

## Editorial

### Editorial: Special Issue: Understanding Disability in Sub-Saharan Africa

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#### Abstract

This essay provides an overview of the Special Issue: Understanding Disability in Sub-Saharan Africa, and briefly outlines its intentions and the thematic content of the issue.

*Keywords:* Sub-Saharan Africa, disability, human rights, decolonial

Ways of understanding disability in much of the world are heavily influenced by Western-dominated scientific and medical representations of the body. The understanding of disability in postcolonial sub-Saharan Africa is largely dependent on the Western models embedded into African societies during colonisation - those that the *United Nations Toolkit on Disability for Africa* calls the ‘older models’, which consist of the medical model and the charity model. However, more recently, there has been an increased interest in more inclusive and decolonial models of disability. These models instead explore cultural, ontological, religious, and aesthetic understandings of disability within African societies. The *United Nations Toolkit on Disability for Africa* signals that these ‘newer models’ of understandings of disability consist of the social model and human rights model (<https://www.un.org/esa/socdev/documents/disability/Toolkit/Intro-UN-CRPD.pdf>). But even

views such as these must still be interrogated, since the social model may still be profoundly shaped by western models of considering the body. Most importantly, such views may overlook indigenous understanding of wellbeing and care as they relate to disability and indigenous models of duties toward disabled people. Such views also fail to acknowledge that the concept of the human in the human rights model is normative, highly contested and fluid (Imafidon 2022b). On the other hand, a decolonial and inclusive perspective seeks to unearth and explore the positive and negative impacts of deeply entrenched cultural understandings of disability in all its dimensions and ramifications. This includes epistemological, ethical, medical, aesthetic, ontological, religious and other consequences for the wellbeing and lived experiences of persons with disabilities.<sup>1</sup>

Sub-Saharan African cultures hold their own conceptions of disability. These may include explanations for, and representations of, different forms of disabilities, attitudes towards disabilities and persons with disabilities, ways of coping with, or managing health and other challenges related to disability, hermeneutics of the disabled body, social categories and institutions for dealing with disability, and the intersections of disability with diet, health, gender, colourism, orality, politics and art. These alternative explanations are not only long-standing in indigenous cultures and sustained from generation to generation, but they are also deeply embedded into the fabric of community life and everyday activities, and intersect.

These notions of disability are so prominent that they permeate daily existence and have real consequences for persons with disabilities. Consequently, it will do real harm and injustice to persons with disabilities in sub-Saharan Africa if attention is not paid to them in the research on disability in Africa, which remains largely shaped by the medical, charity and

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<sup>1</sup> This special issue has emerged from a series of workshops held as part of the Disability and Inclusion Africa project, which is funded by the Arts and Humanities Research Fund and the Global Challenges Research Fund. The project is interested in the impact of alternative explanations for disability on disabled persons, their communities, advocates and policy makers.

human rights models. In modern-day Africa, with the influx and growing impact of scientific explanation for disabilities into African places and growing awareness of medical and scientific models of disability, indigenous explanations and understandings remain intensely felt and continue to shape the lived experiences of persons with disabilities in these societies.

This special issue of the *Review of Disability Studies* consists of original articles and creative works that take seriously and explore some important aspects of sub-Saharan African perspectives on disability and their impact on understandings of disability and the lived experiences of persons with disabilities in African societies. This special issue focuses on communities in countries including Nigeria, Ghana, Ethiopia, South Africa, and Zimbabwe and general understandings of disability. It examines the lived experiences of persons with disabilities, as well as specific disabilities such as podocniosis (a skin disease that appears to be caused by exposure to soil irritants), albinism, autism, dyslexia, and visual impairment. As such, it brings together important theoretical, qualitative and artistic work on disability in sub-Saharan Africa. The articles cover themes and issues including cultural understandings of disability and diet, understandings and theorisation of moral obligations to persons with disabilities, and literary and poetic representations of disability. They explore African ontological foundations of disability, as well as linguistic, gender and economic dimensions, and questions of colourism. This special issue therefore shifts attention from a largely Western narrative to a decolonial, inclusive and indigenous understanding of disability in sub-Saharan Africa. For example, Oche Onazi explores the moral obligation that emerges from, and the practical applicability of, African communitarian philosophy for persons with disabilities, proposing an asymmetrical conception of obligation and tax as a means to practically discharge obligations. Edwin Etieyibo examines the metaphysical and epistemological foundations of understandings of disability in sub-Saharan Africa and their connection with a holistic ontology that intertwines the physical and the non-physical, or


supernatural. Kenneth U. Abudu examines indigenous colourism in selected Nigerian cultures such as the Yoruba and the Esan, and how it provides a basis for understanding discrimination against persons with albinism. Francisca Anita Adom-Opare explores the fascinating connection between disability and dietary requirements during pregnancy by examining indigenous food taboos in Ghana.

Kidus Meskele and Enoch Acheampong et al. explore how indigenous understandings of disability in different sub-Saharan African communities in Ethiopia and Ghana respectively impact healthcare systems and practice. Firdaws Oyebisi P-Ibrahim deduces important indigenous understandings of disability in Nigerian cultures from selected Nigerian prose works, showcasing the physical and non-physical dimensions of disabilities. Chikuta, Chitambara, and Matura's qualitative study analyses how indigenous notions of disability impact employment and the economic life of persons with disabilities in the hotel sector in Zimbabwe. Jean L Cathro provides an interesting analysis of a sculpture made by Njabulo Hlongwane and the learners of Mason Lincoln Special School in Umlazi Township, Durban, South Africa. Finally, two creative pieces invite us to reflect on the implications of different understandings of disability in African places. The first is South African poet Kobus Moolman's 'Fourteen Critical Questions', and the second is a series of production stills taken from a web series directed by Karolina Wambui that portrays a young woman with albinism working in the matatu (bus) industry in Korogocho, a slum neighbourhood of Nairobi, Kenya.

While the articles in this special issue do not exhaust the study of indigenous understandings of disability in sub-Saharan Africa, it is our hope that they stir up the right conversations and interests that would enrich a decolonial and inclusive approach to disability studies.

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## **Realizing the Right to Health of People Living with Podoconiosis: Lessons from the Field**

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### **Abstract**

Podoconiosis is endemic non-filarial elephantiasis which affects people who walk barefoot on irritant clay soils for many years. A significant number of people are living with the disease in Ethiopia and other parts of the world. Despite the disease being a cause and consequence of illness and poverty, little attention was given to the disease from the right to health angle in Ethiopia. Although the Constitution of Ethiopia does not explicitly recognize the right to health, Ethiopia has ratified international and regional human rights instruments which guarantee the right to health as a fundamental human right. In particular, this article explores gaps in implementation of the right to health of people living with podoconiosis based on lessons from field observation.

*Keywords:* Podoconiosis, right to health, human rights, Ethiopia

### **Author Note**

The author declares that he has no competing interests. The author conceived the study, designed and drafted it and carried out the field study. The author is grateful to the late Mr. Meskele Ashine, the director of Mossy Foot Association, for his assistance during data collection.

## Background

Podoconiosis (endemic non-filarial elephantiasis) is a chronic disease characterized by the development of persistent swelling in the lower leg. It is non-infectious disease, apparently resulting from inflammatory blockage of the lymphatic system of the limb. It almost always affects the lower limbs, especially the feet, and it rarely extends above knee (Price, 1984b). Podoconiosis has been recognized as a specific disease for over 1000 years and is widespread in Tropical Africa, Central America and North India, yet it remains a neglected and under-researched condition (See Price, 1984b). The disease causes immense social and financial consequences in endemic areas. Its public health and socioeconomic impact result from its incapacitating effects, which hinder individuals from working, e.g., pursuing farming and other activities involving extensive walking. People with podoconiosis may abandon agricultural work because the disease condition becomes severe as a result of repeated ulceration and secondary infections (Price, 1974). The disease, although not fatal, causes progressive deformity and disability, and the presence of so many disabled adults in a largely subsistence economy represents a considerable drain on limited resources (Destas et al., 2002). Although the real cause of the disease has not been identified until recently, and several studies attempting to find the cause of lower-leg-elephantiasis in Ethiopia have failed to show infectious cause, many podoconiosis studies have suggested that the red clay soil of endemic area that is rich in fine particles (mostly less than 10 micrometer) of silica and alumino-silicates plays a significant role in the pathogenesis (Price, 1988).

Despite the fact that the disease is easily preventable by wearing shoes to avoid contact with the irritant soil, it is still debilitating the lives of the poor in developing countries. Reasons include lack of money and low level of awareness in the community.

Unfortunately, most patients in endemic areas are unable to afford the cost of durable shoes in different sizes for growing children and may instead wear locally made open sandals (Destas et al., 2002). In early onset of the disease, foot hygiene is very helpful to halt and reverse progress of the disease. It involves washing the feet with soap and water, use of antiseptic and emollients, and consistently wearing shoes and socks (Price, 1975). Furthermore, public health programs can improve understanding of the risks of developing podoconiosis through teaching individuals to recognize early signs and encouraging good hygiene and care for those who have already developed the condition.

The right to health is a human right which is shared by all states to maintain health for every individual. This right is stated and recognized in many international, regional and domestic human rights instruments. Among the international human rights instruments, the most explicit reference for the right to health is contained in International Covenant on Economic, Social and Cultural Rights (ICESCR). In addition, the right to health is included in regional human rights instruments such as African Charter on Human and Peoples' Right, European Social Charter and Additional Protocol of the American Convention on Human Rights in the Area of Economic, Social and cultural Rights. All of these human rights instruments define the content of the right to health and impose obligation on member states to assure health care services and to promote and protect the health of their populations. Furthermore, the role of United Nation Charter and WHO Constitutions can also not be overstated with respect to development of the right to health.

The right to health is a fundamental part of human rights and an understanding of a life with dignity. Internationally, it was first articulated in the 1946 Constitution of the World Health Organization (WHO). The 1948 Universal Declaration of Human Rights also mentioned health as part of the right to an adequate standard of living. The right to health was



again recognized as a human right in the 1966 International Covenant on Economic, Social and Cultural Rights. Since then, other international and regional human rights treaties have recognized or referred to the right to health or to elements of it, such as the right to medical care. The right to health is relevant to all States, with every State ratifying at least one international human rights treaty recognizing the right to health. Moreover, States have committed themselves to protect this right through international declarations and domestic legislation and policies (Committee on Economic). Additionally, the United Nation Committee on International Covenant on Economic, Social and Cultural Right (ICESCR) has issued the General Comment 14 on May 15, 2000 which clarifies the content to the right to health (Committee on Economic).

Despite this widespread international recognition of right to health as basic human right, and although several people are affected by podoconiosis in Ethiopia, these people has received little attention regarding implementation of the right to health. No study has yet identified the gaps in implementation of the right to health instruments concerning podoconiosis patients in Ethiopia. We therefore aim here to assess to what extent the right to health contents reflected in international, regional and domestic human rights law has been implemented, and moreover to advance recommendations as to how this right might be implemented to fully realize the right to health of podoconiosis patients.

## **Methods**

### **Ethics statement**

Approval letters for this study were obtained from Ethical Approval Committee of

Wolaita Zone Health Departments. As most of the study participants were unable to read and write, the written consent form was read to them, and oral informed consents were obtained from each study participant. This verbal consent was approved by the committee. Each study participant was clearly informed about the objectives of the study prior to the interview process. Participants were informed that they had the full right to withdraw from participation or to skip questions during the interview. Participants were also told that names and other identifying information would not be disclosed to any third party. Finally, permission was obtained from respondents to disseminate the research findings through publication.

### **Study area**

The study was conducted in Wolaita Zone, Southern Ethiopia, which is 380 kms from Addis Ababa, the capital of Ethiopia. The Wolaita Zone covers a total area of 4541 sq. km and has an estimated population of 1.7 million (Central Statistical Agency, 2008). Wolaita is one of the most densely populated zones in the country with an average of 290 people per square kilometer. The majority of people in the region earn their livelihood from subsistence farming (Central Statistical Agency, 2008). Farmers in the study area rarely wear shoes while working in their fields and hence are in direct contact with the soil. A non-government organization, the Mossy Foot Treatment and Prevention Association (MFTPA), has been providing communitybased treatment and prevention of podoconiosis through fifteen clinic sites in this region since 1998.

### **Study design and sampling**

A cross-sectional qualitative study was conducted using semi-structured in-depth interviews, key informant interviews, and focus group discussions (FGDs). Interviews and FGDs were done with podoconiosis patients, representatives of relevant governmental

institutions and non-governmental organization working on podoconiosis. The interview instruments were prepared in English, translated into Amharic or Wolaita as appropriate and then translated back into English to check for consistency.

A theoretical sampling technique was used to recruit the study participants. Interviews and FGDs were conducted in an environment conducive to conversation. Five of the fifteen MFTPA out-reach clinic sites were selected on the basis of high patient flow and years since establishment. Thirty-three patients (all above 18 years old), who came to receive treatment and advice from the MFTPA out-reach clinic sites were selected for in-depth interviews. Four officers from government health sectors were also present in these interviews. Thirty-six FGD participants were identified from the government health sector and MFTPA out-reach clinic sites. A total of six FGDs were formed: (a) two for government health sector workers; (b) two for male and female patients mixed; (c) one for male patients only and; (d) the last one for females only. The number of FGDs was determined by saturation of ideas, where no new information came up in further interviews. Each FGD contained six participants. For key informant interviews, participants from MFTPA (a project director, one nurse and one social worker) and the government health sector (one nurse and one health officer) were identified.

### **Data collection**

Semi-structured interview guides were designed for the in-depth interviews (IDIs), key informant interviews (KIIs) and focus group discussions (FGDs). The data collection was done for a period of one month in October 2010. All interviews and discussions conducted at MFTPA out-reach clinic sites were processed in the Wolaita language (local language). During this process, notes were taken, and discussions were tape-recorded.

## Data analysis

All the data noted and recorded in the local language were transcribed and translated into English. During transcription and translation, efforts were made to keep phrases and words as in the spoken language to maintain originality of the information. For in-depth analysis, international and regional human right instruments, the Ethiopian constitution, Ethiopian health policy documents and human rights committee recommendations were used as tools.

## Results

This study included 78 participants (38 males and 40 females). Sixty study participants were recruited from MFTPA (project office and out-reach sites) and 18 from the government health sector (Ministry of Health, zonal health departments and *woreda* health stations). The age of respondents ranged from 22 to 70 years. Most of the patients participating in the interviews and focus group discussions had had no formal education. The following findings showed the existence of gaps in implementation of the right to health of podoconiosis patients.

### **Interview Findings: How has the right to health of podoconiosis patients been implemented?**

The right to health of podoconiosis patients has not been implemented by the government. Some of the in-depth interview and FGD participants from the government sector stated that podoconiosis was ignored from the right to health perspective despite its health and socio-economic challenges. At the time, it was not included among the government's priority list of diseases.

*The government has a health extension program which is planned to train and deploy health extension workers in all Kebeles in Wolayta zone. These workers have been given short term training on the major communicable disease. Unfortunately, podoconiosis has not been the subject and the workers have not yet made any report to the health department about the socio-economic burden of the disease in the Zone because the training focuses on the diseases which are prioritized in the health sector development program. [Key informant interview, Coordinator of Disease Promotion and Prevention Department, Wolayta Zone Health Department]*

Although podoconiosis has existed in Ethiopia for centuries, it has received very little or no attention from government except the fact that the disease was included in the national master plan a few years ago. Informants suggest the need for the government further including it in programs such as education.

*I have been working in the NTDs for long time but I have not heard of podoconiosis as equally as other diseases. I took one course at undergraduate level on filarial elephantiasis but I don't know about podoconiosis. This is mainly because the disease is not directly included in the country's educational program. [Key informant interview, from the Ministry of Health]*

Additionally, podoconiosis patients were greatly affected because of poor accessibility of health facilities and information on the disease. An informant further suggest that accessibility is another component of the right to health that the government could offer podoconiosis patients.

