An Exploratory Study to Exterminate Hepatitis in Pakistan Using Digital Means

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Abstract

In this study we explored the problems of the patients of hepatitis in Pakistan and means to improve awareness among general public about Hepatitis. We put forward very novel design and technology solutions to bridge the doctor patient gap faced by the patients of hepatitis. Results showed that introducing technology in native language can actually help the people of Pakistan to get awareness and get themselves tested in the end.

Author Keywords

Hepatitis; technology; Healthcare; Mobile health; Pakistan

ACM Classification Keywords

H.5.2 [User interfaces]: prototyping, evaluation/methodology

Introduction

In the recent past we have observed that technology has taken a boost in the developing countries too [1]. Rapid increase in the use of smart phones have introduced a new era of mobile health. The growth of Information and Communication Technology (ICT) around the globe has provided an unprecedented

opportunity for transfer of healthcare facilities and infrastructure in these rural areas of Pakistan along with in other developing countries [6].

Pakistan is one of the most affected country from a widely spreading disease: Hepatitis. It has symptoms that could be misleading. It has 5 viruses i.e. A, B, C, D and E. Today hepatitis is an alarming issue of Pakistan. Stats says that 4 million people are at a risk of getting infected from HBV (B virus) whereas 8 million are at a risk of HCV (C virus). Studies have shown how rural areas of provinces like Punjab, Baluchistan and Sindh are in danger of getting infected [2].

Unfortunately no substantial work has been done to support the patients of hepatitis here in Pakistan using smart phone technology. A country wise pervasiveness study was done by Pakistan Medical Research Council (PMRC) in 2007-08 which was about 8 years ago [3]. A book entitled Hepatitis C, Symptoms, Diagnosis and Treatment (Hepatitis C, Allamaat, Tashkhees aur Illaj) was written and published in 2015 in Urdu to spread awareness [3].Major work that has been carried out consists of running temporary awareness campaigns. Few hospitals themselves have taken this initiative to commemorate World Hepatitis Day every year. Although these have created a significant mark in raising awareness but are still not enough.

On the contrary world is using mobile technology to assist the cause of elimination of hepatitis. Many apps like "HCV guidance app" [4] and hepCure [5] have been launched worldwide.

User Research

The aim to conduct user research was to recognize the real problems encountered by the hepatitis patients and the reasons why still there is lack of awareness among general public of Pakistan.

Participants and procedure

Participants included patients of hepatitis and general public. We conducted interviews and surveys in different hospitals of Lahore and Sheikhupura to assess problems faced during and post disease. Further interviews and surveys from people of different backgrounds were conducted to evaluate the level of awareness among people of Pakistan.

User Research findings

Demographics: During our study we found out that 70% of the patients were middle aged people and were born or brought up in rural, underdeveloped areas of Pakistan. Resources are very less and no proper means of communication are available however smart phones have become quite popular among people of those areas. "My name is Nasreen. I came here from Nawashabad, as there was no hospital in our village. I was unware of the of the prevention methods, if anybody could have told me earlier, I could have saved myself from this deadly disease". [P#11]

Environmental Conditions: 85% of the patients had poor sewerage conditions and awareness regarding hygiene and sanitary disposal was minimal. "We don't have proper washrooms and we have to use canal water for household purposes". [P#3, 4]

Communication gap: One of the major finding was that 65% of the patients were mostly illiterate. Although
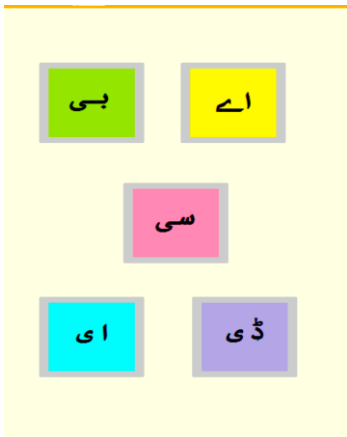
Figure 1: Paper prototype flowchart

Figure 2: Final Protype

their kids had taken at least primary, the patients themselves never went to school. Although they didn't have access to print and social media they or their family members owned smart phones. Our user research revealed that their children attended Urdu medium schools, they couldn't read or write English so hepatitis apps in English were of no use to them. "I go to school, I am in 8th grade, but in our school nobody ever transferred knowledge about hepatitis. We even don't have television at home" [P#6]. Doctors communicate and advise verbally to patients which patients tend to forget very quickly. "I have to remember my prescriptions because I am not literate. My son knows how to read Urdu so he keeps on reminding me. Reminders for specific medicines would be great help" [P#6, 7].

