Mobile Communication Tools for a South African Deaf Patient in a Pharmacy Context

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Abstract: This paper presents a case of iterative community-based co-design to facilitate the emergence of an innovative mobile system to address a potentially life-threatening scenario for Deaf people in South Africa. For Deaf people who communicate in South African Sign Language, miscommunication due to language barriers, under-education and under-employment can lead to a potentially dangerous therapeutic outcome when Deaf people misunderstand a pharmacist's instructions on how to take prescribed medicine. The design for a mobile communication aid to address this problem emerged from iterative cycles of action research performed with a local Deaf community that also involved pharmacists and a multi-disciplinary research team. Conventional user-centred design techniques were innovatively appropriated for the community-based co-design. The paper illustrates the community-based co-design process and points the way toward imminent implementation, as well as the potential application of the mobile solution to other scenarios in Deaf people's lives.

Keywords: eHealth & Health Information Systems, ICT for eInclusion and eAccessibility, Transformation of Research Results into Local Innovation.

1. Introduction

This paper presents a case of iterative community-based co-design to facilitate the creating of an innovative mobile system to address a potentially life-threatening scenario for Deaf people in South Africa. Many Deaf people in South Africa use South African Sign Language (SASL) as their preferred language and struggle to communicate with hearing people [1]. Many Deaf people in South Africa have never attended school or have attended school at a very late age [2][3]. Like other signed languages, SASL has vastly different syntactic characteristics from South Africa's 11 official spoken/written languages. Low spoken and written literacy combined with a serious lack of interpreters, makes communication with the majority hearing populace even more difficult for Deaf people [4][5]. In a pharmaceutical context, Deaf patients can take medication incorrectly with potentially dangerous therapeutic effect, and add complication to treatment and even risk of life. To eliminate poor communication between a Deaf patient and a pharmacist a solution

based on a mobile phone was co-designed by Deaf people in a local community, pharmacists and the research team. Although many of the Deaf participants are functionally illiterate, they are experts about their communication realities. Thus the research team focuses on understanding a Deaf community's perspective on problems in communication with healthcare professionals, and pharmacists in particular, to address this problem via user-centred methods.

Deaf with a capital D indicates the cultural identity of a deaf person who uses a signed language, e.g. SASL, as the primary language of communication [1]. There are around 600,000 Deaf people in South Africa [6]; however, the number of SASL interpreters is a tiny fraction compared to actual need. Having an interpreter for demanding situations, e.g. to communicate in a healthcare setting, can be extremely difficult and costly for Deaf people [7].

We have found very little research concerning technology design for Deaf communities and communication in developing countries [6]. Members of our team have been involved with Deaf communication research via an iterative series of overlapping investigations and interventions based on prototype co-design and evaluation, mostly utilizing focus groups [7][8]. Our current multidisciplinary research team comprises members from three universities, two in South Africa and one in Europe. The research team works with members of a local Deaf NGO (non-governmental organization), with whom collaboration is on fully equal grounds [8]. The mutual intention is to implement valuable social solutions [9] for and in this particular Deaf community, and we hope to move co-designed solutions forward, to be introduced to other Deaf communities via 'viral' spread, i.e. word of mouth.

Applying the methods described in Section 3, answers to research questions were generated, and the research questions were defined during the process. To foretell, we present the answers here, and we view them as results (see Section 6).

- Deaf people reported on actual experiences of doubts concerning prescribed medication. They often did not understand the instructions explained by the pharmacist.
- As a consequence, Deaf patients sometimes took their medicines incorrectly or ineffectively. Ineffective treatments worry Deaf patients' companions and healthcare professionals; and are a waste of healthcare expenditure.
- Many Deaf patients do not understand most of the existing pharmaceutical pictograms that are intended for communication.
- Deaf users found that mobile phones which are currently available on the market are not intuitive and do not serve Deaf people well.
- Many Deaf patients miss their turn in public hospitals because of the verbal queue notification system that is not applicable to 'all'.

2. Objectives

To solve or meet our objectives the research questions are:

1. What are the problems with communication between Deaf patients and healthcare professionals in the pharmacy context?
2. How should the Deaf user interface and elements be designed, such as interface structure, symbols and pharmaceutical pictograms?
3. What are Deaf users' wishes and needs for their mobile phones and other possible tools for communication?

