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Development of a Telemedicine Model for Emerging Countries: a Case Study on Pediatric Oncology in Brazil

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***Abstract*- This article discusses a telemedicine model for emerging countries, through the description of ONCONET, a telemedicine initiative applied to pediatric oncology in Brazil. The ONCONET core technology is a web-based system that offers health information and other services specialized in childhood cancer such as electronic medical records and cooperative protocols for complex treatments. All web-based services are supported by the use of high performance computing infrastructure based on clusters of commodity computers. The system was fully implemented on an open-source and free-software approach. Aspects of modeling, implementation and integration are covered. A model, both technologically and economically viable, was created through the research and development of in-house solutions adapted to the emerging countries reality and with focus on scalability both in the total number of patients and in the national infrastructure.**

I. Introduction

Pediatric cancer represents the second most common cause of childhood death in Latin America [1], [2]. The main reasons for this are: (a) the lack of medical specialists, mainly in the most remote regions; (b) the poor allocation of financial resources and lack of investments in the health department; (c) the heterogeneity in the cancer treatment.

With proper diagnosis and treatment, the cure rate among pediatric cancer patients can be over 70% [3]. This is achieved in the best Latin-American hospitals [4], [5], which are located in the most developed regions. Large numbers of patients from remote regions seek for high quality health care in the urban hospitals [6], leading to overcrowding of these hospitals. The use of the Internet and its open protocols represents one possible way of offering advanced services at distance [7]. This should assist medical practice, improve medical care services and disseminate knowledge throughout the field.

Childhood cancer care, especially in remote regions of Brazil – a continental-sized country -, lacks the offer and quality of health services [8]. Usually, the reference centers are located in the metropolitan areas and many patients have to migrate for specialized treatment [9].

Cancer registration is the foundation stone on which cancer control rests. Lack of reliable data on the cancer burden of a country is a serious barrier to effective planning and cancer control activities [10].

Hospital registration is the first step in collecting information that will eventually lead, on a macro scale, to estimate the burden of disease in a country [11], [12]. Registries also provide the key data that can be used to allocate limited human and financial resources correctly. Multi-centric hospital cancer registry software in low-income Latin American countries is needed for public policies and care, but most software is not available in languages other than English and is not targeted towards childhood cancer [13].

ONCONET offers a new cancer registration tool that facilitates standardized collection of childhood cancer data on a hospital level in Latin America, a first step towards population-based registration.

Other initiatives in telemedicine in Brazil failed or were not well disseminated due to the use of incompatible technologies [14], which are economically non-viable in our reality.

ONCONET (also known as the Brazilian National Telemedicine Network in Oncology) started in 2000 with a pilot study linking two sites through an ISDN videoconferencing link, one located at the Children's Institute of the Universidade de São Paulo and the other located at the Base Hospital in Porto Velho, Rondônia, 3000 km away from Sao Paulo [15]. The pilot study evaluated the use of videoconferencing for second medical opinion and patient follow-up. From March 2000 to March 2002, 33 patients were evaluated, through 69 videoconferences. The conclusions of this pilot study were:

1- it is possible to create a network for pediatric oncology and other subspecialties to diagnose and supervise the treatment of patients in remote areas.

2- a higher bandwidth is required in order to make the videoconference more natural to accommodate the participants' requests. There is also a need for more interactive ways to conduct the conferences in order to keep all parts interested.

3- Even though the mortality rate was higher than our institution's average, it was still significantly lower than the previous levels in the referring institution (62% versus 80%). The main cause for patient mortality – hospital

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infection - was not one that could be addressed directly by such telemedicine approach.

4- although not an obstacle during the course of the pilot, the telecommunication costs were the biggest hurdle for the network.

5- a better model for future Brazilian telemedicine projects was necessary.

After the pilot study the project evolved to a pioneering initiative for a national telemedicine program, comprising a national network of universities, research institutes and medical institutions, to support distance medical practice in pediatric oncology.

The specific goals for the project are:

1- Establishment of a network comprising the Brazilian Society for Pediatric Oncology (SOBOPE) [16], six pediatric oncology centers on six different states and three universities (Figure 1);

2- Development and implementation of a cluster-based architecture for medicine;

3- Offer of advanced on-line health services, such as: multimedia patients' records, multimedia cooperative cancer treatment protocols, collaborative second medical opinion, electronic medical record, distance learning and statistical quantification applications;

4- Offer a system service framework based in the Childhood cancer Web Portal [17].

Figure 1 – ONCONET Sites

The technological platform was notable for its low production cost. It thus appears to be a sustainable solution to the problem of delivering continuing medical education in a large country with widely dispersed health professionals.

II. MATERIALS AND METHODS

A. Architecture and Implementation

The project's central idea is the use of free distribution open source software tools, from the operating system to the application server. This system will be available through the Internet, through a Medical Server built as a cluster of commodity computers.

