



# ‘When I don't have money to buy the drugs, I just manage.’—Exploring the lived experience of persons with physical disabilities in accessing primary health care services in rural Ghana



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## ABSTRACT

The United Nations Convention on the Rights of Persons with Disabilities recognizes the rights of persons with disabilities' access to health care, including primary health care (PHC). However, growing evidence indicates that individuals in rural areas generally experience health access issues, and these issues are even worse for those with physical disabilities. Knowledge about such experiences is critical for policy design and clinical practice to promote PHC access for persons with physical disabilities in rural areas. This study seeks to explore the experiences of persons with physical disabilities in accessing PHC services in the predominantly rural Upper West Region of Ghana. We conducted semi-structured interviews with 18 participants living with physical disabilities, and used both deductive and inductive approaches to analyze the data. Participants shared experiences at three broad levels: the health system level, individual level and health-seeking behaviors level. Within the health system level, we identified three main categories: service availability (presence of health facilities, deficient drug supply and lack of providers), acceptability (positive and negative attitudes of providers and perceived high and low quality of care) and accommodation (inaccessible health facilities and equipment). The experiences at the individual level included financial constraints and mobility to health care facilities. Health-seeking behaviors related to how the individual reacted and responded to access barriers, which included searching for traditional healing, resorting to self-medication, making sacrifices in managing their conditions and relying on spiritual means. The information provided in this study is potentially important to policy makers and PHC providers as it presents evidence on the barriers and facilitators to PHC access in a rural setting. In particular, understanding individuals' experiences and how they develop health-seeking behaviors to overcome access barriers will be critical for policy design and client-centered service delivery in rural Ghana and potentially other low- and middle-income countries.

## 1. Background

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities recognizes the rights of persons with disabilities' access to health care, including primary health care (PHC) (United Nations, 2006). The United Nations Declaration on Sustainable Development Goal 3 also emphasizes the importance of “leaving no one behind” in achieving access to quality health and equity in health care (United Nations, 2015). However persons with disabilities are more likely to experience physical, knowledge, attitudinal and systemic barriers in accessing care than the general population (McColl and Jongbloed, 2006; Vergunst et al., 2015). These barriers are further pronounced for persons with physical disabilities in rural areas (Ahmad, 2013;

Davidsson and Södergård, 2016; Vergunst et al., 2015).

Access to health care is also a key indicator of the performance of health care systems (Levesque et al., 2013; Russell et al., 2013). Access is a complex concept with different interpretations. Indeed, researchers have drawn attention to the lack of consensus about defining and measuring access (Berk and Schur, 1998; Levesque et al., 2013). Early research conceptualized access in terms of entry into the health care system, suggesting that access requires the use of service rather than the mere presence of a facility (Donabedian, 1973). Similarly, access is theorized in terms of potential or actual entry into the health system (Aday and Andersen, 1974; Andersen, 1995). Andersen further considers service utilization or realized access as a proxy of access partly because it is easier to measure realized access than potential access

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(Andersen, 1995). As such, the use of health care service is determined by the characteristics of the population (predisposing, enabling, need) and the characteristics of the health care delivery system (policy, resources, organization) (Aday and Andersen, 1974; Andersen, 1995). This provider/user interface was further expanded by Penchansky and Thomas (1981) to include the degree of “fit” between health provider/systems and their clients.

Expanding on these foundational works, Russell et al. (2013) recently developed a framework for understanding PHC in rural areas. They defined access to PHC as “the potential ease with which consumers can obtain health care at times of need” (Russell et al., 2013, p.62). Russell and colleagues conceptualize access as a multi-dimensional construct that incorporates the “fit” between the characteristics of the individual (demand) and the health care system (supply) across seven dimensions; availability, geography, affordability, accommodation, timeliness, acceptability and awareness (Russell et al., 2013).

Access has often been used to measure quality, equity and health outcomes (Campbell et al., 2000). Therefore, designing health care systems to meet the needs of clients and broadly assessing the clients' experiences have become the focus of health services researchers, practitioners and policy makers (Ho et al., 2017). A recent review has shown growing evidence from some low- and middle-income country (LMIC) contexts pertaining to the experiences of clients with disabilities and the barriers they face in accessing PHC services in rural areas (authors, under review). In particular, persons with physical disabilities in rural areas commonly experience barriers including physically inaccessible healthcare facilities and equipment, inaccessible transport options and stigmatization, and discrimination from health care providers (Ahmad, 2013; Davidsson and Södergård, 2016; Mactaggart et al., 2016; Vergunst et al., 2015). However, these experiences may not be universal and may differ across LMICs due to factors such as context variations in geographical, political, socio economic and health care systems. For instance, Ghana is one of the few LMICs with a national health insurance scheme that supports health care for all residents (Akazili et al., 2017). The majority of empirical studies on this topic in Ghana have been quantitative-based studies in urban settings, and studies that provide information from people with different forms of disabilities (Badu et al., 2016; Badu et al., 2016; Badu et al., 2015). These studies provide a broad overview of factors affecting access to health care for persons with disabilities that might be applicable in rural Ghana. However, they are unable to offer in depth insights into experiences of persons with physical disabilities in accessing PHC services in rural Ghana specifically.