3. Methodology

In order to address the objectives/research questions, we built a design team that was mutually collaborative from an action research perspective [10][11][12], comprising Deaf and pharmacist end users, ICT developers, industrial designers and a Deaf education

specialist. We performed community-based co-design in what could be considered a Living Lab setting[13], although we feel the dual imperative of action research [14] more accurately defines our approach (and also that such discussion is beyond the scope of this paper). The Deaf community plays the steering role. The research team is tasked to find solutions that are feasible and we take it forward together.

Vision in Product design (ViP) was applied in the design process for structural steps [15][16]. The designers give attention to the 'present', when there are no tools to assist the pharmaceutical communication, and the 'future', when the communication tools are designed. The attained aspects are as follows: properties of mobile phones and their useful applications for Deaf users, interaction between a pharmacist and a Deaf user, and the context of the pharmaceutical communication as described in Figure 1.

Traditional Human Centred Design (HCD) methods were co-opted for the community-based co-design process. These methods and techniques were selected to serve the steps and aims of ViP. There are three main phases in the process; 'Hear' (H), 'Create' (C), and 'Deliver' (D). The process and the set of techniques are used to attain empathy concerning the Deaf end users with whom the designer co-creates new solutions, including products, services, environments, and interaction [17]. All techniques used are illustrated in Figure 1. Problems in the pharmaceutical communication context between a Deaf patient and a pharmacist, and mobile phone use behaviours are addressed. Participants contributed design ideas for pharmaceutical communication and also design ideas for a 'Deaf' mobile phone, following on ideas of one of our designers via a story board. Finally, all ideas were synthesized toward a solution. Then an application mock-up was tested with simulated communication flows. From there, recommendations on the design of related communication tools, such as mobile phones for Deaf users and a queue notification system, were established.
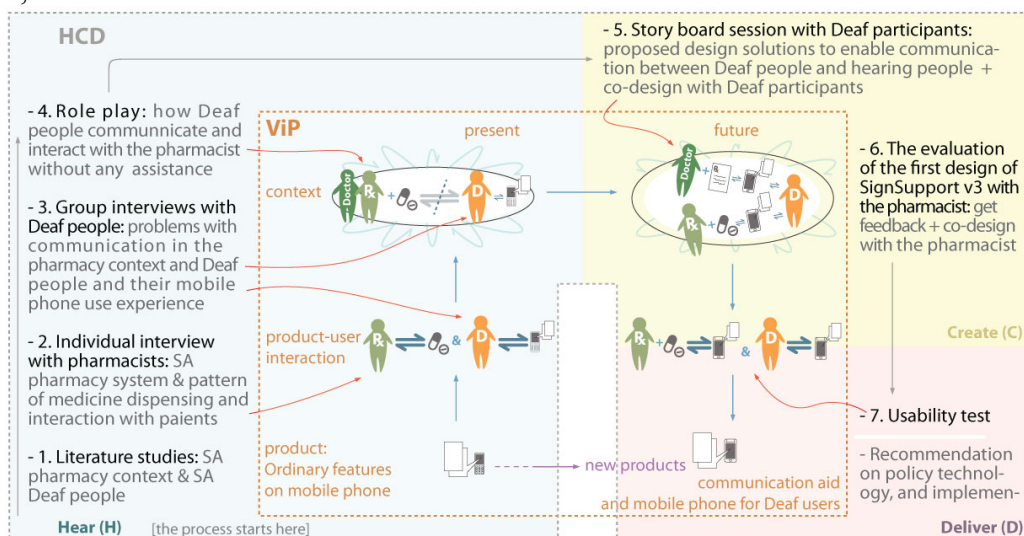

Figure 1 Vision in Product [15][16] and human-centred design methods

Deaf participants were from a Deaf NGO and all tests with them were situated at their community building. The pharmacists were studying at a South African university and had some work experience in public hospitals. All individual tests with the pharmacists were conducted at their university. In the usability test, the application mock-up was tested on a laptop. The test was based on the aspects of user interface design principles: structure, simplicity, visibility, and tolerance [18], plus the aspect of ergonomics. Each usability test session consisted of role-playing. The time spent to communicate in the pharmacy setting was measured to predict how feasible this communication tool is for the real situation with limited time, typically 2-6 minutes per regular customer or patient. The results from the

usability test will be taken into account for the next development of the application before being implemented on a mobile phone.