*I think it is government's obligation to educate patients and healthy individuals in the community about any disease including podoconiosis so that individuals will know*

*how to prevent and treat diseases. I am a citizen of this country and my family pays tax to the government. Thus, the government has to fulfill any health education and services and then enable me to treat podoconiosis just like it has done for malaria and HIV/AIDS. [In-depth interview informant, 35 years]*

Another participant further builds on this observation and states that patients' ignorance regarding the implementation of right to health concerns for patients has not only affected the well-being of individuals and their families but has also more largely harmed the country's economy.

*Podoconiosis affected me a long time ago. During the time all my family and I could do was just to look what would happen next because my family was too poor to provide me treatment. After a while, my legs became bigger and bigger, which prevented me from farming and sometimes walking. Now I am worthless to my family and my country. My poor family did nothing, but the government has to do something to prevent and treat the disease. I am a human being just like others in the country. If I work I will help my family, me and the country. [FGD participant, male patient, 36]*

Moreover, health care facilities and trained medical professionals were said to be inadequate or essentially unavailable. As some study participants explained, this is a manifestation of negligence to implement the right to health of podoconiosis patients.

*When I was 26 years of age, I came to figure out that podoconiosis affected me. From that moment onwards I started looking for any treatment options. I went to different places looking for holy water and went to different hospitals. But, no improvement was seen. My foot was getting worse from time to time irrespective of my effort.*

*Despite all the efforts the only thing I got was losing all I had. Thus I decided not to try for another treatment. [FGD participant, male patient, 42 years]*

Similarly, another FGD participant also explained about unavailability and inaccessibility of health care facilities.

*I have lived with podoconiosis for the last 17 years. I didn't know the cause of the disease; however, I did my best to cure myself using different traditional medicines. Despite my effort, my legs became bigger and bigger. Finally, I decided to go to government health centers. Thus, I went to different hospitals and clinics; however, the response of health care providers was not more than giving me a pain killer. [FGD participant, male patient, 47 years]*

This lack of access is even more pronounced for podoconiosis patients living in very remote rural areas. They were the worst affected and the most ignored as they could not visit clinics because of the difficulty of walking long distances.

*I have been living with podoconiosis for the last 12 years. It is unthinkable to me to visit any health institution with my big water bag legs. It takes two to three hours on foot to reach the nearest health center. My foot was developing wounds as a result of walking barefooted on stony road to health center. I then preferred not to go anywhere and stayed at home even if I am sick. [FGD participant, female patient, 30 years]*

More broadly, some FGD participants identified poverty as a major hindrance to access to and utilization of health care services provided privately and publicly.

*My legs developed swelling and inflammation seven years ago. My family did their best to treat me using traditional medicine, but no changes were observed. Through*

*time, my foot started to produce many nodules around the toes. The only chance to get back my foot was surgery. I went to the government hospital in the area, but the health care provider advised me to go to skilled professionals in a private hospital. That was a time I had lost my hope after they asked me to pay huge amount of money which I couldn't afford. [FGD participant, male patient, 29 years]*

These factors are all compounded as implementing the right to health of podoconiosis patients was neglected because no information was given to patients or the community on cause and prevention of the disease.

*I have never used shoes during farming because I don't feel comfortable. In addition, I walk a long way barefooted. Accidentally my foot started swelling. I thought it was due to snake bite, but later I was told that it was podoconiosis. I didn't know what podoconiosis is and how it comes until I was briefed at MFTPA later in my life. [FGD participant, male patient, 41 years]*

Additionally, stigma and discrimination within the community, schools, and workplaces were all described as barriers to patients seeking social support, diagnosis, and treatment. Podoconiosis patients avoid appearances in public places to overcome the stigma they face in the community.

*I have worked in Sodo Health Center as health officer for the last three years. During this period, I recognized that few podoconiosis patients visited this health center. I think the main reason for this is that podoconiosis patients hide themselves even to the extent that they feel ashamed when they are observed by others. As a result, some patients have fear of being identified as podoconiosis patients in health center. [Key informant, head of the health center]*



A social worker in the MFTPA further disclosed the impact of stigma and discrimination on treatment seeking behavior of podoconiosis patients.

*One day, in my home-to-home visiting duty, I met with a boy who is a podoconiosis patient. He has never attended health centers due to unwillingness of his parents. I then asked his parents why they didn't let their boy at least visit health centers. Their immediate response was that 'there is nobody sick in our home'. What I understood from their action is that they feared not to be identified as a family having a podoconiosis patient. [Key informant, social worker at MFTPA clinic site]*

### **Discussion**

The existence of podoconiosis in Ethiopia was first reported by the adventurer James Bruce in the 1770s (Davey et al., 2007), and its prevalence was later reported to be high in areas in which irritant red soil is common - approximately 18% of the surface area of Ethiopia (Price, 1974). In Wolaita Zone, where the present study was conducted, prevalence of the disease is 5%, mostly affecting people between the ages of 18 and 60 (Destas et al., 2002). Despite the evidence that podoconiosis is a significant public health and socioeconomic challenge in Ethiopia, it has been given little or no attention by health and legal policy makers to fully implement the right to health concerns of people living with the disease. This inaction to implement the right to health content in the country may be seen as due mainly to ignorance, lack of reliable data, lack of funding, lack of participation by podoconiosis patients in community and the like.

Despite this inaction, Ethiopia has ratified or acceded most of the international and regional human rights instruments which give recognition to the right to health. The most

important ones from the acceded instruments are the International Covenant on Economic, Social and Cultural Rights (ICESCR) (*International Covenant on Economic*, 1966), the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) (*Convention on the Elimination*, 1965), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (*Convention on the Elimination*, 1979) and the Convention on the Rights of the Child (CRC) (*Convention on the Rights of the Child*, 1989). At a regional level, Ethiopia has also ratified the regional-level human right instruments of which the African Charter on Human and Peoples' Rights (ACHPR) is the most important one (*African Charter on Human*, 1981).

Among others, the ICESCRs which provide the most comprehensive article on the right to health in the international human rights law in recognizing the health needs of the vulnerable groups including persons living with podoconiosis and explains through illustrations a number of steps to be taken by the Ethiopian government to achieve full realization of the right to health of vulnerable groups, including persons living with podoconiosis. It imposes multifaceted obligation on the Ethiopian government with regard to the right to health. These are the duty to protect, respect and fulfill guarantees of the right to health. Additionally, Ethiopia is required to adopt legislative measures and to employ all appropriate means to ensure persons living with podoconiosis can enjoy the rights conferred by the treaty. This means, the international treaty provisions must be incorporated into the domestic legislation. Consequently, the 1995 Constitution of Ethiopia has made all international and regional human rights instruments acceded by the State as an integral law of the land. Thus, within the jurisdiction, the mentioned instruments which are ratified or acceded by Ethiopia entitle the right to health to every individual including persons living with podoconiosis. In addition, the FDRE Constitution enshrines socio-economic rights, though not expressly, providing for the right to health both in the Bill of Rights and in the

National Policy Principles and Objectives. Article 41, entitled “Economic, Social and Cultural rights” provides the following: *That every Ethiopian national has the right to equal access to publicly funded social services and obliges the State to allocate ever-increasing resources to provide to the public health, education and other social services.*

As such, the FDRE Constitution therefore entitles the enjoyment of publicly funded social services to all Ethiopian citizens on equal footing. Thus persons living with podoconiosis have the constitutionally guaranteed right to access every social service provided by the State without discrimination based on status. Moreover, the FDRE Constitution under National Policy Principles and Objectives requires the government to develop policies that enable the enjoyment of rights by citizens. Hence, Ethiopia has enacted a health sector policy in 1993. In the national health policy, primary health care service is designed to include prevention, promotion and basic curative and rehabilitative services. The main policy objective is to prevent the disease from causing undue social and economic burden on vulnerable groups including people living with podoconiosis. Subsequently, Health Sector Development Program (HSDP) has launched for implementation of the national health policy over the next twenty years. This program, in its health service extension, gives priority to prevention and control of HIV/AIDS, malaria, tuberculosis, leprosy, blindness, child mortality, maternal health and onchocerciasis. However, podoconiosis has neither been given a place in priority lists nor have persons living with this disease been the subject of health service extension program. Reasons for this omission include the following: Firstly, the program was designed based on the Health Sector Development program, and this program does not include the problem of podoconiosis. Secondly, the extension program has trained and deployed the workers only on the prioritized diseases; so that the workers do not have sufficient know-how how to deliver health services on podoconiosis and to persons living

with podoconiosis. Therefore, persons living with podoconiosis do not have a chance to get health services from extension workers.

The United Nation Committee on International Covenant on Economic, Social and Cultural Right (ICESCR), in its General Comment 14, provides the authoritative interpretation of the right to health and addresses the content of the right to health and its implementation. While General Comment 14 refers to a range of health issues and it adopts a generic approach to the right to health. According to this document, Health consists of many dimensions. General Comment 14 noted that the right to health is not the right to be healthy, but it is the right to enjoyment of varieties of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health. Accordingly, the General Comment 14 clarifies the content of the right to health as a broad and an inclusive right containing both entitlement and freedom towards health facilities, goods and services, while these essentials must be available, accessible, acceptable and quality. Freedom includes the right to control one's health and body whereas entitlement includes a system of health protection, including healthcare and the underlying determinants of health, which provides opportunity for people to enjoy the highest attainable standards of health. These standards include the right to prevention, treatment and control of diseases, access to essential medicines, equal and timely access to basic health services, the provision of health-related education and information, and participation of the population in health-related decision making at the national and community levels. So while podoconiosis patients have the right to a system of health protection which may enable them to enjoy the highest attainable level of health, patients haven't yet been enjoying the aforementioned right to health contents. The health protection system should provide equality of opportunity for everyone, including podoconiosis patients, without any distinction of any ground.

Further augmenting interventions to ensure equality of opportunity for the enjoyment of the right to health will require the fulfillment of conditions like training of adequate numbers of professionals to work toward the care and full integration of podoconiosis patients in the community. To date, little or no government effort in Ethiopia has been observed towards training health professionals on podoconiosis. General practitioners and other primary care providers should be provided with essential healthcare and disability sensitization training to enable them to provide front-line healthcare delivery to podoconiosis patients. Besides, functioning public health and health-care facilities, goods and services must be *available* in sufficient quantity within a State for this disease. For podoconiosis patients, it has been widely observed that supply of essential medicines, through few non-governmental organizations, is inadequate. These people are in-need of scientifically and medically proved treatment procedures.

Additionally, the well noticed condition regarding persons living with podoconiosis is that patients predominantly live in areas where health facilities, goods and services are inadequate or essentially unavailable. Therefore, most of these patients have been trying different means to get access to treatment. However, their efforts have been hampered due to inaccessibility of the health care facilities, good and services. In addition, persons living with podoconiosis have been facing obstacles to get appropriate treatment even after traveling to the remote health centers because of lack of awareness among health professionals on the disease. Health professionals also have misconceptions about the cause, prevention and treatment of podoconiosis despite the disease is widespread and well known in the country (Yakob et al., 2008). According to the CESC, health facilities, goods and services must be accessible to persons living with podoconiosis, taking into account four overlapping dimensions. Those dimensions are (1) non-discrimination; (2) the provision of health facilities "within safe physical reach for persons living with podoconiosis including in rural

areas"; (3) economic accessibility or affordability, meaning that costs for health care services "whether privately or publicly provided, are affordable to all, including persons living with podoconiosis"; and (4) "the right to seek, receive and impart information and ideas concerning health issues.

Notwithstanding the stipulation of the General Comment 14, persons living with podoconiosis have been facing accessibility barriers to health care and an adequate standard of living because of remoteness and poverty. Discrimination is also severely affecting podoconiosis patients. Due to this, most patients remain unable to go to health centers and take part in community activities. Patients have been describing the influence of discrimination in access to general healthcare services or stigmatizing attitudes within these services, which dissuade them from seeking health care. In addition, information on health (and other) matters, including diagnosis and treatment, must be accessible to persons living with podoconiosis, to the parents of children living with podoconiosis and to the community at large who are living in podoconiosis-endemic areas. However, even among podoconiosis patients themselves, awareness of the cause of the disease and its early symptoms deviates from the cause of disease proved through pathological investigations. This is either due to an information gap or lack of attention paid by policy makers that the pathology and means of preventability of podoconiosis are not widely known in podoconiosis endemic areas (Yakob et al., 2008). Thus, there is a misconception about the disease in both patients and other community members regarding the cause and prevention of the disease.

In view of the fact that Ethiopia has become party to international and regional human rights instruments, it has an obligation to respect, protect and, more importantly, fulfill and promote the right to health towards persons living with podoconiosis. The right to the "highest attainable standard of health" takes into account differing levels of available

resources. It acknowledges that countries, particularly developing countries, may have limited capacity to actually implement their obligations under the right to health, and it allows for flexibility in the manner and timing of implementation as befits each individual country (Judith, 2004).

However, despite this flexibility, the CESCR obliges Ethiopia at least to implement the minimum obligation immediately through, for example, legislative, policy and regulatory measures towards persons living with podoconiosis. In spite of this fact, podoconiosis has not been discussed as a public health concern in the health policy document in Ethiopia until the Ministry of Health's recently issued National Plan on Integrated Neglected Tropical Diseases (NTDs) for the period of 2012-2015, which has recognized podoconiosis as one of NTDs in the country. However, the right to health of persons living with podoconiosis continues to be violated due to government failure to fulfill its minimum core obligations such as ensuring the right of access to health facilities and goods and services, providing essential drugs, ensuring equitable distribution of health facilities, goods and services, adopting a national health strategy and plan of action, taking steps to prevent, treat and control podoconiosis, & finally providing health education and access to information regarding podoconiosis in the community who live in the endemic area of podoconiosis; and provide appropriate training for health personnel including education on podoconiosis and the right to health of persons living with podoconiosis.

### **Conclusion**

Persons living with podoconiosis clearly have a right to health care, which includes right to health care facilities, goods and services. This right is contained in various international and regional human rights instruments to which Ethiopia is a party. Although the country has ratified numerous international human rights instruments that recognize the

right to health as fundamental, this right is not implemented in Ethiopia for podoconiosis patients. The government and its sectors must ensure that this right is respected, protected and fulfilled. Therefore, the Ethiopian government should realize the right to health of podoconiosis patients through full implementation of the right to health contents.

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**Realizing the Right to Health of People Living with Podoconiosis:**

**Lessons from the Field** by Kidus Meskele

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## Qualitative Exploration of the Experiences and Coping Strategies of People with Disabilities at Some Selected Healthcare Facilities in the Bosomtwe District of Ghana

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### Abstract

Discrimination in healthcare may exclude or deter people with disabilities from seeking health services for fear of stigma and discrimination. The purpose of the study was to explore the experiences of people with disabilities at healthcare facilities in the Bosomtwe District of Ghana. A case study design with qualitative approach was adopted in which data was collected from 30 people with disabilities using purposive sampling through face-to-face interview and focus group discussions and data were audio-and video-recorded, transcribed, and categorized into themes. The study found that people with disabilities experienced communication difficulties with healthcare providers, neglect and nepotism, abuse and insults by healthcare providers. It is recommended that the heads of the various hospitals should establish a unit in each hospital to attend to the healthcare needs of people with disabilities who visit their facilities so that the stress people with disabilities go through whenever they visit their facilities could be reduced.

*Keywords:* heathcare, access, Bosomtwe District of Ghana

The Sustainable Development Goal 3 and subsection 3.8 talk about achieving universal health coverage, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines for all (United Nations, 2015). People with disabilities have health needs arising from their primary impairment as well as their general health needs (Shakespeare, 2012). Yet evidence shows that these health needs are not adequately met, due to financial access and attitudinal barriers as shown in the World Health Survey that people with disabilities were twice as likely to find health care provider skills and equipment inadequate to meet their needs; three times as likely to be denied care; and four times as likely to be treated badly by health care providers (WHO, 2011).

