HomeSenseALS: A mobile app for people with Amyotrophic Lateral Sclerosis

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This paper describes the user research and design of HomeSenseALS, a mobile app for patients with Amyotrophic Lateral Sclerosis (ALS), that supports self-report and passive sensing. Interviews with patients, carers, and doctors showed the importance of avoiding confronting patients with their condition and progression. We thus designed the HomeSenseALS app to minimise self-reflection and the tracking. Insights from this work should inform the design of technologies for ALS or other neurodegenerative conditions.

Additional Key Words and Phrases: Amyotrophic Lateral Sclerosis, Self-care, Self-care technologies, Symptom monitoring

1 INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a chronic neurodegenerative condition that strongly impacts the quality of life [4]. The death of motor neurons is responsible for muscle weakness, motor and gait impairments, as well as difficulties in breathing, speaking, and swallowing. ALS is a progressive condition, which means that, as the condition evolves, the patient faces further disability and need for support. Unlike other degenerative disorders, ALS progresses at a fast rate, and most patients die withing 2-5 years of disease onset.

The medical community argues that giving patients self-care apps can help assess functionality at a distance, enabling more efficient drug development trials [6] or more informed appointments when the patient returns to the clinic [2, 3]. Prior work has shown that patients can use the ALS functional scale (ALSFRS-R) by themselves, reporting results on a web [6] or mobile app [2, 3], and perform regular activities or measurements using sensors [6]. The project HomeSenseALS will take these apps a step further by drawing on passive sensing to monitor functionality.

This paper presents ethnographic accounts of the (self-)care of people with ALS and describes the functionalities of a mobile app we created for patients. Our contribution lies in recognising the patients' right to avoid being confronted with the condition and its evolution, and in a mobile app that aims to respect that wish.

2 INTERVIEWS WITH PATIENTS, CARERS, AND DOCTORS

To understand the care of people with ALS, we conducted in-depth interviews with patients, carers, and doctors. Interviews were qualitative, loosely structured, and focused on the diagnosis, condition follow-up (monitoring), treatment, everyday self-care, and the role of informal carers. We involved 6 patients, 5 carers, and 7 doctors. The carers were either spouses (3) or siblings (2). Five doctors were neurologists, and one was a family doctor. 10 hours of audio-recordings were partially transcribed and coded for themes by two researchers. The Mural software was used to gather quotes, codes, reflections, and to enable Affinity Mapping sessions by the same two researchers. All participants provided informed consent, and the study was approved by the ethical committee of the Lisbon School of Medicine (Portugal).

2.1 Clinical care

People with ALS are followed at the hospital by a neurologist every 3-6 months. Neurologists start by collecting information on the patient's current status, and any hospitalisations, sicknesses, or important life events, they faced since the last appointment. They then perform a complete physical and neurological exam focusing on speech, cough, breathing capacity, and strength. Results from recent respiratory tests or electromyography may complement the

examination. The most important issues are discussed with the patient and carers, together with any medication prescriptions or referrals to other specialties (e.g., physiotherapy, speech therapy, psychology, pneumology). Family support and social care options are also discussed.

Information about ALS symptoms and disease progression is carefully considered and dosed. Since the first appointment, neurologists actively try to understand *"what the person wants to know"* and *"what information they are ready to receive"*. They make sure patients know their condition will be progressive and impact motor abilities, strength, and speech. Still, the details about the condition's next phases or death are not discussed if the patient does not want to know them beforehand. As the disease progresses, neurologists bring to the discussion specific topics. For example, the need for ventilation support at night encourages discussions on advanced directives for resuscitation or invasive breathing support. However, even then, neurologists will put great care into understanding patients' wants regarding information and will not hesitate to avoid some topics or words to leave the patient more at ease.

2.2 Self-care and informal care

The self-care of people with ALS is often related to accepting the condition and finding ways to avoid thinking about it. Continuing to work is helpful to some patients, even if during shorter hours. Patient 1 (P1) mentioned that he *"works just to distract himself"*. The impact of his work on the family budget was reduced, so he could stop if he wanted, but working helps him distract from the condition. Other patients fill their schedules with multiple physiotherapy sessions, sports, gardening, or other distracting leisure activities. Another way to avoid thinking about the condition is to stop more challenging activities. Several participants refer to writing as an example of a task that is greatly affected and mirrors the disease evolution. Consequently, it is common for patients to avoid writing or reading documents that contain their former handwriting.

Carers usually play an essential role in the care of people with ALS. As patients lose motor skills and strength, spouses or siblings become further involved in care and activities of daily living. One carer referred to us: *"He goes to the garden, and I have to go after him"*. In this particular case, the patient could work on the garden, but reaching for tools and moving was extremely restrictive, so the carer was needed for gardening to take place. Carers also play a role during medical appointments. When patients have difficulties speaking, they become 'interpreters', listening carefully to patients and repeating what they said at a higher volume, expanding on content the patient would have liked to voice to the doctor. Carers also bring issues from their perspective to the neurologist, helping to get a more complete picture of the patients' condition and its impact in their everyday life.

2.3 Implications from fieldwork

Reflecting on the fieldwork, we derived three main implications for design: (1) Avoid displaying progression in the app, to skip confronting patients with things they do not want or are not prepared to know; (2) Avoid very regular tracking for the same reason; and (3) Expect carers to use the patient's app, due to the roles they play in care and appointments.

3 DESIGNING THE HOMESENSEALS SYSTEM

The HomeSenseALS app is an Android app that supports the care of people with ALS. The app enables patients to: (i) self-report their functionality and health events; (ii) perform health measurements, for example, of their breathing; and (iii) monitor their gait passively, when they walk with the smartphone in their pocket. HomeSenseALS connects to an oximeter to measure blood oxygenation, and a spirometer to measure peak respiratory performance. Here we describe the four features of the mobile app most influenced by the fieldwork.