4. Technology Description

The use of off-the-shelf technology is one goal for the development team. Therefore, the application is designed to be installed on a mobile phone, which most Deaf people tend to own. We chose an Android platform as it is a rapidly growing mobile platform that lends itself to open source development and we want the application to be free for Deaf people. In addition, the application is meant to support communication in a hospital pharmacy as most Deaf patients choose to visit public hospitals because of the free medicines and treatment offered by the health policy of South Africa [19]. Hence we can also leverage ubiquitous Bluetooth capabilities on a mobile phone to keep Deaf patients informed about their turn in hospital waiting room queue. Table 1 lists and describes the involved technology.

Table 1 Functionality of each component

Components	Activities	Working principles	Software/hardware
Software application	- Support communication between a Deaf person and a pharmacist →dispensing medicine. - Help Deaf person to understand the purpose of medicine(s) on the go→ medicine summary - Help Deaf person take medicine effectively → reminders& dairy - Prevent Deaf person from allergic reactions→ allergy check for pharmacist - Provide portable patient data→ to pharmacist	Application on any Android smart phone (can be cheap or not)	In the implementation phase of the design on an Android phone Java was used as a programming language because it provides an already existing infrastructure to develop an application of this nature.
Mobile phone	- Work as a communication tool for different scenarios. - Display and record clear signed video messages. - Assist the user in accomplishing activity.	Android OS	480 x 800 pixel resolution, large touch screen size 4.3 inches, 3264 x 2448 pixel resolution camera with built-in higher current flash and self standing feature or stand.
Bluetooth on phone and/or bracelet	- Notify Deaf patient when it is their turn to consult the doctor or to collect their medicines.	Bluetooth	Bluetooth built into most mobile phones (requires pairing) or with a bracelet.
Notifying board	- Pharmacy staff notifies the Deaf patient when it is time to approach the pharmacist by pushing a button on the notifying board – a signal is stent to the phone by Bluetooth.	Bluetooth	Bluetooth component on the patient's 'board' (given to the doctor when prescribing medicine).

When the components mentioned in the table above are implemented, a Deaf patient can register to get the queue notification board when entering the hospital, then pair his/her phone with the board's Bluetooth device. The nurse will use a non-permanent marker to write the patient's name on it. The patient brings the board to the doctor[1] and hospital staff will pass the board to the pharmacy along with the prescription(s). When it is the Deaf patient's turn, e.g. in the pharmacy, one of the pharmacy staff members presses the button on the board to notify the patient; the mobile phone or bracelet vibrates via a Bluetooth signal from the board. The patient then walks to the counter to 'speak' with the pharmacist.

The prescription is on the notification board with a note alerting the pharmacist that the patient is Deaf and is about to hand over a mobile phone with instructions in English. The user interface is structured as a wizard, guiding the users by questions and (to be selected) answers or options. Also making a picture of the medicine is wizard style. The pharmacist is guided to fill in the complete medicine information via a series of graphical and button

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[1] Note that we, or someone else, will at some point address the communication between a Deaf patient and a doctor, as the communication domain is too wide to 'can' onto the phone. We expect most South African doctors to be capable of dealing with communication barriers that a multitude of official languages bring to bear; recall there are eleven in South Africa, of which SASL is not one.

screens. The pharmacist is also asked to take a photograph of each medicine for the Deaf person to visually connect to the instructions/information. The patient can then view SASL videos of those medicine instructions for each medicine. The videos are stored locally on the phone (there is no mobile data connection required) and assembled in an order that faithfully represents the information, e.g. the number of pills to take, before or after food, and how many times a day, and for how many days. The information is saved as a medical summary to be reviewed later to confirm and reinforce understanding, and can be viewed at any time simply by tapping on a picture of a particular prescribed medicine.

We followed Watermeyer and Penn (2009) medication explanation strategy, which is meant to promote a patient's understanding of the provided medication instructions [20]. All SASL videos were pre-recorded based on the study of actual communication patterns during the testing (described below). The pharmaceutical pictograms and symbols used for the user interface were co-designed by Deaf participants, pharmacists and the designer.

