WELCOME project: What do Stakeholders want?

In Depth Analysis of COPD Patients, Carers and Healthcare Professional Views

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Abstract — **Chronic obstructive pulmonary disease is a growing health concern worldwide. Telehealth can facilitate integrated COPD care by providing an opportunity for remote monitoring, early diagnosis and clinical intervention. A design for a telehealth-based system called Wearable Sensing and Smart Cloud Computing for Integrated Care to COPD Patients with Co-morbidities (WELCOME) has been proposed. This study identifies patients', informal carers' and HCPs' acceptance of and requirements for the WELCOME system in four European countries: the United Kingdom (UK), Ireland, Greece and Netherlands.**

Keywords-WELCOME; COPD; integrated care; telehealth

I. INTRODUCTION

COPD (Chronic Obstructive Pulmonary Disease) is a major chronic respiratory condition that affects millions of people worldwide and its prevalence is growing [1]. Treatment is complex, necessitates polypharmacy and a multidisciplinary team of healthcare professionals (HCPs) involved in patient care [2-3]. In addition, COPD is frequently accompanied by a number of co-morbidities: chronic heart failure [4], diabetes [5], anxiety and depression [6], all of which complicate the clinical management.

Telehealth is a way to facilitate the care of such complex patients through provision of remote monitoring and facilitation of integrated care. Telehealth can be defined as remote monitoring of patient's health by HCPs using mobile medical devices to support early diagnosis and prompt intervention. [7-8]. It has been shown that telehealth can lead to a reduction in mortality and length of hospitalisation in diabetes, heart failure and COPD [9].

WELCOME is an innovative telehealth system that proposes to develop a wearable vest with sensors for monitoring of a number of physiological signals, such as chest sounds, heart sounds, ECG, etc. Other measuring devices to be used as part of the Welcome system are: a blood glucose meter, weight scale, blood pressure machine and an inhaler monitoring device. This will be accompanied by a patient/carers support system that will address disease/medicine education, lifestyle advice, mental health assessment and coaching etc

The aim of this study is to identify COPD stakeholders' acceptance of and requirements for the WELCOME system in the UK, Ireland, Greece and Netherlands. The stakeholders were identified as patients, informal carers (family members or partners of patients who care for them) and all HCPs involved in their care

II. METHOD

This is a qualitative study conducted in the UK, Ireland, Greece and Netherlands between January and June 2014. This included focus groups with COPD patients and their carers and semi-structured interviews with all healthcare professionals involved in the care of these patients.

The focus group schedules for patients and carers were designed to include the following sections: perception of current care, oral medicine/inhaler adherence, perception of technology, telehealth and the WELCOME system overall and its components.

The interview schedule for healthcare professionals included sections on views about the current healthcare system and its challenges, perception about the WELCOME system and its components, monitoring parameters and their frequency etc.

To facilitate Greek and Dutch data collection, the schedules were translated from English to Greek and Dutch respectively. Data collection was conducted by moderators over 2-hour focus groups with patients and carers separately and 1-hour

semi-structured interviews with HCPs. Those were recorded on digital voice recorders, and subsequently transcribed verbatim. The Dutch and Greek transcripts were translated into English. All transcripts were coded to identify recurring themes as part of a cross sectional thematic analysis.

A. UK

The UK focus groups and interviews were conducted at Croydon University Hospital. The former involved 10 COPD patients (1 patient with COPD alone, 2 with COPD and diabetes, 2 patients with COPD and heart disease, 5 with COPD and depression) in one group and 6 of their informal carers in another group. The interviews were conducted with 8 HCPs (general medicine doctor, cardiologist, pulmonologist, diabetologist, 3 nurses and a physiotherapist).

B. Greece

In Greece, 3 focus groups were conducted with a total of 7 patients (1 with COPD alone 2 with COPD and diabetes, 2 with COPD and anxiety or depression, 2 with COPD and congestive heart failure) and 7 informal carers. Four one-on-one semi-structured interviews were conducted with 4 HCPs (cardiologist, pulmonologist, internal medicine specialist/diabetologist, and a psychiatrist).

The participants were recruited from G. Papanikolaou General Hospital of Thessaloniki except for the Psychiatrist and the Cardiologist who work at the Psychiatric Hospital of Thessaloniki and the General Hospital of Naoussa respectively.

C. Ireland

In Ireland, the two focus groups involved 7 patients and 4 informal carers in separate groups. The semi-structured interviews were conducted with 5 HCPs (pulmonologist, COPD specialist nurse, diabetologist, physiotherapist and a psychiatrist)

The participants were recruited from Beaumont hospital in Dublin.

