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A cloud-based mobile system to improve respiratory therapy services at home

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ABSTRACT

Chronic respiratory diseases are one of the most prevalent health problems in the world. Treatment for these kind of afflictions often take place at home, where the continuous care of a medical specialist is frequently beyond the economical means of the patient, therefore having to rely on informal caregivers (family, friends, etc.). Unfortunately, these treatments require a deep involvement on their part, which results in a heavy burden on the caregivers' routine and usually end up deteriorating their quality of life. In recent years, mHealth and eHealth applications have gained a wide interest in academia due to new capabilities enabled by the latest advancements in mobile technologies and wireless communication infrastructure. These innovations have resulted in several applications that have successfully managed to improve automatic patient monitoring and treatment and to bridge the distance between patients, caregivers and medical specialists. We therefore seek to move this trend forward by now pushing these capabilities into the field of respiratory therapies in order to assist patients with chronic respiratory diseases with their treatment, and to improve both their own and their caregivers' quality of life. This paper presents a cloud-based mobile system to support and improve homecare for respiratory diseases. The platform described uses vital signs monitoring as a way of sharing data between hospitals, caregivers and patients. Using an iterative research approach and the user's direct feedback, we show how mobile technologies can improve a respiratory therapy and a family's quality of life.

1. Introduction

1.1. Respiratory therapies at home

High hospital costs and the comfort of home treatments are driving the global population to choose home therapies over hospitalization. Healthcare at home can range from general care to highly specialized services for managing chronic conditions. Patients suffering from chronic diseases are the ones who can receive the most benefits from such treatments. Chronic diseases, such as cardiovascular diseases, cancer, diabetes and chronic respiratory diseases, represent the most common causes of premature adult deaths in the world (they accounted for 35 out of an estimated 58 million deaths from all causes in 2005) [1].

Chronic respiratory diseases encompass all chronic diseases that affect the airways and the other structures of the lungs. They include asthma, respiratory allergies, chronic obstructive pulmonary diseases, occupational lung diseases, sleep apnea and pulmonary hypertension. According to the World Health Organization, chronic respiratory diseases account for 6% of all yearly deaths and, in 2005, they represented around 4% of Disability-Adjusted Life Years (DALY), an indicator for the amount of years lived in poor health. Moreover, it is estimated that around 300 million people suffer from asthma or a Chronic Obstructive Pulmonary Disease (COPD) alone, and around 90% of all COPD deaths occur in low and middle-income countries [2].

In order to treat chronic respiratory diseases, medical services and public health organizations offer Respiratory Therapy (RT) services that comprise a variety of interventions related to airway management and maintenance of lung health. Examples of such treatments include oxygen therapy, ventilation, tracheostomy care, medication management and teaching of inhaler usage techniques. Respiratory therapy services often require home visits in order for technicians to set up medical equipment and check on the patient.

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This type of homecare service began to emerge in Chile around the year 2000, with respiratory therapies and special programs focused on children and adolescents such as the SAVED and AVNI programs [3]. Based on the good results of these programs, in 2015 the Chilean Ministry of Health created the AVNIA program for noninvasive ventilation of adult patients [3]. Thanks to this program, interventions can be partially or fully reimbursed by the government depending on patient eligibility.

These initiatives involve an active role of both formal and informal caregivers for proper treatment of the patients. While medical specialists are necessary for technical tasks such as calibrating ventilation machines, the role of the informal caregivers cannot be understated as they are paramount in assisting with daily life activities and providing emotional support. Studies also show that their presence increases adherence to medications and other medical recommendations [4]. Nevertheless, their involvement is usually so taxing that several informal caregivers end up experiencing a deteriorating quality of life [5,6]. In some cases, it even results in increased stress and depression.

Mobile healthcare (mHealth) and electronic healthcare (eHealth) have been proposed as an effective technology for improving patient monitoring for those living at home [7]. These technologies leverage network and communication infrastructures to bridge the distance between medical personnel, caregivers and patients. Furthermore, they enable access to real time vitals information and other medically relevant data, and may issue warnings when any of these values deviate from expected figures. There are multiple benefits to this approach. First, the availability of objective parameters at all times results in a greater engagement on the part of the patient to better take care of him or herself and better manage his or her condition. Indeed, several studies have shown that more informed patients can better take care of themselves and, through this, enjoy a higher quality of life while simultaneously depending less on others [8,9].

