

What information do
patients with copd
feel they need



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This study hopes to assess the viability of using digitally based patient information to support patients with COPD in a future funded study. The proposal is: this study will use the Maavis program.

Maavis is an application providing simplified access to the Internet, computer programs, and a range of media - potentially to those who otherwise wouldn't be able to use it. It achieves this using a simple customisable interface, consisting of simple words or icons. This is suitable for patients with COPD as it is a condition predominantly affecting the elderly.

COPD is characterised by irreversible airflow obstruction, specifically during exhalation. To the layman, it can be thought of as a chronic, irreversible form of asthma. Common symptoms include breathlessness (dyspnoea), fatigue, and a productive cough. With no cure, it is the fourth leading cause of mortality worldwide. COPD also has an economic cost: COPD exacerbations are the commonest cause of hospitalisation in both sexes in the USA and Europe, and account for 24 million lost workdays annually. This totals to approximately 2 billion GBP per year in the UK [1]. The severity of the condition varies between patients, and in severe cases, it can lead to a patient being housebound. The exacerbations of breathlessness - defined as 'subjective experiences of breathing discomfort that consist of qualitatively distinct sensations that vary in intensity' [2] - are a common complaint for patients [3][4][5][6], who describe them as extremely frightening and distressing [7][8]. It significantly impacts the quality of their life [9][10], causing depression [2] and impairment of normal activities of daily living [10] [11] This project will mainly focus on those with moderate and severe

COPD, as these are more likely to benefit from a digital / home-based support.

The planned approach is to first use information available in the literature to find out what information patients with COPD feel they need, and then consider whether Maavis can be used as a platform to deliver this information?

Literature review

Due to the short-term nature of this project, this literature review is being used as a primary source of evidence - thus it does not have the typical content. Instead, it compiles the information from relevant papers to give an overview on a need for patient information in COPD. The results from this review are reported in the results section, where conclusions are drawn from the analysis. These will mainly focus on the information needs of patients with COPD, and the requirements for an intervention.

According to Maslow's hierarchy of needs[12], an exacerbation of breathlessness is a threat to the most basic need of humans: a biological need. Ergo, it is very important for clinicians to try and improve the symptoms of breathlessness. This can be partly achieved by giving patients information so that they know how to improve the symptoms, and what to do during an exacerbation of breathlessness. Unfortunately, this isn't the case; one study found that 8% of patients didn't know what to do when breathing worsened, and 36% did not know when to call an ambulance [13].

This lack of patient information is widespread: 21% of patients with COPD did not know the name of their disease, 55% were exercising inappropriately, and 8% were confused with medicines [13]. This has been expanded on in other studies:

One study focused on confusion with medications - stating that steroids, a common treatment for COPD, were a major source of anxiety of patients. This came from a lack of information, with much of their knowledge coming through hearsay or the media[8]. In another study, it was found that 100% of patients describing knowing when to take medications as a very important information need.

Another focused on exercising: it found that it is hard for a patient to know if they are exercising appropriately, as 'the level of exercise appropriate (for a patient with COPD) is often hard to define'. However, exercise should be encouraged as the study found that 'if (exercise) is carried out properly - often in the form of pulmonary rehabilitation classes - it has been found to enhance patients' quality of life and sense of control over the condition' [7] [8]. Indeed, a systematic review found that exercise is one of the most successful non-pharmacological approaches to managing breathlessness[14].

When trying to devise a suitable intervention for these needs, it must be remembered that they vary for each patient - depending on both the disease and the person themselves[4][13]. However, this is assuming that an information need is only present if the patient thinks so. This isn't the case, as one study concluded that an information need is also present 'if a clinician

believes that a patient's...self-management is compromised'[13]. Indeed, this paper also found that this information need is more prevalent, and interestingly, the only information need found to be scored higher by patients was 'what the lungs look like'.

Satisfying these information needs is important, as it has been found to improve a patient's quality of life[15]. However, it must be remembered that other factors influence the quality of life of a patient with COPD - such as social isolation, uncontrolled symptoms, and psychological morbidity [9]. Despite this, current trends towards informing and empowering patients are slow to present themselves in daily practice[8]. Such failure has led to a study[10] concluding that the quality of life of patients with COPD is at least as bad as those with lung cancer: 90% of patients with COPD suffered clinically relevant anxiety or depression, compared with 52% of patients with non-small cell lung cancer[10], and some patients said their situation was worse than death[16].

Promoting patient information can help a patient self-manage, which was found in a 2009 systematic review to be associated with a reduction in hospital admission, with no observable detrimental effects[17]. This could be particularly important, as one study found that the 'trend of caring for patients at home is likely to continue'[19].

Ethical considerations

In doing a literature review there are no ethical considerations, other than choosing ethical studies.

In PPI (patient and public involvement), the volunteers were treated as peers in the research team - and not participants - thus no further ethical considerations are needed.

methodology

Again, the short-term nature of project influences this section of the project. Instead of a typical methodology, it should be viewed as the initial stage - with a view to building a complete project later.

This study uses both positivism and constructivism. The need for including both through mixed methods is now widely recognised by the Medical Research Council [18] and many design philosophies for complex interventions.

PPI - which is included - is now also expected by the National Institute of Health Research to be present in all research and development projects funded by them. Constructivism is becoming disseminated in a world where previously positivism was solely dominant following a surge for evidence based medicine, however, to discuss the appropriateness of this decision - and the suitability of mixed methods in general - wouldn't be appropriate here.

To conclude, although much of the study is positivist - in that most of the results generated will be quantitative data from positivist studies - much of the content discussed is constructivist.

Research methods

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This study started by using a literature review to obtain pre-existing information in regards to patient information and COPD. This information was then systematically analysed to identify potential solutions for identified problems. As a group, a SWOT analysis was conducted that assessed the viability of using Maavis to solve these problems. A PPI session was then conducted to refine these proposals.