D. Netherlands

In the Netherlands, the two focus groups involved 8 patients and 6 of their informal carers in two separate groups. The semi-structured interviews were conducted with 6 HCPs individually (pulmonologist, specialist nurse, dietician, physiotherapist, internist and a physician's assistant).

The participants were recruited from CIRO+ (Centre for Expertise for Chronic Organ Failure) in Horn, Netherlands.

III. RESULTS

This cross sectional thematic analysis resulted in the following recurring themes across all stakeholders.

A. Perception of the Current Care

Across the four countries, all patients and carers complained that healthcare services for COPD patients are fragmented with limited communication between different HCPs involved in their care. Moreover, it was reported that patients face long waiting times before getting appointments/getting referred to specialists.

- *'I am staying at the village. I have to go to the health centre. This has to be done with an appointment. But it is now that I am in pain. What is the use if they book me an appointment for next week?'*
- *'you don't have the access [to medical care] you need when you need it'.*

Fragmentation of communication between HCPs was highlighted by Irish HCPs, as continuity of care and knowing what happens to patients on a day to day basis was described as a challenge in their work.

Moreover, carers across the board expressed their frustration with having to make a judgment call about their patients' health status when they are suffering from an exacerbation. They don't always know when to call and seek help.

B. Barriers for Optimal Care

Lack of adherence was identified as a common theme. Some reasons behind this were forgetfulness, busy lifestyle, pill burden, concern over side effects, swallowing difficulty and health beliefs. The latter was reflected in some patients/carers who were concerned about 'over dosing on inhalers' and expressed their misconception about steroids and inhalers:

- *'afraid they [inhalers] won't work anymore'.*

Challenges with inhaler technique were also discussed, and some patients indicated that they had to use spacers or had to be changed from metered dose inhalers to dry powder inhalers.

- *'I have a problem how to use them technically. [...] I don't know how to press and how to breathe. You have to breathe out at first and then to breathe in'.*

It was also evident that patients/carers don't have enough information about the medicines, their side effects and how to prevent the latter.

- *'I take 6 inhalers. That doesn't make any sense to me. Are they working together? Are they working against each other?'*
- *'I ended up with glaucoma from the inhalers, the nebulizers. Which nobody told me about. I could have been wearing protective glasses. [...]. It's from inhaling the steroids. They never told me'.*

In contrast, HCPs reported there is poor engagement by patients in their care and they were not sure how to encourage patients to better manage their medication and treatment of COPD. This is particularly an issue in light of the complications from complex treatment regimes.

C. Acceptance of WELCOME system

The WELCOME system was very well received by all stakeholders in all 4 countries.

The patients/carers were very impressed and thought it was 'brilliant and creative'. Overall they accepted all elements of the proposed system including the vest and inhaler monitoring device.

- *'I tend to wait too long before I ask for help because I feel I'm being a burden, bothering people. In that kind of situation Telehealth could be good. '*

There was little concern over security and confidentiality, as patients and carers felt that the benefit of such a system outweighs any concerns.

The HCPs indicated it'll be helpful for housebound patients and for avoiding hospitalizations through early detection. Moreover, they felt it will reduce the delay currently observed with patient seeking medical advice. Therefore the risk of hypotension, acute renal failure and hospitalization will be reduced.

- *'I do think for the right people it would be very useful because there are patients who, especially the house bound ..... It's harder to do that to go out to see them. And also, we don't do those clinics often enough as much as they may well need it. (..) So I think for, especially chosen patients, I think it would work really well.'*
- *'The usefulness will relate to keeping patients out of hospital who have recently been discharged following treatment of an exacerbation of heart failure in particular.....give more reliable data on the patient's risk of readmission and whether further intervention is necessary to prevent that.'*

D. Stakeholder needs from the WELCOME system

1) *Vest Concerns:* The main concern over the WELCOME system was the vest and its level of comfort (weight, materiel, tightness etc). However, this was not identified as a barrier.
- *'my health comes first. And I would wear it all the time if it's going to help my health'*
- *'I think it is best to remove it during sleeping time. Unless there is a problem. It is good to also wear it at sleep, when the condition has worsened.'*

Another concern came about from one carer whose patient has a pacemaker and was worried that the wireless signal in the vest might interfere with it. Moreover, patients/carers would like the vest to have an indicator to show whether the vest is working or not.

2) *Experience with Technology:* It's important to note that most patients/carers were not very comfortable with technology, and the use of smart devices was not part of their daily life.
- *'I believe that this is a very big step, but if it starts right now it will target people from a specific age group that are not familiar with technology. My father [age 75], for example, at this moment does not even know how to use a mobile phone. It will be very difficult for this to be done by people of his age.'*

3) *Access to monitoring data:* Patients and Carers did not agree fully about who has access to the monitoring results. Carers were definitely interested in this data, however, some of the patients did not want to grant their carers access. However, they wanted all HCPs involved in their care-including their pharmacists- to be able to see their results.

