
LiveDliver & HepOrganizer: A Digital No to Hepatitis in Pakistan

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Abstract

Nowadays technology is being used worldwide to cure deadly diseases. Hepatitis is rapidly spreading in Asia over time. Every 12th Pakistani is suffering from a specific form of hepatitis. In this study, we have explored design and technology solutions for assisting patients of hepatitis and to create awareness among the general public. We have suggested an android app, LiveDliver and a paper-based diary, HepOrganizer to help the patients manage their disease and the general public to acquire awareness. The evaluation results show how these measures improved the patient's journey towards the cure and how the spread of awareness aided people to get tested in the end.

Author Keywords

Hepatitis; technology; Healthcare; Mobile health; Pakistan

ACM Classification Keywords

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

Introduction

Mobile phone use has been rapidly spreading in third world countries over past few years [1] and the exponential increase in usage of smart devices has enabled people to use them for managing their health

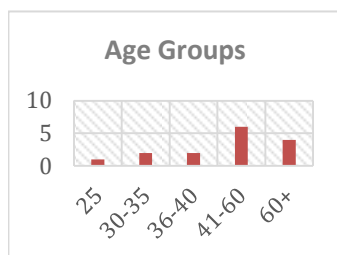


Figure 1: Age demographics

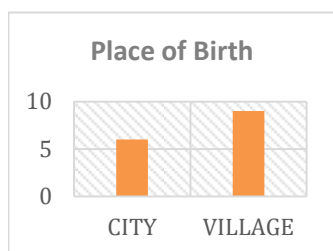


Figure 2: Birth demographics



Figure 3: Roadside dentist

and lifestyle. Many mobile health platforms have been developed which help people in managing both chronic and non-chronic diseases. One disease, which in the recent past, has gained a lot of attention is hepatitis. This disease has symptoms that could be misleading. There are five hepatitis viruses, A, B, C, D and E that have been categorized and two others are in the pipeline. These viruses also have the potential for outbreaks and epidemic spread if not contained.

In Pakistan, hepatitis has become a major issue. Four million people are at risk of getting infected by hepatitis B (HBV) whereas eight million are at risk for hepatitis C (HCV). Rural areas of Baluchistan, Punjab and Sindh are at the most risk to exposure [2].

Since 1999, Al Khidmat Welfare Society [3] has been fighting the battle against Hepatitis by building awareness and broadcasting information. In 2005, The Pakistan Medical and Research Council [4] launched a campaign in collaboration with W.H.O to raise awareness of the hepatitis virus in 10 rural villages of Nowshera. In Khyber Agency, Bajaur Agency and Peshawar, free screening camps [5] were set up under the orders of the Governor of Khyber Pakhtunkhwa. Many hospitals in Pakistan commemorate World Hepatitis Day every year by organizing health walks, seminars, workshops, screening camps and free vaccinations. Last year, the Sindh Institute of Urology and Transplantation (SIUT) [6] arranged an elaborate program for public education and awareness whereas the Aga Khan University Hospital [7] organized an awareness seminar respectively. Although these seminars have created a significant mark in raising awareness but are still not enough.

Technology is being used worldwide to eliminate hepatitis and create awareness among people through the smart phones they carry in their hands. On World Hepatitis Day last year, the National Liver Foundation in Bangladesh launched a mobile app, "Learn about Hepatitis and Live Well" [8] in their national language, Bangla to raise cognizance regarding Hepatitis in around 300 million Bangla-speaking people. Another such app is HepCure [9], which also supports doctors by allowing virtual treatment decisions. Furthermore, the Centers for Disease Control and Prevention [10] in USA has a five-minute web based risk assessment questionnaire that determines if the user should get tested and for which Hepatitis virus. In New York, another app, Liver Health – Hepatitis C [11] was also developed for risk assessment but it also included information regarding the virus, hepatitis services site locator and updates on current news.

With respect to the mobile health platform in general and for hepatitis in particular, unfortunately nothing of any major importance has been done in Pakistan yet.

