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Supporting Home Based Health Care in South African Rural Communities Using USSD Technology

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ABSTRACT

Poor infrastructure, inadequate literacy, availability of technology and socio-cultural settings are a few factors in the myriad of challenges facing the development of rural areas in South Africa. Healthcare is one of the most important sectors where governments of developing countries strive to enhance the situation by utilizing affordable ICT solutions. However, unlike developed regions, in rural areas within a developing context, issues are intertwined. This requires truly innovative solutions that are affordable, robust and above all sustainable. We propose a patient monitoring system using USSD technology which is a very easy to use mobile phone application. This information system facilitates patient information flows from homebased care workers to a local clinic. Clinic sisters have instant access to patients' vital signs via a desktop computer. The results presented in this article are tested by means of a prototype, which is currently in use and producing data.

Keywords

Rural community healthcare, e-health, tele-monitoring, USDD, healthcare information system, home-based healthcare

INTRODUCTION

Rural areas in South Africa are characterized by the class of society living below subsistence level and poor access to basic infrastructures (Republic of South Africa, 2000). This restrains the communities from economic growth and development, which is also reflected by the health care delivery. Hospitals and clinics are poorly equipped and understaffed. Furthermore, the population of rural areas has a low life expectancy and there is a high incidence of infectious and chronic diseases (SADOH, 2004). Adherence to treatment of chronic diseases is less than 50% (Sabate, 2003). Life expectancy in South Africa is 47 and 49 years for males and females respectively (WHO, 2006), and the estimated prevalence of HIV infected adults is 18.3% (UNAIDS, 2008). In these circumstances, a strong tradition of home based health care (HBC, also referred to as informal healthcare) has become increasingly important, but it is also threatened by implosion under its severe pressure (Mashiri et al., 2007). However, HBC is also challenged by several issues that, in part, can be remedied using adequate ICT support.

ICT can be a powerful solution for poor health care deliveries in developing countries (see for example Greenberg, 2005) but successful implementations of scalable health related ICT solutions in developing countries remain forthcoming (infoDev, 2006). Our research objective was to explore how ICT systems can support the South African informal health care processes in rural areas and to develop and test a robust and sustainable prototype of an ICT based solution. The proposed solution was a remote monitoring system, which facilitated transmission of patient information from caregiver to clinic sister. One of the main challenges of the project was to understand the social context of the problem and embodiment of these challenging factors into the system design and design process.

Our initial investigations into the problems associated with informal health care started in 2006 when surveys were held in the current geographic research area to assess local mobility and health problems. Investigation of the broad diversity and interdependency of problems and informal ways of working led to the designing of an ICT enabled patient monitoring system in mid 2008, supporting the practices of the home based health care. The prototype is the result of a joint research program

between the Dutch University of Technology Delft (TU Delft) and the South African Council for Scientific and Industrial Research (CSIR). The prototype, a USSD application on caregivers' mobile phones (a sort of 'interactive SMS'), was mainly used to study users' acceptance. The reported work is still a research in progress. Nonetheless, this first fully functioning prototype allows for significant reflection on the research and practical challenges we focused on.

The structure of the paper follows our research process and starts with relevant background on the rural areas in South Africa, the informal Home based Care and the research area. Subsequently the problem and its proposed solution are discussed after which we will elaborate on the specific problem context and design challenges and discuss the followed requirement engineering approach. Following, we describe the prototype and display the main technical aspects of the system: the caregiver interface (using USSD technology) and the sister interface (web based application). We conclude with the evaluation approach, intermediate results and a discussion.

BACKGROUND INFORMATION

In this section, we give background information that covers the country level situation, the home-based care relation to formal medical centers, and the geographic region where the project was carried out.

