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Sickle cell disease (SCD) is the most prevalent blood inherited disorder in the world. Patients suffer from several chronic issues, comorbidities and high-mortality rates. Despite its prevalence, the disease remains largely ignored. A literature review was conducted and a questionnaire was sent to patients in order to understand the potential of e-health tools to support people with SCD. Additionally, focus groups have been conducted to detail respondents’ answers. The results showed that patients felt isolated and misunderstood. They also highlighted patients’ wishes for a social network able to make them feel less scattered. Using participatory-design techniques, we designed a prototype of user-centric interface for an online self-supportive SCD patient community. The mock-ups include chatrooms, forums and videoconferences capabilities. They illustrate how SCD patients’ social networking and caregivers-patient relationship needs could be met. Future work will focus on the implementation and evaluation of the system.

Reference


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User-Centric eHealth Tool to Address the Psychosocial Effects of Sickle Cell Disease

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Abstract. Sickle cell disease (SCD) is the most prevalent blood inherited disorder in the world. Patients suffer from several chronic issues, comorbidities and high-mortality rates. Despite its prevalence, the disease remains largely ignored. A literature review was conducted and a questionnaire was sent to patients in order to understand the potential of e-health tools to support people with SCD. Additionally, focus groups have been conducted to detail respondents’ answers. The results showed that patients felt isolated and misunderstood. They also highlighted patients’ wishes for a social network able to make them feel less scattered. Using participatory-design techniques, we designed a prototype of user-centric interface for an online self-supportive SCD patient community. The mock-ups include chatrooms, forums and videoconferences capabilities. They illustrate how SCD patients’ social networking and caregivers-patient relationship needs could be met. Future work will focus on the implementation and evaluation of the system.

Keywords. Sickle-Cell disease, Self-management, Social networks, Patient empowerment, Participatory design, e-Patients, Doctor-patient relationship

1. Introduction

Sickle cell disease (SCD) is one of the most prevalent genetic disease in the world. Approximately 300 million patients are affected [1]. Despite its commonness, the disease remains largely unknown, resulting in suboptimal care and health policies. In particular, limited attention is given to the psycho-social implications of SCD. Since the use of mobile applications and social networks to support self-management of chronic diseases has shown encouraging results [2], the authors were interested in identifying the requirements for the development of comprehensive tools addressing the whole needs of patients.

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2. Methods

Beforehand, a literature review was conducted to highlight the common issues faced by patients and to understand the potential of eHealth tools for self-management of patients with SCD. During the study, thirty-three patients answered an online survey, sent worldwide through patient groups. In order to detail the respondents’ answers, three focus groups including four patients have been conducted.

3. Results and discussion

The results demonstrated that patients are feeling scattered and lonely. They are finding difficult to receive adequate help and support when needed. They associated this with the disease’s general lack of awareness and dearth of well-trained and specialized healthcare professionals. Results highlighted also that low-prevalence countries had less patients’ communities. Respondents identified tools that could allow them setting up a trusted online patients’ community. They demonstrated an interest in using existing social networks platforms such as PatientsLikeMe. On the other hand, they accentuated the need of having a moderation of discussions and a verification of information by medical experts. They appeared willing to share advices enabling other patients to live healthier, exchanging for instance how to make decisions and take actions for a better quality of life (QoL). During the focus groups, we created a user interface prototype for smartwatches and mobile applications. These mock-ups defined a virtual way of communication such as the organization of social activities. Items, such as group discussions, chats, video conferences or forums including doctors were also sketched. Patients argued that the presence of gamification items was not necessary. Indeed, they said that a mobile social networking tool would be a sufficient motivation. Finally, despite the limited number of respondents, our study showed clear tendencies. It demonstrated the potential of such tools in offering an opportunity to meet their social needs and set up self-supportive communities. Ensuring a good quality, trustworthy and accurate information is of major importance. Doctors-moderators could support this constraint. The next step will be to detail the specifications of the system, to implement the online community and to evaluate the QoL outcomes.

4. Acknowledgments

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References

[1] WHO | Sickle-cell disease and other haemoglobin disorders