Accordingly, in many developing countries around the world, people with disabilities may feel reluctant to access health services although they may have significant concerns that require health care (Shaikh & Hatcher, 2007). Patients' ability to accept and utilize services has a relationship with service providers' attitudes (Shaikh & Hatcher, 2007, d'Ambruso et al., 2005, Jones et al., 2008). It has been established in previous studies that attitudes and behavior of primary health care providers were barriers for people with disabilities as they seek health care (Jones et al., 2008, Badu et al., 2016). Discrimination in health-care settings is often driven by stigma—negative beliefs, feelings and attitudes towards people with disabilities. Such individuals and groups also experience intersecting or compounding forms of discrimination on the basis of their age, sex, race or ethnicity, physical or mental health status, disability or vulnerability to ill-health (United Nations, 2006). Negative attitudes of providers may discourage the use of services by the users with disabilities, and negative attitudes may foster low expectations, encourage discriminatory behaviors and marginalization of people with disabilities among health providers themselves (WHO, 2011, Kleintjes et al., 2013).

Similarly, other writers have highlighted the importance of fairness, respect, equality, dignity and autonomy in healthcare delivery. If human rights are to have any meaning or force, the authors suggest, then they are particularly relevant to vulnerable groups and marginalized minorities (Fish & Bewley, 2010). The way people with disabilities are received and treated at health care facilities can serve as either a barrier or a facilitator to accessing health care services. Past experiences of negative health worker attitude discourage the use of health services in the future. Several studies suggest healthcare providers show negative attitudes towards people with disabilities (Barratt & Penn, 2009, Ravim & Handicap International, 2010, Coomer, 2012, Munthali et al., 2013). In most instances, healthcare providers fail to acknowledge the fact that different lived experiences impact access to care when designing services (McColl, 2005). Healthcare providers appear to be somewhat insensitive, whether on purpose or because of a lack of knowledge about the needs of people with disabilities (Gainhre, 2016, Kritzinger, 2014). Verbal, physical and mental abuses characterize the negative attitudes experienced by people with disabilities at healthcare facilities. Other studies have also reported of instances where healthcare providers have refused to either shake hands with or treat a person affected Hansen's disease (leprosy) (Dadun et al., 2016). Again, it is reported that people who are blind are ridiculed by health workers for requesting HIV/AIDS testing (Mulumba et al., 2014). The negative attitude of healthcare providers towards people with disabilities is heightened when it comes to women with disabilities (Mulumba et al., 2014).

Further intensifying these concerns, many societies in sub-Saharan Africa have historically linked the appearance of physical, intellectual, sensory or mental health disabilities with witchcraft, sin, or have seen such as evidence of retribution for some action or wrong committed by the individual or a family member (Batterbee, 2010, Byrne, 2011, Cimpric, 2012 Groce et al., 2011, McGeown, 2012). Consequently, people with disabilities

and their families have often suffered social isolation, discrimination and, in the most extreme cases, violence and death as a result of such widely held folk beliefs (Batterbee, 2010, UNICEF, 2005). Such underlying beliefs have resulted in many with disabilities being denied access to modern healthcare because their conditions are viewed as not requiring modern healthcare services but instead needing traditional and spiritual forms of treatment.

Consistent with this, in Ghana, where there is strong belief in myths and the existence of supernatural powers, it is not uncommon to associate the cause of disability with spiritual factors such as witchcraft, sorcery and magic (Avoke, 1997). Article 25 of the United Nations Convention on the Rights of People with disabilities enjoins member states to undertake to adopt immediate, effective and appropriate measures to ensure the right of people with disabilities to equally enjoy “the highest attainable standard of health without discrimination on the basis of disability.” Furthermore, states are to provide free or affordable general and specialist health services to those with disabilities.

Aligned with this, the mission of the Ghana Health Service (GHS) is to contribute to socio-economic development by promoting health and vitality through access to quality health for all people living in Ghana using well-motivated personnel (Ministry-of-Health, 2014). The significant inequalities in healthcare in Ghana have persisted for years (Ministry-of-Health, 2014). Health status of those with disabilities is improving much more slowly than that of the rest of the country’s populace (Eyob et al., 2012; Frimpong, 2013). The Ministry of Health through the Ghana Health Service launched the Ghana Health Policy to help promote the health of Ghanaians. However, this policy does not have any specific aspect which is dedicated to the health needs of people with disabilities. The assumption, therefore, is that people with disabilities have the same health needs as non-people with disabilities. In 2006, Ghana's Parliament passed the People with Disabilities Law in an attempt to help improve the general living conditions of people with disabilities in the country. In section 31

of this law, it states "The Ministry of Health in formulating health policies shall provide for a free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons with total disability." This provision on healthcare in the act is problematic because the act failed to indicate precisely who 'a person with a total disability' is. It is therefore important to note that people with disabilities will find it difficult to access healthcare because there is no clear definition of who has 'total disability'. It is against this background that this study to explore the experiences of people with disabilities at selected healthcare facilities in the Bosomtwe District of Ghana was conducted.

### **Methods**

The Bosomtwe District is in the central part of the Ashanti Region of Ghana in West Africa and lies within Latitudes 6° 24' South and 6° 43' North and Longitudes 1° 15' East and 1° 46' West. The population according to the 2010 Population and Housing Census is 93,910, representing 2.0 percent of the region's total population. About 2.9% of this population has some form of disability. The proportion of females with a disability is slightly higher (3.2%) than males (2.7%) (Ghana Statistical Service, 2010). The health delivery system in the district is made up of sixteen (16) public and private health institutions which include 3 hospitals, 3 health centers, 7 clinics, 5 maternity homes, 4 Community Health Planning Service (CHPS) Compound and 1 Midwifery Training Institution. The district also has 52 outreach points where reproductive and child services are rendered (Ghana Statistical Service, 2012).

The design of this study was a case study. A case here referred to a single community, institution, group or organization (Quinn, 2002). The Bosomtwe district of Ghana was used as a case for the purpose of doing an extensive study to find out how disability stigma has

affected people with disabilities' access to healthcare. A qualitative study approach was employed because it explains the culture and behavior of humans and their groups from the viewpoint of those being studied and does so in a natural real-life setting (Quinn, 2002).

The purpose of the study was to explore the nature and extent of the effects of stigma on people with disabilities' access to healthcare services. The target population were all people with disabilities registered by the Department of Social Welfare within the District, and also registered members of recognized Disability Organizations in the District. There were 502 people with disabilities who had been registered and certified by the Department of Social Welfare (Department of Social Welfare Disability List, 2019). The study employed purposive sampling in selecting the respondents for the study (people with disabilities). Purposive sampling helped in getting individuals directly linked to the issues under consideration. The set of inclusion and exclusion criteria associated with purposive sampling helps researchers to get rich information and helps prevent the possibility of recruiting participants who may not have any idea or may not be affected by the research problem.

Furthermore, purposive sampling helps to recruit 'qualified participants'. First, the list of all registered people with disabilities within the district was taken from the Department of Social Welfare. This list served as the sampling frame from which participants were selected. The inclusion criteria for people with disabilities were: (1) the person must have been certified and registered by the department of social welfare as disabled; (2) they must have had the condition not less than one year; (3) they must be 18 years and above; (4) and they reside within the district at the time of data collection. Individuals with all forms of disability were considered as potential participants. A total of 30 participants were selected based on the principle of saturation, the point at which responses received were being repeated and no new information was being given (Quinn, 2002).



Specifically, the study employed in-depth face-to-face interview and Focus Group Discussion to collect data from participants. Semi-structured interview guides with open questions were used for the in-depth face-to-face interviews. The focus group discussions were conducted in addition to the in-depth interviews. Focus group discussion was employed because they provided the opportunity to study ways in which individuals collectively make sense of a phenomenon and construct meaning around it. An empathetic stance in interviewing was adopted to avoid being judgmental and to allow neutrality during data collection by showing openness, sensitivity, respect, awareness and responsiveness throughout the interaction (Quinn, 2002). Two research assistants who were Postgraduate students at the University who were also knowledgeable in sign language helped in the data collection exercise. The research assistants were given a two-week training in qualitative research data gathering with special focus on interviewing and focus group discussions skills and techniques (Quinn, 2002). The interviewers had no familial relationship with participants and did not know any of the participants prior to data collection.

Regarding format, the interviews were conducted at the home of each disabled participant. Each interview session lasted for an average of 45 minutes per participant over a period of three (3) months. The choice of these venues was to help participants feel at home so the research could take place in the natural settings of participants, this being a strength of qualitative research (Quinn, 2002). Regarding focus group discussions, they took place in a rented community center with an enclosed room. There were five (5) different focus group discussions with the following composition: (a) 3 disability specific groups (as none of the participants had multiple disabilities); (b) an all-male group; and (c) an all-female group). These compositions helped in obtaining rich information from each group as participants were more comfortable in giving out information as all members in a group had similar

characteristics in terms of disability and gender. Non-participants were not present during data collection to avoid possibility of influencing responses with their presence. Data was audio-and video-recorded. For the hearing impaired, data collection sessions (interview and focus group discussions) were video-recorded.

Additionally, an inductive analysis approach was used (Quinn, 2002). The strategy was to allow the analysis dimensions to emerge from patterns found in the cases under study without presupposing in advance what the important dimensions would be (Quinn, 2002). This approach helped in understanding the multiple interrelationships among dimensions that emerged from the data. This is without making prior assumptions or specifying hypotheses about relationships (the linear or correlative) among defined variables. Data-led analytical principles such as categorization, exploration and confirmation were employed to establish creative synthesis through themes (Quinn, 2002). The audio data was transcribed from Twi to English verbatim with a professional language translator from the department of modern languages at the Kwame Nkrumah University of Science and Technology-Kumasi. The video data was transcribed by the sign language interpreters who doubled as the research assistants. Cross-case analysis was done on transcribed data to establish patterns and themes that cut across individual experiences in terms of the various groups under study and how those experiences are related to disability stigma and access to healthcare (Quinn, 2002). The cross-case analysis was done by three research assistants under the guidelines of the principal investigator, with each analyst blind to the work of the other and later converged to compare notes and transcripts to correct discrepancies. (Quotes have been used when necessary to support the analysis).

### **Ethical issues**

Ethical approval was obtained from the Committee on Human Research, Publication

and Ethics of the Kwame Nkrumah University of Science and Technology-Kumasi, Ghana. Other ethical issues that were considered included the following: the purpose of the study was explained, and verbal consent was also obtained from every participant to tape record the discussions. The respondents were assured of confidentiality and anonymity and were informed that the information retrieved was for academic purposes. To ensure this, identifiers such as names, street, position, contact numbers of participants were not taken during interactions. Participation in the research was solely on a volunteer basis. No form of inducement was used to entice participants to partake in the study. Data collected were transferred to the personal computer of the researcher and kept under security password to prevent unauthorized access. After the completion of the research, data was moved to the research repository of the Department of Health Promotion and Disability Studies at Kwame Nkrumah University of Science and Technology-Kumasi, Ghana.

## Results

### *Demographic characteristics of participants*

**Table 1**

#### *Demographic Characteristics of Participants*

<b>Variables</b>	<b>Frequency(f) N=30</b>	<b>Percentage (%) 100</b>
<b><u>Age group</u></b>		
Below 20 years	3	10.00
20-29 years	6	20.00
30-39 years	11	37.00

40 years and above	10	33.00
<b><u>Gender</u></b>		
Male	14	46.40
female	16	53.60
<b><u>Religion</u></b>		
Christianity	25	83.40
Islam	5	16.60
<b><u>Disability type</u></b>		
Hearing impaired	10	33.30
Physically impaired	10	33.30
Visually impaired	10	33.30
<b><u>Employment status</u></b>		
Employed	13	44.00
Unemployed	17	56.00
<b><u>Educational background</u></b>		
Tertiary	5	16.60
Senior High School	4	13.40
Junior High School	6	20.00
No formal education	15	50.00

Source: Field Data (2019)

The demographic characteristics of participants can be seen in Table 1. From Table 1, it can be observed:

1. 50% of the participants have had some form of formal education ranging from tertiary, senior high and junior high schools, while
2. the remaining 50% have not had any form of formal education,
3. 56% were unemployed,
4. the following disabilities were distributed evenly, 33.3% each: hearing impaired, physically impaired and visually impaired.
5. In terms of gender, 53.60% were females and 46.40% were males;
6. With respect to age, 33% were either 40 or more, whereas the remaining participants, 67%, were below 40.

### **People with disabilities' experiences at the hospital**

The organization-level experiences which affect access to healthcare as revealed by people with disabilities who took part in the study have been presented here as the main findings. They include: neglect and nepotism (with people who are friends and relatives given unfair advantage), insults and verbal abuse, lack of prescribed medicines, long hours of waiting, inaccessible healthcare facilities, and communication challenges.

### **Neglect and nepotism shown by healthcare providers**

At the organizational level, one negative factor found affecting people with disabilities' access to healthcare was neglect and nepotism shown by healthcare providers. Most people with disabilities indicated frequent neglect by healthcare providers. The healthcare providers appeared to give preferential attention to friends and cronies, even when they arrive later than others.

*“...Their attitude is not good, because me as a disabled person when I visit the hospital, they [are] supposed to attend to me [quickly] but sometimes someone will come late and they say protocol and send the person in while you are sitting outside”*

(A 33-year-old hearing impaired female participant, individual interview)

*“...While some of us will join the queue, they will be taking others in as protocol (their friends and cronies). This their attitude is not good”* (A 23-year-old physically impaired male participant, individual interview)

### **Insults and verbal abuse by healthcare providers**

The study again found that healthcare providers frequently insulted and verbally abused people with disabilities. According to the people with disabilities, without provocation, healthcare providers shout at them and insult them. This is especially true if one's name is read aloud off of a folder and one does not respond immediately or appropriately. Many participants felt this treatment made them less likely to seek care at facilities even when they needed them.

*“...I had stomach ache, and my daughter took me to the hospital, and because of the pains I was going through, I screamed, and one of the nurses came to me to [shouted] at me that I was disturbing their peace because I am not the first person to have such a condition so I should stop the drama.”* (A 45-year-old visually impaired male participant, individual interview)

*“...Instead of attending to the patients, some will pick their phones, and for them to put the phone down and attend to you is an issue. The one even asking you where is*

*paining you, has the phone at the other side conversing with it.” (A 56-year-old hearing impaired female participant, individual interview)*

### **Lack of availability of prescribed medicines in hospitals**

Most participants lamented the frequent lack of availability of prescribed medicines. In most cases, they were asked to buy prescribed medicines outside the hospital premises because the hospitals did not have the necessary medicines in their pharmacies. This was not aligned with their expectations that once they visited the hospital with their National Health Insurance Card that all medicines would be readily available at the hospital. Some felt this lack of availability of medicine was intentionally done to discourage visits. Nonetheless, the challenge posed by seeking medication elsewhere is a significant barrier to equitable health care.

*“...I do not know what the problem is in some of the hospitals in this district...Always they will tell you we do not have the medicine here so go and buy it in town. I think is deliberate that they ask us to buy the drugs from town because sometimes they mention the name of specific shops we will get the drugs from of which I suspect they own...” (A 59-year-old hearing impaired male participant, individual interview).*

### **Relatively long hours of waiting at the hospital**

The study found that people with disabilities generally spend several hours at the hospitals in an attempt to access healthcare at the Out Patient Department (OPD). Upon arrival at the hospital, 3 to 4 hours can pass before they finally see the doctor for examination and diagnosis. It takes another 1 hour before to finally get their drugs from the pharmacy. This long wait appears consistent with a lack of concern also attitude shown by healthcare providers as well as frequent neglect and nepotism. Many participants viewed the long wait they experienced as evidence that providers were neither concerned nor focused on attending

to their needs. Participants felt that rather than attending to them, many healthcare providers were pre-occupied with their phones and casual conversation between themselves, all while people with disabilities waited in queue. At the same time participants felt this indifference also frequently occurred throughout the country and in other countries as well. Regardless, this perception of indifference discouraged people with disabilities from seeking care.

