

Design Direction Analysis for a Health Knowledge Transfer System for Deaf People and Health Professionals in Cape Town

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Abstract— Many South African Deaf people use South African Sign Language (SASL) for communication, but are less skilled at reading and writing. In the context of healthcare, adult Deaf patients and health professionals therefore face problems with communication. These communication barriers hinder many Deaf people from accessing health information from various sources. Deaf patients need to understand conversations at a health facility, and also to receive accurate and comprehensible health information that supports their understanding of the diagnosed disease for self-management. Health Knowledge Transfer System (HKTS) is a proposed branch from a research and development project on a mobile communication tool (SignSupport) for a Deaf person in healthcare contexts. This paper describes the findings retrieved during the exploration phase regarding the design direction of the HKTS using a community-based co-design (CBCD) approach. Deaf adults and health professionals from Cape Town participated in this research. Health information about Type 2 diabetes as a case study and mobile devices as information transferring tools were selected. The HKTS is envisioned as part of an assistive device for health care system integration to provide information in SASL thus serving the needs of the Deaf patients. It focuses on a scenario in which the targeted diabetic Deaf patients can access health information from anywhere.

Keywords—Deaf patients; low health literacy; community-based co-design; health information sources; mHealth.

I. INTRODUCTION

Deaf with a capital ‘D’ refers to a cultural group of people with hearing loss who mainly use a signed language for communication; many of them have limited reading and writing skills [1]. In the South African healthcare context, Deaf patients and health professionals have problems with communication, in the absence of a SASL interpreter, due to their language differences [2]. Therefore, our research team, together with a Deaf NGO, started developing a communication tool on Android mobile phones called “SignSupport” to bridge limited and patterned conversations through the CBCD approach [3]. The communication during a medication dispensing process was taken as a specific case study. SignSupport prompts a pharmacist to explain the medication instructions by typing in and selecting buttons matched with pre-recorded SASL videos, so the Deaf patient can view and understand the instructions [4][5]. The research team later found that Deaf patients needed to acquire

additional health information to support their understanding of the diagnosed disease and self-management. Consequently, we decided to branch out with a sub-project to design and develop a HKTS which addresses this need amongst Deaf patients and health professionals. The system aims to provide adult Deaf users with comprehensive information in signed language and in their preferred presentation method on a low cost mobile platform.

Section 2 of this paper presents the background information from literature reviews. Section 3 accounts the methodology used in the project. Section 4 describes the empirical findings covering the current situation of health information distribution from the point of view of both Deaf people and health knowledge providers, including the ideas for solutions from all participants. Section 5 explains the decisions made on the design direction. Section 6 envisions the integration of HKTS and SignSupport, and the co-design of the information content and its presentation techniques as future work. Section 7 concludes with the work that will be proceeded after this exploration.

II. PROJECT BACKGROUND

Many South African Deaf people experience a disparity in accessing comprehensive health information.

A. Problems in health communication

Health professionals and Deaf patients in South Africa frequently experience communication problems in the absence of the scarce, and relatively expensive, SASL interpreters. The most common problems are as follows:

1) *Language differences*: A signed language cannot be translated word-for-word to a spoken or a written language, or vice versa, due to the differences in sentence structure [6]. This is why the majority of Deaf people find it difficult to learn and understand a spoken or a written language [7]. The majority of South African Deaf adults can therefore read and write only simple vocabulary, are unable to communicate with health professionals, and have limited exposure to health information from the mass media. Problems in health communication can have an adverse effect on the patient’s health condition [8][9].

2) *The lack of SASL interpreters*: The communication problem could be overcome with the assistance of signed

language interpreters. However, only 84 SASL interpreters are registered at the National Institute for the Deaf [10]; this number of registered SASL interpreters is inadequate to serve the demands of approximately 600,000 South African Deaf people across the country [11]. In addition, 90% of the Deaf population is born into hearing families many of whom cannot sign [12]. These reasons explain why many Deaf patients cannot easily find a SASL interpreter or a family member who is capable of communicating in SASL to escort them to a health facility [2].

B. Interferences with information understanding and adherence

Misconceptions and the lack of fundamental knowledge can interfere with the understanding of the given health information and the subsequent adherence to the suggested treatment from a health professional [13].