The implementation and development of the applications are based on the use of free software and open platforms. The use of programming languages such as JAVA, HTML, XML, SQL together with the adoption of the LINUX operational system, to diminish the system development costs.

The architecture of the Medical Server refers to a largely adopted model for application on remote services: the multi-tier model. It has horizontal and vertical scalability, making possible the insertion of new nodes on the overloaded layer. Another important property of this kind of architecture is the resultant system's maintainability, characterized by nodes repairing without service becoming unavailable.

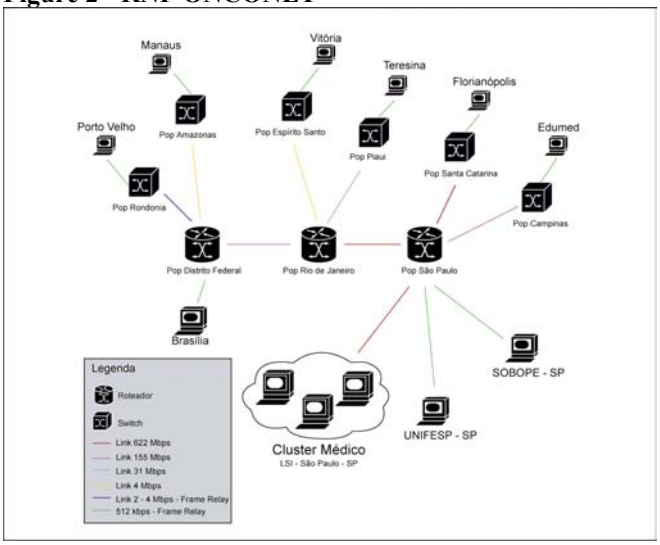
In relation to the operating system, the chosen one is the Linux Red Hat. This free software platform supports the system basic components on the cluster nodes, like Apache Web Server and Tomcat Application Server.

B. The Telehealth Network

In the ONCONET project we incorporate and integrate the research results and developments of digital multimedia protocols adopted by the local pediatric cancer care medical community. As a project requirement, all applications and system service routines are executed in high performance computing infrastructure based on clusters of commodity computers for web (Oncocluster).

The system is web-based and when completed it will have 6 hospitals connected in broadband through the National Education and Research Network (RNP – Rede Nacional de Ensino e Pesquisa) and 52 hospitals associated to the SOBOPE through conventional Internet access. The RNP is the Brazilian infrastructure of advanced network for collaboration and communication in the fields of teaching and research [18]. Besides connecting all federal institutions of higher education and research, this infrastructure provides a test bed for the experimental development of new applications and network services for the benefit of its users.

Figure 2 - RNP ONCONET



The specification of minimum bandwidth for each hospital is of 512 Kbps, and the ideal is of 1 Mbps. These

values of bandwidth are necessary for the flow of multimedia medical data (text, voice, video, image).

In each state of Brazil, the RNP arrives at a regional PoP (Point of Presence), had been established connections among the PoP and the hospitals of the ONCONET (Figure 2).

C. Oncocluster Server

The system server is based in clustering techniques (figure 3), that are based on functional layers: WEB, application, data base and storage, being developed as a system of high performance of critical mission, that is, strong tolerant the faults, high availability, and support to the scalability and load balancing. The use of the commodities computers turns itself in low cost platform. Figure 4 displays the network's setup.

Figure 3- Oncocluster Model

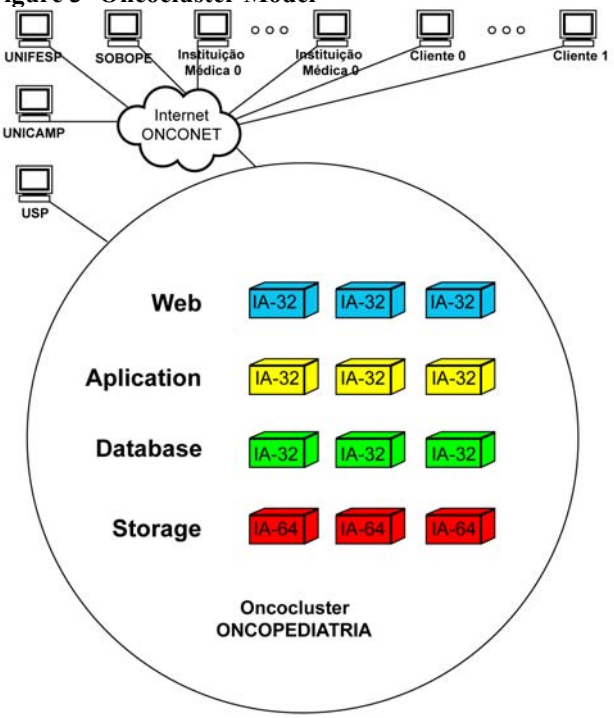
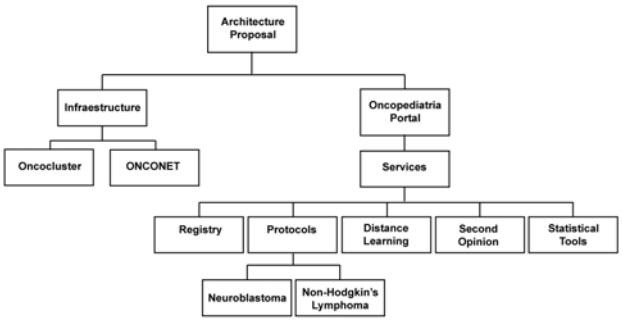