*“.....Whenever, I am going to the hospital, I make up my mind that I will not have any other activity for the day because I know it will take very long time before I return. Too much time is wasted at the hospital and still you are told to go and buy the medicine from outside” (A 25-year-old hearing impaired female participant, individual interview)*

#### **Inaccessible healthcare facilities**

These significant delays are compounded by additional challenges as well. Due to the lack of accessible buildings, many have to endure the shame of having to be carried by others to receive healthcare in the first place. According to the many of the disabled participants, these situations effectively disclose participants' health conditions to their assistants. At times this can be a significant break of privacy if they do not wish to or elect to share specifics of their particular impairments.

*“...My wheelchair cannot move freely around the hospital because there are no ramps or elevators to help me move freely. If you do not get people to lift you up, sometimes it is hell before you can get to the pharmacy to collect your medicine.” (A 20-year-old physically impaired participant, male individual interview)*

*“...The hospital buildings are not accessible at all, especially the eye clinic... you*



*have to climb two different stairs before you get there and considering my age and condition, it is very difficult anytime I come for review” (A 34-year-old visually impaired participant, individual interview)*

### **Communication barrier between healthcare providers and people with disabilities**

The study found widespread challenges in participants’ communication with healthcare providers, something found particularly true for those Deaf or hearing impaired participants. Language barriers in exchanges with providers can serve as another major impediment to access to healthcare access.

*“...You go to the hospital and there is no one there who understands your language and you too could not hear whatever is being said. I find it difficult to tell them rightly my problem because I am hearing impaired and cannot hear what they say.” (A 22-year-old hearing impaired male participant, individual interview)*

### **Coping strategies adopted by people with disabilities to manage their experiences**

#### **Refusal to use the facility in the future**

Many participants appeared to choose refusal to use a particular medical facility as a coping strategy. A negative experience receiving healthcare led to participants visiting a different hospital, not visiting any at all, or choosing instead to use other unconventional means, including self-medication.

*“...I have vowed not to use one hospital in this district again because of the difficulties I went through at the hands of some small girl who was a nurse...She*

*shouted at me and insulted me with my condition. I will never go there again, and I have informed my children that they should never send me to that hospital again.”* (A 41-year-old visually impaired male participant, individual interview)

*“...I do not think if I am disrespected in a particular hospital I will go there again even if they can provide the best treatment for my condition.”* (A 50-year-old hearing impaired female participant, individual interview)

### **Confronting healthcare providers when they try to abuse them**

Another coping strategy of some participants was confrontation. Here they attempt to challenge and confront healthcare providers who tried to abuse them or neglect them because of their conditions. Sometimes exchange of words and insults are inevitable.

*“... Sometimes when you stand up and talk, they attend to you and treat you well so I think for me, I use confrontation to cope with any difficulty that comes my way at any of the hospitals that I have visited in the past.”* (A 30-year-old hearing impaired male participant, individual interview)

### **Report to hospital authorities over challenges they face**

Some participants reported problems with healthcare access to the hospital authorities. However, they could not ascertain whether their reported cases were dealt with by the authorities.

*“...I will report them to the leaders, maybe the District Chief Executive. I can also say it on radio that this is what this particularly hospital is doing. That, because I am disabled, they don't openly attend to me, so that they can also speak for me and ask*

*whether it is right for them to treat me like because I am disabled.* (A 26-year-old physically impaired female participant, individual interview).

### **Patience and endurance**

The study also found that patience and endurance were strategies adopted by people with disabilities to manage problems encountered. Participants believed that when a person needs treatment, it is important to ignore possibilities of ill treatment and instead focus on the reason why one needs to visit the hospital.

*“...I am the one who is sick so I have to remain calm and get treatment.... I do not think that I have to say anything because if I get healed, I will not come to the hospital again for them to disrespect me so for me the strategy is just simple, keep quiet and get treat and go home.”* (A 40-year-old hearing impaired female participant, individual interview)

*“...I keep quiet and get my treatment so I can peacefully go home.... If I talk and they refuse to attend to me, what will I do? I have nowhere to go so I do not think it is important to do anything apart from ignoring them.”* (A 21-year-old physically impaired male participant, individual interview)

### **Discussion**

The examples of barriers encountered in accessing medical care stand in contrast to Sustainable Development Goal 3 Subsection 3.8. This talks about achieving universal health coverage, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines for all (United Nations, 2015). People have health needs arising from their primary impairment as well as from their ability to access care

(Shakespeare, 2012). This is especially true for those who lack influence. This is consistent with United Nation findings that discrimination in health-care settings is often directed towards marginalized and stigmatized populations (United Nations, 2015).

These and other inequities found in this study mirror those found elsewhere globally. A 2017 study conducted in Nepal in 2017 found that poor care and rude staff affected women with disabilities' access to maternal healthcare services (Devkota, 2017). Another study suggests providers' discomfort working with people with disabilities and lack of disability-specific knowledge are important interrelated factors hindering access to quality health care (Lam et al., 2010). Moreover, experiences of people with disabilities in the Bosomtwe District of Ghana regarding lack of availability of prescribed medicine are consistent with experiences by both disabled and non-people with disabilities at various healthcare facilities depending on the geographical settings (Mannava et al., 2015, Nair et al., 2014). Problems with excessive waiting times to receive care at facilities are also reported elsewhere. Relevant findings indicated that people with disabilities continue to experience discrimination from National Health Service staff who fail to treat them with dignity and respect and appear to devalue the lives of people with disabilities in general (Mencap, 2012). Another study also addresses similar communication barriers with providers found in this one (Devkota et al., 2017). Finally, these experiences of barriers to care are also consistent with other findings that such concerns are particularly relevant to vulnerable groups and marginalized minorities (Fish & Bewley, 2010). As such, the findings provide further evidence for the need to address these barriers.

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 **Qualitative Exploration of the Experiences and Coping Strategies of People with Disabilities at Some Selected Healthcare Facilities in the Bosomtwe District of Ghana** by Enoch Acheampo, Anthony Kwaku Edusei, Peter Agyei-Baffuor, Reindolf Anokye, and Godfred Atta-Osei  
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## What Obligations Should Be Owed to [African] People with Disabilities?

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### Abstract

Although obligations are central to African communitarian philosophy, little is known about how they account for people with disabilities and even less about their practical application. An asymmetrical conception of obligation is proposed to remedy the exclusion, and tax as a means to practically discharge obligations to people with disabilities.

*Keywords:* African philosophy, obligations, disabilities

Obligations are at the core of the literature on African communitarian philosophy. They are fundamental to defining what it means to be a person and what it means to share and experience community with others. Despite the importance of obligations, little is known about how they account for people with disabilities and even less about their practical application. Given that personhood can be earned only by individuals who live up to their obligations to others and/or to the community, individuals who cannot are designated the lower status of “human beings.” “Persons” are distinguished from “human beings,” with persons more highly valued, consequently undervaluing people with disabilities, particularly people with cognitive and extreme physical disabilities. Put differently, demanding obligations may overlook the particular characteristics of people with disabilities, who are thus excluded from the regime of obligations synonymous with being part of a community. I am not suggesting that people with disabilities cannot contribute to or be recipients of the obligations of others. Nevertheless, it must be recognized that the ability or capacity to contribute to or benefit from obligations may be contingent on the type of disability concerned. Some have disabilities that make them unable to participate in or benefit from mutual reciprocal obligations. This may be better appreciated in the context of the social model of disability, which can be used to make clearer the environmental barriers and social or cultural attitudes that may prevent people with disabilities from participating in or experiencing obligations because of their impairments (Grut et al., 2012, p. 154). In relying on insights from the social model of disability, I am not insensitive to or unaware of the relationality between impairments and disabilities (World Health Organization & World Bank, 2011, p. 4). Neither am I unaware of the limits of the social model of disability (Maybee, 2017; Shakespeare, 2013; Oliver, 2013), particularly the neutrality it assumes over the creation or production of certain impairments (Soldatic & Grech, 2014). Despite this limitation, the social model provides the analytical tools necessary to appreciate the

implications of exclusion from a regime of mutual reciprocal obligations.

This article has two related aims. First, it offers an asymmetrical conception of obligation, which better accounts for people with disabilities. My argument here is contingent on understanding obligations as a product of a fundamentally “altruistically freighted” (Gyekye, 1997, p. 67) morality, which imposes obligations on capable members of a community to assist vulnerable co-members, particularly those not able to reciprocate or, at least, to equally reciprocate. This is at the core of the distinction I draw between those with disabilities and those without disabilities, even though I am not unmindful of the continuity between the former and latter. I argue that asymmetry offers a more accurate interpretation of the diverse needs and abilities of members of a community, including how they may support and be supported by each other, particularly in times of need because of the irreducible vulnerable nature of being human. In the course of this argument, I identify and show how core obligations in African communitarian philosophy resonate with and can be used to counter many exclusions or injustices faced by people with disabilities. If it is not already obvious why people with disabilities should be owed special obligations, anecdotally, the vast majority of the approximately 80 million disabled Africans (World Health Organization & World Bank, 2011, p. xi) count themselves among the most marginalized and poorest people on the continent who suffer exclusion and injustice (Onazi, 2020). Together with other vulnerable people on the African continent, poverty exacerbates their exclusion and negatively impacts the quality of community experiences and relationships of people with disabilities (Onazi, 2020; Eide & Ingstad, 2013). Exclusion and poverty are just some of the injustice that have made an obligation-based approach to disability justice a necessary, but underappreciated, response to violations faced by people with disabilities across the African continent.

Given that little is known about the practical application of obligations (i.e., whether this is in relation to people with disabilities or to other members of society), the second aim of this article is to consider what these obligations will look like in practice. It proposes a hypothetical tax scheme as a vehicle to concretely convey the obligations of people without disabilities to people with disabilities. Tax is not a perfect institution, but it provides the most fitting medium to collectivize and institutionalize the core obligations in African communitarian philosophy in ways that can have a substantive impact on the lives of people with disabilities. This would range from implementing structural changes to public infrastructures to meeting urgent basic needs, healthcare services, educational and employment opportunities, housing, and assistive services (e.g., wheelchairs, walking sticks, and other technologies).

The argument will be presented as follows. First, I clarify how obligations, including the importance attached to them, are characterized in African communitarian philosophy. After showing how the routine characterization of obligations as mutual reciprocal concepts leads to the exclusion of people with disabilities, an asymmetrical conception is proposed as a remedy, including how it can be extended to people with disabilities. Finally, a hypothecated tax scheme is offered as a means for people without disabilities to practically discharge their obligations to people with disabilities.

### **Obligations in African communitarian philosophy**

Broadly speaking, obligations mean to be bound to do something through a particular course of action. Obligations commonly refer to ties or bounds between people that cuts across personal and institutional relations (Veitch, 2021, p. 8, 2017, p. 416). Obligations, according to Himma (2013, p. 20), are “claims about what someone (or some class of persons) ought to do in some state of affairs[...], which] arise only where there are

prescriptions that guide and enable the appraisal of human acts” (Himma, 2013, p. 21). Thus, obligations are normative and practical in nature (Berthea, 2019, p. 30). In a normative context, obligations refer to standards that guide and enable appraisal, “by thus securing a basis for judging one’s performance as correct or incorrect,” while in a practical context, they serve “as a means by which our conduct is guided and assessed” (Berthea, 2019, p. 30).

Therefore, obligations are “action-centred” because they are “concerned with one’s doing, or acting” (Berthea, 2019, p. 30).

Obligations can be distinguished from duties in that the former is a voluntary undertaking whereas the latter is natural, unconditional, and binding on each person (Rawls, 1971, p. 98). Traditionally, obligations have been associated with promises or agreements, even though obligations have been understood outside these contexts. Over time, obligations have been extended to other uses in different contexts (Gilbert, 2006, p. 28). Although the word has had an older usage, obligation is commonly fused as a synonym for duties: “whereby a person’s duty or obligation is equivalent to the right thing to do, the best thing to do or what a virtuous man would do” (Whiteley, 1952, p. 96). Obligations and duties are synonymous in this article because of the interchangeable use of the terms in the literature on African philosophy. More rarely, obligations are a synonym not only for duties, but also for responsibilities (Gyekye, 1997, p. 66).

While obligations are often treated as correlating to rights (Van der Walt, 2018; O’Neill, 2000; Hohfeld, 1913), they can be understood independently or ahead of rights (Veitch 2017, p. 417; Weil, 2002, pp. 4–7). This is because some practices make it inaccurate to speak of obligations and rights in correlative terms (Veitch, 2017, p. 417). For instance, obligations to future generations, family, and friends, and to the poor, needy, and vulnerable—in addition to, as argued in this article, people with disabilities, particularly those with extreme or cognitive disabilities—arise not because they have some clearly defined

rights over the obligation bearer. African philosophy is precisely a tradition that prioritizes obligations and not rights in theorizing about justice, including, in this context, disability justice. Although African philosophy tends to be seen as a reflective exercise of the culture and beliefs of Africans "...which rigorously and critically explicate a life-world" (Janz, 2007, p. 690), it is also a recent academic or professional discipline with an evolving body of literature as well as "...codes, standards, recognized practitioners, and customs" (Janz, 2007, p. 690). While not mutually exclusive, this distinction represents the oral and written African philosophical tradition. In this article, I draw from the written rather than oral African philosophical tradition because I want to avoid arriving at conclusions that are too particular and relativist (Hallen & Sodipo, 1997; Oruka, 1990; Hountondji, 1970) to meaningfully contribute to our understanding of obligations to people with disabilities in abstract, general, or universal philosophical terms. While it may be tempting to argue as some writers (Cornell, 2014, p. 159) have done that community and the obligations intrinsic to it are a historic, contemporary, and universal feature of the traditional thought of all African societies, my claim is, rather, that they can be understood in an abstract and general way that make them applicable to different African societies. For example, although Kwame Gyekye's (1997) seminal account of obligations or Godfrey Tangwa's (2000) account of personhood (both discussed in this article) may be influenced by the traditional thought of the Akan people of Ghana and the Nso people of Cameroon, respectively, my interest in them is only to explore how they can be universally extended to people with disabilities across Africa.

In the literature on African philosophy, an understanding of obligations is contingent on appreciating how personhood is integral to the formation of community. Obligations are usually referred to as virtues and human excellences derived from community membership and participation (Metz & Gaie, 2010, p. 275; Menkiti, 1984, p. 171). This is also because obligations are distinctively relational. Social relations are predicated on a morality that is

based on obligations among those who share community life. Therefore, obligations are not only central to constituting community, but also vital in constituting what it means to become a person. In the process of constituting community, personhood is achieved or granted to those who can discharge their obligations to others. In other words, personhood is contingent on a type of mutual reciprocity (Stuit, 2016, p. 15; Sanders, 2007; Tutu, 1999, p. 67) between each member of the community. Kwame Gyekye (1997), whose influential work provides one of the most compelling insights into obligations in African communitarian philosophy, calls this feature “social reciprocities” (p. 67), which make (or should make) the concern for the interests of others a mandate for African communitarian morality. For this reason, Gyekye suggests that African communitarian morality is best understood as “an altruistically freighted morality” (Gyekye, 1997, p. 67). According to Gyekye (1997), an altruistically freighted morality of obligations

...requires each individual to demonstrate concern for the interests of others. The ethical values of compassion, solidarity, reciprocity, cooperation, interdependence, and social well-being, which are counted among the principles of the communitarian morality, primarily impose duties on the individual with respect to the community and its members. (Gyekye, 2010)

The strongest undercurrent in the passage above is altruism, which is also distinctly present in Gyekye’s definition of obligation. For Gyekye (1997), an obligation is “a caring attitude or conduct that one feels one ought to adopt with respect to the well-being of another person or other persons” (p. 66; for similarities, see Metz, 2015, p. 189; Matolino & Kwindigwe, 2010, p. 199; Bell, 2002, p. 59). This definition can be broken down into the following core obligations: “the obligation to help others in distress, ...the obligation to show concern for the needs and welfare of others, and...the obligation not to harm others”



(Gyekye, 1997, p. 66). These core obligations resonate with the exclusions or injustices faced by people with disabilities, who are among the most excluded people on the African continent. Obligations, as will be shown in the next section, can be relied on to respond to injustices and exclusions suffered by people with disabilities because obligations have a stringent and compelling nature that distinguishes them from supererogatory acts.