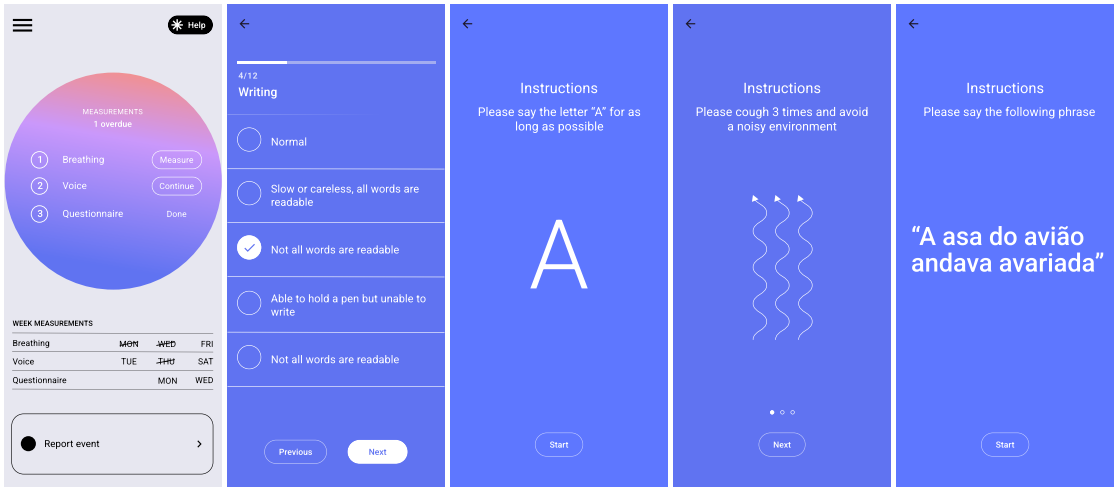

Fig. 1. Screens from HomeSenseALS mobile app.

Report functionality without reminding condition impact. The HomeSenseALS app enables patients to report their functionality using ALSFRS-R [1], the key functional scale in ALS care, which the project adapted to reduce the number of questions asked to patients. First, the app asks users if they observed changes in a specific area, e.g., voice, and only if users answer positively it displays questions related to the functional impact of voice issues (e.g., screen 2 of Figure 1.) This design decision reduced the number of questions asked from 12 to a minimum of 4, and avoided confronting patients with questions and answers related with increasing functional decline. The app reminds the user to fill-in the scale every two weeks, to minimize how often people are reminded of their condition by answering the scale.

Perform measurements without displaying an assessment. The app guides users in performing health measurements of voice and breathing. Similar to the clinic, patients are asked to: cough, read sentences out loud, and say vowels for as long as possible. To support measurements, the User Interface (UI) offers simple instructions and practical advice. For example, in preparation for cough measurements, patients are asked to cough three times, at a distance of 20 cm, while avoiding coughing directly at the microphone. The visual representations that accompany measurements draw on abstract shapes without showing levels, to avoid assessment. Repeating the same sentences could trigger patients to reflect on their progressions. Thus we decided to rotate between a set of sentences. Moreover, patients can listen to their recordings to check the audio quality and repeat if necessary, but there are no visual performance indications.

Display previous measurements without tracking evolution. Having performed a measurement in the app, it becomes available on the History screen, where a temporal log of measurements enables patients to view or (re)listen to themselves. We considered adding plots for tracking the evolution of collected data, but that would likely mean patients would track disease progression as well. The temporal log enables users to click different entries and compare them, but only patients that seek that comparison will be confronted with it.

Show measurements and questionnaires for the week, enabling people to choose when to address them. The home screen of the app (screen 1 of Figure 1) shows the measurements and questionnaires the user is expected to complete during the week. Patients can choose when to act on these, enabling them to do it when symptoms are milder. Considering the condition's impact on patients, providing strict deadlines was inappropriate and could lead to reminding patients of things they could not do when symptoms ran stronger.

4 PRELIMINARY FIELD TRIAL RESULTS

Field trials of the HomeSenseALS project are ongoing. Patients will be using the system for up to a year and receive regular home visits to monitor disease activity and the impact of the system. We interviewed three patients who had been using the system for more than two months and we uncovered two interesting insights.

One patient referred she missed feedback when using the system: *"I thought there would be something for me to see that I am walking (...) I used the smartphone for so many hours"*. The patient knew that the system monitors their gait and physical activity, and expected to receive insights regarding how much physical activity she performed. This made us reflect that it might be relevant for a future version of the system to have the option to display movement tracking data. Visualising this information needs to be optional for not confronting patients with their condition, but it might interest some patients who are still in an early stage of the disease.

Another patient said he sometimes missed measurements due to lack of a reminder: *"Sometimes I do not perform the measurements; I forget, but it is because I am ok"*. The patient associated missing the measurement with having the symptoms controlled, because if the symptoms were not so controlled he would want to track them with the system. The app raises one reminder for the measurements, but these are not repeated during different times of the day or week, which may lead to forgetting. In a future version of this system we will revisit the design of the reminders.

5 CONCLUDING REMARKS

The interviews with patients, carers, and doctors showed the importance of avoiding confronting patients with the condition or its progression. Considering many self-care applications are created to collect relevant data about the condition to support reflection and shared decision-making [5], it was challenging to think about how to design a self-care app that would not lead to tracking condition progression. Our study's insights will support the design of technologies for ALS or other neurodegenerative conditions, especially as people face strong symptoms and disability.

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