South African rural areas

Many South African rural areas face isolation and have poor levels of access to services and facilities. These circumstances position these areas at a disadvantage compared to many urban centres which often results in unbalanced development. Present settlement patterns reflect the distortions and policies of the past (Maritz, 2006). Approximately 70% of South Africa's poor people live in rural areas. Their incomes are constrained because the rural economy is not sufficiently vibrant to provide them with remunerative jobs or self-employment opportunities. Their cost of living is high because they spend relatively more money on basic social services such as food and water, shelter, energy, health and education, and transport and communications services (Republic of South Africa, 2000). Although research shows that South Africa is leading with ICT development in the African continent, it does not necessarily translate to good access and better usage, especially in the rural areas (Research ICT Africa, 2008, Gillwald et al., 2005). One of the sectors that ICT is poorly utilized in is healthcare in rural areas.

Home Based Care

Primary health care in South Africa starts at the level of the clinic. However, a further level of health care has developed spontaneously within rural communities. This is known as Home-based care (HBC), it is the provision of basic nursing care needs by formal or informal caregivers to people in their own homes. This service is available to people who have mental, physical, emotional and social needs. The care given is meant to restore and maintain the individual's maximum level of comfort, function and health (Cape Gateway, 2009). Caregivers' activities consist of more than the basic nursing. They provide broad social assistance, such as physical, educational, psychological and spiritual care for both patients and their families (Mashiri et al., 2007). By decentralization of health care to the district level, the scope of operations and the quality of the HBC differ throughout the country. In order to demark the focus of our research, we confined our project to four specific rural communities.

Research area: the Leroro Communities

The research area, referred to as 'the Leroro Communities' is located within the north-eastern part of South Africa, and consists of four clustered communities in the Ehlanzeni District in the northern part of Mpumalanga province bordering the Blyderiver Canyon (see figure 1a). Each community has approximately 9 000 inhabitants. One hospital, situated north of Matibidi A, serves the area. Three clinics are located in the communities of Matibidi A, Matibidi B and Moremela (see figure 1b). The areas are accessible by surfaced road with the exception of Matibidi B which can principally be accessed by gravel road. Mobile phone coverage is good in most parts of the area. Caregivers in Moremela and Leroro report to the sisters in the Moremela Clinic. The Matibidi A and B caregivers report to the Matibidi B Clinic.

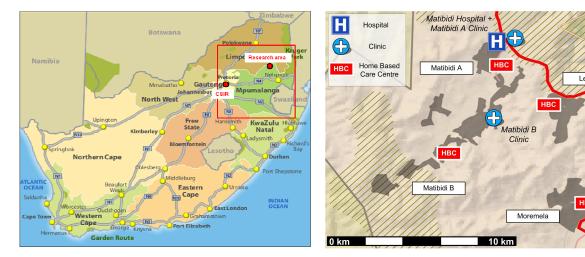


Figure 1a. Research area in South Africa

Figure 1b. The four communities in Ehlanzeni District, Mpumalanga

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PROBLEM STATEMENT AND PROPOSED SOLUTION

In this section, we first formulate the problems based on the preliminary studies including the earlier conducted surveys. Subsequently we propose a solution that will be discussed throughout the paper.

Problem statement

The home based care system works as follows: once discharged from the hospital a patient who requires follow-up can use the provisions of the Home Based Care organization. A caregiver is allocated to a patient, who will be visited on a daily to weekly basis. Since the caregiver acts as the direct communication link between the patient and the clinic, he or she is supposed to compile reports and discuss them with the sister in workshops that are organized between once and four times per month. At present, accurate patient information cannot be gathered because caregivers are not equipped with instruments to measure vital signs. And as a result of long walking distances and time pressure, sisters and caregivers don't interact frequently. The absence of accurate and timely patient information at the clinic implies that the patient cannot be monitored on a frequent basis, meaning that the sister cannot take actions as promptly as desired. Patients and caregivers cannot assess the severity and criticality of situations and try to postpone transport to clinic or hospital as long as possible due to high travel costs and efforts. In the eyes of caregivers and sisters, deaths can potentially be prevented when sisters are aware of patients' health conditions in an earlier stage.

