



Keeping secrets in the cloud: Mobile phones, data security and privacy within the context of pregnancy and childbirth in Tanzania



Kristy M. Hackett^{a,b,*}, Mina Kazemi^c, Daniel W. Sellen^{b,d,e}

^a Department of Global Health and Population, Harvard T.H. Chan School of Public Health, United States

^b Dalla Lana School of Public Health, University of Toronto, Canada

^c Women's College Research Institute, Women's College Hospital, Toronto, ON, Canada

^d Department of Nutritional Sciences, University of Toronto, Canada

^e Department of Anthropology, University of Toronto, Canada

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ABSTRACT

Growing evidence points to the potential value of mobile phone-based technologies ('mHealth') to help strengthen community health systems in low- and middle-income countries, but mHealth approaches also carry considerable risks with respect to data security, individual privacy, and confidentiality. We examined the perspectives of frontline community health workers and their female clients regarding data security and privacy within the context of an mHealth intervention to improve women's uptake of maternal health services from October 2013 to July 2014 in rural Tanzania. Qualitative findings demonstrate that the use of new technologies to capture health service user data during pregnancy and childbirth has both positive and negative impacts on perceptions of personal privacy and confidentiality. Women's concerns regarding privacy aligned closely with a belief that pregnancies and expected delivery dates must be kept secret, reflecting fears that pregnancy renders women vulnerable to witchcraft by jealous neighbors. Women also shared concerns that health workers' male partners could access their private information. Strong community-based engagement is recommended from the outset when developing a mHealth intervention to integrate beliefs and gender dynamics that may influence acceptability and implementation of new technologies.

1. Introduction

The use of mobile technologies in health and development initiatives continues to expand with increased global connectivity, with mobile health ('mHealth') initiatives gaining considerable momentum in recent years (Agarwal et al., 2015; Labrique et al., 2013; Lee et al., 2016). Increasing availability and affordability of mobile phones in low- and middle-income countries (LMICs) generates unprecedented opportunities to collect and analyze health-related data, and to bridge the 'digital divide' by enabling widespread dissemination of health information (Ginsburg et al., 2014). In particular, investments in mHealth technologies to improve maternal health knowledge, behavior, and service uptake have increased dramatically in LMICs (Al Dahdah et al., 2015; Chen et al., 2018; Tamrat and Kachnowski, 2012). When user data privacy and security concerns are well addressed and integrated, mobile technologies may strengthen health system performance through enhanced service delivery, improved coverage, quality, equity, or efficiency (Labrique et al., 2013; Tamrat and Kachnowski, 2012).

1.1. mHealth, data security and privacy

Despite growing evidence of the value of mHealth in LMICs (Agarwal et al., 2015; Labrique et al., 2013; Lee et al., 2016; Tamrat and Kachnowski, 2012), such approaches may also incur considerable risks with respect to data security, privacy, and confidentiality. A 2011 World Health Organization (WHO) report highlighted data security as one major barrier to scaling up mHealth in LMICs, calling for the development and implementation of appropriate strategies to protect individuals' right to privacy (World Health Organization, 2011). A consortium of international development organizations recently developed 'The Principles for Digital Development' to encourage and guide integration of established best practices into technology-based development programs (Digital Development Principles Working Group, 2016). Principle 8 is to address privacy and security through assessing risks to users and their data, and developing risk mitigation plans. These Principles are endorsed by UNICEF, WHO, and other organizations, but it remains unclear whether and how privacy and security guidelines are operationalized and quality assured in practice.

* Corresponding author. Department of Global Health and Population, Harvard T.H. Chan School of Public Health, 677 Huntington Avenue, Boston, MA 02115, United States.
E-mail address: khackett@hsph.harvard.edu (K.M. Hackett).

1.2. Geographic context of the study

As elsewhere, many African countries have no comprehensive mHealth regulation or data protection legislation in place, underlining the need for prioritization by policy makers, implementers and evaluators (Townsend, 2015). Any privacy and data protection measures that are in place are often embedded within broader privacy and data protection legislation and not specific to the healthcare sector (Townsend, 2015). Tanzania is among several countries where no explicit privacy policy related to mHealth exists, with few specific laws to guide use and disclosure of health and medical data (Baker & McKenzie and Merck, 2013). One principle of Tanzania's national electronic Health strategy is to “guarantee patient information right, integrity and confidentiality in line with emerging public health access needs” (p.4) (United Republic of Tanzania Ministry of Health and Social Welfare, 2013). The current strategy underscores the importance of prioritizing individual data protection, but does not provide specific interpretation or outline concrete procedures, allowing wide scope in application by implementers.