General public belonging to better economic and financial background knew about hepatitis but couldn't differentiate between the symptoms as they match to other diseases. "I actually have no idea how I got infected, I even didn't know that this is such a dangerous disease. "[P#4].

Design and Evaluation
In the first part of the project we built an android app with multi-lingual and voice over support (Urdu, English and Roman Urdu) to help the patients of hepatitis during the course of disease and we included general awareness section for the public from all demographical backgrounds as well. Figure 2 shows a design version of hepatitis type's home screen. This app not only provides awareness and disease related information to the patients and general public but also helps the patients set reminders and alarms for their doctor appointments and medicine intake. . The features of

the mobile app include, 1) Awareness; what is hepatitis? Symptoms, causes, prevention and cure of hepatitis. It has information about all strains of the disease 2) Tracking; appointments and medicines reminders 3) Risk factor analysis to get diagnosed in time and 4) Awareness videos. Risk factor analysis section collects the user data as well, which will be a good a data source in future to extract insights about the hepatitis prone areas of Pakistan. Further to help the people who didn't have smart phones we designed a paper based Diary which had sections to keep track of appointments and charts to fill for the medicine intakes. In addition it has images related to "what food to eat'' i.e. a healthy diet, "daily exercise'', "how to keep yourselves and the environment clean'' i.e. hygiene and "a healthy mind'' i.e. stay happy for a healthy life. User research showed that if the patients themselves were not literate their kids knew Urdu. This Diary was designed using minimal text that too in Urdu. To reach out to every section of the society we launched awareness campaigns on social media as well.

When we conducted the initial evaluation of the app we received positive feedback from the patients of hepatitis. We visited different hepatitis wards in different hospitals and evaluation study was conducted from 30 patients and 15 general public. 70 % of the patients were of the view that mobile app in Urdu was a good idea along with the images and icons provided in all of the sections of the app. People who were illiterate i.e. 60 % found the icon voice over feature supportive to get guidance. Patients who did not own smart phones found the Paper diary attractive over doctor prescriptions. They showed interest to use Diary to record their medicine intake and appointments. The evaluation shows that this app can help in inculcating

awareness about the disease among general public as well. [1]

Generally patients and public also believed that government level campaigns and support should be launched with free screening camps so that people with low socio-economic backgrounds could be benefitted most and the cause of elimination of hepatitis could be facilitated.

Discussion and Future work

We have tried to provide the HCI community with a glimpse inside the socio economic condition of hepatitis patients in Pakistan, where a significant part of the population is suffering from the disease. In the first part of "Hepatitis extermination project" we launched an app and Diary. Patients and general public gave feedback and the app is still being improved in an iterative manner. Early results reveal that app+diary is a viable solution and patients can easily incorporate it into their lives. Challenges faced by the patients of hepatitis in Pakistan are similar to those faced by the people of other third world countries. This demands a more collaborative and shared solution to the cause of hepatitis elimination. First time initiative of this kind has been taken in Pakistan to assist the patients using technology. We are hopeful that people will react positively to the idea of using digital means against hepatitis. Currently we have launched the app and social media campaign in Lahore and suburbs of Lahore, but we intend to reach out places like inner Sindh, Baluchistan and KPK. We intend to incorporate NFC chips in the paper based diaries so that we can provide an end to end solution that will assist the doctors as well. Doctors will need to enter the record for the patient once and rest will stored in the NFC chip

in the Diary. Next time the Diary will be swapped against Doctor's system only to launch the patient data on the screen. This will provide an opportunity to collect data about the patents as well.

This workshop is a good opportunity to connect with other members of the HCI society and work collaboratively on problems of third world countries using technology. Finally we believe that HCI Across borders workshop will provide an exceptional platform for sharing our interests and insights with the wider public, which we gained while working with a diverse community from a very specific and relevant region.

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