Proposed solution

We follow the assumption that frequently providing clinic sisters with patient information that is relevant, easy accessible and accurate will benefit patients in multiple ways. Earlier diagnoses can be made, better treatments can be started, but also travel costs and effort can be reduced for both patients and caregivers. This will result in better life quality and expectancy for patients, but we also expect that providing such information to the clinic has a positive effect on the workload and joy for both sisters and caregivers. Facilitating transmission of patient information by technology operates in the field of telemonitoring (or remote monitoring) which is a branch of e-health. E-health has medical, technological, spatial and beneficial perspectives (Sood et al., 2007). Telemonitoring includes the collection of clinical data and the transmission of such data between a patient at a distant location and a health care provider through electronic information processing technologies (Home telehealth Reference, 2005). E-health and telemonitoring applied in home health is widely used in developed countries and has proven its value, however such systems have not successfully been applied on a big scale in developing countries and rural areas in particular (Ouma and Herselman, 2008, infoDev, 2006). In the following section we will discuss the challenges that come with the design of a telemonitoring system in rural areas in developing countries.

RESEARCH APPROACH

In this section we discuss the starting points for the design process: the social context and the related design challenges, followed by the requirements engineering approach.

Social context and design challenges

Physical, financial and skill accesses (Ouma and Herselman, 2008) are tangible boundary conditions to successful ICT implementations. However, acceptance of communication technologies for health care systems is itself a challenge in developing countries and especially in cultural diverse countries (Ganapathy and Ravindra, 2008). The high rate of failure in ICT programs is explained by Heeks (2002, p. 101) as a 'mismatch between Information System design and local user actuality'. Morales-Gomez and Melesse (1998) blame poor analysis of the social and cultural dimensions of ICTs to harness ICTs for development in their own context. Some of the social and cultural circumstances specific for our research, which have been embodied in the design process are described below.

Originating from many forms of inequalities and experiences with corruption and political mismanagement, the rural population has a low esteem of government actions. Furthermore, many projects that have taken place, started by government or non government organizations have resulted in failures, or 'white elephants'. This idiom is commonly referred to and is described by Robinson and Toryik (2005, p. 2) as 'investment projects with negative social surplus'. This has resulted in a certain reserve towards new projects and it affects caregivers' and sisters' motivation and willingness to share information with the researchers. Some other aspects make it difficult to gather valid information: informality of business processes, 'yesnodding', and stigma around some diseases like HIV/AIDS. Burdened with more fundamental problems, caregivers and sisters are tended to disagree about the proposed problem to be solved (lack of communication) and the proposed solution (ICT). Caregivers have limited professional training and are of semi or low literacy level. This limits the extent to which system requirements can be elicited. Furthermore, a substantial part of the patients doesn't have faith in western medicine and more traditional medicine is practiced.

Elicitation of requirements

To develop a sustainable system a key requirement is that the community adopts the system, maintains the system and has a sense of ownership with respect to the system. To achieve this, user involvement in all stages of the development process is considered very important. To develop commitment from stakeholders in using and maintaining the system we can refer to Meyer and Alien (1991) who found that there are three components of commitment; (1) affective or emotional commitment, presented in the patient-caregiver relation, (2) continuance commitment, based on the benefits or utility people obtain from participating, and (3) normative commitment, a felt obligation to continue, strengthen by the sense of community and being needed. Normative commitment has in our context a critical additional factor, the tradition and informal ways of working in the current system are valuable to the community and should not be thwarted.