User Research

We conducted user research to understand the real problems of the patients of hepatitis by listening to the victims themselves. Also, we conducted surveys with the general public to get an idea about their awareness levels. Using contextual inquiry that includes video, audio and textual interviews of patients and doctors from various hospitals (CMH, The Medicators, University of Lahore-pathology department and Akhtar Saeed Trust) we tried to find the gap between the patients and their lack of awareness. In addition to the doctors, we also interviewed herbal and homeopathic pharmacists.

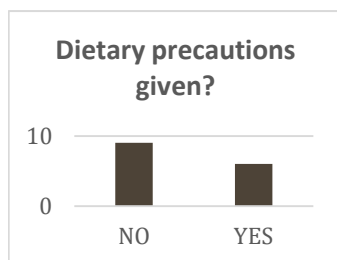


Figure 4: Dietary precautions given



Figure 5: Info Regarding Hepatitis

Research participants comprised of non-patients and patients of hepatitis. 16 patients and 15 people from the general public agreed to participate in our research, which included audio and video interviews and a survey. The study was conducted over a period of two weeks. Members of the research group were designated from different demographic areas of Lahore. Firstly, a survey for patients and non-patients including twenty questions was constructed in Urdu keeping in mind the user audience and their literacy limitations. Secondly, patients of CMH medical center, Akhtar Saeed trust hospital were interviewed.

We also conducted video and audio interviews with 5 doctors who are currently practicing in CMH, Akhtar Saeed trust, The Medicators and UOL respectively and one is a member of the VFAHT [16] team. We present some of our major findings below:

Demographics: Majority of the participants of the survey belonged to the 41-60 age group (figure1) whereas around 26 % were above 60 years old. Figure 2 shows that 60 % of the participants were born and brought up in rural areas. Thus, one of the major causes for the lack of knowledge is due to no proper means of communication about the causes, symptoms of hepatitis and its prevention methods. "We live in Hayatabad, there is no hospital in our village. Somebody told us to come to this trust hospital. Initially I couldn't even get tested because the local dispenser in our village told us that it's just seasonal fever. Had I been communicated to properly, the situation wouldn't have turned this worse". [P#11]

Environmental Conditions: One of the major reasons for the spread of Hepatitis A and E in the country is the

poor sewerage condition and the unavailability of clean water. Furthermore, barbers and dentists in rural areas use unsterilized equipment (figure 3) because of the lack of awareness of its adverse effects. "We usually use tap water as drinking water. If I get time I boil it, otherwise I don't and we use it as is". [P#3]

Communication gap: The lack of awareness among the people is due to illiteracy issues and inaccessibility to print and social media in rural areas like in other third world countries [12][13][14]. 40% of the participants of our survey never went to school while 27 % studied till the primary level and 33% only studied till matric. None studied above matric. But shockingly if they themselves did not understand how to operate smart phones, their family members or children were well aware. Further results revealed that their children or the next generation were going to Urdu medium schools. These results combined with the demographics, show a direct relation between literacy and awareness regarding diseases. "I have done matriculation, but in our school nobody ever communicated about these things. Although we have television in our village, but even that didn't tell us what measures to take which could have protected us from this fatal virus" [P#15]. Most of the apps are developed in English [11] [9] which is not the first language of Pakistan i.e. Urdu. Majority of the people had one or two smart phones in their family. Due to illiteracy issue and lack of print material doctors communicate verbally with the patients, which is easily forgettable. Schedules of the treatment and appointments are tracked on a notepad prescriptions. "I cannot read what medicines doctor has written, my daughter knows how to read Urdu so she tells me, and



Figure 6: lo-fi prototype app

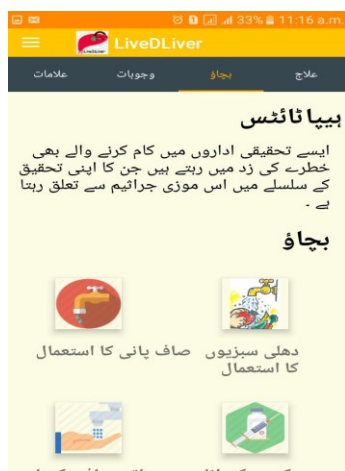


Figure 7: LiveDLiver app

I usually forget when to take them. Reminders for specific medicines might help". [P#15]

