Perceived mHealth barriers and benefits for home-based HIV testing and counseling and other care: Qualitative findings from health officials, community health workers, and persons living with HIV in South Africa

Alastair van Heerden, PhD. [a, b], Danielle M. Harris, M.A., M.P.H. [c], Heidi van Rooyen, PhD. [a], Ruanne V. Barnabas, MBChB, DPhil [d], Nithya Ramanathan, PhD. [e], Nkosinathi Ngcobo [a], Zukiswa Mpiyakhe [a], W. Scott Comulada, DrP.H. [c, *]

[a] Human and Social Development Research Programme, Human Sciences Research Council, South Africa
[b] Developmental Pathways to Health Research Unit, School of Community Medicine, University of the Witwatersrand, South Africa
[c] Department of Psychiatry & Biobehavioral Sciences, Global Center for Children and Families, University of California, Los Angeles, 10920 Wilshire Blvd, Suite 350, Los Angeles, CA 90024, United States
[d] Global Health and Medicine, University of Washington, Seattle, WA, United States
[e] Nexleaf Analytics, Los Angeles, CA, United States

A R T I C L E   I N F O

A B S T R A C T

mHealth has been proposed to address inefficiencies in the current South African healthcare system, including home-based HIV testing and counseling (HTC) programs. Yet wide-scale adoption of mHealth has not occurred. Even as infrastructure barriers decrease, a need to better understand perceived adoption barriers by stakeholders remains.

We conducted focus group discussions (FGD) in South Africa in 2016 with 10 home-based HTC field staff, 12 community health workers (CHWs) and 10 persons living with HIV (PLH). Key informant (KI) interviews were conducted with five health officials. Perceptions about current home-based HTC practices, future mHealth systems and the use of biometrics for patient identification were discussed, recorded and transcribed for qualitative analysis. Themes were based on a conceptual model for perceived mHealth service quality.

Stakeholders brought up a lack of communication in sharing patient health information between clinics, between clinics and CHWs, and between clinics and patients as major barriers to care that mHealth can address. CHWs need better patient information from clinics in terms of physical location and health status to plan visitation routes and address patient needs. CHWs perceive that communication barriers create distrust towards them by clinic staff. PLH want automated appointment and medication reminders. KI see mHealth as a way to improve health information transfer to government officials to better allocate healthcare resources. Stakeholders are also optimistic about the ability for biometrics to improve patient identification but disagreed as to which biometrics would be acceptable, especially in older patients.

All stakeholders provided useful information towards the development of mHealth systems. Hospitals are adopting patient-centered approaches that solicit feedback from patients and incorporate them into decision-making processes. A similar approach is needed in the development of mHealth systems. Further, such systems are critical to the successful extension of the health system from health facilities into people's homes.

© 2017 Elsevier Ltd. All rights reserved.

* Corresponding author.
E-mail addresses: avanheerden@hsrc.ac.za (A. van Heerden), dmharris@mednet.ucla.edu (D.M. Harris), hvanrooyen@hsrc.ac.za (H. van Rooyen), rbarnaba@uw.edu (R.V. Barnabas), nithyaar@gmail.com (N. Ramanathan), NNgcobo@hsrc.ac.za (N. Ngcobo), zmpiyakhe@hsrc.ac.za (Z. Mpiyakhe), wcomulada@mednet.ucla.edu (W.S. Comulada).

1. Introduction

mHealth, i.e. healthcare systems and services that are supported by mobile devices, is rapidly evolving in low and middle income countries (LMIC) in response to outdated healthcare practices that are outpaced by the growing burden of disease (Mukund and Murray, 2009; Leon et al., 2012; Padma, 2010). In many LMIC, home visitation is an important first step in healthcare delivery through community health worker (CHW) programs and home-based HIV testing and counseling (HTC; Were et al., 2003; WHO, 2008); trained personnel conduct home visitation, administer rapid diagnostic tests for HIV, and refer individuals who test positive, i.e. persons living with HIV (PLH), for clinic care. Driving home-based HTC is its ability to improve HIV testing and diagnosis as the first step in the HIV care continuum; non-clinic attending populations are reached (Ganguli et al., 2009) and common barriers to facility-based care, including lack of transport are reduced (Geng et al., 2010). Success has been demonstrated with home visitation where CHWs and medical personnel are equipped with mobile phones for data collection and supervision (Tomlinson et al., 2009; Wouters et al., 2009). Despite the potential, wide-scale adoption of mHealth has not occurred (Krah and de Kruijf, 2016; Leon et al., 2012). Barriers need to be explored across the spectrum of stakeholders from health officials to patients. In this article, we fill in gaps by presenting findings from qualitative interviews that were conducted with South African health officials, research field staff, CHWs and PLH.

