Supporting collaboration among healthcare professionals and disease surveillance in remote areas

Saturnino Luz∗
School of Computer Science and Statistics
Trinity College Dublin
Dublin, Ireland
luzs@scss.tcd.ie

Masood Masoodian
Department of Computer Science
The University of Waikato
Hamilton, New Zealand
masood@cs.waikato.ac.nz

Manuel Cesario
Graduate Programme on Health Promotion
University of Franca
São Paulo, Brazil
manuel.cesario@uol.com.br

Bill Rogers
Department of Computer Science
The University of Waikato
Hamilton, New Zealand
coms0108@cs.waikato.ac.nz

Abstract

It is estimated that global climate change and regional land use and cover changes in the Amazon region will contribute to the spread of vector-borne diseases such as bartonellosis and leishmaniasis. The large geographical distances and the sparsity of human settlements in the region pose challenges to the collaboration among health professionals whose goals range from diagnosing diseases to monitoring their spread. This paper presents work in progress on a system to support the tasks of local healthcare professionals and enabling collection, compilation, sharing and visualisation of data for purposes of epidemiological research and disease surveillance in remote regions.

1. Introduction

The provision of healthcare services to populations located in remote regions and often dispersed over large extensions has long been considered a difficult issue from the perspective of health systems management [7]. In the Amazon region, the focus of the work presented in this paper, in addition to the natural geographical obstacles and the consequent scarcity of human resources, the phenomenon of global climate change has compounded the problem. Climate change has altered the pattern of land use and cover in the region and it is expected that it will continue to do so with growing intensity [3]. These factors combined are contributing to the spread of diseases, such as cutaneous leishmaniasis, and increasing the likelihood that diseases not yet found in the Amazon region, such as bartonellosis, will reach the region.

While specific telemedicine approaches have been employed elsewhere with some success to tackle the issues of remote assistance to diagnosis and treatment [9], the situation described above implies needs that go beyond the usual functionality of telemedicine systems. Health management in such situations requires a more comprehensive approach capable of dealing with issues of human ecology and disease surveillance, in addition to patient care [14]. In terms of computer support for these activities, a broader information ecology [20] also needs to be considered. That is, support for collaboration needs to be adaptable and provided at different levels in aid of different though inter-related activities. At one level, primary care activities are often carried out in remote locations by nurses and community health-care workers. The latter have generally little training and would therefore benefit from support, specially under circumstances involving the identification of diseases that are rare in the areas in which they operate. Communication with specialists and researchers might help improve primary care provider performance. At a higher level, the healthcare system needs to collect and maintain patient records, and these may be accessed, among others, by epidemiological surveillance bodies which have the need to gather accurate information on disease occurrence, including patient location. These collaborations may also have a transnational character, as in the case of bartonellosis which is endemic in some areas of Peru, has spread in recent years,
and risks reaching the disease-free Peru-Bolivia-Brazil tri-national borders [3].

An approach combining mobile devices for fieldwork, centralised databases and support for both synchronous and asynchronous communication may be suitable to address, at least in part, this complex set of needs. This paper presents ongoing research into the problem and an initial prototype designed to allow us to explore the potential role this combination of technologies could play, both in patient care and in a broader system for surveillance of emerging diseases.

2. Mobile healthcare

Time and space can often be barriers between healthcare providers and their patients, as well as between healthcare providers themselves. Information and communication technology has been seen as a tool for breaking down such barriers [21]. Telemedicine has been a focus for CSCW research since its inception, in the mid-1980s. This led to development of a number of early telemedicine systems, generally for supporting collaboration between distributed teams of medical practitioners [10, 13].

While applications of telemedicine, in various forms, have existed for many years, the use of mobile technology for supporting healthcare is relatively recent. In most cases mobile wireless technology is seen as a low-cost and rapidly-deployable solution to address common diseases affecting developing regions [19]. As such, these systems generally aim to use mobile phones to provide the functionality of biomedical devices, such as a microscope or spectrometer, to assist healthcare providers with diagnosis of diseases such as malaria or tuberculosis [2, 19], which are still common in many parts of the world. Other medical uses of mobile technology include training of health workers in rural areas [15] and provision of home-care [8].

One important application area for mobile technology which has so far been somewhat neglected by researchers is its use for collection of public health information and monitoring the spread of diseases. This is despite the fact that information is considered to be fundamental to public health, and the use of ICT an indispensable part of healthcare [16]. As Vanden Eng et al. [22] point out “Access to good quality, up-to-date national and regional data on disease burden, needs assessment, or intervention coverage is essential to help inform national policy decisions; guide relief efforts; monitoring control programs; and evaluate their impact, progress, and cost-effectiveness”. This led to their development of a mobile device fitted with a global positioning system (GPS) which they have used for probability sampling and data entry in household surveys in Africa.