1) *Health misconceptions*: Several misconceptions about various diseases, their prevention and detection, and treatment were found by different researchers. Deaf people in a community share similar health misconceptions through close-knit communication, e.g., the so-called “grapevine”; and it is difficult for a hearing health professional, who is an outsider, to influence them [4][14]-[16]. Many Deaf individuals do not question new information they receive from others, unless it goes against their own beliefs [2].

2) *The lack of fundamental health knowledge*: This is caused by a number of issues which are that (1) Deaf people receive inadequate health education during childhood [4], (2) many Deaf individuals miss opportunities to receive health information through incidental learning, especially from their hearing family members [17]. Lastly, (3) due to functional illiteracy, the vast majority of Deaf people have limited exposure to health information promoted via the mass media [18]. Without fundamental knowledge, Deaf people can hardly detect erroneous health information shared among their Deaf peers nor understand the health explanations from health professionals.

III. METHODOLOGY

A. CBCD approach

In the field of Information and Communication Technologies for Development (ICTD), the CBCD approach is applied by research groups in different countries to deal with multiple stakeholders and social complexity [19]. Our research team applies CBCD as part of action research, which involves end-users and communities with their social and cultural factors in design stages. We explore and develop solutions with participants in order to achieve an accessible and viable HKTS in the Cape Town context [3]. The decisions for the design direction of the HKTS were made based on the preferences, ideas and preliminary requirements from Deaf and health knowledge provider participants. There were four main considerations within this decision making process, which were: (1) the type of

media to provide Deaf people access to health information (i.e., TV or mobile phone), (2) health information of interest and relevance for Deaf participants (i.e., type of disease), (3) the targeted group(s) of Deaf users of the HKTS, and (4) the targeted group(s) of health knowledge provider users of the HKTS. The research team then planned to start the design and development process with a relevant case study.

B. Methods

Interviews with sensitizing tools were applied to the research with Deaf participants and health knowledge provider participants. All the Deaf participants were interviewed in groups, while the health knowledge providers were interviewed either in groups or individually based on their availability. The interviews aimed to (1) identify the organizations and individuals who are the current health information sources to Deaf people in Cape Town, (2) investigate problems in the transfer of health information between the information sources and Deaf people, (3) define both effective and ineffectual techniques in health information transfer, (4) identify urgently needed health information among Deaf people, and (5) elicit ideas for solutions for improved health information transfer.

The interviews were conducted with different groups of Deaf people: males, females, and Deaf families. These interviews covered topics (1) to (5). Next, we approached health professionals who were frequently mentioned as health information sources by the Deaf participants. The interviews with these health professionals touched upon topics (2), (3), and (5). The health professional participants were health policy makers, Deaf health workers (health workers who are Deaf themselves), and hearing healthcare providers. These participants have experience in providing health information and services to Deaf people. A qualified SASL interpreter assisted in all interviews with the Deaf participants.

C. Techniques used for data collection

1) *Question sets for the interviews*: There are two different sets of questions— one for Deaf people and one for health professionals. The questions facilitate them to think about their experiences during health communication and solutions that could meet their needs.

2) *Sensitizing tools for Deaf people’s reflection on their access to health information from different sources*: The researcher wrote down on sticky notes each health information source mentioned by the Deaf participants during a group session. After leading the participants through the questions, they were asked to discuss within their group, and rate their accessibility to, each mentioned source on a ‘map’ of A0-sized paper. The map was divided into five areas, using scales of zero to five, from very poor to high accessibility, respectively. Thereafter, the participants were asked if they wanted to adjust their rating or to add any missing health information sources.

3) *Sensitizing tools for eliciting ideas for solutions from Deaf people and health professionals*: After sharing their

experiences and the communication techniques used during health communication, the participants were asked to think of solutions that could meet their needs in effective health information transfer. Sheets of A4-sized paper, coloured markers, stickers in different shapes and colors were provided to participants to express their ideas.

D. Participants

Participants were invited from different Deaf communities and health organizations in Cape Town.

1) *Deaf people:* (1) Male group and female group— Six Deaf males and six Deaf females were invited from two Deaf communities. Their level of hearing loss, education, health literacy, and experience with telecommunication and technology were disregarded. (2) Deaf family groups— Three Deaf families (altogether eleven participants) who have low-to-medium experience with technology and the internet, were invited from two Deaf communities to join separate group interviews. Each group consisted of a Deaf father, a Deaf mother, and at least one child who was attending school regardless of the child’s hearing ability.