Even a low-end Android phone can be used. It must, however, have an acceptable resolution front camera for video relay (explained below), preferably with a built-in flash to provide sharp and clear photos of the medication packaging. We designed a mobile phone prototype with a moveable leg at the back to enable the phone to stand by itself for hands-free operation by a Deaf user to sign with both hands, although a wire, plastic or wooden stand could also work with an off-the-shelf phone. Internet and Bluetooth are also required. The product use scenarios are as shown in Figure 2.
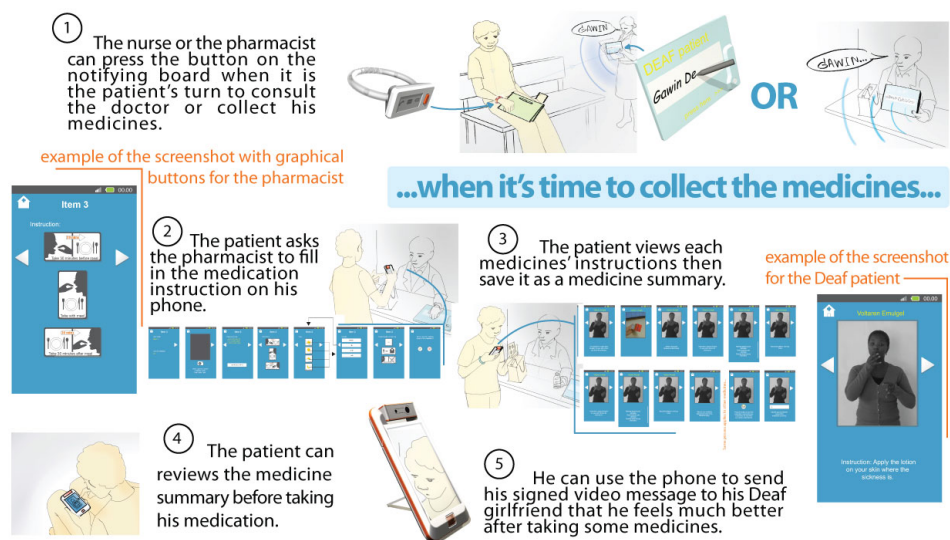

Figure 2 Activities concerning the products' usage

5. Developments

If the communication becomes too complicated to be managed by the application, the Deaf patient can request a video relay service [21] to communicate with the pharmacist via a SASL interpreter, as illustrated in Figure 3. We are currently investigating how to perform video relay in a cheap and effective way to a) take advantage of the paucity of SASL interpreters in South Africa and we would assume, in other sub-Sahara African countries as well, and b) facilitate mobile video data that can be played on a mobile phone as a video relay device. The work on mobile video relay is beyond the scope of this thesis, and has been addressed elsewhere [22]. However, in order to support the creation and population of the SASL video 'corpus' to support the limited domain communication flow between the Deaf end user and pharmacist, we must provide an authoring tool with an easy-to-use interface, mostly designed by and for the pharmacist, together with the Deaf education specialist on our team.
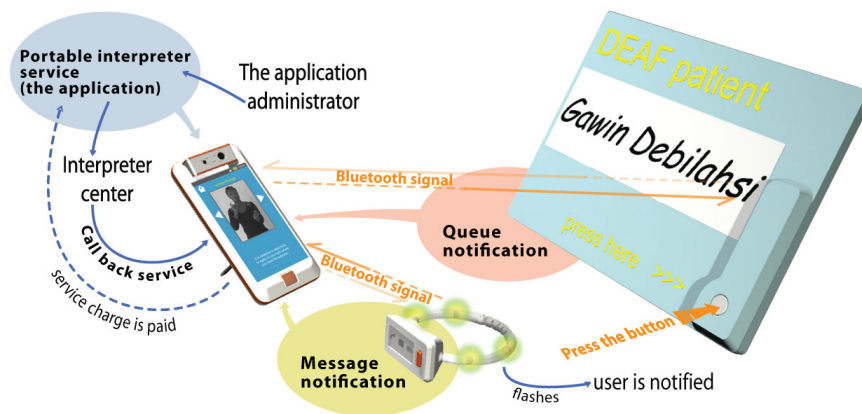
Figure 3Overall system-supported communication flow

6. Results

Collaboration with Deaf participants yielded valuable information as Deaf people fully understood their problems in communicating with a pharmacist, and they know which solution fits them best. The comments from pharmacists during the design development helped the application comply with the medicine dispensing practice. The results are essentially on the design concept and can be considered co-evaluation performed by the multi-stakeholder co-design team. Feedback from eight Deaf participants and a pharmacist, exposed to the conceptual mock-up for the first time, found it to be satisfactory. Most participants, except two Deaf participants, found the interface easy to use. However, all Deaf participants clearly understood the information delivered via the application, notably, because it was provided in SASL with pictograms. The provided guidance was sufficient for both types of users. The co-designed pharmaceutical pictograms and symbols were comprehensible for both Deaf participants and the pharmacist.

