required or not. If required, a clinician will be alerted and an ambulance requested if necessary. If clinical help is not required, a prediction model will establish the best intervention advice to be provided. The system will then continue to monitor the user and evaluate health for improvement or decline.

4.1 Visual Interface Module
The visual interface offered to the user should be appealing, and intuitive. The interface will provide the user with feedback on recorded data and symptoms in addition to offering educational material and intervention advice. The feedback will be provided at the user’s request and also as and when necessary. Proposed screens are shown in Figure 2. It is imperative that recorded data is not overwhelming while providing the user with an overview of their health status, clearly showing improvement or decline. It is asserted that this visual representation may potentially encourage behavioral change.

Figure 1 The System architecture of the proposed self-management tool, with each element defined

Figure 2 Initial screens showing how data may be presented to the end user

4.2 Context Aware / Tele-Monitoring Module
This module ensures that data relevant to a user’s health condition is monitored and recorded thus generating a dataset for assessment and providing information relevant for helpful advice to be provided. For example, information on environmental factors such as air pollution, which has been directly linked to increased hospital admissions for those with COPD [36] can be harvested from online weather sources directly. Mobile accelerometers combined with GPS data will be used to determine user location and subsequent activity levels or in some cases, lack of activity. It is conceivable that a combination of environmental, location and accelerometer data could determine that the user is exercising in an area with poor air quality that should be avoided. This module will also monitor diet, sleep and vital sign data through a combination of body worn and wireless sensor devices and when necessary user inputted information.

Figure 3 Depicting data that will be recorded in the Context aware / tele-monitoring module

All data monitored through the context aware tele-monitoring module will be stored in an SQLite database on the mobile device. This database will store raw data recorded and associated timestamps.
4.3 Health Evaluation Module (Healthy or Not Healthy)
The health evaluation model comprises a number of rules that determine if the data recorded implies that the user is either healthy or unhealthy. These rules will be based on preset ranges specific to each individual user. If vital signs are within preset safe ranges, the monitoring process will continue uninterrupted. If the user is deemed to be unhealthy based on the data analyzed, one of two outcomes will occur. If the user is deemed to be dangerously unhealthy, a clinician will be contacted and an ambulance requested if necessary, if, however, it is determined that the user is not in danger or in need of clinical assistance the probabilistic module will then be initiated.

4.4 Prediction Module
A prediction model will be employed to determine appropriate intervention advice to be provided to the user if their health is found to be declining. Clinical experts working in the area of COPD self-management will have validated the intervention advice to be provided. An example use case for this module could be for a user lacking exercise alongside increased levels of fatigue. The module would analyze all recorded data and determine that user had not been consuming enough calories, as such, intervention advice encouraging a higher calorie intake would be offered. It is proposed that this intake might then provide the required energy to reduce fatigue levels and therefore motivate the user to exercise. It is conceivable, in such a scenario that recommendations on diet plans specific to that user could be offered.

If it is deemed necessary, following intervention advice being provided, detailed information specifying the initial health decline encountered and the subsequently prescribed intervention information could be securely transmitted through to a clinician.

It is proposed that the creation of an automated self-management tool, providing relevant and timely intervention advice alongside self-management and educational information to the end user. The suggested system should be enjoyable to use, therefore encouraging behavioral change in a novel manner. At present no research has been found relating to the provision of a mobile smart device as a tool providing a significant health overview whilst also detecting subtle changes in health so that an oncoming setback can be prevented. It is also conceivable that such a system may be of use in determining how medication changes affect the health of a patient.

5. CONCLUSION
This paper provides an assessment of mobile self-management solutions for those with COPD. It was found that while significant work has previously been carried out, there is still room for improvement, specifically with regard to patient empowerment, monitoring of health and providing relevant contextual, educational and management information. It is proposed that the development of an unobtrusive self-management platform aimed at overcoming limitations in the autonomous nature of mobile systems alongside improvements in the transmission of necessary data and ensuring systems are intuitive to use will bring with it great benefits for those with COPD.

Development of this system is currently ongoing and will be evaluated by a cohort of users with COPD. Presently, no dataset has been found that provides all data required to develop and evaluate such an approach. Therefore, the creation of a symptom emulator will also take place. Initial development of the COPD symptom generator has commenced with the platform currently enabling users to generate COPD symptoms ranging from mild, moderate and severe.

6. REFERENCES