Figure 4- System architecture proposal



The Oncocluster has seven nodes, with six Intel Xeon2 2,4 dual GHz processing, 1GB of RAM, two 36GB hard-disks working with mirror storage, two Gigabit Ethernet network interfaces, redundant Source. It has a Intel Itanium2 node of 1GHz dual processing, 8GB of RAM, three 36 GB hard-disk, with one for the Operational system and two for mirror storage, redundant Source, two Gigabit Ethernet network interfaces [19].

The architecture of the medical cluster refers to a largely adopted model for application remote services: the multi-tier model. This one has horizontal and vertical scalability, making possible the insertion of new nodes on the overloaded layer. A Gigabit Ethernet Network Switch connects the nodes. Another important property of this architecture is the resultant system's maintainability, characterized by nodes repairing without service becoming unavailable. The project's central idea is the use of free distribution open source software tools, from operating system to application server. In relation to the operating system, the chosen one is the Linux Red Hat. This basic software platform supports the system basic components on the cluster nodes, like Apache Web Server and Tomcat Application Server that joins the Java technology to the Apache Server. To make the balancing requisitions in order to provide better cluster performance, it was used the LVS (Linux Virtual Server) [20], that is a kernel Linux extension for creating a load balancer. The Heartbeat was used to provide high availability, eliminating possible hardware and software failures [21].

D. The Oncopediatria Web portal

The Oncopediatria portal (www.oncopediatria.org.br) is a web-based system, which offers services and information regarding pediatric cancer and is focused on maintaining electronic patient records and cooperative treatment protocols (Figure 5).

The main objectives are:

- to improve the information flow in research programs and cooperative treatment protocols
- to disseminate and harmonize treatments through the use of protocols that produce the highest cure rates
- to establish the basis for a national demographic record of pediatric cancer
- to make available statistics, demographic data and analyses of the results of treatments using the protocols.

The system uses the recording standards of the Brazilian Health Department [22], which establish norms for the construction of electronic records, and define the content and logical structure of information regarding health care. The architecture and implementation have been described elsewhere.

D.1. Patient records and cooperative treatment protocols

In Brazil, patient records are often incomplete or only archived on paper, leading to poor quality records of cancer incidence. Brazilian statistics are derived from North American incidences, impairing the country's cancer management. The Brazilian Society of Pediatric Oncology (SOBOBE) publishes cooperative protocols on pediatric cancer treatment, which are based on research by

cooperating groups. These treatment protocols define the most advanced treatment programs in childhood cancer, offering better cure rates and improved survival. Nevertheless, current dissemination methods are inefficient and several institutions still follow obsolete protocols. Even institutions, which have already adopted the SOBOPE protocols, experience difficulties in sharing patient data and publishing results.