Secondly, new opportunities have risen for caregivers, who are now able to remotely monitor their loved ones' status and therefore endure a smaller impact on their lives. As such, mHealth and eHealth present themselves as viable alternatives for chronic respiratory disease healthcare with the added benefits of reduced caregiver involvement and reliable vitals analysis for opportune medical interventions, all of which result in better healthcare for the patient and an increased quality of life for him or her and his or her caregivers.

In this paper, we describe the architecture of a new Cloud-based Mobile System (CMS) for assisting home healthcare for patients suffering from chronic respiratory diseases. In the development of this solution took special care to not only provide a reliable patient monitoring mechanism, but also to improve the quality of life of their informal caregivers. In order to ascertain this claim, we used the Impact on Family Scale (IFS) to quantify the platform's effectiveness. This project is trying to take the first step in Chile towards understanding how we are able to improve quality of life not only for patients, but also for the family caregiver support network.

The following sections describe common problems found during respiratory home treatment and related work in the field. Section 2 presents the research methodology and the proposed system, Section 3 shows the research results and patient testing experience, and finally, Section 4 presents conclusions and future work.

1.2. Caregivers at home

All chronic respiratory diseases need permanent treatment; the most common ones include various oxygen therapies, tracheotomy and mechanical ventilation. Several problems can arise when providing these types of treatments at home, most of them related to the quality of life of a patient and caregivers.

All home therapies require care, understood as the management and generation of resources for the daily maintenance of health and life and the daily provision of physical and emotional well-being. The care given at home must include several aspects: health, education, social protection, and labor policies. Such care includes everything that is related to helping others meet their basic needs, developing social skills and alleviating pain and suffering.

Formal care is provided primarily by professionals and experts in different areas of health. The unpaid care provided by family, friends, neighbors, or relatives is called "informal" or "family" care. Informal care is provided at all ages and for a wide range of conditions and diseases.

Several studies have shown the burden that informal caregivers bear, which can lead to depression and anxiety [5,10,6]. It is common that spouses acting as informal caregivers see their roles undefined and constantly changing [5], which generates a direct impact on their quality of life. Being an informal caregiver of a patient with COPD also leads to anxiety, depression, social isolation and a more strained relationship with the patient [10,6]. In these situations, the caregiver's burden is a major determinant of the impact of caregiving and the well-being of the patient [6]. Some studies even report a significant relationship between hypoventilation symptoms and caregiver burden [11].

Caregivers do not always have the time or the skills needed to provide quality care. At the same time, they are a key factor in the patient's treatment, quality of life and the feasibility of home care. This problem is where modern technology can make an impact. Information and communications technologies (ICTs) have been considered internationally as a strategy that strengthens the attention and care of long home treatments. They create support networks around patients and can provide and generate permanent interactions among patients with chronic diseases, their family caregivers and the health team [12].

The next section describes related work in the field and different approaches using technology.

1.3. Related work

Telemedicine is the use of information technologies to provide health care at a distance. Telemedicine solutions often work hand in hand with Body Area Networks (BAN), wireless networks of wearable, usually non-invasive computing devices, that are constantly monitoring for relevant healthcare information (such as vital signs) and transmitting it to a hub. BANs are a key technology in helping individuals attain a more proactive and affordable healthcare. They enable individuals and caregivers to closely monitor changes in the patient's status and provide opportune feedback to help maintain an optimal health status. When integrated with a telemedical system, a professional medical staff can then review this data and provide a more accurate diagnosis in case mishaps occur [13]. Several studies have shown that remote patient monitoring systems significantly contribute to the patient's quality of life [14,15]. They promote patient activation, self care and better disease management. Home-based telehealth and self-monitoring have also been used to reduce the incidence of hospitalizations and emergency department visits for people with COPD [16].

There has been a large growth in tele-monitoring techniques and preventive care for older adults [17,18]. Most of these platforms focus their attention on specific diseases such as dementia, Parkinson's, and Alzheimer's. They provide active health care and alarms for critical patients. However, few of these systems offer the possibility to share the patient's data in real time with families and caregivers; they are instead built as a tool for helping medical teams detect risky situations.