Indeed, Gyekye's work is helpful in understanding this. African communitarian morality collapses the distinction between binding moral obligations and supererogatory acts (Gyekye, 1997, pp. 71–72). Unlike supererogatory acts, obligations have a degree of stringency that imposes moral sanction and/or criticism on those who fail to assist people in need or distress (Gyekye, 1997, pp. 71–72). For example, it would be considered morally reprehensible to refuse to aid a person in distress or need. Only morally weak or incompetent persons may be exonerated from discharging their obligations to others (Gyekye, 1997, p. 72). The lack of capacity, practicality, social rules, or individual rights of autonomy should not exonerate anyone from living up to their obligations to others. As Gyekye, 1997, p. 75) argues, no obligations that ought to be performed for the purposes of cooperative living and human well-being should be considered supererogatory or morally optional.

In combination, the compelling and altruistic character of obligations explains the skepticism or rejection of rights-based conceptions of justice in certain strands of the literature on African communitarian philosophy. Once more, Gyekye's work is illuminating. Rights-based conceptions of justice lead to unsatisfactory outcomes in the context of "a communitarian morality [where] ...love or friendship or concern (compassion) for others may be considered the first virtue of social institutions" (Gyekye, 1997, p. 66). Gyekye raises doubts about the possibility of cultivating the virtues of compassion and love through the dominant liberal individualist rights-based paradigm. Although the liberal rights-based

paradigm offers attractive values of fairness and equality that can lead to charitable and generous behavior, it is difficult to cultivate such conduct through an individualist rights-based justice paradigm. As much as Gyekye's argument is not open to thinking of justice independently of rights, the broader point he is making is that obligations are not derived from or correlative of rights, as is commonplace in the literature (Molefe, 2019; Menkiti, 1984; Famakinwa, 2010). It would be wrong to suggest that there is a consensus on rights skepticism, because some leading African philosophers are supportive of rights, particularly human rights (Metz, 2020, 2014a, b). In my view, there is very little understanding of the applied dimension of obligations to reach an informed opinion either for or against rights or obligations. In the context of disability justice, it is dominated by rights-based perspectives (United Nations, 2006), which make it clear how to respond to exclusions or injustices. Disability justice is largely uninformed about obligations, particularly how they can be applied to contemporary exclusions or injustices faced by people with disabilities.

### **Obligations to people with disabilities**

With their fundamental compassionate and altruistic starting point, it is not difficult to appreciate how African communitarian obligations offer a framework to recognize and respond to the exclusions and injustices experienced by people with disabilities. The compulsory and non-supererogatory nature of obligations further contributes to their attractiveness, as they could be used to create a mandate for people without disabilities to respond to the needs of people with disabilities among other vulnerable people. Nevertheless, the difficulty is that the literature has not been attentive to people with disabilities due to the routine characterization of obligations in mutual reciprocal terms. My argument is that this leads to a demanding standard of obligations that overlooks the particular characteristics of

people with disabilities, who are excluded from the regime of obligations synonymous with being part of a community. Although the mutual reciprocal nature of obligations is prominent in the literature (Gyekye, 1997, p. 67; *Bhe and Others v. Magistrate, Khayelista, and Others*, 2005, para. 163), the problems it presents for people with disabilities can be illustrated from this comment by Drucilla Cornell (2014):

...what makes us human is not just the reality of our social connectedness, but the way in which each of us lives up to the obligations to those who have supported us, and to the broader community in which we live. But this living up to the obligation is not altruism or sacrifice, because the other side of it is that others must live up to their obligation to us [...]. (p. 69)

In the above passage, the demanding nature of obligations is apparent, which explains why Cornell rejects that obligations are altruistic. Cornell appears to be alluding to the mandatory or, indeed, non-supererogatory character of obligations, which are never optional. Everyone must contribute to the flourishing of each other and/or of the community. The problem is that this reading of obligations is not accommodating to those who cannot live up to their obligations. Perhaps due to the perfectionist nature of personhood (Metz & Gaie, 2010, p. 275), it is assumed that all individuals would have no difficulty in living up to their obligations. As a result, little is known about those who cannot perform such obligations or those on the other side of the obligations of others. People with disabilities, particularly those with cognitive and extreme physical disabilities, are most likely to fall in the category of individuals who cannot perform obligations. My aim is not to characterize people with disabilities as individuals lacking in agency; neither do I suggest that they can only be the passive recipients of the obligations of others. As much as the term “disability”—“a human condition with a diverse and unsettled range of meanings that stretch across the biomedical,

psychological, social and cultural domains” (Onazi, 2020, p.7)—attempts but fails to capture the immense variety of and differences in impairments among people, so too it would be wrong to suggest that all people with disabilities are incapable of performing obligations. Seminal insights from the social model of disability can shed light on obstacles that might affect a person’s ability to perform obligations, particularly if the impairment in question is socially, environmentally, or culturally (Shuttleworth & Kasnitz, 2006) conditioned. The combination of the absence of assistive and mobility devices and the lack of infrastructure, ranging from inaccessible roads, street sidewalks, and public transport to inaccessible buildings, would certainly affect the ability to perform obligations. Poverty, not simply in economic terms, but in terms of lack of access to healthcare, food, education, housing, and employment opportunities, among other things, would also be a huge obstacle to the ability of people with disabilities to perform their obligations. Many people with extreme disabilities, ranging from those with spinal cord injuries, cerebral palsy, cystic fibrosis, and multiple sclerosis to people with severe cognitive impairments, mental illness, and brain damage, among other conditions, may not have the capacity to perform ethical obligations (Onazi, 2020). The same can be said of people without the ability to speak or see, if such are prerequisites for discharging certain obligations. Discharging an obligation will also depend on their institutionalized form. An obligation that takes the form of military or community service may prove too difficult for a person with a disability to discharge without reasonable adjustments (Onazi, 2020).

### **Asymmetrical obligations**

Having described the problems with the conventional characterization of obligations, an asymmetrical conception of obligations is proposed as a remedy. My argument hinges on amplifying the fundamentally altruistic nature of obligations in African communitarian

philosophy. There is no better way of achieving this than emphasizing the profoundly moral nature of the African communitarian civic order, which elevates acts of compassion and care or concern for others to the highest value. This is a salient aspect of the literature. For instance, Masolo (2010) underscores the significance of charity and other altruistic virtues as the most important practical manifestation of African philosophical communitarian ideals. Similarly, Gyekye (1997, p. 70) writes about how African philosophical communitarianism is underpinned by a moral universe of caring, compassion, and generosity, while Bell (2002, p. 59) suggests that African philosophical communitarianism is fundamentally a compassion-based and moral civic order.

My argument here is simple. A civic order that presupposes compassion, care, and concern for others cannot at the same time presume mutual reciprocal obligations. While it is not unusual to find forms of social cooperation based on mutual compassion and benevolence (Nussbaum, 2006), asymmetry is a more attractive way of recognizing altruistic obligations. This is because a person who is unable to reciprocate an obligation is likely one who requires the compassion, care, and concern of others. Compassion, care, or concern for others does not (and should not) apply only to those who can reciprocate. My argument is that asymmetry, and not symmetry, is not only a more attractive way of understanding obligations but a more accurate interpretation of the concept in the context of the altruistic underpinnings of African communitarian philosophy. If an obligation means “a caring attitude or conduct that one feels one ought to adopt with respect to the well-being of another person or other persons” (Gyekye, 1997, p. 66), then it is fundamentally altruistic in nature and must entail regard for others, particularly for people incapable of reciprocation. A caring attitude and conduct that respects the well-being of others must entail charitable, sympathetic, generous, benevolent, kind, helpful, respectful, sacrificial, and hospitable dispositions toward others, which are values that further lend themselves to an asymmetrical conception of obligations. Having an

attitude positively oriented toward the well-being of others, including the belief that the “other merits aid for her own sake, an empathetic awareness of the other’s condition, and a sympathetic emotional reaction to this awareness” (Metz, 2015, p. 189), cannot be properly appreciated in terms other than asymmetry. It importantly draws attention to the diversity of the needs and abilities of members of a given community, inclusive of how they support or are supported by each other in times of need (Onazi, 2020).

Despite the attractiveness of asymmetrical obligations, their inclusiveness depends on their ability to recognize the equal humanity of people with disabilities. In other words, asymmetrical obligations must recognize that people with disabilities are equal to other people. Therefore, there is a need to rethink the dominant conception of personhood in African communitarian philosophy in a way that recognizes people with disabilities as persons and not simply human beings. A plausible way of achieving this is to think of personhood along the lines of the conception of “person” associated with the Nso people of Cameroon. The most influential account of the Nso conception of person is found in the work of Godfrey Tangwa (2000). Captured by the phrase *Wir dzi wir* in Lamnso language, which means “a human being is a human being is a human being, purely and simply by being a human being” (Tangwa, 2000, p. 39), the Nso conception of person, importantly, makes no distinction between human beings and human persons. It asserts an equality between all human beings, who are defined independently of their features or properties. Human beings are defined by an open-endedness that adapts to changes in shape, size, and weight. In doing so, the Nso conception of person is resistant to rigid definitions of human beings. As Tangwa (2000) explains, any attempt to define or place the notion of person into “...a hard analytic frame, by specifying necessary and sufficient criteria, conditions, or capacities for being human or for being a child, would make it evaporate into thin air” (Tangwa, 2000, p. 40). Such flexibility ensures that the moral worth of human beings is consistently valued,

regardless of “physical, mental, and socio-politico-economic changes” (Tangwa, 2000, p. 40) to the lives of individuals. Given that it does not attach any significance to the individuating features (age, characteristics, status, or social rank) of each human being, the Nso conception of personhood is best understood as non-essentialist. The attractiveness of the Nso conception of person is the way it values all human beings, even though the properties of being human are not permanent, but rather adaptable and inclusive (Tangwa, 2000, p. 39).

If it is not already obvious how the Nso conception of person is inclusive to people with disabilities, its comprehensiveness can further be demonstrated by the way it conceives of obligations to entities (nonhuman animals, plants, and inanimate objects) that are incapable of reciprocation. It is this feature that has the greatest bearing on people with disabilities, as through its obligations it ceases to have an exclusive function in creating persons. An individual is a person irrespective of the lack of capacity to live up to their obligations to others. A further effect of the Nso conception of person is that it “widens the scope of people to whom obligations are owed, since the moral consideration of others is not contingent on individuating features or moral qualities” (Onazi, 2020, p.26). The only criterion to be the recipient of the obligations of others is that one is a human being. This implies that “people incapable of reciprocation are owed obligations in the same way as they are owed to people capable of reciprocation” (Onazi, 2020, p.26). Although obligations are no longer fundamental to attaining personhood, the suggestion is not that they desist from being valuable. Rather, the Nso conception of person transforms and enriches obligations into an asymmetrical concept.

### **Institutionalizing obligations: Tax as a bridging instrument**

This considers what asymmetrical obligations to people with disabilities would look

like in practice. I start by revisiting Gyekye's (1997) definition of obligations, broken down into the core obligations "...to help others in distress, to show concern for the needs and welfare of others, and... not to harm others" (p. 66), to ask the question: How do African states, societies, and communities realize these obligations in practice? How should such core obligations, which largely require altruistic forms of behavior, be implemented or practiced widely in countries across Africa? Put differently, how do members of a state, community, and society, particularly people without disabilities, convey their obligations to be generous, benevolent, compassionate, and friendly or to love, help, and respect the most vulnerable people with disabilities? Given that I have suggested in the previous section that such obligations are not supererogatory acts, this requires some understanding of how a state, community, and society should commit to them collectively, as opposed to leaving it up to citizens on an individual and voluntary basis. In exploring this, my aim is not to discourage or undervalue the importance of individual or voluntary obligations that people with disabilities should encounter daily from people without disabilities; rather, it is to understand how such obligations can be widely institutionalized and used to tackle large forms of injustices suffered by people with disabilities in Africa.

I start with the third obligation from Gyekye's (1997) account—the obligation not to harm others—because, unlike the first and second, it appears to be much easier to achieve in practice. The obligation not to harm others has a striking resemblance to a negative obligation that would require people without disabilities to desist from habits and practices that harm other people in general and people with disabilities in particular. Negative obligations not to harm people with disabilities should be straightforward and relatively easy to institutionalize (Lichtenberg, 2010, p. 559). In the African context, harmful practices are defined as the "...behaviour, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the fundamental freedoms of persons with disabilities



or perpetuate discrimination” (African Union, 2019, Article 1).

Harmful cultural and traditional practices are widespread across Africa and are easy to identify. For instance, an obligation-based approach that outlines the negative duties of citizens among other duties could easily lend itself to African states to fulfill their undertaking under the Protocol to the African Charter on the Rights of Persons with Disabilities to “take appropriate measures, including legal sanctions, educational and advocacy campaigns, to eliminate practices, such as witchcraft, abandonment, concealment, ritual killing or the association of the disabilities with omens” (African Union, 2019, Article 11). Legal sanctions could be introduced by states that would take the form of negative obligations to desist from carrying out such harmful practices.

The first and second core obligations—to help others in distress and to show concern for the needs and welfare of others—are more complex and difficult to implement legally or achieve in practice. Indeed, it is difficult to understand how these core obligations can be anything other than moral obligations that all individuals ought to discharge. It is rare to find examples of situations where individuals are legally penalized or sanctioned for failing to help people in distress or to show concern for the needs and welfare of others (Brady, 1980). The lack of generosity, compassion, care, and kindness or the unwillingness to help can lead to the discrimination, abuse, or exclusion of a person with a disability, but it does seem implausible that the failure to show compassion, generosity, or benevolence toward, or to care for or help, people with disabilities can or should attract legal sanctions or penalties.

Considering the above observations, tax is proposed as an instrument that can convey the obligations of people without disabilities to people with disabilities. Tax may be seen as a bridging concept that can transform and translate such obligations into legally binding commitments to people with disabilities. Like obligations in African communitarian

philosophy, tax not only has a binding and stringent character, but is also moral and legal in nature. While the obligation to pay tax is primarily a moral obligation, it is, in the absence of law, unfinished, empty, and uncertain (Honore, 1993, p. 5). Tax without law is simply a moral obligation that cannot command extensive conformity.

Therefore, tax is proposed to channel the ordinary and abstract moral obligations of people without disabilities into practicable and legally enforceable commitments to people with disabilities. Tax is not simply a source of revenue for the state, but a placeholder of the altruistic obligations of people without disabilities to be generous, benevolent, compassionate, and friendly, or to help, love, and respect the most vulnerable people with disabilities. For this to be properly appreciated, tax itself is understood as "...a means through which citizens in a political community share the burdens of living together based on fraternity and mutual dependency" (Saffie, 2014, p. 199), which entails a collective obligation to care for the sick, elderly, poor, and vulnerable, including people with disabilities. As discussed earlier, people with disabilities are likely to be among the poorest and vulnerable in Africa and, therefore, people to whom obligations are owed. Tax may be seen as an obligation through which members of various communities support the physical, mental, biological, and social welfare of people with disabilities. From removing the barriers to sharing community relationships with others, to enabling access to public goods and services, tax may provide people without disabilities across Africa with an important legal mechanism to discharge their obligations to show concern for the needs and welfare of people with disabilities among other vulnerable people.