Figure 5 - The Oncopediatria Web Portal

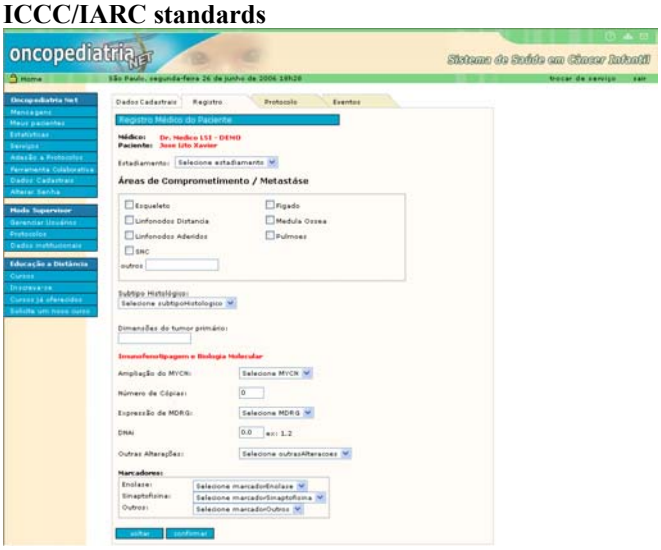
D.2. Multimedia patient registry

The Oncopediatria system has adopted the record structure of the International Classification of Childhood Cancer (ICCC) proposed in 1987 by the International Agency for Research on Cancer (IARC) of the World Health Organization. The adoption of ICCC guarantees the possibility of Multilanguage patient registry for international cancer care programs. The system provides a user-friendly multimedia interface, allowing secure access to electronic medical records via the Internet. Medical professionals have different levels of access to the data according to the security rules defined by SOBOPE and the Brazilian Federal Council of Medicine. Patients can view their own data but can only modify their contact information. One interface is shown in Figure 6. The treatment results are anonymous, to protect the individual patient's privacy.

D.3. Multimedia cooperative treatment protocols

Some of the SOBOPE cooperative protocols have been implemented, offering protocol guidelines for physicians. The applications model the events of the treatment phase, such as diagnosis, chemotherapy cycles, radiotherapy sessions, surgical revaluations, bone marrow transplant, laboratory examinations and imaging. The first such multimedia treatment protocol concerns the treatment of high-risk neuroblastoma (NEURO-IX-2000). A protocol for non-Hodgkin's lymphoma is also being developed, divided into Burkitt, lymphoblastic and anaplastic lymphoma. In the multimedia protocol, much of the record is textual, but parts of the record are medical images. The system allows images to be stored in several common image formats such as JPEG and DICOM (Digital Imaging and Communications in Medicine).

Figure 6 - A patient's tumour record interface, based on ICCC/IARC standards



D.4. Development of the website

Members of the SOBOPE community started using the Multimedia Patients Registry in 2004. In May 2005, the system had 142 registered doctors and the database had records for approximately 5200 patients from 30 Brazilian hospitals across 15 national states.

Doctors from the six hospitals comprising the Neuroblastoma Cooperative Group are using the Neuroblastoma multimedia protocol as well. Thirty doctors from these hospitals evaluated the system and provided feedback to the design team.

The evaluation of the SOBOPE doctors who used the system was positive, mainly because the system allows easy online access but also because the electronic register performs data validation when information is inserted. This produces better quality data. There was some resistance from certain doctors to using the Internet, since they were not familiar with such technology. This is a problem related to culture change in the community.

III. Results

Doctors from six hospitals that compose the Neuroblastoma Cooperative Group are using Neuroblastoma Multimedia Protocol as well. These doctors have voluntarily evaluated the system by providing feedback to the design team. We do not have results and evaluations from outside this group.

The evaluation made by SOBOPE doctors that use the system was positive, mainly because the system allows easy on-line access, and also because the electronic register does data validations when data is inserted. This way, with use of electronic patient records, one has better quality data. Besides that, there is some resistance from some doctors to use Internet, since they are not familiarized with such

technology yet. This is a problem related to culture changes in the community.

IV. Discussion and Conclusion

We consider that the project managed to create a model that is technologically and economically viable as a telemedicine project, through the research and development of in-house solutions based on free software and open standards and adapted to the Brazilian reality. We believe that it is essential to master the technological applications in the health sector and to also provide the maintenance of the respective technology-based products in our country, such as cluster platforms or software components for health services.

At the moment, the project has managed to provide a collaborative environment for institutions that are part of the project. This project has also pioneered the joint work of universities and health institutions for the creation of a nation-wide Brazilian telemedicine project.

Through the use of the ONCONET and its' collaborative tools we were able to integrate remote institutions, enabling an improvement of the disease diagnosis and increasing the agility and accuracy of the radiological analysis.

Our aim is the improvement and standardization of the patients' treatment on a national level, also making available up-to-date information provided by the best treatment centers in the country. The standardization of treatment and improvement of the treatment conditions of childhood cancer, even in regions with extreme lack of resources, may have an impact in the overall survival.

The Oncopediatria portal finds itself in stage of implantation in 58 hospitals of Brazil. Activities covering development of related to Ewing tumor treatment protocol were started, as well the bone marrow transplant protocol analysis.

The implementation of the entire technological platform also deserves distinction in this project. It has a low production cost and, based on that, we do not doubt the necessity of continuing this form of dissemination of knowledge for the pediatric oncology professionals, particularly in a country with continental dimensions, great geographic dispersion of the health professionals, and with the difficulties and costs usually involved in the continued medical education.

The system presented in this article offers a radical change of treatment paradigm of childhood oncology in Brazil, acceptance aspects, usability and Internet use culture.

We verify that it's possible the use of web-based medical system to offer health services at distance, as the patients' records and guidelines of treatment protocol in pediatric oncology, through of the implementation and development of the applications based on the use of free software and open systems and platforms.

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