2) *Health professionals:* (1) Health policy makers— Two participants from a governmental organization were approached for a group interview. (2) Deaf health workers— Four health worker participants who are Deaf from a Deaf community were invited. These participants were trained specifically for HIV/ AIDS counselling. (3) Hearing healthcare providers— Two doctors, one nurse, and one clerk were approached from a public health community centre where several Deaf people visit.

E. Ethics

All participants were informed about the objectives of the interview, the activities, and also their participation rights. The participants were asked to give consent to the research team before the interview started. All interviews were video recorded and were to be kept in secured storage with access by the research team members only.

IV. RESULTS

The outcomes that are of relevance for the upcoming CBCD process can be described as follows:

A. Overview of health information distribution modes to Deaf people

The Department of Health of the Republic of South Africa promotes the distribution of information about diseases by partnering with Deaf organizations. The Deaf organisations invite Deaf members to distribute the information through health events. There are only four Deaf health workers in Cape Town, and all are based at one Deaf NGO. These Deaf health workers organize health events and individual counselling in SASL through available subsidy. In addition, Deaf people can also acquire health information during consultations with doctors.

B. Problems in health information transfer

Health policy makers were aware of the problems in distributing information and services to the Deaf population. They also realized the critical lack of SASL interpreters in the health care context.

Several of the hearing health professionals tended to write to communicate with the Deaf patient during the communication in the absence of a SASL interpreter, without knowing that the patient could not fully understand the written messages nor easily find someone at home to interpret for them. Some auxiliary information, which could help the patient build up their understanding and knowledge about the disease, was discarded due to communication breakdowns. In addition, some health professionals also required lip reading skills from Deaf patients during the explanation about health information.

Deaf health workers are eligible persons who are Deaf or have SASL competence. They are trained for specific counselling, viz. HIV/AIDS. These workers may not have knowledge about other diseases beyond their trained subject. However, Deaf clients normally approach them with questions about all types of diseases.

Health information available in the mass media is not fully understood by a Deaf audience due to their functional illiteracy and hearing loss.

C. Existing vs. ideal health information sources

Deaf people mentioned a range of existing sources for their acquired health information. The two most frequently mentioned sources are consultation with a doctor in the absence of a SASL interpreter, and health workshops and counselling provided by Deaf health workers from a Deaf NGO in Cape Town. Several other health information sources such as the mass media (e.g., newspapers, TV programmes, and health pamphlets) and individual persons (e.g., friends and parents) were considered as existing health information sources with less frequent mention. Figure 1 presents the ranking of existing against ideal health information sources.

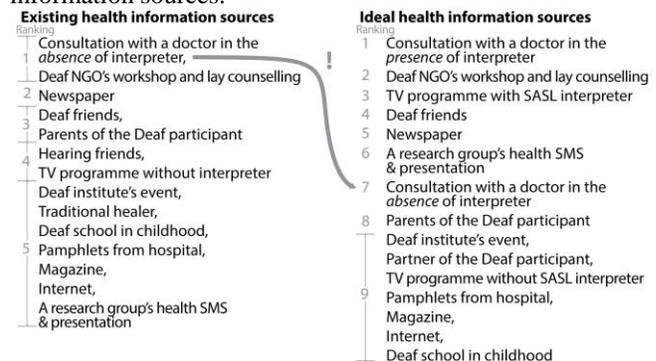


Figure 1. Existing vs. ideal health information sources.

Consultation with a doctor in the absence of a SASL interpreter was noted as a frequent health information source. However, the information provided by doctors (or other health staff) was not understood by the Deaf patients. As a

result, the ranking of this source as an ideal health information source to Deaf people is relatively low. Health workshops and counselling provided by Deaf health workers from a Deaf NGO was highly rated as an existing source that Deaf people turn to, and also as an ideal information source. Deaf participants expressed their satisfaction with health drama in SASL performed by the Deaf health workers, who also provided a Q&A platform to the Deaf audience.

D. Health information of interest to Deaf people

Deaf males, Deaf females, and Deaf families were asked to discuss and prioritize the top three health information topics which are the most relevant for their own group. The Deaf health workers were also asked to prioritize the health information which is urgently needed by all Deaf people. The results are described in Table I.