Given these constraints we took the following steps to derive the requirements for the system and to develop a prototype that meets these requirements. At the start of the design process, the problem, the solution and its technology were flexible and depended on stakeholders' input. Informal semi structured interviews in small groups were held during the first two visits to assess users' needs. A workshop attended by all relevant stakeholders was organized to define problems they encounter and how they could be solved. A secondary goal was to achieve consensus and build commitment. Also the first basic requirements were elicited and ranked by importance. During the third visit, more detailed requirements were again discussed in small groups and participants could state their technology preference (call centre, spoken dialogue system, SMS or USSD) after simulating interaction with these technologies. The medical equipment was distributed and in the fourth visit medical training sessions were held by the sisters. The goal of the fifth visit was to setup the desktop computers for the sisters and to train them. Caregivers were trained in the use of the USSD system. The sixth and seventh visits were used to fix problems and retrain users, and for usability and usage observations. Questionnaires were administered during the eighth visit for evaluation purposes. The time span between the first and final visit was seven months.

PROTOTYPE DESIGN

In the previous section we elaborated on the design approach, the social context and its challenges. The goal was to design a robust and affordable ICT enabled system through which caregivers can submit vital patient information to the clinic sister. The prototype, which is currently tested, meets its functional and technical requirements for the most part. Therefore, the proposed solution and the prototype are jointly discussed in this section.

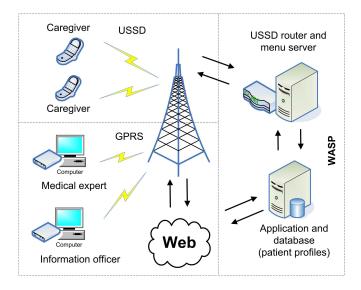
The prototype

Per community three caregivers, each nursing about twenty patients, were selected and equipped with basic medical instruments (see figure 3). After visiting a patient and measuring the vital signs, the readings are submitted via a USSD menu on their own mobile phones. Once submitted, two sisters in Moremela and Matibidi B clinic have immediate web-based access to these data via a desktop computer. A home based care coordinator in Leroro is assigned as an information manager,

and updates the information system with the new patients and correct profiles. Implementation and training took place near the end of December 2008 and the system is operational and self-sustainable since January 2009. Currently, evaluation activities are in progress. The system is required to be low cost, toll free, teachable, usable, confined to current communication tools and confidential for patient information. Costs for the use of the system are R 0.20 (\$ 0.02) per 20 seconds. One session takes roughly one minute and a half, which is approximately R 1.20 (\$ 0.12) on average per session. No cost benefit analyses have been carried out yet. For the test period it was not yet possible to redirect costs to one account. This is an administrational matter which has to be processed via telecom providers like Vodacom which was not accomplished before the test started. This problem was temporarily solved by distributing airtime vouchers among the caregivers.

Technical architecture

USSD stands for Unstructured Supplementary Service Data. USSD allows for the transmission of information via the Global System for Mobile communication (GSM) network. USSD is best explainable as 'interactive SMS'. Text messages are sent to and received from a caregiver's mobile phone through a real time connection to the GSM network. A wireless service access provider (WASP) routes the messages from the mobile network to a server with the application and database. Sisters and information officers have web based access to the application and personal health records (PHR) via a 3G modem and a desktop computer. Figure 2 presents the technical architecture. A big advantage of the use of USSD is that it is easy accessible (by simply dialing a number) and easy to use (simple menu structure). USSD works on almost all mobile phones and it is generally used in South Africa, for example to load airtime on a mobile phone. A drawback is that the open connection is disabled after three minutes.



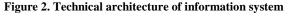




Figure 3. Caregiver equipment containing a thermometer, weighing scale, blood pressure meter and stethoscope, watch, urine-strips and first aid kit

