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# Health Literacy and How Rural Communities Understand Hypertension Information in Kabale, Uganda

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**Abstract:** This research examines health literacy and how rural communities understand hypertension information in Kabale, Uganda. Commonly defined as an individual's ability to access, understand, and use information to promote and maintain positive health and well-being, health literacy and hypertension has yet to be problematized within an African context.

## Introduction

The research and discussion on health literacy are rich, complex, and ongoing. The definition of the term "health literacy" has generated fierce debate and continues to be interpreted, defined, and operationalized in multiple ways. Consequently, the definition of *health literacy* and *health illiteracy* is muddled by the multitude of actors who possess competing agendas, ideologies, and cultural values. Elements of a common definition have emerged over the last five years to include an individual's ability to *access*, *understand*, and *use* health information to promote and maintain positive health and well-being. These common attributes are further defined by Sorensen et al. (2012) as an individual's ability to "seek, find, and obtain health information (*access*)... comprehend the health information that is accessed (*understand*)... and apply the information to make decisions to maintain and improve health (*use*)" (p. 9). While the operationalization and problematizing of these elements becomes muddled depending on one's ideological framework, scholars do agree on the associated evidence between low health literacy and health related skills.

In adults, moderate evidence suggests that low health literacy is associated with patient access to care and health-care related skills. Studies suggest low levels of health literacy have affected the following areas:

- Increasing emergency care and hospitalization amongst elderly patients with low health literacy (Cho, Lee, & Arozullah, 2008; Howard, Gazmararian, & Parker, 2005).
- Reading and interpreting medical labels correctly (Davis et al., 2006).

Additionally, research has concluded that while low health literacy is found across all demographic groups, it disproportionately affects non-White racial and ethnic groups, the elderly, individuals with lower socioeconomic status and education, people with physical and mental disabilities; those with low English proficiency (LEP), and non-native speakers of English (Kutner, Greenburg, Jin, & Paulsen, 2006; Neilsen-Bohlman, Panzer, & Kindig, 2004). Furthermore, Schillinger (2011) found the following:

Vulnerable populations have been described as subgroups that, because of shared social characteristics, are at higher risk of risks. This implies that their vulnerability is socially determined by the structural nature of society, and that vulnerable populations, by virtue of being vulnerable, are much more likely to be at high risk of being exposed to risk of

illness. Vulnerable populations are exposed to contextual conditions that distinguish them from the rest of the population (p. 13).

Nowhere are vulnerable populations and its shared characteristics more prevalent than in Sub-Saharan Africa. People in Sub-Saharan Africa (SSA) have the worst health, on average, in the world. The World Health Organization (WHO) estimates the region has 11% of the world's population but carries 24% of the global disease burden (WHO, 2006). With less than one percent of global health expenditure and only three percent of the world's health workers, Africa accounts for almost half the world's deaths of children under five, it has the highest maternal mortality rate, and it bears a heavy toll from infectious diseases such as HIV/AIDS, tuberculosis, and malaria (WHO, 2006). Yet, while infectious diseases currently dominate the discourse of disease burden and donor support, there is an emerging epidemic that poses a major threat to the health of African nations. According to the WHO, the largest increase in Noncommunicable disease (NCD) deaths will occur in Africa. Furthermore, in African nations NCDs are projected to exceed the combined deaths of communicable and nutritional diseases and maternal and perinatal deaths as the most common causes of death by 2030 (Mathers, Fat, & Boerma, 2008).

Noncommunicable diseases also known as chronic diseases, can be categorized into four disease types: (1) cardiovascular diseases (CVD), (2) cancers, (3) chronic respiratory diseases and (4) diabetes. These four disease types account for 80% of the 36 million NCD deaths per year and outnumber worldwide death, disability, and economic burden rates of more well-known infectious diseases (WHO, 2013). While high-income economies have made significant gains in reducing chronic disease mortality in the past decades, low and middle-income countries (LMIC) are facing the mounting burden of risk factors that lead to chronic disease. According to the WHO (2013), "Nearly 80% of NCD deaths—29 million—occur in low- and middle-income countries. More than nine million of all deaths attributed to NCDs occur before the age of 60; 90% of these "premature" deaths occurred in low- and middle-income countries."

Today, hypertension is the leading cause of cardiovascular mortality (heart failure) worldwide, both in industrialized and in low-income developing, countries and increasing rapidly in SSA (Lopez et al., 2006; Seedat, 2000). Additionally, if left untreated, hypertension can lead to kidney failure, blindness, stroke, and enlarged arteries (aneurysm). As the global disease burden of hypertension becomes more understood by the academic and medical community, the amount of research conducted in developing countries has started to increase. For example, recent cross-sectional studies of the prevalence of hypertension in SSA have demonstrated significant prevalence. The Millennium Village Project found a hypertension prevalence of 27.3% in Malawi and 26.8% in Mbola, Tanzania. It is even more prevalent in the semi-urban areas, for example in Ghana at 29% and in Tanzania at 40% (de Ramirez et al., 2010). In Uganda, a recent study concluded that "one in every three adults aged 20 years or older in the rural Ugandan district of Rukungiri is hypertensive" (Wamala et al., 2009, p. 157). This becomes worrisome when one considers in 1941 the first published report on hypertension prevalence in Uganda estimated prevalence at 2.9% among adults (Williams, 1941, as cited by Wamala et al., 2009).

