Use of technology in follow-up of HIV positive pregnant women and their babies till 18 months of age- an innovation by Maharashtra State AIDS Control Society (MSACS), India

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Objective

The purpose of this study is to assess the utility of web-based mobile technology monitoring tool, for ensuring linkages, and tracking of HIV-exposed child until 18 months of age.

Methods

The 'early infant diagnosis (EID) Follow-up System' was designed as a tool for reminding the field level staff for follow-up of HIV-exposed babies. Using Java Swing Framework, software was developed which generates automatic advance SMS alerts regarding patient information to the Counsellor of the respective Integrated Counselling and Testing Center and district supervisor, 7 days prior to due dates. Simultaneously, system generated e-mail is sent to district program officer for monitoring and updating the line-list.

Results

Before the introduction of 'EID Follow-up System' in June 2013, only 55.9% (637/1139) of the HIV-exposed babies born were tested at 6 weeks for DNA-Polymerase Chain Reaction during April 2011–March 2012. However, after its introduction, 68.4% (1117/1631) of them were tested during April 2012–March 2013. Correspondingly, the 18 months confirmatory HIV testing in eligible babies increased from 45.6% (934/2044) to 54.7% (1118/2044) during the same period.

Conclusion

The replicable technology driven initiative would help in strengthening the follow-up mechanisms and reach every HIV-exposed child for EID.

Keywords

early infant diagnosis, follow-up system, mobile technology

INTRODUCTION

Globally, mother-to-child transmission of HIV-1 results in approximately 370 000 infant infections each year [1]. HIV-1 early infant diagnosis (EID) programs aims to detect HIV infection as early as possible in HIV-exposed infant and to link them to care and treatment. EID of HIV confers substantial benefits to infants and families, both for HIV-infected and uninfected infants, as well as to programs providing prevention of parent-to-child transmission (PPTCT) services, including HIV Counselling and testing, family centric approach, provision of care, support and lifelong treatment for HIV positive women, provision of ARV and

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cotrimoxazole prophylaxis and early infant diagnosis services for HIV-exposed children, guidance on feeding and nutrition practices, and immunization services.

The HIV prevalence among pregnant women in India is 0.35%. Maharashtra is one of the high prevalent states in the country with HIV prevalence of 0.4% among antenatal women and 0.42% in adults [2] and Ante Natal Case prevalence 0.40%. Early infant diagnosis was launched in the country in April 2010, which entails follow-up of babies born to HIV positive women for HIV DNA Polymerase Chain Reaction (PCR) test and subsequently final HIV test at the age of 18 months of age.

A major priority for PPTCT services is ensuring pregnant women pursue their care and treatment, including testing of babies at regular intervals for EID. The common barriers reported in qualitative studies regarding low uptake of PPTCT-EID services for mother and baby both include confidentiality, stigma, availability of testing facility, financial issues, behavior of health staff, fear of baby's HIV test result, cultural barriers, long waiting time [3]. In addition, health workers are unable to monitor pregnant women because of inadequate data management system across the service continuum. WHO estimates that only 6–15% of HIV-exposed infants under 1 year of age accessed EID programs in 2008–2009 [4], highlighting that the implementation of effective EID programs has been challenging in resource-limited settings and demands careful attention.

Although there are many reasons for the lack of continuity of care, there is a need to improve the adherence and retention in care and this may be improved by maintaining better communication between program officers and field staff.

Mobile phone technology has the potential to serve as a strategic intervention medium to improve patient management [5]. Owing to the widespread use and low cost of this technology, it pervades all age groups and many cultures and socioeconomic backgrounds. It allows communication across geographic boundaries and reaches people directly where they are located [6]. But there is also a need for interactive program management by reacting promptly and effectively to deviations from program plans. This may include operational decisions for short-term management of patient retention at individual care centers, tactical decisions such as reconfiguring the messaging based on performance, and strategic decisions such as data collection or preservation.

Hence, an integrated mobile phone text messaging system was designed, developed, and implemented to follow the babies under EID in Maharashtra (excluding Mumbai) in June 2012.