Caregiver interaction process

After measuring a patient's vital signs, a caregiver dials a USSD number (*120*667*4247# in the test case, see figure 4a). The application recognizes her phone number and answers 'Hello caregiver {name}, please enter your personal code'. After entering and sending her personal code, the application responds 'please enter patient number now' (figure 4b). The application recognizes the submitted patient number and answers with the main menu. Figure 4c is an example of the main menu for patient number 0001, an imaginary patient named "Patient Fakes". The main menu shows five types of vital signs (option 1-5), the alarm (6) and the Submit data option (7). The caregiver can choose to enter the vital signs in any order. For entering the temperature, she answers by sending a '1'. The next screen (Figure 4d) asks for the temperature. After entering the temperature, the application returns the main menu, including the reading of the temperature she has just entered. Figure 4e presents how a fully entered main menu can look like. If all vital signs are entered, the caregiver chooses option 7 to submit the data. In fact this is redundant, because the application already has received the information, but in the tests, it turned out that caregivers appreciated a confirmation message.

A frequently heard complaint of the caregivers was that they didn't know how to act properly when they encountered a critically ill patient. The 'ALARM' option, number 6 in the main menu, meets this need by sending the sister an automated SMS, containing the patient's name and caregiver's name and phone number. The sister can call back the caregiver to assist.

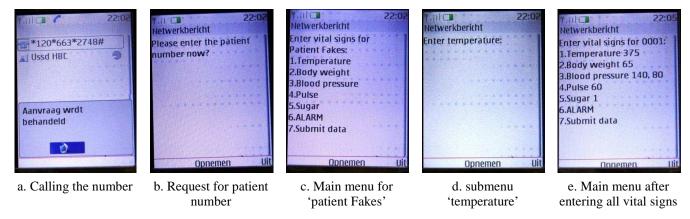


Figure 4. Some screenshots of the USSD interface on a cell phone

Sister interaction process

Via a 3G modem, a sister can access the internet on her desktop computer in the clinic. The application is stored on a site which has been set as home page. After logging in, the sister has access to the patients listed by patient number, or the patients whose vital signs have been submitted the last days. After clicking on a patient name, his or her personal health record (PHR) is displayed. Figure 5 shows an example of a PHR. More options can be added, such as displaying line charts, adding comments, or viewing patient's clinic history. For the test however, a lean and simple interface has been pursued.

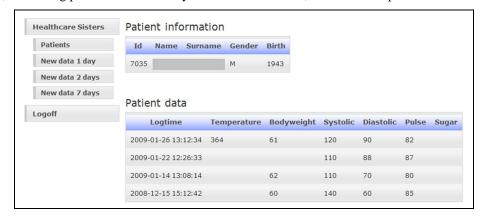


Figure 5. Screenshot of a web based personal health record

EVALUATION OF THE PROTOTYPE

Evaluation is in progress, but we will briefly discuss our evaluation approach and intermediate results.

Evaluation approach

The goal of testing the prototype is to determine its success and to investigate its potential in comparable areas. The technology acceptance model (TAM) was used to predict and explain users' acceptance of the telemonitoring system. Basically, this type of model assumes that perceived usefulness and perceived ease of use determine the attitude toward using a system, and it states that the last aspect mentioned predicts actual use (Davis, 1989). In our research, we are not only interested in the actual usage of the prototype, but also especially in users' perceptions as described above and in the factors that determine these perceptions. It is possible to find a high usage during prototype testing, while at the same time the perception of usefulness and ease of use, and thus attitude toward using, is negative. This outcome is undesirable, meaning that it is unlikely that the same system will be successful in other communities under comparable conditions. Two rationales for this possible outcome are, firstly, that the long term presence of the research group may have established a certain

compliance among the caregivers and sisters, and secondly, it may have caused a situation in which the caregivers and sisters want to live up to expectations that are raised. This effect is referred to as subjective norm (see for example Ajzen and Fishbein, 1980, Davis, 1993). Another example of subjective norm is that the caregivers feel compelled to use the system. Although being volunteers, local charismatic people like HBC managers or sisters could incite the caregivers to use the system, without being convinced that it has an added value. Secondly, the perception of usefulness and ease of use can have been strengthened during the several participatory design stages. All current users have frequently been consulted about their opinions and preferences. This has undoubtedly led to a better understanding of the design choices that have been made.