South Africa is the country with the largest total number of people living with HIV. The national prevalence rate is around 12%, with higher rates in regions like KwaZulu-Natal (25%) (Shisana, 2013), where this study took place. Home-based HTC is a key component of home visitation programs in South Africa due to its demonstrated scalability (Naik et al., 2012) and the great need for HIV services. The value of home-based HTC and CHWs programs is highlighted by the South African government's plan to train between 700,000 and 1.3 million CHWs by 2030 (National Planning Commission, 2012; Singh and Sullivan, 2013).

Despite successes, poor integration between home visitation programs and the healthcare system is a significant barrier for home-based HTC and other CHW initiatives in the current era of paper registers. This includes difficulties in tracking the number of people who receive health services in the home (Tomlinson et al., 2013), ensuring referral and linkage to care, and a lack of adequate communication between CHWs and referral clinics (Macintyre and Littrell, 2008; AMREF, 2012). Monitoring CHW services is also challenged due to the lack of adequate and standardized health information tools and processes, poor integration of information into existing routine health information systems and the absence of dedicated monitoring and evaluation staff (Leon and Schneider, 2012). Integration and monitoring issues will only increase as home-based HTC programs attempt to scale to meet the burden of HIV and other diseases. The increased CHW workload has had the unintended consequence of reducing the quality of data going into the Health Information System. Register data is fragmented, error prone, incomplete and inaccessible (Mate et al., 2009; Sherman et al., 2004).

A key integration challenge is how best to identify and track enrollees in home visitation programs, including through the HIV care continuum. These data are critical to achieving the UNAIDS 90-90-90 targets. It is well-known in the healthcare community that early HIV testing and engagement with ART reduces morbidity, mortality (Coetzee et al., 2004; Wouters et al., 2007) and

infectiousness, and therefore, onward transmission of the virus (Cohen et al., 2011; Mills et al., 2011; SANAC, 2011). Yet the drop-off that occurs at each step from HIV testing to viral suppression results in up to 30% of those tested retained in care (Mugglin et al., 2012; Rosen and Fox, 2011). Moreover, the link from HIV testing to initiation of care is often weak, with large numbers of HIV+ persons delaying or never initiating ART. Studies have estimated that as few as 63% of individuals who test HIV-positive are linked to care (Rosen and Fox, 2011) and subsequent retention is far from optimal. The inability to track PLH also impacts retention estimates themselves as PLH travel and migrate; a patient lost to follow-up in an analysis may be retained in care at another clinic (Geng et al., 2010). Moreover, the inability to share patient records that include ART initiation and staging information impedes ART regimen maintenance (Hickey et al., 2016). mHealth tools have been introduced to streamline CHW programs that rely on paper registries. Technological advances have brought opportunities for improved patient identification through fingerprint scanners and other biometric identification devices that connect to mobile platforms. Across 70 LMIC, there are now over 160 biometric programs covering 1 billion people (Gelb and Clark, 2013). Improved identification and tracking strengthens the ability to share patient information between CHWs and clinics. mHealth tools pick up where current home-based HTC protocols leave off after testing and diagnosis to fill in additional gaps in the HIV care continuum, including retention in care and ART adherence. For example, PLH can receive appointment and medication reminders on their mobile phones (Forrest et al., 2015; Mukund and Murray, 2009; Lester et al., 2010).

Despite the potential of mHealth, wide-scale adoption has yet to occur. In South Africa, there are an estimated 42 mHealth services to address HIV/AIDS (Cargo, 2013). Obvious barriers in the South African information and communication (ICT) infrastructure need to be addressed, including the cost of linking information between different health systems and poor network coverage in some areas (National Department of Health, South Africa, 2015). Yet improvements in infrastructure will not be enough. Bukachi and Pakenham-Walsh (2007) state a need to better understand local conditions, health worker training, and how to select appropriate ICT tools before scaling mHealth programs. Patient confidence in healthcare services is paramount to engagement (Kaplan and Litewka, 2008; Dagger and Sweeney, 2006), especially when considering mHealth (Ahluwalia and Vershney, 2009; Kaplan and Litewka, 2008) and biometric technology (Chandra and Calderon, 2005). Issues relating to user acceptability, trust, and privacy are potentially amplified by mHealth systems.

The current study reports on qualitative data that was collected in South Africa to inform the development of an mHealth platform to support home-based HTC. We examine perceptions towards mHealth, biometric identification and essential features in future mHealth systems. We build on prior qualitative work in South Africa that examined perceptions of Mxit (a social media network) users towards the proposed National Health Insurance plan (Weimann and Stuttaford, 2014), perceptions of young people towards youth-oriented health services (Schriver et al., 2014), CHW roles (Druetz et al., 2015; Kane et al., 2016; Mlotshwa et al., 2015), perceptions of program managers and researchers towards mHealth capabilities and CHWs (Leon and Schneider, 2012), and perceptions of bank employees (Pooe and Labuschagne, 2011) and the general population (Riley et al., 2009) towards biometric technology used for identification.

Our work adds to this body of literature through inclusion of stakeholders across the spectrum of users who would engage an