### **Hypothecated tax scheme**

To better understand how tax can serve as a placeholder for the altruistic obligations

of people without disabilities to people with disabilities, a hypothecated tax scheme (Barrett, 2012, p. 111) is proposed to earmark (Buchanan, 1963) revenue from a single source or diverse sources (Wilkinson, 1945) to care for the needs of people with disabilities. Because hypothecation is defined as the practice “of directing the revenue from tax to funding of some relatively narrow set of policies” (Halliday, 2015, p. 128), it is precisely the type of collective device that can be used to demonstrate how people without disabilities can fulfill their obligations to people with disabilities. Hypothecation can be either strong or weak (Barrett, 2012, p. 111). In the former sense, it entails setting aside the income from a type of tax for a particular purpose, such as building or maintaining roads or transportation (Barrett, 2012, p. 111), while in the latter sense, it entails crediting the income generated from a particular tax into a general account to fund a specific expenditure (Barrett, 2012, p. 111).

For purposes of the argument here, it is suggested that a strong version of hypothecation should be adopted to enable people without disabilities to live up to their obligations to people with disabilities. Taking a cue from the stringent and binding nature of obligations in African communitarian philosophy, it is important that all (and not just a few) people without disabilities should be encouraged to live up to their obligations to people with disabilities. Income generated and set aside from a particular type of tax (e.g., income tax or consumption tax) should be used to create a national disability service, particularly in African countries where none exists. In countries with national disability services of some sort (e.g., national disability commissions), hypothecation can be used to provide an additional stream of revenue. A national disability service would, in turn, serve as a body representing the collective obligations of people without disabilities to people with disabilities. Primarily, it would be responsible for distributing funds in response to the different needs of people with disabilities, while more broadly carrying out research, formulating, implementing, and coordinating policies and practices concerning people with disabilities (Onazi, 2020).

To effectively fulfill its remit, a national disability service should have a country-wide presence to enable it to administer, distribute, and provide relevant services to people with disabilities (Onazi, 2020). Not only would this ensure that it reflects local knowledge, it would also give local communities a sense of ownership and respond to a diverse range of needs. In fulfilling its mandate, a national disability service would have oversight and supervisory functions over structural changes to public infrastructures and the physical environment (public transportation, wheelchairs, buildings, pavements, or ramps) to make them more inclusive to persons with disabilities relative to their needs (Onazi, 2020). A national disability service would “fund healthcare services, scholarships, housing, assistive devices (i.e., wheelchairs, walking sticks and technologies, etc.), and establish welfare programs for the poor and destitute as well as creating caring institutions (with professionally trained staff) for the community participation of persons with extreme physical and cognitive impairments” (Onazi, 2020, p.160). A national disability service would also be an important avenue to provide financial support to families and caregivers to show concern for the needs and welfare of people with disabilities, particularly the most vulnerable ones among them. My aim here has not been to be exhaustive; it has been to sketch out some possibilities. Countries interested in these proposals can certainly expand on and adapt them to meet their own needs and contemporary realities.

Objections may be raised about relying on a hypothecated tax scheme to fund a national disability service. This is partly because the success of a hypothecated tax scheme is contingent on the economic well-being of each country, making it an unsuitable option for a large majority of poor African countries. Hypothecation may also be unsuitable for relatively economically strong and stable African countries because of the low tax base due to the generally large informal economic sector (Simone, 2001, 2004) in Africa, as well as doubts

about whether a national disability service could survive periods of economic hardship, recession, or political instability. Regardless of the level of wealth of an African country, tax is generally a weak institution across the continent, in addition to its susceptibility to corruption and abuse by the state. In response to these objections, hypothecation is precisely the kind of approach relevant to the unique problems of Africa, because it is one of the best ways to secure and protect resources for specific policy objectives such as discharging a collective obligation to show concern for the needs and welfare of people with disabilities. The urgent and drastic human condition of millions of people with disabilities across Africa points to the need to explore new solutions. Therefore, hypothecation may be an important option worth considering. It may provide an immediate and short-term solution to the pressing nature of the problems until national disability services or other interventions become permanently written into the legal and political order or general tax systems of various African countries. Regardless of the merits or demerits of hypothecation, the argument here should not be lost: *Tax* provides a viable means to enable people without disabilities, particularly those with the ability to pay, to discharge their obligations to show concern for the needs and welfare of people with disabilities.

### **Conclusion**

Two related contributions have been made in this article. First, an asymmetric conception of obligations has been proposed to remedy the neglect of people with disabilities in the literature on African communitarian philosophy. I have argued that asymmetry offers a more accurate interpretation of the diverse needs and abilities of the members of a community, including how they may support and be supported by each other in times of need, particularly considering the irreducible vulnerable nature of being human. The success

of this argument is contingent on rethinking the concept of personhood in ways that its boundaries for inclusion are flexible, open-ended, and non-essentialist. Second, the article has contributed to our knowledge of how obligations to people with disabilities can be achieved in practice. It has set out the case for a hypothecated tax scheme to serve as a vehicle to translate obligations to people with disabilities into concrete terms. Acknowledging that tax is not perfect, I have nonetheless argued that it provides the best medium to collectivize and institutionalize obligations of disability justice in a way that can have a substantive impact on the lives of people with disabilities in a diverse number of ways. Even if it fails to live up to this objective, it would at the very least provide resources to respond to the variety of drastic and urgent needs faced by people with disabilities.

Cumulatively, these proposals offer some new ideas of what can be achieved in diverse African countries to attain disability justice, which in theory and practice has been dominated by rights-based approaches. As with any new ideas, the proposals here are open to refinement and further modification. It is for this reason that the ideas here have been presented as abstract and general as possible, so that they are adaptable and applicable to different African countries. The proposals have been presented in the form of a prolegomenon; they are not a blueprint on how to create and implement a hypothecated tax scheme. For this, more research is required, and experts in other fields (e.g., economics) should be consulted to explore the viability and practicability of these ideas. Similarly, the acceptance of these proposals also depends on opportunities for democratic debate (in consultative forums, town hall meetings, and legislatures) in African states to examine, discuss, and, where necessary, modify and legitimize them.

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 **What Obligations Should Be Owed to [African] People with Disabilities?**

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## Disabilities in an African Cultural Worldview<sup>1</sup>

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### Abstract

Disability carries different meanings and symbolisms depending on the social and cultural contexts which may cause or perpetuate pejorative and discriminatory attitudes and behavior towards people with disabilities. In this paper, I discuss a holistic (African) notion of disability in the context of the social and cultural mediation of disability and standpoint epistemology as part of my larger aim of exploring the nature of disabilities in Africa. I examine the sense in which metaphysical disability is related to physio-mental disability and gesture towards the importance of valuing difference, taking the experiences of people with disabilities seriously, and avoiding a normalizing culture.

*Keywords:* Africa, African, difference, disability, disabilities, ontological foundation, standpoint epistemology

Disability is everywhere even though people with disabilities and their needs may often be functionally invisible to many, particularly to people without disabilities. This invisibility make take the form of pejorative and discriminatory attitudes and behavior towards people with disabilities, in dynamics that may mirror in some respects other forms of discrimination, namely, racial and cultural discrimination, gender and sexual discrimination and religious discrimination. Focusing here on engagement with disabilities in Africa, I wish to discuss a holistic notion of disability, which I take to be an African cultural worldview on disability. As part of my discussion of the holistic notion of disability, I survey some beliefs about disability in Africa predicated on deficit models of disability and look at the benefits of advancing frameworks that honor difference and thus affirm the experience of disability. To do so, I examine disability meanings and symbolisms, difference and normalizing, and standpoint epistemology, gesturing towards the importance of valuing difference and taking the experiences of people with disabilities seriously.

### **Disabilities Meanings and Social Contexts**

Some of the discussions that explore what disabilities stand for in different social contexts and the weight given these representations may be oblivious to aspects of cultural stereotypes of disabilities that percolate around pejorative expressions and meanings of disabilities. These harmful notions may not be helpful to the self-perception of people with disabilities or to how they may navigate the world. These symbolic meanings that disabilities have may be connected to the general attempt to construe people with disabilities as “the Other.” To say that there are symbolic meanings attached to disabilities recognizes that different disabilities can have different meanings within a society. However, even at that,

Susan Wendell has reminded us that “within a society, there seem to be meanings associated with having any physical disability” and that “[t]here also seem to be some similarities in the meanings of having a physical disability across societies and over time” (1996: 63). The point is that to speak of different meanings of disability in space and time does not preclude the fact that even though there may be no broad representation types of disabilities or for disability in general, disability (as a concept), as Wendell rightly notes, in dominant discourse “tends to be associated with tragic loss, weakness, passivity, dependency, helplessness, shame, and global incompetence” (1996: 63).

This deficient model of disability may be particularly pronounced in a society in which science is lionized and which bodies are also evaluated on their perceived deviance from ideals of physical or bodily perfection. In such a model, disability may be seen as an affront to the promise of science and medicine, with “people with disabilities [as] constant reminders of the failures of that promise, and of the inability of science and medicine to protect everyone from illness, disability, and death” (1996:63).

In what would seem like a contrast to this, in such a model people with disabilities may be described as heroes, particularly when seen accomplishing tasks not considered unusual or remarkable for the nondisabled. That is, they are taken to be symbolized heroes displaying amazing heroic acts in being able to perform tasks and in exercising bodily control against all odds. In this control, they may be held as some sort of exemplars to people without disabilities who are comforted in the sense of not only reaffirming the possibility of overcoming the body but also serving as inspirations for people without disabilities. The shadow side of this apparent celebrating of people with disabilities is when their accomplishments are seen solely from the prism of providing comfort for people without disabilities or such accomplishments are used to castigate other people with disabilities who have failed or unable to perform tasks and exercise control against all odds.

Consistent with a broad social model of disability, this discussion sees disability as socially and culturally mediated. This is in obvious contrast to the so-called medical model of disability in which disability is generally understood as being limited to being a medical condition exclusively involving physical features of individuals. By contrast, the expanded perspective invited by the broad social model of disability (although not without its own theoretical and practical limitations) gives primacy and importance to certain social contexts such as politics, empowerment, citizenship and choice in the expression of disability. Disability is construed in terms of society's failure to provide adequate and appropriate services for its citizens. This is the model we see expressed by the World Health Organization (WHO), which takes disability as an 'umbrella term, covering impairments, activity limitations, and participation restrictions' (2011; see also WHO 2018a & 2018b). As such, this model sees disability not just as health problem, but as a complex phenomenon, reflecting the interaction between a person's body and characteristics of the society or environment in which he or she lives. That is to say, disability does not simply refer to an individual's intrinsic features but comes about as "a result of an interaction between a person (with a health condition) and that person's contextual factors (both environmental and personal factors)" (WHO 2011) and as 'mainly as a socially created problem, and basically as a matter of the full integration of individuals into society' (WHO 2018a; Etieyibo 2020: 61).

### **The Nature of Disability (Disabilities) in Africa**

Looking at some literature on perceptions of disability in Africa, Etieyibo and Omiegbe have discussed different perceptions, beliefs and attitudes of disabilities in Africa and across some societies in Africa. They note that a key idea or notion running through some of these perceptions, beliefs and attitudes of disabilities pertain to the cause(s) of disability, where disability and its cause(s) are understood in terms of "some spiritual forces."



These forces are sometimes connected to the African belief in divinities (2017:19). Regarding forces that are connected to divinities, one is urged to be in the good books of the divinities to avoid being visited with disasters and misfortunes, with many believing divinities can help solve one's problems (Etieyibo and Omiegbe). Divinities are believed to have wide influence: helping the poor, the needy and helpless; increasing the trader's sales, and generally having the ability to change one's bad destiny to a happy and good one. These divinities are also seen as posing danger, being able to inflict sickness, death or other misfortunes on the innocent. They are thus 'ambidextrous', that is, they can be both good and bad (2017:19-20).<sup>ii</sup>

A brief survey of some of these beliefs can provide useful insight into concepts of disability in Africa. In general, disability and disabilities are presented as implicating spiritual entities. To say this is to clearly indicate an ontological foundation of disability, one that is both spiritual and physical. Simply stated, disability involves some spirits and the spiritual world and may be related to events and practices such as reincarnation, destiny, witchcraft, etc. as outlined below.

Regarding supernatural or spiritual causes of disability Bolaji Idowu (1973) "asserts that persons, animals or birds are believed to be instruments of spiritual entities, that is possessed by spirits of all descriptions, good or bad, vengeful or helpful. It is generally believed that spirits cause insanity or other diseases, miscarriages in women or a host of disabilities in humans. The witch with perversely strong will power is seen to always operate psychologically to cause, first, psychical and then physical disasters" (Etieyibo and Omiegbe 2017: 17). Similarly, Kwabena Amponsah has discussed how in many societies in West Africa, disability is explained not in terms of Western scientific paradigms but in spiritual and non-mechanistic terms. That is, in these societies spiritual entities are postulated as causes of all sorts of calamities. This view is grounded on the belief that nothing happens without a cause;

therefore, things such as illnesses or diseases and other adversities are attributable to some spiritual or supernatural forces. The supernatural forces include witches who operate in the universe (Amponsah, 1974).

Such witches are often seen to be the one of the causes of illness and misfortunes in Africa. In focusing on the Akan society, Amponsah “notes that some misfortunes in Akan society in Ghana are attributed to dangerous and powerful witches. They are said to cause infertility, impotency as well as being capable of ruining a person financially or causing alcoholism. Additionally, these witches are said to have the powers to remove the brain of their rivals’ children and add it to their own children’s so that they can do well at school. According to Amponsah, the Akans believe that witches can only do harm to their close relatives. It is believed that a disease caused by witchcraft cannot be cured at the hospital but only by the medicine men and people who have ‘second sight’” (Etieyibo and Omiegbe, 2017: 18).

Similarly, in the Ndembu (in Zambia) cosmology, sickness and misfortune are also said to be caused by sorcerers, witches, or ancestor spirits. Sometimes a diviner would be seen as necessary to help ascertain the source of concerns. In this society, according to Carl Elliot, sickness was seen as retribution by a spirit who had ‘caught’ an individual in some misdemeanor. Different ancestor-spirits would be seen as powerful forces able to cause different outcomes whether, Hansen’s Disease, menstrual problems, or twin births. Consequently, the way to deal with sickness or to obtain desired states was to perform what Turner called a ‘ritual of affliction’ (2004: 218). Similarly, in Lele society in Zaire, malevolent persons are said to be able to impact fortune and cause disability (Meir, 1979). As in other regions, malevolent people with occult powers as seen to be at work in the events in people’s lives through magic, poisoning and charming. Some of these people with occult powers are seen as needing victims to sustain their powers or seeking vengeance or to punish

others, sometimes with disability (Etieyibo and Omiegbe, 2017: 21).

A link may also be seen between this belief in the cause of disability by spiritual forces and the African belief in reincarnation. The idea of reincarnation presented in some African societies is one way of affirming the time transcending continuity in human existence (Booth, 1977). And Amponsah (1974) has noted how “the Akans in Ghana like other West African ethnic groups believe in reincarnation of ancestors.” “[A]ny ancestor who does not complete his work in this world is likely to come back to complete it.” Such a child is given the name “Ababio” and seen as continuously reincarnated to haunt parents after a mother’s loss of several babies. The corpse of such a child is maltreated with marks to stop it from being able to continue to reincarnate. Names such as Mossi, Bola, Donko, etc. are given to children born to women who have lost several babies continuously. Marks made to the children’s cheeks or around their hips indicate “the enslavement of such children who would not be born again” (Etieyibo and Omiegbe, 2017:19).

Similarly, what Amponsah notes about the Akans can also be said about the Yorubas and Igbos in Nigeria and reflected in many names given to individuals. Among the Yorubas, this includes female names like Yetunde (which can take forms like Yejide, Yewande, Yetide, Yetunji, Yeside, Yebode or even Iyabo or Iyabode) which means mother has returned or has been reincarnated. It is also reflected in male names like Babatunde, which can take the forms Babatunji, Bababode, Babs, Babaside, Babajide, Babawande, or Babatide and means mother has returned or has been reincarnated. Among the Igbos, the word Ogbanje is generally used to refer to children who are often reincarnated or ‘who come and go.’