TABLE I. THE PRIORITIZED HEALTH INFORMATION OF INTEREST AND RELEVANCE FOR SPECIFIC GROUPS OF DEAF PEOPLE

For the interest and relevance of	Information of interest in prioritized order		
	1 st	2 nd	3 rd
Young Deaf men	safe sex	sterile circumcision	sexually transmitted diseases
Deaf women	cancer	depression	swollen feet
Deaf parents	diabetes	cancer	children's health
All Deaf people	diabetes	hypertension	tuberculosis

As a result, diabetes was concluded as the most popular and relevant health information of interest among the Deaf participants.

E. Effective and ineffectual techniques in delivering health information to Deaf people

These findings were extracted from the responses of all participants.

1) *Effective techniques*: (1) SASL is the “mother tongue” among South African Deaf people. Therefore, delivering health information in SASL is the most effective technique. (2) Drama in SASL is a form of health information delivery that Deaf people appreciate. The health drama delivers information inclusive of entertainment. It also covers information to correct health misconceptions among Deaf people. (3) Pictures with concise text descriptions. Some Deaf participants mentioned optimizing their understanding of concepts with pictures combined with short descriptions.

2) *Ineffectual techniques*: (1) Communication that requires reading and writing skills from Deaf people is not effective because many Deaf people are functionally illiterate. (2) Communication that requires lip-reading skills is also ineffectual. The accuracy of English messages understood via lip-reading is only about 30-35% [20].

F. Ideas for solutions from all participants

We retrieved 45 ideas from drawings and verbal/signed explanations by participants. These ideas were sorted into three categories, which are solutions through the use of (1) human-to-human interactions (16 ideas), (2) mass media (12 ideas), and (3) ICT (information and communication technology) (17 ideas). The most popular ideas from each category respectively are an increase of the health drama teams by involving more Deaf members (C 1), TV programmes, health videos at health facilities, and health DVDs with SASL interpretation (C 2), and mobile devices as a health knowledge tool (C 3). Table II shows the analysis of the suitability of each popular idea as a solution in the Cape Town context.

TABLE II. ANALYSIS OF SUITABLE SOLUTIONS FOR IMPROVING THE HEALTH INFORMATION DISTRIBUTION IN THE DEAF CONTEXT

Considered performance	Popular solutions proposed by participants		
	(C 1)	(C 2)	(C 3)
Accommodate different data types of information (SASL videos, pictures, texts)	√	√	√
Available health communication bridging	×	×	√
Allow information reviews, private search, self- learning	×	× (TV programmes & health videos at health facilities) √ (health DVD)	√
Can be updated by health knowledge providers	√	√ (health videos in the waiting areas of health facilities & health DVDs) × (TV programmes)	√
Initial cost of production and development	Medium	Medium	Medium
Operational cost	Medium	Low (health videos at health facilities & health DVDs) High (TV broadcasting)	Medium

Costs were estimated from the monthly allowance for a research assistant to develop and maintain the system and an allowance for groups of four Deaf people to prepare a drama.

V. DISCUSSION

This section discusses the decision-making on the design direction of the HKTS design and development.

A. Decision-making on the design direction

1) *Type of solution to improve access to health information*: The type of solution was selected based on the considerations as stated in Table II. Mobile devices have the potential to present information in SASL videos, as Deaf people explicitly expressed this need, and in mixed media.

2) *Information for the disease of interest among Deaf people:* Type 2 diabetes is selected for this case study due to the interest of Deaf participants and also its prevalence in the health care context of South Africa. There are 3,500,000 people in South Africa (6% of the population) suffering from Type 2 diabetes [21]. We can assume 1%, i.e. 35,000, are Deaf (similar to the 1% of the population being Deaf as opposed to deaf and/or hard-of-hearing).

3) *Targeted groups of Deaf users:* Middle-aged males and females and mothering females are the targeted groups of Deaf people for this case study. These people are in the age range of diabetes onset, and they are amenable to the use of mobile devices as the tool for accessing information.

4) *Targeted groups of health knowledge providers:* Doctors and ancillary staff who are involved in diabetes care will be invited to join this participatory research. They will be asked to provide insights into what diabetic patients should know, understand, practice, and manage.

