

# Importance and use of psychosocial information to inform chronic care decisions in the US, considered against ICT capabilities in the developing world

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## Abstract

Chronic disease morbidity and mortality is increasing in the U.S. and the developing world, despite effective treatment regimens. Low adherence is a primary driver of incidence and disease progression, and psychosocial factors influence recommended self-care behavior. In the U.S. despite increased use, health IT tools (e.g., EHR) do not support the collection and use of psychosocial information which practitioners indicate influences chronic care decisions. In the developing world, HIT-enabled capabilities are limited by lack of resources. Despite this, practitioners in the developing world currently use mobile telephony and social media to engage their patient community. But little is known as to how these tools support collection and use of psychosocial information. As HIT-enabled capabilities continue to expand in the U.S. and the developing world, lessons learned can help inform the development of capabilities to capture and use psychosocial information to support chronic disease care.

**Keywords:** chronic disease self-care; psychosocial information; telemedicine; health IT

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## 1 Introduction

Across the United States (U.S.), chronic diseases such as diabetes, hypertension, and chronic kidney disease are prevalent. In a study across 150 primary care practices which included over 650,000 patients, 20% of patients had one chronic condition, 15% had two, and 12% had three (Ornstein, Nietert, Jenkins, & Litvin, 2013). Adherence to chronic disease treatment regimens remains low, despite well-known health benefits of following recommended self-care behavior. For example, high treatment adherence results in lower risk of co-morbidity (i.e. cardiovascular disease), (Prado-Aguilar, Martinez, Segovia-Bernal, Reyes-Martinez, & Arias-Ulloa, 2009) and decreased mortality (Best et al., 2011). Low adherence is the primary reason for incidence of uncontrolled hypertension, and two-thirds of hypertensive patients do not follow recommended medication self-care because of psychosocial factors, specifically lifestyle demands (i.e., time-constraints) and health beliefs (i.e., fear of addiction) (Marshall, Wolfe, & McKeivitt, 2012).

“Psychosocial factors” is a general term used across healthcare research; they are the psychological factors – how an individual thinks and feels – and the social factors – social milieu – known to affect self-care behavior (Senteio, 2015). Healthcare practitioners recognize that psychosocial factors influence self-care behavior and subsequently health outcomes, but little is known as to how psychosocial factors influence clinical decisions, particularly those that deviate from guidelines. Additionally, little is understood as to how current health information technology (HIT) capabilities (e.g. electronic health record-EHR), support U.S.-based practitioners in the collection and use of psychosocial information.

In the developing world chronic diseases are also prevalent, and are projected to increase to become the *principal global public health issue* (Greenberg, Raymond, & Leeder, 2011). By 2020 chronic diseases may be responsible for 7 of every 10 deaths in the developing world, and chronic disease burden projections indicate that healthcare systems in developing countries will not be able to support the care burden (Boutayeb & Boutayeb, 2005). Also, in many African countries *current levels* of chronic conditions like cardiovascular disease and diabetes cause a greater number of adult deaths, and hospital visits, than HIV/AIDS; the prevalence of chronic diseases is considered a ‘neglected epidemic’ (de-Graft Aikins, Boynton, & Atanga, 2010). In sub-Saharan Africa, age-specific mortality rates are higher due to chronic diseases than virtually all other regions of the world (de-Graft Aikins, Unwin, et al., 2010). The extensive literature describing the influence of psychosocial factors on chronic disease self-care, and subsequently health outcomes is largely based on U.S.-based patient populations (Auchincloss et al., 2009; Beaulac, Kristjansson, & Cummins, 2009; Delamater, 2006; Pandit et al., 2014; Russell, Suh, & Safford, 2005; Unruh, Weisbord, & Kimmel, 2005), but we postulate that psychosocial factors influence self-care in the developing

world. However, little is known as to how HIT capabilities are prepared to support the collection and use of psychosocial information.

## 2 Objective/Purpose

We took recent insights of U.S.-based HIT capabilities for the capture and use of pertinent psychosocial information to support chronic care decisions and considered them in the context of HIT use in the developing world. We selected Nigeria based on the second author's direct experience with healthcare delivery and HIT capabilities, specifically in the areas of Lagos and Port Harcourt in southern Nigeria. We consider U.S. capabilities documented through empirical study, juxtaposed with the direct experience of a U.S.-trained Nigerian physician experienced with HIT capabilities in the developing world.