This study was conducted to assess the utility of web-based mobile technology monitoring tool, for ensuring linkages, and tracking of HIV-exposed child until 18 months of age.

METHODS

Maharashtra State AIDS Control Society developed a web-based system that provides support to EID program. A broad set of usability requirements was identified during brainstorming design sessions between the researchers, program officers, and developer. The program officers in Maharashtra State AIDS Control Society, with strong program backgrounds and substantial experience in health-care and understanding of the field problems, outlined the requirements that they anticipated the system should offer. These requirements were then documented and elaborated in more detail as new ideas were exchanged within the design team (two program officers and one computer experts) and final design principles of the system were derived.

The development team and the program officers assessed the responses from field staff in the current system, which were stored in a Microsoft Structured query language server, to identify patterns that could be used to define relevant answers. The output was a list of possible automatic SMS text message replies through Symbian supported mobile.

The 'EID Follow-up System' was designed as a web-based tool using Java Swing Framework which generates automated SMS and e-mails for reminding the field level staff for follow-up of HIV-exposed babies 7 days prior to the follow-up date. The information was collected through field tested excel-based HIV positive pregnant women line-list format incorporating the major key indicators of PPTCT program. This line list is generated at the HIV testing facilities where the pregnant woman is detected HIV positive. Format is then shared through e-mail with HIV treatment facilities to update the treatment details of the pregnant women. This line list is then compiled at all the 33 districts. The line list is further updated on periodic basis whenever the pregnant women is accessing the PPTCT services at HIV facilities. The individual records in the line list are monitored and crossverified by district and state level officials during the supervisory visits to these centers on periodic basis. The data collected through line list from different districts is then compiled by the state.

For the software, we used the variables like name of mother and child, date of birth of baby, mobile number of counsellor and district supervisor, email of district official, and name of the HIV testing facility. This information was periodically updated.

FIGURE 1. EID Follow –up system: Development process and work flow.

Database of HIV positive mother and her exposed child with date of birth was updated on monthly basis. Deliberation with various stakeholders on development of tracking system led to use of mobile technology in follow-up mechanism. The software developed sends required information (name of mother/child, facility name, and follow-up date) to the counsellor of the respective facility and district supervisor as mobile text message alerts on daily basis and simultaneously, system generated e-mail is send to district officials for monitoring and following the baby for EID. We used brainstorming techniques to solicit usability requirements, focus group meetings to discuss and define system architecture, and prototyping to test in real environments and to improve the system (Fig. 1).

Telecommunication costs

In this kind of system, there are telecommunication costs involved. It is imperative to be able to make favorable bulk mobile text messaging contracts on

the part of the healthcare provider, but also to be efficient in messaging so as to reduce the traffic. On a pilot basis, we have purchased SIM card at state for sending mobile text message from the same number to counsellors and district supervisors.

Privacy and data security

Data security is a crucial issue in any healthcare process. State developed an authentication mechanism for personal computers located at the state office. All transactions go in one direction from the state computer to the server. The connection between the server and the client mobile is made using a web service.

Text message content

A set of text messages was developed based on discussion involving the design team and the program officers. Suggestions for message formulations were reviewed and amended during team meetings,

FIGURE 2. Follow-up text message examples.

resulting in a final set of three messages, which were approved by all involved. In both sets, messages for testing of baby for EID were divided into four categories: 6-week follow-up reminders, 6-month follow-up reminders, 12-month follow-up, and 18-month follow-up reminders. Examples of the types and content of messages are provided in Fig. 2.

The messages did not include general information about the health status of the patient because such status information may be difficult to communicate in an unambiguous way. As the mobile networks in Maharashtra are often unreliable, especially in rural areas, we designed a mechanism of e-mail to District AIDS Prevention and Control Unit (DAPCU) and DAPCU will follow-up at field level. This way, we were able to, in most cases, get daily updates, although not necessarily at a predefined time every day.