Several issues were suggested for redesign. The pharmacist mentioned a list of primary pharmaceutical questions that should be asked of the patient before starting to fill in the medicine's information and instructions on the phone. This can be easily accommodated via the authoring tool by editing the communication flow and content, and recording the appropriate SASL videos. We expect that during future trials in the next round of the research wheel, during prototype implementation, many new elements such as this will emerge, which is exactly why this authoring tool is also meant to be iteratively co-designed. A second issue is the load of the task required to complete the communications, e.g. clicking a 'next' button too often. This should be reduced by changing the presentation style of the numerous SASL videos. Another issue of concern was the average time of the medicine dispensing process. The pharmacist participant and the Deaf participants spent around 13minutes,on average, to fill in information and to view the complete medicine instructions in SASL videos. The average time to complete the process via the application is still much longer than the average time that pharmacists currently spend per patient in a public hospital. However, the pharmacist does have the responsibility to explain things to people who cannot communicate well. Regardless, our communication aid still requires further development to speed up the overall process at the pharmacy.

7. Business Benefits

There is as yet no commercial mobile communication aid in South Africa that enables Deaf people to communicate with hearing people. Therefore, it could be a business opportunity to support pharmaceutical communication between a Deaf patient and a pharmacist to penetrate the market. It could also be positioned as social responsibility for a company such as Telkom, who has tried to offer a product for Deaf people in the past [23].

Alternatively, the implementation of the application can be made freely available as open source software to facilitate uptake as well as benefit from crowd-sourcing ideas and refinements of the eventual implementation. The development of this pharmaceutical application may take several years to be ready for actual use by Deaf people. We have already applied for research funding to explore such open source commercialization. We expect that the South African government would appreciate and support such asocially beneficial project for national health and human rights; where Deaf people can take medicine properly and responsibly, with information in a local signed language. We expect that research subsidy would no longer be needed as the application grows in usage. It would be ideal if national, and even international, Deaf associations could join together in an open source fashion and become future co-designers of such a service; in this way a niche market could be scaled up, e.g. to Deaf people in more countries simply by changing the signed language in the pre-recorded videos. We believe in this way, the system could be developed in a sustainable fashion, e.g. with and by non-for-profit or even for-profit organizations and an open source viral business model to drive future development.

8. Conclusions

The design for this Deaf communication aid emerged from a process we call community-based co-design. We employ conventional user-centred methods; however, we do not consider the Deaf participants and pharmacists as experimental subjects but rather as experts in their communication realities. This approach has shown to be very promising to effect real social change. As such, we feel the so-called 'lines' between stakeholders are blurring via our interpretation of the action research process in a way that can truly yield a locally relevant and innovative solution to help South African Deaf people communicate with a pharmacist, thus potentially saving thousands of lives. We also feel that this process can inform other researchers who are working towards societal change as it has proven to be an effective way to design and evaluate technology which is feasible for the end users.

Future work, then, includes the implementation of the mobile communication tools described herein: the mobile application on a commodity-type smart phone; an authoring tool to populate the 'corpus' of signed language videos and English text to support a Deaf patient's conversation flow with a pharmacist; the queue notification system that enables the Deaf person to approach a pharmacist in the first place; and a cheap and efficient video relay system to help clear up any misunderstandings using a minimum number of SASL interpreters. We fully intend to test the system on a small scale first, in a local pharmacy, leveraging the participation of the local Deaf community who actually produced the ideas for this project, especially as co-evaluators to feed back into an iterative loop of 'product' design. From there, we hope to take this mobile communication aid to the larger Deaf community in the Cape Town area, and at some point consider adding additional scenarios for the tool, e.g. a more generalized visit to the doctor, police station or Department of Home Affairs. In our view, the tool can be designed in a way to support a variety of 'canned' interactions in situations where Deaf people could leverage such a tool in lieu of a proper interpreter.

Acknowledgement

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