The poster will describe a U.S.-based investigation of practitioners' access to, and use of, psychosocial information for outpatient diabetes care decisions in order to: understand how this information may be used, and the degree to which current HIT tools support clinical decisions. We will also describe the degree to which HIT tools in the developing world support practitioners' chronic care clinical decisions based upon healthcare delivery experience in two regions of Nigeria.

## 3 Methods

The U.S.-based empirical study followed the sequential exploratory mixed method approach. Physician interviews (n=17) preceded an internet-based survey of physicians, nurses and diabetes educators (n=229). Participants were purposively sampled. They were experienced treating underserved patients whose self-care is particularly influenced by psychosocial factors. These insights are considered with observations from a U.S. trained physician with telehealth implementation experience, across the U.S. and in Nigeria.

## 4 Results

The U.S.-based study resulted in four key findings.

- a) Psychosocial information is most considered when a patient: 1) has poor glycemic control, and 2) experiences worsening of glycemic control.
- b) Patients share psychosocial information within clinician-patient relationships characterized by patient autonomy and privacy, physicians use specific techniques to build these relationships.
- c) Awareness of psychosocial information may trigger decisions to personalize HbA1c targets or augment guideline-concordant treatment with actions to address self-care barriers, such as referrals to prescription assistance.
- d) HIT (EHR) designs are *not optimized* for capturing and retrieving qualitative and situationally-dependent psychosocial information, which tends to come in a narrative form.

In the developing world, medical information is typically handwritten and kept in manual filing systems. And as in the U.S., psychosocial information is not gathered at routine medical visits. HIT capabilities are just beginning to be implemented at more sophisticated, well-resourced private tertiary care facilities, based on the second author's direct experience in Lagos and Port Harcourt (urban and semi-urban areas of Nigeria). For example, Gold Cross Hospital in Lagos is a private tertiary care facility that implemented an EHR in early 2016. Implementations like this can be associated with infrastructure and training challenges due to inconsistent and, often unpredictable access to electricity and telephone interconnectivity (Idowu, 2015), as well as poor overall knowledge of computing systems by local practitioners. Some of these barriers are overcome as healthcare facilities use generators to address outages, and some HIT vendors offer on-site 24/7 technical support, but these are available only for well-resourced facilities. Even among the few healthcare systems with access to these resources, they still must justify the return on investment, which is particularly challenging for HIT first-movers. As the early adopters realize the gains from data insights enabled by HIT capabilities, we expect more facilities may invest in technology-enabled capabilities to capture and use data to help manage their patients. But, as in the U.S. standard capabilities may not include the capture and use of psychosocial information to inform chronic care decisions.

Given barriers to access HIT a growing number of practitioners in the developing world are embracing ICTs, specifically telephony and social media, to engage their patient community. For example, in Nigeria the second author observes physician's routinely providing patients their *persona*/ mobile phone number to convey medical information remotely, a practice described in recent literature on ICTs and healthcare across Africa (Idowu, 2015). The growth in telecommunication since the introduction of GSM in Nigeria in 2001 will continue to expand telemedicine-driven healthcare capabilities to help connect patients and practitioners. Additionally, health-specific websites enable patients in the developing world to solicit

information from practitioners. For example, Kangpe.ng is geared toward mobile users; it enables patients to ask practitioners questions. Webdoc.ng is a similar site which also provides disease risk calculations. These ICT-enabled uses are in their nascent stages but they represent important technology-enabled capabilities for connected care in ways to help inform HIT advancements and usage, both in the developing world and in the U.S.

## 5 Discussion

Findings offer new insight for the importance of care continuity for psychosocial information use. Moreover, effective use of psychosocial information requires enhanced digital tools for its capture and retrieval. U.S.-based study results can support the development HIT capabilities to improve use of psychosocial information at the point of care. These findings support the expansion of personalized medicine capabilities to the individual, potentially facilitating improved chronic disease health outcomes. Insights from the U.S.-based study can be considered in the context for current ICT-enabled HIT capabilities and usage in the developing world. As HIT capabilities expand both in the U.S. and in the developing world, lessons learned from each can help the development of tools designed to capture and use psychosocial information to inform chronic care decisions, and support addressing the considerable imminent global chronic disease burden.

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