To accommodate the requirements, architecture was developed (Fig. 3). The main elements of this architecture include the following:

The SMS server, as shown in Fig. 3, interacts with field staff that uses their mobile phone set and the

SMS messaging service to send messages to the system. At the lowest level, the SMS server interfaces with a Global System for Mobile (GSM) modem that sends field staff's SMS text messages through an SMS service provider (mobile operator). Once the data are imported in software from excel sheet, the SMS server performs checks on its content and responds to the field staff accordingly (automatic reply feature). Safeguarding the privacy, confidentiality, and security of any public health information is an important undertaking. The system only collects data necessary for the server to process and send text messages. The system was operational 8 h a day, 6 days a week.

The system comprises an application layer for the capture and delivery of patient information, including date of next appointment and next date of testing, to a remote server by means of a GSM modem. The server generates personalized appointment reminders as SMS messaging and e-mails.

Six sets of system requirements that need to be addressed for success are – data collection, telecommunication costs, privacy and data security, text

FIGURE 3. SMS server.

message content, connectivity, and system scalability. A text messaging system was designed and implemented in 578 HIV testing facilities and district supervisors in 33 districts in Maharashtra. These sites feed data into a central data repository, which was used for analysis of operations and decision support. Based on the follow-up schedule, the system automatically generates appointment reminders as mobile text message to counsellors and as emails to DAPCU officers.

Healthcare professionals, technical experts, and an interdisciplinary group of researchers were involved in the design, development, and implementation processes to enhance the utility and functionality of the system.

RESULTS

Before the introduction of 'EID Follow-up System', only 55.9% (637/1139) of the HIV-exposed babies born were tested at 6 weeks for DNA-PCR during April 2011–March 2012. However, after its introduction, 68.4% (1117/1631) of them were tested during April 2012–March 2013. Correspondingly, the 18 months confirmatory HIV testing in eligible babies increased from 45.6% (934/2044) to 54.7% (1118/2044).

DISCUSSIONS

This study summarizes the processes of design, development, and implementation of a remote management system using mobile technologies to help field staff and supervisors to track mother and children for HIV testing.

Our study endeavors to design, develop, and implement a tool to empower health staff in tracking HIV-exposed children. Mobile phones are available and are practical, low-cost tools that may facilitate and support health staff in follow-up of babies. Our study showed that mobile phone text messaging provides an effective communication mechanism between healthcare providers and supervisors, provided it is implemented well. It has been shown that regular follow-up is possible through mobile technology intervention [6].

Design of a system for follow-up of specific diseases like HIV/AIDS, based on mobile phone text message and e-mail technology, includes careful attention to not only the theoretical underpinning of the strategic intervention and associated content, but also the requirements for optimal design, including how each part of the system has to be placed together. Crucial parts of a successful text messaging intervention include how messages are tailored, how participants may be directed to

different content based on their situation, and the intensity of the communication. The system must also include cost-effective mechanisms so as to minimize costs of both technologies involved (including costs for GSM network communication and GSM modems with its data plan) and of sending messages to patients. Other costs include having human resources for data entry at regular intervals.

Trust, usefulness, and usability are crucial issues for both health staff and professional users, and it is important that features installed also work properly and meet privacy standards. Therefore, it is better to move slowly in making the system more advanced and, at the same time, making sure to have users on board.

LIMITATION OF STUDY

The basic input information required for system to generate the follow-up is being manually compiled through excel-based format on monthly basis leading to delay in updating the base data in the system.

CONCLUSION

This study demonstrated that it is possible to design, develop, and implement an integrated remote patient management system using the mobile phone's text message feature to communicate with field staff regarding alerts on follow-up of children. The study shows that it is necessary to address the following six different requirements: data collection, telecommunication costs, privacy and data security, the content of text messages, connectivity, and system scalability.

RECOMMENDATIONS

State may plan for an evaluation of the system, including a satisfaction survey of the health professionals and field staff that used it. Additionally, plan to perform a cost-benefit analysis and to implement the system permanently with advanced technology using android-based smart phone.

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Conflicts of interest

There are no conflicts of interest.

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