Health concerns: There is no evident cause of infection of HCV or HBV as in most cases neither blood transfusion nor organ transplants took place. The source could be infected equipment like needles. Some patients believe their previous operations and injections might be the cause. According to 60% of patients, doctors do not give any dietary plan as in figure 4. More than 50% patients (figure 5) have no knowledge of what the disease is, how it spreads, what are the symptoms and how to prevent it. "I actually don't know how I got infected, I even didn't know that this is such a dangerous disease." [P#3]. In most of the cases, the hepatitis virus was diagnosed only because of ongoing treatments of other diseases they were suffering from (Tuberculosis, eye operation etc.).

Despite no self-awareness, patients believed they should get their family members tested and vaccinated as well after we spoke to them. According to Dr. Ejaz Khan of The Medicators, no proper sterilization is used in almost all medical institutions in Pakistan.

Myths and misconceptions: During our interviews with the patients and general public, we came across several myths and misconceptions, which hinder the treatment protocol. Several were avid believers of holy men. Other myths regarding the causes of the infection include black magic and excessive intake of meat products.

"It is not that serious, I know this is some kind of black magic being done on me by my mother in law. I'll visit the popular saint in our village and this disease will go

away" [P#3]. Also, patients feel reluctant to go to doctors because of the fear that they will be treated differently once everyone knows they are ill with such a taboo disease.

Design and Development

After analyzing the users' requirements, we found that a mobile app (liveDLiver) in conjunction with a paper-based health diary "HepOrganizer" will be the best suited solution to address the problems identified in the user research phase [1]. If users themselves do not have smart phones or cannot read, somebody else in the family definitely can. The app "LiveDLiver" is for mobile users to help them track their disease and perform the risk assessment analysis test. The app in combination with the diary is the best solution in the given scenario as a significant number of the population suffering from liver infections in Pakistan belong to rural areas and might not be owning a smart phone themselves, hence "HepOrganizer", an appealing diary solution to benefit the vast majority of people in Pakistan who do not own a smart phone to keep track of their appointments and vaccinations.

LiveDLiver" is an interactive and self-explanatory app as it is mainly composed of images, audios and videos. It also includes text wherever it was deemed to be necessary. We provided multiple language support for the mobile app (i.e. Urdu, English and Roman Urdu) due to two major constraints imposed by most of the population in Pakistan. Firstly, variance in literacy level of the user and secondly, ease of accessibility of the features in the app. Most of the people suffering from this disease are living in rural areas, are comfortable with Urdu as it is the national language and used by the vast majority. The features of the mobile app include,

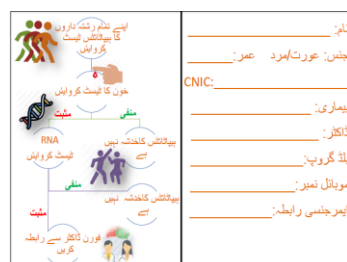


Figure 8: HepOrganizer: Paper Diary

Task A

1. Set reminder for medicine
2. Set reminder for appointments

Task B

1. Find: what are symptoms of hepatitis A or B or C or D or E?
2. Find: what are causes of hepatitis A or B or C or D or E?
3. Find: what are precautions of hepatitis A or B or C or D or E?
4. Find: what is the treatment of hepatitis A or B or C or D or E?
5. Find: whether you should get tested or not?

Figure 9: Evaluation Tasks

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.

"HepOrganizer" is a paper-based diary which includes

- 1) Introduction; information about the owner of the diary
- 2) First things first; contains important tips about a healthy life style. It will include 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
- 3) Hepatitis?; includes what is hepatitis and what are its different types, symptoms, causes, precautions and treatment
- 4) Track your Disease; includes tracking for appointments
- 5) Schedule your treatment and vaccinations; to keep track of medicine and vaccine schedules.