In Uganda, hypertension health literacies have yet to be problematized and examined. Thus, it is imperative that its common attributes *access*, *understanding*, and *use* are investigated, analyzed, and compared within their own cultural context.

## Research Questions

This intrinsic case study used qualitative research methods, specifically semi-structured interviews, observations, and document analysis to understand how hypertension health literacy information was accessed, understood, and used by community members and how those choices affected health outcomes in Kabale, Uganda. Specifically, the research sought to answer the following questions:

1. How do adults diagnosed with hypertension in Kabale, Uganda access, understand, and use hypertension information?
2. What barriers exist in accessing, using, and understanding hypertension information and how do existing barriers impact hypertension care?
3. What cultural perceptions hinder or enable access, understanding, and use of hypertension information.

### **Research Site**

Kabale is located in Kabale District; in the Kigezi region of southwest Uganda. The center of town is marked by small retail shops that provide goods and services to truckers using the main road to transport goods to the capital cities of Kampala in the north and Kigali, Rwanda to the south. Another road just outside Kabale will route travelers westward to the Democratic Republic of Congo. Although primarily used as a transportation hub, Kabale does attract tourists on their way to Bwindi National Park to track endangered gorillas. Other key demographics include:

*Kabale General Population:* 498,300

*Language:* Rukiga, Luganda, English

*Employment:* Eighty-five percent (85%) of the population in Kabale are engaged in full-time agriculture. Of this segment, 84.6% are dependent on subsistence agriculture as the primary source of livelihood.

*Hypertension prevalence:* One study conducted in Rukiga estimated hypertension prevalence to be 30.1% (Wamala, et al., 2009)

### **Summary of Findings**

This summary of research identifies key findings for each research question based on interviews, observation, and analysis.

#### **Key Findings Related to Research Question 1**

*How do adults diagnosed with hypertension in Kabale, Uganda access, understand, and use hypertension information?*

1. Hypertension information was accessed from both formal and informal knowledge bases. These included the hospital, church, radio, newspaper, traditional healers, witchdoctors and rural community members.
2. Participant understanding of hypertension was limited to symptomatic and behavior modification knowledge. Participants could identify symptoms and list certain foods to eat or avoid, but were unable to conceptualize and associate factors of risk, causation, treatment, disease association, and psychological and physiological effects.

3. Participants took four actions in accordance with their access and understanding of hypertension information: Modified their diet, took prescription medication, visited a traditional healer or witchdoctor, or took no action at all.

**\*Note:** Although the diet modification and prescription medication are the best biomedical solutions for treating hypertension, the barriers to these options often precluded participants from taking any action at all.

### **Key Findings Related to Research Question 2**

*What barriers exist in accessing, using, and understanding hypertension information and how do existing barriers impact hypertension care?*

1. Hypertension has yet to be problematized in Uganda, thus traditional health literacies used to create awareness and inform the communities about hypertension have not been developed.
2. Lower levels of the formal health system are ineffective providers of information and care for hypertension due to a lack of training and resources. This might explain why participants experienced symptoms of hypertension for a significant amount of time prior to a biomedical diagnosis.
3. Physical access barriers to the hospital such as poor roads, long distances, and transportation costs limited the utilization of health care and treatment options for participants.
4. Print literacies were ineffective in the rural communities.
5. The church was an effective place to access health information, yet lifestyle modification messages and a more dangerous message of prayer over seeking medical treatment were problematic.
6. “Free” hypertension medicine was often not available at the government hospital, thus patients were referred to private dispensaries where they had to pay for their medication, which they often could not afford.
7. Lifestyle modification messages were ineffective in the absence of education, support, and available resources.
8. Radio information was limited and communicated a lifestyle modification message when discussing hypertension.

### **Key Findings Related to Research Question 3**

*What cultural perceptions hinder or enable access, understanding and use of hypertension information for adults diagnosed with hypertension in Kabale, Uganda?* In the absence of hypertension information, cultural perceptions of disease and symptoms were attributed to the supernatural and bewitching.

### **Discussion**

It is evident from this research that significant barriers to access, understanding, and use of hypertension literacies need to be addressed if this burgeoning chronic disease is going to be effectively managed in rural African communities. Hypertension continues to escalate in low- and middle-income countries where health systems are weak and the resources and capacity to address disease is limited. This leads to an increase in people living with hypertension going “undiagnosed, untreated, and uncontrolled” (WHO, 2011, p. 10) which ultimately contributes to high rates of cardiovascular mortality in these countries. Hypertension can be prevented, but it

will require a coordinated and integrated approach by multiple stakeholders including government policy makers, health professionals, private industry (e.g., food manufacturers, pharmaceutical companies, medical device suppliers) academia, and civil society (WHO, 2011).

Access barriers to lower levels of the health system contributed to symptoms going undiagnosed and an increase in health risk for participants. Limited lifestyle modification messages prescribed by doctors and communication modalities such as the radio and newspaper were ineffective and created more confusion and frustration than understanding and action. Cultural perceptions of the supernatural and bewitching were reinforced in the absence of information, contributing to a low utilization of the health system and increasing the health risk for participants.

The challenge ahead for key stakeholders is significant. As adult educators, we must force our way into the conversation and make known the value we add in promoting a participatory approach to education. If left to policy makers and health professionals, a top-down Western based “condomcentric food-pyramid” approach to hypertension education is imminent. Research participants in this study require more and deserve better. Adult educators must answer the bell, accept the challenge, and forge our way into the conversation. We must be the voice at the table for rural communities like Kabale, Uganda.

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