At present there is also a need for systems that combine collected information about public health and spread of diseases to other relevant information, such as geographical and environmental data, to produce useful visualisations for field use by researchers and carers on mobile devices. Interactive map visualisations, for instance, have been found to be invaluable in monitoring public health issues [11].

In addition, researchers have suggested other possible uses of mobile devices to provide health workers with guided steps through established protocols for diagnose and treatment of common diseases. One of the few examples of such a system to be discussed in the CSCW literature is e-IMCI [4], a prototype for Integrated Management of Childhood Illness (IMCI), jointly developed by the World Health Organization and UNICEF. A pilot evaluation in Tanzania showed that the system leads to better adherence to the IMCI protocol, as well as greater speed and flexibility than the paper booklet version. The developers of IMCI note that there is a similar screening protocol for HIV, for which an expert system could be developed. A less explored alternative would be to provide health workers, particularly community health workers who have little training, with access to formally trained medical professionals through the use of mobile devices such as smartphones and tablets.

3. Theoretical background and methods

An assessment of the needs of individual actors and organisations involved in treatment and monitoring of emerging infectious diseases in the Southwestern Amazon region, including health professionals from Brazil, Peru and Bolivia has been carried out through survey of the literature, fieldwork, questionnaires and informal interviews. One of the authors (Prof Cesario) has worked in the region since 1985, and lived at the tri-national Southwestern Amazon region in the last decade. The work described in this paper is complimentary to his fieldwork, so ethical concerns and access to data and to local people is being facilitated accordingly. Following this fieldwork, three initial interviews were conducted in the past year a medical researcher and an epidemiologist working in the area to delineate a situation of concern. Concept videos and questionnaires were presented to 13 health professionals involved in primary care, epidemiological research and disease surveillance.

In this initial investigation, rather than committing to a specific theoretical orientation for analysis, we adopted the meta-level approach proposed in [5]. This approach consists in employing key concepts from well-established CSCW frameworks and case studies of their application in mobile healthcare situations in order to facilitate requirements elicitation. We focused on the concepts of mobility work [1], common information spaces [17] and coordination mechanisms [18], and explored their implications with respect to the activities of health workers in remote regions. Application of this method resulted in iterative refinement of the assessment, which is consolidated and presented in
the next sections. It also served as a basis for the specification of a first prototype which will, in turn, be instrumental to the next phases of this research.

4. Assessment of needs and goals

Monitoring, prevention, treatment and research of emerging diseases involves a complex interleaving of actions by several actors of heterogeneous backgrounds. Building a common information space [17] for these various actors involves an understanding of their activities, knowledge and representations, as well as the articulation work needed to enable effective sharing and use of information. While this paper focuses on support for health professionals responsible for primary care and local data gathering, we briefly outline the roles of the different groups involved in the more general setting.

**Community health workers and nurses** are generally responsible for day-to-day primary care in the Southwestern Amazon region. Community health workers (CHW, “agentes comunitários de saúde”, in Brazil or “agentes comunitarios de salud” in Peru and Bolivia) are members of the community who perform functions related to healthcare delivery and receive basic training in the context of specific interventions, but have no professional degree or tertiary education [12]. In some cases, CHWs may be provided with basic laboratory equipment and get trained to diagnose a specific disease. CHWs also perform other developmental and promotional roles, acting as bridges between the community and formal health services. These local workers may interact with locally-based trained nurses, as well as medical assistants and doctors. In the context of diagnostic and treatment of emerging diseases and epidemiological surveillance these primary care workers could also play important roles in recording details of suspected cases for notification, identification of disease vectors (carriers) which in the case of bartonellosis and leishmaniasis are sand flies, and educate the local communities.

**Medical doctors and specialists** are medical professionals often based in regional hospitals. In addition to treating referred patients, they can provide guidance to the activities of CHWs. Doctors and specialists from regions where a disease is newly emerging may need to seek information from colleagues from regions where it is endemic. This is the case of bartonellosis, for instance, which is endemic to Peru but does not yet occur in the Brazilian Amazon.

**Epidemiology researchers** devise models for disease surveillance. They rely on access to information from a variety of sources in order to assess risks. Of particular interest in the Southwestern Amazon region is the development of early warning systems to anticipate and manage the negative impacts of climate change on the spread of (re-)emerging vector-borne infectious diseases [3]. Such systems need to aggregate data on climate, land use, the region’s general geographic characteristics, vector distribution and case distribution as well as its evolution over time.