Further connection between the belief in reincarnation and disability can be seen in skepticism about the practice of alms-giving. As Aimienmwona and Etieyibo and Omiegbe separately note, giving alms to beggars is viewed with suspicion because it is believed that the reincarnation of sinful human beings is atonement for their sins, and begging for alms is a

means of paying for previous bad deeds. The traditional doctor Okhue Iboi states, ‘Some of these beggars have lived and died in the previous world. Some of them were cruel to their fellow human beings so much that they were cursed.’ As such, providing alms is seen as participating in the beggar’s curse (Etiyibo and Omiegbe, 2017:19; Aimienmwona, 2000).

### **The Ontological Foundation of Disability in Africa**

This brief survey of beliefs tells us something important about the nature of disability in Africa. In general, again disability and disabilities are presented as implicating spiritual entities. To say this is to indicate clearly an ontological foundation of disability, one that is both spiritual and physical, with disability seen as involving spirits and the spiritual world and possibly related to events and practices such as reincarnation, destiny, witchcraft, etc. The claim that disability involves the spirit world or spiritual entities is not a claim that discounts the material component of disability. Elsewhere, I have discussed the relationship between the spiritual and material component of disability in disability discourse in Africa (Etiyibo, 2022).

In previous discussions, I have taken the material component of disability to be “physio-mental” disability which accommodates both for physical disability like blindness or hearing impairment and mental disability like mental illness), and as what “we see or what manifest to us when we see someone that has a disability or when someone with some form of disability bumps against the environment or physical space” (Etiyibo, 2022). On the spiritual component of disability, which I called metaphysical disability, I had in mind “disability implicating the supernatural entities (Etiyibo, 2022). I will call both the physio-mental” disability and “metaphysical” disability as “the holistic notion of disability.” To understand the holistic notion of disability let us take a look at the work of the Belgian Theologian, Placide Tempels and Godwin Sogolo. Tempels’ work emerges in and from the

context of Bantu philosophy and the work of Sogolo is one that takes place in his discussion of causality in African thought. Let me start with Tempels.

In his presentation of Bantu philosophy in his book, *Bantu Philosophy* Tempels takes forces as primordial in the sense that force is integrated in being and being in force. This view of force and being has come to be known as the *force thesis* (Tempels, 1959). In Tempels' *force thesis*, being is said to be force, force is said to be being, and one's status is determined by the amount of force one has. Simply stated, the amount of force coming together determines the nature of a particular being. Léo Apostel, a Belgian philosopher and logician has discussed the philosophical import of Bantu philosophy by presenting what he takes to be its seven (ontological) principles:

- A1: The existence of anything is its being a force, and the essence of anything is its being a force.
- A2: Every force is specific.
- A3: Different types of beings are characterized by different intensities and types of force.
- A4: Each force can be strengthened or weakened.
- A5: Forces can influence each other and act upon each other in virtue of their internal natures. All forces are radically interdependent internally.
- A6: The universe is a hierarchical order of forces according to their strengths.
- A7: Beings occupying a higher rank in the hierarchy can influence all beings of lower rank, at any distance; beings of higher rank can influence beings of lower rank or equal rank, indirectly by using beings of lower rank; beings of equal rank can weaken or strengthen directly and internally the force of another being of equal rank (Apostel 1981, 26-29).<sup>iii</sup>

As for Sogolo, his article, "The Concept of Cause in African Thought" provides an interesting way of thinking about causality, which helps us to link Tempels' *force thesis* with

disabilities in an African cultural worldview. In discussing illness or disease and how it is understood in an African cultural and social milieu, Sogolo speaks of primary and secondary causes (Sogolo, 2003: 228-237). Sogolo addresses how paying attention to the distinction between *primary* and *secondary causes* enhances our understanding of the phenomenon of witchcraft:

Basically, the causes of illness in traditional African thought fall into two major categories, the primary and the secondary [...] Primary causes of illness are those predisposing factors not directly explicable in physical terms. Some of these take the form of supernatural entities such as deities, spirits, and witches; others are stress-induced either as a result of the victim's contravention of communal morality or his/her strained relationships with other persons within the community. Secondary causes, on the other hand, involve direct causal connections similar to the cause-effect relations of the germ theory in orthodox modern medicine. (Sogolo, 2003: 234)

On this view of cause or causality, causes could be understood strictly in mechanistic (scientific/natural) terms or non-mechanistic (spiritual/religious) terms. Mechanistic (scientific/natural) explanation focuses on *secondary causes* and non-mechanistic (spiritual/religious) focuses on *primary causes* (even though *secondary causes* are not necessarily discounted). This idea of non-mechanistic or supernatural causes is one that we saw with Amponsah (1974) above regarding misfortunes in many societies in West Africa and the belief that nothing happens without a cause.

One takeaway then from Sogolo's presentation is that illness or disease in the context of *primary cause* is understood in terms of the individual's relationship with the spirit world and treatment or cure results from addressing both *primary* and *secondary causes*. Thus, if we think of this view of causality in relation to illness or disease as grounded on the same

ontology or metaphysics as the view of disability not just in terms of *primary* and *secondary causes* but also in terms of treatment or cure for the illness or diseases or disabilities, then the plausibility of the primary and secondary causation view (or causality view) is one that may suggest a holistic notion of disability. Having looked at Temple's *force thesis* and Sogolo's causality view, let us now link them together in making sense of my discussion of the holistic notion of disability in Africa.

If one focuses closely on the notion of force, one could simply think of forces either as some kind of energy or more broadly like how in the physical sciences some entities are understood, namely, analogous to the interaction of atoms, particles, molecules and matter. First, we take a being and force or forces as any entity, which is either material or immaterial. Secondly, as atoms, particles, molecules and matter forces are the basic building blocks of all existence, in the *force thesis* "force is being and being is force." Third, what makes one form of being different from another form of being is their forces (their number of quantities and how they are packed together).

This way of thinking of forces and being then makes one able to say that disability (in an African worldview) as presented may be seen as an umbrella term that describes how an entity or being influences another entity or being in the spiritual sphere leading to a visible manifestation of such disability or its expression in the physical sphere. In a way then one might say that what is seen to occur when "the influence" takes place in the spiritual realm or world gives way to or produces metaphysical disability, and the manifestation or expression of metaphysical disability in the physical realm or world refers to physio-mental disability. Accordingly, it could be said that a being without disability and one with disability are simply entities or beings who are in possession of different degree of forces or vitality (that are packed into different forms), just as a being in the spiritual sphere and one in the material sphere are beings with different degrees of forces or vitality (packed into different forms).

More broadly, this holistic view of disability suggests an African cultural worldview on disability emphasizing differences. That is, beings or entities are different in degrees and not in kinds since they are but beings of the same nature or kind. This is so given that beings are in possession of different degrees or amount of forces and that it is this that demarcates or marks difference or differences.

### **Ethical Underpinnings, Value and Persons with Disabilities**

The African understanding and representations of disability that I have discussed in the last two sections show certain ontological and epistemological underpinnings. As I have gestured to and briefly summarized in the section on the ontological foundation of disability on the continent, disability in Africa has both a spiritual and physical component. Although I have not discussed this, it is important to note that there are ethical dimensions and underpinnings to this discussion, both in terms of how disability understandings determine value of, and justify action towards, persons with disabilities. It is not unexpected, as I have discussed elsewhere, that various understandings and beliefs inform attitudes towards persons with disabilities and that these find expressions in actions directed towards persons with disabilities. Etieyibo and Omiegbe (2016) have discussed how discriminatory practices or behavior against persons with disabilities flow from various beliefs that people hold about disability:

Our discussion has highlighted that religion and culture promote certain beliefs and attitudes about disability and people with disabilities that lead to discriminatory practices. That is, they are sustaining factors in discrimination against people with disabilities. (2016: 5)

What Etieyibo and Omiegbe have noted has been echoed by other scholars. The point



brought out by these scholars is a simple one but worth stating: beliefs one holds about disability constitute foundation blocks and essential elements upon which one's attitude and behavior towards persons with disabilities may be grounded (See *Teaching for Diversity and Social Justice*, 2007; Fishbien and Azen, 1975; Ozoji, 1991). This underscores the dangers associated with deficit models of disability and the overall importance of employing models that may allow us to affirm and value difference.

### **Valuing Differences**

Goffman (1963) et al. remind us of the importance of valuing and honoring difference. There are obvious practical implications of valuing disability or disabilities as difference(s), for instance, in relation to efforts to develop technologies to prevent people with disabilities from being born and initiatives to find "cures" for disabilities, which ultimately may be less concerned with alleviating suffering, than with minimizing deviations from what is taken to be "normal." This honoring of differences may also allow us to better appreciate the role disabilities may play in individual's identification (Wendell, 1996: 83).

### **Disability and Standpoint Epistemology**

What I have said about disability in an African cultural worldview may invariably lend credence to standpoint epistemology both in terms of cultural experiences of difference in the context of disability and difference in experiences regarding people with disabilities and people without disabilities. That is first, an African worldview on disability may seem to provide one cultural difference in experience regarding disability compared to other cultural views; secondly, even within a particular cultural worldview there may be multiple experiences of disability; and thirdly, obviously there may be differences in experiences between people with disabilities and people without disabilities.

Here we understand standpoint epistemology as suggesting that there are certain

epistemic experiences of some people (oppressed groups, etc. and in this case people with disabilities) that give them certain standpoint or advantages over others, namely, non-oppressed or dominant groups. Feminists have been in the forefront for the advocacy and advancement of standpoint epistemology, which in feminist space refers to feminist standpoint epistemologies, namely, feminist descriptions of the nature and substance of knowledge and the processes of creating knowledge.<sup>iv</sup> In a nutshell, standpoint epistemology holds that “some groups of people have access to experiences that are not directly available to others, and that those experiences could give them, not only a different, but a truer and more complete perspective on some aspects of the world” (Wendell, 1996:72). Such an epistemology can help us better understand and communicate the contribution the experience of disability makes to communities. To this point, Wendell states:

I want to say that having a disability usually gives a person experiences of a world different from that of people without disabilities, and that being a woman with a disability usually gives a person different experiences from those of people who are not female and disabled, and that these different experiences create the possibility of different perspectives which have epistemic advantages with respect to certain issues. (1996: 73)

In saying that having a disability usually gives a person experiences different from that of people without disabilities, one should be careful not to trade in the currency of homogenizing the experiences of people with disabilities. Such disability homogenization is similar to attempts that homogenize women or the experiences of female subjects, which feminists have warned us to be wary of and which has led to people like Patricia Hill Collins to defend a standpoint epistemology of Black feminist thought (Collins 1989, 1990 & 2004).

If we take seriously the ideas of standpoint epistemology and how disability relates to it in terms of different or privileged epistemic experiences of people with disabilities

compared to the experiences of those without disabilities, then what I have presented as a holistic notion of disability should give us insight into the value of linking standpoint epistemology with disability. The holistic notion of disability, as I have said, can be taken to be an African cultural worldview on disability and I think that this notion of disability may help us explain the experiences of people with disabilities in Africa more generally.

Conceptually, we take disability as a fusion of metaphysical disability and physio-mental disability. However, because we understand the spiritual as important and prominent for an understanding of disability in an African worldview, we expect the experiences of people with disabilities in an Africa space to be influenced by this understanding. This understanding and experiences will invariably be different from the experiences of people with disabilities from a different cultural and social milieu.

### Conclusion

In this paper, as part of my overarching aim of making sense of and presenting a case for a holistic (African) notion of disability, our exploration of disability meanings and symbolisms ultimately makes a case for the role standpoint epistemology may play in a more holistic appreciation of the role of disability in culture. Taking metaphysical disability as spiritual disability and physio-mental disability as material disability, the holistic notion of disability *qua* the African cultural worldview on disability provides another reason or argument for taking seriously standpoint epistemology, in general, and the experiences of people with disabilities, in particular. My discussion of standpoint epistemology and its connection to disability helps us appreciate not just the importance of standpoint epistemology but also the significance of allowing epistemic flourishing. Such flourishing can mitigate the risk of losing out on the knowledge that comes from the context- and regional-specific experiences of people with disabilities.

### End notes

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<sup>i</sup> A version of this paper was first presented at the *Disability and African Indigenous Thought Workshop*. A workshop organized by the Disability and Inclusion Africa Network [Thursday February 25, 2021]. Other iterations of the paper have been presented in different academic fora since then and parts of that presentation has been published in Etieyibo (2022).

<sup>ii</sup> See also Awolalu and Dapamu (1979).

<sup>iii</sup> See also Diagne (2016: 19-20).

<sup>iv</sup> For some discussions of feminist standpoint epistemologies see Harding (1993 & 2004); Hartsock (2004); Longino (1993); Narayan (2004); Rolin (2006).

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**Color Specifications and the Othering of Persons with Albinism in  
Sub-Saharan Africa Traditions**

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**Abstract**

This essay examines the intersection between color aesthetics and the othering of persons with albinism in sub-Saharan African traditions with particular reference to the understanding of colors in Akan and Esan cultures. It also explores the roles that the arts may play in re-representing albinotic bodies in an inclusive manner in contemporary Africa.

*Keywords:* color specifications, sub-Saharan African traditions, persons with albinism

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Recently, there has been increasing attention to discrimination against persons with albinism. This includes disturbing trends seeing persons with albinism kidnapped, maimed, and killed, and their body parts commodified. “In black markets in East Africa, a limb of a person with albinism sells for a minimum of 600USD and the full body sells for as much as 75,000 USD” (Imafidon, 2019).

In sub-Saharan African traditions, prevalent beliefs about persons with albinism abound: persons with albinism are seen as punishment for bad deeds; a consequence of witchcraft; the result of mother of a child with albinism having sexual intercourse with a European; or the popular Yoruba mythological phrase *afin ki n je iyo* which translates as “a person with albinism does not eat salt.” There is ample evidence that in sub-Saharan African traditions that people validate their stereotypes and discriminatory practices against persons with albinism on the basis of what their communities allow in form of belief systems. Imafidon highlights this when he states that persons with albinism often find themselves thrown into existence in a community already saturated with certain ideas about their personalities, how they originated, of what use they are, etc., notions that have acquired the status of objectively given truths (2019). Of note, one belief system that has continued to perpetrate and legitimize the discrimination against persons with albinism is how colors have come to be understood in sub-Saharan African traditions.

Examining how these color specifications serve to legitimize discriminatory practices against/othering of persons with albinism is the focus of this essay. Colors are seen as significant in African traditions to the extent that people often ascribe things, events and occurrences to specific colors. For instance, colors can be used to differentiate the categories of beings involved in a particular ritual ceremony. Also, the social significance of colors is

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reflected in their use in various functions such as marriages, rituals, funerals and other social and or individual functions. I therefore begin this paper by exploring color specifications in sub-Saharan African traditions, paying close attention to specific colors found in the Akan and Esan thought systems. In the second section, I examine some indigenous belief systems that are being used in validating the discrimination against persons with albinism in sub-Saharan African traditions. Consequently, I examine the nexus between color specifications and the othering of persons with albinism in sub-Saharan African traditions. All this is followed by an examination of the roles the arts may play in re-representing albinotic bodies in an inclusive manner.

### **Color Specifications in sub-Saharan African Traditions**

In this section, I explore the specific colors peculiar to some cultures in sub-Saharan Africa. Specifically, I examine color specifications as it relates to the Akan and Esan conceptual schemes. In sub-Saharan African traditions, the importance of colors cannot be overemphasized. In the Akan and Esan conceptual schemes, the understanding of colors does not go beyond three basic colors: black, white and red. In Esan conceptual scheme, there are *ufuamhin* (white), *ubimhin* (black), and *ugianmhin* (red); in Akan thought system, we have *fufu* (white), *tunturn* (black, or dark), and *memene* (red). However, this is not to say that there are no other colors aside the aforementioned ones, but for us to understand other colors, they must be an approximation of these three basic colors listed above.