1.3. Research gaps and opportunities

Research on the privacy and security implications of mHealth initiatives has recently proliferated in high-income countries (for recent reviews see Arora et al., 2014; Martinez-Perez et al., 2015), yet published studies from LMICs are non-existent. While some studies of mHealth approaches in LMICs (Agarwal et al., 2015; Al Dahdah et al., 2015; Källander et al., 2013; Lee et al., 2016) make reference to the importance of data security and patient confidentiality in principle, none investigate whether and how best practices are actually interpreted and applied across contexts. Several studies from high-income countries have examined mHealth users' perceptions of privacy (Atienza et al., 2015; Richardson and Ancker, 2015). However, no published studies from similar contexts in sub-Saharan Africa have examined the views of technology users (e.g. frontline health workers) or intended beneficiaries (e.g. patients or clients) regarding the privacy impacts of mHealth. Understanding these perspectives in relation to maternal health specifically is crucial in East African contexts, where women's health-seeking behavior is strongly influenced by community beliefs and may be shaped by cultural expectations to keep reproductive health information private (Chapman, 2006).

This study explores user and beneficiary perceptions of data security and privacy within the context of a smartphone intervention to improve women's uptake of maternal health services in rural Tanzania. It should be noted that the authors did not set out to investigate this subject explicitly. As part of a larger evaluation, we explored community health worker (CHW) and client perceptions of smartphone-based counseling and data collection. As a result of the qualitative data collection, the themes of data security and confidentiality emerged as significant phenomena, which we will examine here.

2. Methods

2.1. Study setting

This study was carried out within the context of a community-based maternal and child health project implemented by World Vision (WV), a large international nonprofit organization. The smartphone intervention was implemented and evaluated using a cluster-randomized design (Hackett et al., 2018) in rural Singida, a landlocked region in central Tanzania located 325 km southwest of Arusha. Singida is one of the poorest regions in Tanzania; approximately 49% of households live below the poverty line (Kessy et al., 2011). Ensuring widespread access to health services is also a challenge; the region had only 158 health facilities for a total population of 1.4 million people at the time of the study and a high maternal mortality rate (178 per 100,000 live births)

(Manji, 2009). A majority of women in Singida access antenatal care at least once during pregnancy, but only 60% receive at least four antenatal visits, and approximately 40% deliver with no assistance from a skilled birth attendant (Manji, 2009; National Bureau of Statistics [Tanzania] & ICF Macro, 2011).

One of WV's program aims was to improve maternal health through increased support for CHWs. In Tanzania, national recommendations are for each village health committee to appoint at a minimum two CHWs. These individuals must have completed at least basic secondary schooling (form four) and can be male or female. CHWs are elected by members of their communities to conduct basic health promotion activities and are expected to work as volunteers. At the time of the study, the national government recognized the inherent value of CHWs, but the cost of training and monitoring CHWs continued to be covered largely by nongovernmental organizations. To support CHWs in program areas, WV implemented a smartphone-based job aid application for CHWs that captures and coordinates information on key maternal and child health indicators.

2.2. The smartphone application

WV collaborated with D-Tree International to develop a smartphone application for use by CHWs during household visits with pregnant women and mothers. The application is designed as a point-of-care tool, guiding CHWs through electronic protocols and directing them to specific health messages and counseling topics based on women's gestational age and answers to diagnostic questions. In addition, the application facilitates client registration, follow-up, recognition of prenatal and obstetric danger signs, referral to health facilities, client data management, and service delivery reporting.

The application was developed on Dimagi's CommCare platform (Dimagi Inc, 2018) and was intended for use in tandem with Ministry-developed photo flipbooks designed to facilitate prenatal counseling during household visits (United Republic of Tanzania Ministry of Health and Social Welfare, 2012). The mHealth intervention (hereafter referred to as 'SP+') consisted of training on the smartphone application along with the photo flipbooks. WV and D-Tree jointly conducted the SP+ training. After training, CHWs used data collected by the app to help prepare monthly hard copy reports for their facility-based supervisors. Client data collected by CHWs during home visits were uploaded directly to Dimagi's secure cloud server (CommCare HQ) and accessible only to D-Tree and WV field staff and one member of the research team (KH).

2.3. Data collection tools

Focus group discussions (FGD) and in-depth, semi-structured interviews (SSI) were designed to capture detailed information on women's relationships with CHWs and perspectives on the quality of household visits based on mode of support received (SP+ versus paper-based protocols only). SSI and FGD guides included open-ended questions to elicit rich narratives regarding interactions between CHWs and their clients. All study tools were developed in English, translated into Kiswahili, and back-translated into English. Swahili tools were further refined after pre-testing with women and health workers external to the study who had similar socio-demographic profiles as the study population. With assistance from local research assistants, we modified the tools to improve readability, comprehensibility, and cultural appropriateness.

2.4. Recruitment and eligibility

CHWs and a random sample of their female clients were included in this study. CHWs were recruited through WV's program enrolment records. We approached all CHWs trained on SP+ (N = 64). Eligible CHWs had to: a) have completed the national integrated Maternal

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