The purpose of the literature review was to identify whether patients with COPD felt they needed information, and if so, what this information was. This would identify criteria that Maavis would need to fulfil to sufficiently meet patient needs.

A SWOT analysis was carried out to assess the feasibility of using Maavis specifically. Identifying strengths and weaknesses allowed a fair assessment of the feasibility of using this platform for delivering information, as well as identifying areas that could be improved. Opportunities and threats helped to assess the current environment in regards to introducing Maavis, and again to identify any potential improvements.

A PPI session will be organised to receive feedback on any proposals which have been made. The group will be volunteers from an over 50 group

Results

The existing literature clearly identifies a need for more patient information. The commonest complaint was the need for information with regards to exacerbations of breathlessness. Patients wanted to know not only what to

do during these periods, but also why they suffered from them, and what they could do to reduce the frequency of attacks.

Other aspects highlighted were a lack of information about medications (specifically steroids) and appropriate levels of exercise. A problem that arose with patients with severe forms of the condition - or who were very elderly - was social isolation. With such restrictions on the level of exertion that they are capable, patients are often housebound. This limits their contact with people, and depression often follows

The literature review noted that each of these needs varied for each person, but also that a patient may still have an information need even if they don't think they do.

SWOT Analysis

An obvious strength of Maavis identified was that it is easy to use. People who haven't used a computer before would be able to use it, even more so if a touch screen computer is used.

Despite this simplicity, a strength of Maavis is its integration of third party software such as 'DropBox'. This allows a folder to be shared between computers, so Maavis can be continually kept up-to-date. This can allow the user to look at the latest photos uploaded by their relatives, or even allow a doctor to provide up-to-date information to the patient.

Another strength of Maavis is its ability to run other programmes, such as Skype or a web browser. There is an associated weakness however, in that these programmes do not always conform to the simple-to-use philosophy of <https://assignbuster.com/what-information-do-patients-with-copd-feel-they-need/>

Maavis. So integration of applications could be drastically improved if the usability of Maavis were maintained, but the complications of modifying third-part software for a niche audience is hard to overcome.

Another weakness was cost; although Maavis is a free application, the hardware to run it on isn't. With COPD mostly affecting elderly patients, it is reasonable to expect that a significant proportion will not have computers - especially touch screen computers, which, although not necessary, can be helpful. However, this potential cost is reduced by organisations such as 'Age UK' offering discounted computers to the elderly. There are also other associated costs such as a subscription to a broadband connection, but this will become less of an issue with time, as more people continue to use the internet.

Another weakness was an inability to integrate audio and video in the same subfolder. Although a minor issue, it should be mentioned as potentially it can be overcome.

With the aforementioned potential, there are obvious opportunities for the use of Maavis - but there are also rival programmes. These vary in their approach: some being software only like Maavis - namely Pointerware, Alex, and Guide. Pointerware and Alex are different to Maavis in that the software needs to be purchased. Guide can't be used in this project as its main aim is to help patients with visual disturbances - using large font text - which is not of use to the majority of COPD patients. SimplyUnite and SimpliciTy are packages which combine hardware and software, however, they are associated with an inflated cost.

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PPI

The PPI session allowed modifications to be made to a prototype model of Maavis. Parts of the prototype particularly recommended were video conferencing, information about medications, a facility to call an ambulance (and information on when to call an ambulance), and the integration of DropBox.

Suggestions made were incorporating more information into the medications section - such as dosing regimes - and to include a translator.

The session could have been improved if more participants were present, however, it generated useful feedback.

The overall impression of Maavis was positive, particularly its simplicity of use.

Discussion

With a need for patient information identified, Maavis could offer a useful intervention. This information should be provided to them, as there is evidenced based guidance available that proposes solutions for decreasing the frequency and severity of exacerbations.

The information needs can be met in a myriad of ways - from slideshows to audiotapes or videos - and this was displayed in the prototype models. An example of an innovative use of Maavis is providing statistics showing the negative impact of smoking on COPD. Patients with this information may decide to stop smoking, and with Maavis, this information could be

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supplemented with links or telephone numbers to 'Stop smoking' services - making it easier to take action. The use of links to Internet sites can also be used to provide patients with accurate and relevant medication information.

Maavis may offer an innovative intervention for exercising in the form of videos of pulmonary rehabilitation classes, where patients can mimic breathing actions - which can strengthen their respiratory muscles, improving symptoms. This has the added benefits of knowing that the exercise is appropriate to COPD patients, it is a distracting activity, and it improves the symptoms. Videos can also be used to provide information to the patient, as well as social uses - such as videos of movies and television shows.

Maavis can help tackle social isolation and depression via video conferencing using Skype: this offers the opportunity for patients to communicate with relatives, friends, or doctors at home. As well as increasing social interaction for the patient, it will also give them the feeling of more independence.

Another possible solution is linking to peer network sites, where patients with COPD can discuss their illness and help one another.

An innovative use of DropBox could be for the user to upload their most recent lung function results - such as those from a home peak flow meter - so that the doctor can monitor the patient more frequently, and reduce the number of visits needed. This would be suitable for some of the patients who wish to know when the disease may deteriorate.

This is by no means a complete discussion, and merely alludes to how varied the potential uses of Maavis are.

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Conclusion

With so many potential uses of Maavis, it can satisfy information needs as well as other needs - such as social. It does this by handling different types of data - video, audio, text - and by introducing technology to a population who otherwise wouldn't be able to use it.

By satisfying these patient needs, Maavis can help patients self-manage their condition more effectively, which has been shown to improve quality of life and reduce hospital admissions. It can do this by acting as a home-based support present, linking the home-based patient with the clinic-based doctor.