**Policy makers** rely, among other sources, on information and expert recommendations provided by epidemiology researchers in order to decide on prevention policies, tools and strategies to cope with possible outbreaks and epidemics.

4.1. Needs and possible technology support

The tasks performed by the primary care workers (CHWs, nurses, and doctors) have collaborative and mobility work elements which, though not as intense as the mobility work that takes place in hospital wards [1], could benefit from technological support. In the context of medical interventions and surveillance of emerging diseases such as bartonellosis and leishmaniasis in the Amazon region, mobile devices could in addition support other activities identified in our study so far. These activities and their constraints can be described as follows:

**Collection of patient data:** due to the remote and sparsely populated geography of the region, an important goal both from the point of view of healthcare services policy and patient management is to obtain consistent and accurate patient information. The mobility requirements for these activities also involve heterogeneity of linguistic cultural backgrounds due to the fact that the location where such activities take place is near the tri-national borders of Brazil, Peru and Bolivia, where the risk of spread of bartonellosis is greatest. This includes location data, which could potentially be integrated into geographical information systems for the purposes of issuing early warning of outbreaks, as well as use by other healthcare professionals. A typical constraint on this activity is the irregular telecommunication coverage in the region. In the case of CHWs, literacy may also be an issue. In addition to patient and geographical data possibly collected by CHWs, data could be gathered by researchers for the specific purpose of disease surveillance. Such data include: time spent outdoors during sandfly feeding times, insect bite prevention measures, history of insect bites or infestation and place where insect bites occurred, number and type of domestic and peri-domestic animals (known reservoirs of the leishmaniasis parasite [3]) at the home, outdoor occupational and recreational activities, travel and household hygienic facilities.

**Diagnostic assistance:** as noted above, primary care workers working in the region are often members of the communities which they serve, and have only basic training on how to perform very specific interventions. However, emerging diseases may force these professionals to confront situations for which they are ill prepared. Further training and outside assistance would therefore be needed. Physical
distance and mobility constraints make carrying of bulky laboratory equipment and instructional material impractical. Such materials could include, for instance, medical atlases for aiding differential diagnosis of cutaneous lesions, which characterise both bartonellosis the non-visceral form of leishmaniasis, and mobile microscopy for analysis of blood smears for bartonellosis diagnosis. An example of an active cutaneous leishmaniasis lesion is shown in Figure 1.

**Figure 1. Cutaneous leishmaniasis lesion.**

**Access to central knowledge sources:** as with diagnostic assistance, mobile healthcare workers may benefit from access to knowledge compiled from a variety of sources and stored centrally. This includes not only patient records but also references, disease and vector distribution maps, as well as population data.

**Early warning:** if patient, serum-epidemiological and population data can be successfully gathered by primary care workers and researchers working collaboratively at the local level and aggregated into databases and geographical information cases, these data would provide a solid foundation for the implementation of an early warning system for the aforementioned emerging infectious diseases. Data mining techniques could then be applied in order to detect patterns of dispersion, risk modelling etc.

5. A prototype

In order to further explore some of the needs and possibilities discussed above, we have implemented a prototype (called nu-case) which runs on Android™ smartphones and tablets. This prototype aims to support the following tasks: collection of patient data, diagnosis of common and monitored diseases, communication with specialists from regional hospitals and central data repositories, and spatiotemporal visualisation of case reports.

Data collection is supported though different modalities: the user can enter the data through the virtual keyboard and add audio notes for transcription at a later time or incorporation into a multimedia patient record. Precise GPS coordinates can be easily added to the record. A photo of the patient and images of skin lesions can also be captured through the device’s built-in camera and annotated though drawing and textual labelling. Figure 2 shows a sample nu-case data input screen, with the location dialogue box open to acquire GPS coordinates.

**Figure 2. The nu-case prototype on a Samsung™ Tab 10.1, in data input mode.**

Support for diagnostic has been implemented for illustrative purposes, to assist our discussions and interviews with the prospective users, rather than as a tentative approximation of a realistic diagnosis support system. The functionality implemented includes support for acquisition and basic image processing of photographs of skin lesions and visual comparison features. The chronic form of bartonellosis is characterised by one or more reddish eruptive skin lesions. Since specific training is necessary for the differential diagnosis of these dermatological lesions, we have implemented a simple tool with which the acquired images of the patient’s can be compared with positive and negative cases which the user can slide across the screen, while leaving the image of the lesion to be identified statically placed on the bottom half of the screen. It is possible that lesion identification algorithms based on machine learning methods such as the ones used with some success to distinguish nevi, dysplastic nevi and melanoma [6] can be employed in diagnoses of cutaneous leishmaniasis and bartonellosis. The prototype has been designed so as to suggest this possibility, as well as the possibility of flagging a patient case and skin lesion images for further attention of a (possibly remotely-located) specialist when the classifier’s confidence score falls below a pre-determined level. This would in effect establish a coordination mechanism [18] between local healthcare workers and specialists in remote sites. Images may also be captured through a portable electronic microscope connected to the mobile device through its USB