The aim of this study is therefore to understand the experiences of health care access for persons with physical disabilities in accessing PHC in the Upper West Region, the most predominant rural region of Ghana. In Ghana, PHC includes the following components: health education; environmental health; public health nutrition; reproductive and family health; immunization against common communicable diseases; epidemiology and disease control; treatment of common ailments and injuries; and provision of essential drugs (Ghana Health Service, 2005). This study focuses specifically on treatment of common ailments and injuries (e.g. malaria, typhoid, fever) and provision of essential drugs (e.g. antimalarial drugs, paracetamol, diclofenac, amoxicillin) (Ministry of Health, 2010). These focuses have been used because research has shown that persons with physical disabilities are relatively high users of such health services as a result of secondary complications they often develop (Donnelly et al., 2007; Guilcher et al., 2013), yet their experiences in accessing PHC services in rural Ghana have received limited attention. Understanding their lived experiences with the health care system can provide recommendations to inform policy developments and improve clinical practices in rural Ghana.

## 2. Ghanaian context

The Republic of Ghana is a sub-Saharan African nation that lies along the Gulf of Guinea. The country is made up of three major religious affiliations, namely Christian, Islam and Indigenous beliefs. The country has a population of about 25 million as of 2010 (Ghana Statistical Service, 2012). Ghana has 10 administrative regions with the regional capitals as major hubs. Below the regions are 254 metropolitan (population over 250,000), municipal (population over 95,000) or district (population over 75,000) assemblies.

### 2.1. Ghana's health care system

Ghana has a multifaceted and pluralistic health delivery system, in which “conventional” public and private sectors alongside traditional and faith-based healing systems provide health care to citizens. The public or government-run health care system has the major health care facilities and providers, and is also the largest provider of health care services (Tenkorang, 2016). Further, this health care system is hierarchically organized into five different levels; national (teaching hospitals) at the apex, followed by regional (regional hospitals), district (hospitals and polyclinics), sub-district (health centers), and community (Community Health Planning Services (CHPS) compounds) (Ministry of Health, 2015). Our study focuses on the district, sub-district and community levels because they mostly provide health services to rural communities in Ghana. The district facilities provide secondary curative health care and PHC. The sub-district and community health facilities provide basic PHC services, and are thus the first point of contact between clients and the health care system for most rural residents.

Health care is financed through the establishment of a National Health Insurance Scheme, Act 650 in 2003 (Revised to Act 852 in 2012). The scheme is regarded as a universal pro-poor health policy to overcome financial barriers to accessing basic health care for all residents (Agyepong and Adjei, 2008). This initiative was established to replace the hitherto “cash and carry system” (i.e. out of pocket payment) that limited the ability of many people to receive affordable and quality health care services (Dixon et al., 2011). Detailed information about the scheme is explained elsewhere (Agyepong and Adjei, 2008; Awoonor-Williams et al., 2016; Dixon et al., 2011). Under the scheme, an individual needs to pay an annual subscription fee in order to be enrolled on an annual basis. Payment exceptions are provided for persons with disabilities classified as extremely poor and marginalized within criteria set out by the government. However, identifying this group for exemption premium payment has not been successful, partly due to the lack of clarity about the guidelines in determining poverty (Dixon et al., 2011). As a result of this, persons with disabilities continue to experience financial barriers to health care access (Badu et al., 2015).

### 2.2. Persons with disabilities in rural Ghana and access to health care

In Ghana, rural areas are classified primarily on population size. Thus, rural areas consist of localities with 5000 people or less (Ghana Statistical Service, 2012). Almost half of Ghana's population (49.1%) live in rural areas. Ghana also has approximately 3% of persons with disabilities (Ghana Statistical Service, 2012). However, the WHO report on disability estimates the prevalence of disability between 7% and 12% (World Health Organization, 2011). The difference in the estimation may be due to how disability was operationalized and/or perceived by the researchers during the data collection process. For instance, most data collection in LMICs largely excludes persons with “invisible” impairments, such as persons with intellectual and developmental disabilities, HIV/AIDS or mental health issues (Yeo and Moore, 2003). Estimations have also shown that a majority of persons with disabilities reside in rural areas (Ghana Statistical Service, 2014).

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