We designed low-fi prototypes for the mobile app (figure 6) and a layout for the "HepOrganizer" (figure 8) and evaluated it using our target audience. The final version of LiveDLiver is implemented as an android application (figure 7). Its functionality comprises of three modules; awareness, reminders and risk factor analysis. We performed several iterations to design a solution for optimal user experience and provide added support of audios. Each icon in the awareness section (symptoms, causes, precaution and treatment) has associated audios, played whenever an icon is clicked.

Evaluation

We conducted usability tests to evaluate the acceptance, effectiveness and usefulness of the

application and diary. Our evaluation comprised of two groups; patients and the general public. Total 30 of which 15 were infected. 3 patients were female housewives (mean age 38). 6 patients had no experience of using smart phones, thus they were given the diary. In the general public, all participants were educated (mean: graduate; mean age: 25 yrs.).

Our evaluation consisted of three phases. Firstly, pretest questionnaire to find the participants' knowledge about the disease, experience with mobile app and their expectations about the hepatitis app. Then tasks, related to the app and diary, were given to them and finally, a post-test questionnaire and interviews. We have divided the tasks in to two categories; task A and task B as shown in figure 9.

Observations: In order to evaluate the acceptability rates and the effectiveness of our app for knowledge about hepatitis, multiple language support and audios along with icons, we compared pre-test and post-test knowledge of hepatitis through a questionnaire. Most of them had just heard the name but its severity and details were not known [2]. Most were of the opinion that a mobile application is a good idea to spread awareness about hepatitis. Results showed that 80% of people gained knowledge about hepatitis using the app. For usability of multiple language support, we found that results depended upon the background of the user [1]. "I am not educated but my daughter is, she can use this app for me." [P#6]. The majority, especially those who cannot read or understand text, appreciated audio support for images. "With audio it is more understandable" [P#9]. Tasks were assigned to users to test usability of app using three metrics; percentage completion, time taken to complete task and the

number of iterations to complete a task. For both task types, results showed that all tasks given to the users were completed with some variation in time (mean=30sec). This was probably due to the fact that some tasks involve reading text or data entry, which take more time. For the number of iterations to complete the task, we set a threshold for the reiteration for task A and B as ≤ 2 and ≤ 1 respectively. Most of the users took one re-iteration for task A whereas for task B, users completed it without re-iteration.

Impact of our application: The evaluation shows that this app can help in inculcating awareness about the disease [1]. Patients used the app to get additional information about treatment, precautions and for setting reminders for appointments and medicines. Our participants found the interface of the application very interactive and easy to use, "Sliding menu bar was quite helpful in navigation" [P#9].

Multiple Language Support: We found that there are mainly two sectors in society, one who prefer English and the other who are more comfortable with Urdu (mean Urdu: 45%, mean English: 55%). Thus, we kept bi-lingual support in our application. Above 80 percent of the participants rejected Roman Urdu as a medium of language for the app. "Urdu is the national language of Pakistan and making app in Urdu sounds more reasonable" [P#3].

Risk Factor Analysis: Users found this feature very useful. "Risk factor analysis is the best feature of the app as through its use you can get diagnosed in time which will help in reducing complete liver failure" [P#4].

Adding Reminders: Adding reminders for medicines and appointments was very useful especially in the Pakistani context where majority of the hospitals use paper slips for this purpose. Patients without smart phones appreciated the concept of a handy diary for scheduling appointments and vaccinations.

Usefulness of Diary: People and patients who did not own smart phones found the diary quite pleasing and easy to use. About 78% of the participants who did not have a smart phone were satisfied with the diary. However 22% people found no difference between the doctor's prescription and the diary.

Conclusion 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. We implemented a mobile app and diary to not only spread awareness about hepatitis but also to track and maintain the disease by setting reminders for medicine, appointments and vaccinations. Keeping the constraints of the people of Pakistan in mind, we have also provided multilingual support (English, Urdu and Roman Urdu) as well as voice over icons for better understanding. We evaluated our app and diary with patients and the general public and found it to be an effective solution for inculcating awareness and managing the disease. In future, we plan to provide end to end solution in the form of an app with a semi digital diary for tracking and managing patient's records by storing data on a cloud and making it accessible on smart phones, diaries and on doctors' systems by using NFC chips. This will help users to monitor the status of their disease effectively.

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