---

1http://developer.android.com/

Assistance to diagnostic, perhaps via mechanisms such as the one described in the previous paragraph, is not the only form of communication between local healthcare workers and specialists envisaged for the system. Communication can be synchronous and involve sharing of images and other medical evidence if network access is available, or asynchronous and involve gathering of data for uploading once the worker returns to their network connection point, if network access is unavailable or unreliable. The asynchronous communication pattern can also be employed for uploading patient and epidemiological data collected in the field, as well as for downloading instructional and reference material (e.g. updated lesion images annotated by specialists) and the latest data on relevant geographical changes, disease propagation patterns etc.

Finally, the data collected locally and aggregated into a central repository can be returned to the local mobile device where it can be visualised on a graphical display along spatiotemporal dimensions. This information visualisation has been implemented so as to display a map of the region on which the reported cases are shown (see Figure 3). The patient cases used for development and testing of the prototype come from an actual database which contains instances of case notifications in the region, covering a period of eight years. Cases can be displayed by municipality of infection or municipality of notification (GPS coordinates are not available on this database). Circles with diameters proportional to the number of cases in an area are shown on the map. The user can alter the display by selecting, though direct manipulation, different date ranges and combinations of features from patient records. It is also possible to set the initial parameters of the visualisation and then animate it to display progression over time, thus supporting trend analysis and identification of patterns of disease spread.

6. Preliminary feedback

We have produced a concept video demonstrating the functionality of nu-case in order to gather feedback on the needs assessment described above, and assess the perceived usefulness of the different features implemented, their suitability to the tasks they are meant to support, potential pitfalls and constraints etc. This video has been used in conjunction with questionnaires and interviews conducted with Brazilian healthcare professionals. While this work is still in progress, some preliminary observations arising from interviews (following a video-based demonstration of the system) with medical researchers working on disease surveillance in the Amazon region can be reported.

It was generally felt that the system is easy to use and can improve patient data collection in terms of efficiency and quality. Attention was drawn to the fact that it is necessary to distinguish the activities of nurses from those of CHWs in the delivery of primary care. Nurses have greater level of training and often perform roles which might involve coordination of and assistance to CHWs. In remote areas where there is shortage or lack of doctors, nurses, to quote one of the respondents, “carry the health system on their backs”, performing diagnostic and treatment functions. System designers should therefore aim to provide these professionals with a different level of support, and cater for their coordinative activities. There are also other local groups with related coordination roles who could be supported.

Less enthusiasm was felt towards the potential of the system as a tool to aid diagnosis. There was scepticism about the ability of CHWs in the region to use the system, due to their low educational levels. The use of machine learning in lesion identification was seen as too complex for use by fieldworkers. The aid for differential diagnosis by image comparison on the device’s screen was positively assessed, and it was suggested that this function could be invaluable in healthcare education both by providing background study material and reference, and by helping compile new medical atlases for emerging diseases out of images collected by fieldworkers in the monitored regions. In terms of data collection, the issues of legal requirements, image quality, accuracy and dependability were raised.

We also explored the choice of hardware platform in our questions. The general reactions were that: the tablet was not robust enough to cope with the environmental conditions (damp, heat, dust), a more portable and resilient device such as a smartphone may be preferable, and the choice of a

---

2In Acre State, Brazil, where the fieldwork has been carried out, there is reasonable 3G network coverage. At the tri-national region, coverage is less reliable, but landline connection is available on the three sides of the border.
high-end tablet itself suggests use by medical doctors close to urban centres rather than local healthcare workers.

Regarding the visualisation feature, it was remarked that for the system to be useful to an epidemiologist, the area of infection rather than the area of notification should be displayed. The fact that the system showed area of notification was immediately detected, even though a distinction between municipality of infection and municipality of notification was made. This suggests that finer level of granularity (e.g. GPS data) may be required.

7. Conclusions and further work

Requirements for mobile healthcare support in remote regions have been presented, with focus on the tasks of collecting and sharing of various types of data for the purposes of diagnosing, treating and monitoring the spread of vector-borne diseases. A prototype and a concept video based on it, which illustrate functionality and possible use scenarios, have been used to gather initial feedback from the main actors identified in our needs assessment study. We plan on iterating this process to foster user involvement by further conducting structured interviews and live prototype demo sessions. This will help us to evaluate the functionality of the system, as well as elicit other requirements for its future development towards field trials.

References