B. Preferred information transfer methods to Deaf users

Deaf participants required viewing health information in SASL. They also favour health dramas in SASL as they have experienced from a Deaf NGO in Cape Town. However, the entertaining elements in the drama may deflect the audience’s attention from the important health messages. In addition, coherent pictures can enhance the understanding of the information among Deaf users because of their strong visual-spatial working memory [22].

VI. FUTURE WORK

The designed and developed HKTS is meant to complement the use of SignSupport (see Figure 2) as it will be a relevant health education source for Deaf adults.

A. Integration of HKTS and SignSupport

Deaf patients can use SignSupport (Communication tool) to communicate with hearing staff at a public health facility, from arrival until departure. Figure 2 indicates the stages at which a doctor or ancillary staff members can refer to different topics of health information from the HKTS (health knowledge source) to explain the diagnosed condition and self-management. This will help the patient understand the disease in more depth and can help improve or maintain their health condition at home.

B. Co-design of information content and the transfer process with end users

Co-design with Deaf participants with Type 2 diabetes and diabetes doctors and involved ancillary staff will take place in Phase 2 of the research to define the design of the health information content and the delivery structure in detail. Together with these participants, the research team can (1) identify the information (based on or in addition to the topics proposed in Figure 2) which need to be available on the HKTS, and (2) understand suitable methods to transfer health information that meets Deaf people’s requirements and their learning capabilities. We envisage that the end-users will require a mix of techniques in delivering specific health information, e.g., Deaf patients may require explanation about insulin through the combined techniques of animation and SASL narration. This assumption will be explored and validated during the co-design sessions.

VII. CONCLUSION

This HKTS can be one of the ways to solve the challenges of Deaf people’s inaccessibility to health information due to language barriers and the scarcity of a signed language (SASL) interpreting service for healthcare. It will complement the use of the mobile communication tool, SignSupport, to provide access to accurate and comprehensible health information for Deaf people. The design direction of the HKTS is selected. Its content and structure will suit the SASL communication needs of Deaf people. The content and the structure will be designed through a case study of Type 2 diabetes care in the Cape Town context. Deaf users in the middle-aged and mothering phase are at risk of this type of diabetes, so they, and the health professionals (doctors, clinical nurses, and ancillary staff) involved, are invited to join the design case study of the HKTS. These users can have access to the information about fundamental knowledge of the disease, self-management, and life-style modification. The main approach is CBCD, or so called— a participatory design approach. Therefore, Deaf and health professionals will collaborate with the research team to derive an accessible and viable HKTS. We expect that the derived content structure will be applicable to the information for other chronic diseases.

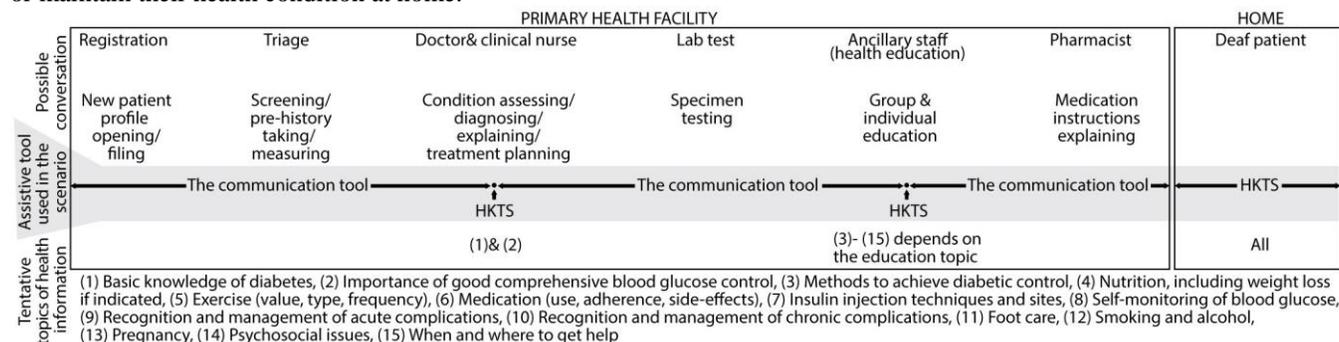


Figure 2. Integration between SignSupport and the HKTS during a patient’s journey in the diabetes care

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