4) *Feedback:*It was agreed that patients should receive feedback/advice based on their results. Even if results are within normal limits, patients should still receive positive reinforcement.

The type of advice/feedback generated in response to an abnormal result should factor patient's mood. Therefore format of the feedback should be indivudualised.

5) *Customizable/individualized algorithms:*The frequency and parameters to be monitored are to be individualised depending on patients' symptoms and condition. Decisions regarding individualisation of parameters and the frequency of measurements should be set by patient's HCPs collectively.

In order to individualise the decision, the results should be compared to patients' individual baseline (measurements taken when in best health) to determine results' severity, instead of comparing to a set standard:

- *'Have a baseline measurement and from there to be able to make a comparison and then the classification as being a disorder or not.'*

IV.   DISCUSSION AND CONCLUSION

This analysis provides an in depth view into the current state of care for COPD patients with/without co-morbidities in the UK, Greece, Netherlands and Ireland along with how the proposed WELCOME project can be implemented to integrate care and improve patient outcomes.

One of the important points raised by all cohorts in all countries centred on the challenges they face in the current healthcare system which included fragmented care, lack of communication and long waiting times to be seen by HCPs. This is also well documented in the literature and is seen as a cause for an increased readmission rate in COPD patients [12].

The WELCOME system promises to facilitate an integrated care model for these patients whereby all HCPs involved in the care of the same patient can communicate and have access to the same monitoring results (Figure1).

The patients and carers were very receptive to telehealth and the WELCOME project, and they raised valuable points that need to be considered in the design, implementation and validation phases. This is also reflected in previous studies whereby COPD patients who experienced telehealth services were very satisfied with what telehealth provided in terms of emotional and medical support [10].

The only major perceived barrier to its implementation is the requirement for technical competence and operation of equipment. This was also identified in other studies such as the Whole System Demonstrator whereby some patients refused to participate in the study due to dislike of technology [11]. However, this will not be a long term issue as the patients of the future will be very comfortable with technology and the use of smart devices. For current telehealth use, this needs to be considered during patient recruitment as patient's comfort with and acceptance of technology is imperative for the success of any intervention.

Another concern that was echoed by the patients and the carers was the comfort of the vest. Moreover, the schedule of self-monitoring (by the vest and other devices) should be flexible and not regimented so as not to interfere with daily activities

Reported adherence was suboptimal with patients forgetting or choosing not to take their medicines as prescribed. Health beliefs are well documented in the literature and are known to influence adherence rates in COPD patients [13]. It was interesting to note that the patients never discuss these issues with their HCPs which led the latter to accuse their patients of being unengaged in their care.

Besides monitoring physiological parameters, the WELCOME system will give patients access to educational functionalities regarding their disease, medicines and lifestyle. Moreover, the inhaler monitoring device will assist the HCPs in identifying low adherence and /or poor inhaler technique. The system will also provide feedback to the patients related to their results, and thus allow them to adjust their medicines / lifestyle accordingly before complications/deteriorations arise.The stakeholders were very receptive of such feedback as it will provide valuable support and will allow patients to have an active role in their treatment.
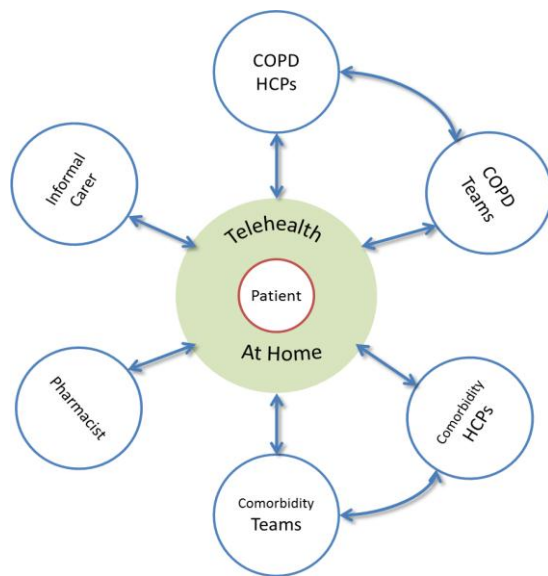

Figure 1. Sample Integration of telehealth into care pathway

The design of the WELCOME system will take into consideration all the results of this analysis in an effort to produce a system that will integrate care from different HCPs while empowering patients to self-care.

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