Submitted patient information (by caregivers) and login data (from sisters), questionnaires and user observations will be used to disentangle factors that led to high or low user acceptance. Factors that determine ease of use are based on the usability heuristics from Nielsen (1994). Factors that possibly determine user acceptance are for example referent power, years of professional experience, experience with a mobile phone or computer, age, education, learning curve, technology aversion, availability of airtime and network coverage. By investigating these underlying factors and by profiling comparable communities, future behavior and potential can be assessed.

Intermediate Results

The evaluation phase is currently in progress, but some general preliminary findings are worth noting. Besides our experience that the attitude towards the system is very positive, one of the most obvious findings is the diversity in usage behavior among sisters and among caregivers. The sister in the Moremela clinic was very enthusiastic and cooperating. She monitors patients on a daily basis and contacts caregivers if submitted data seem untrustworthy. The sister in the Matibidi B clinic is a bit reserved in using the system. Although enthusiastic and cooperative, she hardly started up the system after the implementation of the prototype. Last named is less experienced in using a computer. Diversity in usage between caregivers is also distinct. Not only the degree of system usage, but also the number of mistakes and reliability of patient data differs greatly. Most caregivers mastered the USSD within a few trials, but some of them were still struggling after weeks of practice. Medical instruments were handled improperly, which resulted in an emphasis on new medical training sessions instead of focus on the ICT system. This on itself was a good sign, because both sisters and caregivers felt that accurate measurements are a necessary precondition. Another difference is the difference between the caregivers in Moremela and Leroro and the ones in Matibidi A and B. The first group performs much better. The sister that is monitoring their patients has a higher usage of the system and we expect that this is a reinforcing mechanism. High caregiver usage and accurate patient information motivates the sister to use the system, which in turn reflects on the caregivers and motivates them to keep using the system. Another reason for better performance of Moremela and Leroro caregivers is the presence of a charismatic HBC manager in Leroro. Also the living standards, infrastructure and education seem to be slightly better in these communities which could also affect usage behavior. During the test phase the number was not toll-free yet and airtime vouchers needed to be distributed which caused many problems and unintended use of airtime. This confirmed the necessity of a toll-free number. Also in places where network coverage was not 100%, system usage seems to be much lower.

DISCUSSION

This paper provided an overview of several design processes that have led to a prototype of a telemonitoring system that is currently in use in the home based care organizations of four rural communities in South Africa. Communication is one of the most important components in providing home based care, which is currently undermined by several financial and social factors. This paper proposes an ICT enabled information system whereby caregivers can transmit patients' readings of vital signs to the clinic. Caregivers submit the vital signs via USSD technology on their own mobile phones. Sisters examine the personal health records on the web via a desktop computer. USSD is best explained as "interactive SMS" which is very easy accessible and easy to use. Our research approach had a social problem solving perspective and we strived for a highly participatory design process. Preliminary results are very promising, although some tantalizing challenges remain. Caregivers and sisters have been trained to operate the system in a very short period and although medically trained, caregivers lack practice with medical equipment. For some caregivers this resulted in inaccurate readings and unreliable submitted data. This in turn, might cause the sisters to lose trust in the system. On the contrary, proper system usage by caregivers motivates the sisters and this again reinforces the use among caregivers. In our experience patients, caregivers and sisters see a great added value in the system. Caregivers and sisters communicate more often and better and they have more joy in their work. One of the negative experiences is that patients regard the monitoring system as a replacement for a visit to the clinic and not as supplementary. This makes some of them unwilling to travel to the clinic. A more extensive evaluation will provide more insight into real acceptance and the potential of the system in the long run and in other environments then the research area. Future activities will focus on other long term effects, such as reduction of unnecessary transport and related costs or the increase of patients' life expectancy. This will also encompass cost benefit analyses and the legal and confidential aspects of the system.

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