In “A Note on Akan Color Symbolism.” G.P. Hagan argues that each color has its significance in the Akan conceptual scheme. To him, *fufu* which means white, light, plain, untainted, incorrupt, clean, pure, is a color of rituals which symbolizes victory and purity. The reason why the *fufu* is significant in relation to victory and purity is that it is often

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considered as the color of the gods, and it is the color that is reserved solely for sacred places. Thus, *fufu* also expresses joy, hope and well-being. That aspect of the human person which bears a man's destiny and directs his fortunes (*KRA*) is associated with *fufu*. And the expression *Kra-biri* (the dark Kra) refers to the state of a person who has lost hope and lost his ritual bearings (Hagan, 2009). This suggests that the white color in Akan conceptual scheme is synonymous to good tidings and positive things.

In contrast, in the Akan conceptual scheme, the dark color is known as *tunturn*. According to Patrique deGraft-Yankson, *tunturn* in the Akan conceptual scheme does not only stand for black, but also connotes absence of lightness, happiness, piety and sparkle. However, *tunturn* is not used synonymously with doom or solely negative connotations. To the Akans, the general use of these specific colors cannot be done in isolation of the particular context in which such individual is using it. For instance, the weight and compactness of *tunturn* also represents unmatched strength and solidity. This is why we see expressions such as black beauty, black power, black star, black magic, which connote the highest levels or degree attainable in the referent condition (2020). While this is the case, there is a general understanding among the Akans that *tunturn* as the dark color might represent a particular phase of an individual's life, that is, a stage of misfortune. As a consequence, *tunturn* does not signify victory, neither does it signify celebration, but often expresses sorrow associated with ill-luck. This explains clothing associated with mourning in sub-Saharan Africa. For instance, when an individual dies at old age, people often put on white clothes to symbolize the celebration of life. If an individual dies untimely, people often wear black to show that the individual's death is painful, or perhaps considered an unnatural death.

The last specific color in the Akan conceptual scheme *kobena*, red, also has its own complexities. Some Akans often use it interchangeably with blood which represents vitality

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and life force. Again as we see contradictory meanings as the word can also connote something negative, especially when blood is spilled for no reason. According to Hagan, this act of blood spilling which cannot be justified can desacralize sacred objects. The implication of this is that no one should ever take the life of another or engage in unwholesome activities.

Mirroring the Akan thought system, in the Esan conceptual scheme, there are also three specific colors. All other colors are considered approximations of these. In “Western Specifications, African Approximations: Time, Color and Existential Attitudes,” Imafidon states:

Among the Esan people of southern Nigeria, where I come from, the three colors that exist are *ufuamhin* (white), *ubimhin* (black) and *ugianmhin* (red). Every other color tends to be an approximation of these three colors or is not acknowledged within the conceptual scheme of the culture. There are constructions within the Esan language that suggest that the color of a thing approximates the three basic colors, such as *odia bhe begian* (“it looks like it is red”) and *ofua se se se* (“it is so white”). (2019)

Similarly, Hagan argues in the same vein in Akan thought system, except in a few cases involving the use of green (*bun*), all colors used in ritual ceremonies appear to fall under these three broad terms; so that the terms *Fufu*, *Tunturn*, *memene* (and their cognate terms) tend to apprehend wider ranges or spectra of color than would normally fall under them in a naturalistic classification of colors (Hagan, 2009).

### **Indigenous Beliefs about Albinism in Sub-Saharan African Traditions**

This section examines indigenous beliefs about persons with albinism in sub-Saharan African traditions and the ways in which such belief systems are used to justify discrimination against persons with albinism. In sub-Saharan African traditions, there has been a prevalent indigenous understanding that persons with albinism are “ghosts,” or, as

previously stated, the product of sexual intercourse with a European man. For instance, Olagunju argued that in Yoruba tradition, persons with albinism are seen as ‘punishment’ from the ancestors and consequently, people continue to discriminate against them (2012). For example, a 41-year-old male with with albinism from South Africa retells the following:

[S]ome shops, especially those owned by West African migrants or black South Africans often do not like to attend to albinos in the morning. One of them was bold enough to tell me that whenever an albino or someone with a disability comes around to the market, it affects sales negatively. There are so many ‘superstitious’ beliefs. It hurts to recount them. (Ikuomola, 2015)

Similarly, among the Shona people of Zimbabwe, illness and disability, including albinism, may often be explained by witchcraft and other supernatural forces. According to Baker *et al* (2010), fear of contagion often shapes attitudes and treatment, with the belief that contact with a person with albinism suggests that at one point in an individual’s life, either he or any of his family member will have a baby born with albinism; or will somehow be impacted in the domains of marriage and children, employment, education, and so on. This discrimination may contribute to their being considered outcasts by others. For instance, a Rixi taxi driver bluntly made the following observation to Owen Sheers during Sheer’s extensive research on albinism in Zimbabwe: ‘Unlucky, [...] I would not like to be one’ [...] ‘You are black, but you are white, so you belong nowhere. Nobody likes you (Sheers 2004).

Concepts around the birth of a baby with albinism are also informed by indigenous understanding. Many believe albinism to be cause by a mother’s encounter (physical or sexual) while pregnant, with another individual with albinism. Other beliefs exist that it may be a curse, e.g., for marital misdemeanor within the family (Lund, 1998).

More recent, “modern” beliefs about albinism in sub-Saharan Africa suggest sleeping with an individual with albinism cures HIV/AIDS. According to Baker *et al.* (2010), a

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woman in Bulawayo remarked, “and now people think that to sleep with albino woman [sic] is a cure for AIDS. They use you, all the time. They sleep with you and then they run away; and now all albinos are dying because of this thing, they are dying of HIV.”

In addition to being subject to these abuses, persons with albinism are often believed to possess immortality. A man from Venda in South Africa noted he had to invite the people of his village to the burial of a relative with albinism so they would believe that those with albinism also die. Also, a woman in Zimbabwe comments on the supposed immortality of persons with albinism stating:

They think we do not die, ha. I went to Harare for 8 months once, and when I came back people were screaming spook, ghost, they thought I had died and come back.

They think albinos [sic] do not die; they wander off into the bush. I even thought that myself before, I had never seen a dead albino. But now with the skin cancers I have seen many dead albinos. But an albino funeral, that is a thing that is always very well attended. Not just because he has many friends. People come to see for sure that the albino is dead; they even touch him in the coffin to make sure he is really dead.

(Baker, 2010)

### **Color Specifications and the Othering of Persons with Albinism**

The idea of color specifications in sub-Saharan African traditions, as discussed earlier, suggests that the understanding of colors does not go beyond three basic colors: black, white and red, such that the conception of any other color is often seen as an approximation of these colors. My intention in this section is to examine how the understanding of these specific colors is one of the bases of the discrimination against persons with albinism in the sub-Saharan African traditions.

In her conference keynote address, “Different Shades of White: Interdisciplinary

Perspectives on the Albinotic Body,” Ikponmwosa Ero argues that the discrimination faced by persons with albinism is based on two grounds: their disability and their skin color (2018). Regarding skin color, there is what I call “aesthetic exclusion.” While the word albinism is derived from the Latin word *albus* which means white, those with albinism are considered as racial minorities because their skin color does not match nor approximate any specific color in sub-Saharan African aesthetic tradition. Regarding the prejudicial marginalization of persons with albinism on the basis of their skin, for instance, the director of the Albinism Society of Southern Africa writes: “when we get into taxis, people still move to the other side, or even refuse to use that taxi. We are still called *isishawa* (a Zulu word for a person who is cursed) and *inkawu* (an Nguni word for ‘white baboon’) (Fazel 2012). In a similar vein, the *Vanguard Newspaper* of August 17, 2015, reported an incident in which an individual with albinism took his own life due to the stigma, discrimination and social ill-treatment he received overtime. *Vanguard Newspaper* reports the case as follows:

A 23-year-old man, Ugochukwu Ekwe, yesterday committed suicide at Festac Town, Lagos, over the color of his skin being an albino [sic]. His dangling body was discovered in an apartment [...] where he lived with his parents and siblings.

*Vanguard* gathered that the deceased refused to eat since Saturday in protest of what he said was people’s rejection and stigmatization because of his skin condition. He was also said to have refused to go to church with other members of the family yesterday. When the family returned from church, Ugo, as he was fondly called, was dangling at the end of a rope tied to the ceiling fan [...] *Vanguard* gathered that the deceased had attempted to take his life before now (*Vanguard Newspaper*, 2017).

Such events reflect the daily discrimination and lived experiences of persons with albinism. Because of prejudices regarding skin color, many are seen as a “troubling anomaly” in the eyes of those without albinism.



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The non-government organization, Under the Same Sun (UTSS 2014) concluded, among many factors, that “nearly all misunderstanding, mystification and stigma [with respect to albinism] are traceable to the most visible aspect, which is their appearance.” In the same vein, a UN Independent Expert on minority issues stated that these problems such as stigma, lifelong social exclusion and discrimination, are similar to the experiences faced by vulnerable racial minorities *because of their skin color* (See Joint Press Release by UN Rapporteurs, 4 May 2013). In other words, persons with albinism experience colorism. Colorism is a global phenomenon incorporating stereotyping, prejudice and discrimination based on skin color, between and within races. The highest level of diversity in skin color, due to differing levels of melanin, is within populations in sub-Saharan Africa (Relethford, 2000). Colorism differs from racism here as it is seen as an intra-racial discrimination on the basis of skin color, while racism is seen as an inter-racial discrimination on the basis of skin color. Thus, the discrimination faced by persons with albinism in sub-Saharan Africa is colorism since they are marginalized by people of the same race.

The meanings ascribed to the difference in color in sub-Saharan African traditions, and to the condition of albinism, contribute to societal discrimination of people with albinism. Ultimately, they may become the “object of discrimination [...] and into a cash transaction much more cruel than the slave trade” (Guardian 15 December 2012). Their color difference is portrayed as an important aspect of the objectification and commodification of their bodies and ascription of supernatural powers. As stated previously, albinotic bodies are perceived as highly valuable due to beliefs they have special powers. “Just because of the difference in the color of the skin, eyes and hair the society believes after being convinced by witchdoctors that they possess magical powers worth millions of shillings” (Guardian 4 December 2011). Hence the different color is linked to myths and false beliefs that “the legs, genitals, eyes and hair of people with albinism can help [...] achieve instant wealth”

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(Guardian 27 November 2011). These beliefs fuel the violent attacks on Tanzanians with albinism. All these, no doubt, are tied to how specific colors are understood in sub-Saharan African traditions. Again, as skin color of persons with albinism cannot be approximated with the specific colors in sub-Saharan Africa, this has continued to fuel discrimination against them.

According to Imafidon, this discrimination has both ontological and moral imports. Regarding the ontological implication, Imafidon argues that persons with albinism are often ontologically excluded in the community in which they belong, that is, persons with albinism are not considered as part of beings that make up the African ontological worldview:

[A]though persons with albinism are visibly different and alleged to be queer and unusual in a densely black-populated Africa, they ought not to be ontologically unusual since they share the same common essence, vital force, with other beings. The principle of being ought to enclose rather than isolate as queer the being of persons with albinism as human beings. (2019, 45)

Aside the ontological implication of colorism for persons with albinism, there has always been an exclusion of persons with albinism from the standpoint of African moral humanism. In this stance, the humanism embedded in African morality has its limit when it comes to persons with albinism. Put differently, African moral humanism dehumanizes persons with albinism when compared to persons without albinism. To Imafidon:

African moral humanism justifies the cruel treatment of persons with albinism. When persons within an African community cause harm, maltreat, stigmatise and discriminate against persons with albinism, they do not often feel they are doing something wrong in the same way they would feel when they are hurting a fellow human [...] their interaction with a person with albinism, cruel as it may be, is not considered the same as an interaction they would have with a fellow human being

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[...] the ill-treatment of persons with albinism protects the community from harm.  
(2019: 82)

These negative views become inscribed in language. For instance, in the Yoruba thought system, an albino is called *afin* which means horrible. In Benin and Esan thought systems, a person with albinism is called *eyaen* and *anyaei* respectively. We see similar dynamics elsewhere:

Among the Yoruba people of Nigeria in West Africa, there are various explanations for albinism in humans. A popular notion of albinism is that persons with it are agents of divinities (*eniorisa* as they are often called) sent to families who have erred against some divinity or ancestral spirit as some forms of punishment or curse. They are therefore often called *afin*, meaning horrible beings. For this reason, persons with albinism are often sent to serve in shrines, and some individuals draw the conclusion that since they are agents of the divinities, their body parts and blood must have superhuman powers that can be used for ritual purposes such as money-making rituals and charms for long life and different forms of protection. (Imafidon, 2019: 19)

Evidently, this conception of persons with albinism as mysterious beings is not only limited to Yoruba tradition alone, as there are culturally embedded understandings that cut across other sub-Saharan African traditions. This has made it even more difficult for persons with albinism to obtain access to education, job opportunities, health, marriages, and relationships, etc. The implication of this is that being different, especially in skin color of a particular aesthetic tradition, often carries the risk of discrimination. Our idea of the color of a human person in Africa is fair or dark, and not white, which is why persons with albinism living in areas dominated by dark skin Africans, are often seen as the “other.” This is tied to the understanding that whiteness in sub-Saharan African aesthetic tradition is exclusive of albinotic bodies. Due to this, Scott (1999) argued that albinism should be considered a new

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category of color in order to distinguish it from the normal white as we have in African aesthetics.

### **The Role of Arts in the Inclusion of Albinotic Bodies**

In considering this mistreatment and discrimination and abuse, what role, if any, can the arts, especially in sub-Saharan Africa, play in re-representing albinotic bodies in a way that is inclusive? Attempting to answer this question forms the bulk of this section. From the arguments thus far, it is evident much needs to be done for the rights of those with albinism. It is obvious that, among other factors, the understanding of colors in sub-Saharan Africa has over the years contributed to the violation of their personhood. We turn now to consider what role the Arts may play in countering prejudice and perhaps helping with efforts towards greater equity and inclusion. (By the Arts, we are considering movies, music, dance, drawings, literary works, painting, modeling, etc.)

The reason why exploring the role of arts in the inclusion of albinotic bodies is important is that decades ago, arts contributed immensely to the dehumanization of, and discrimination against persons with albinism. In movies and drama series, especially in schools, churches and soap operas, persons with albinism were frequently used to play the roles of “ghosts” or mysterious beings. Consequently, there grew a prejudicial understanding that persons with albinism cannot play a suitable role other than that of a “ghost.” Hence, my intention here is to expose how these forms of arts can ensure the re-representation of albinotic bodies in a positive and inclusive way. Perhaps the arts in various forms may be used as a medium of correcting and addressing social anomalies such as the discrimination against persons with albinism. For instance, as music can serve as a great avenue to talk about issues that directly affect the society, influential artists may develop songs and arrange concerts advocating for the end of discrimination against persons with albinism. Music

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videos could also play an important role in re-representing albinotic bodies in ways that are positive and less demystified. The musical videos by two popular Nigerian artistes: Omah Lay and Terry G featuring Skibii in their songs *Lolo* and *Adura* respectively come to mind here. In these videos, women with albinism are used as models, and they portrayed themselves without fear of discrimination. These musical videos promote diversity and the inclusion of persons with albinism. With the widespread access of digital streaming platforms like YouTube and Netflix, artists therefore need to take up the responsibility of ensuring that persons with albinism are represented and re-represented in more positive and inclusive ways. By this, people who over the years have had this negative conception about persons with albinism, will no doubt, begin to have a rethink.

As an example of this, in Tanzania, the popular artist group Tanzania Albinism Collective released a song album entitled “White African Power”; the songs in this album assert the power and dignity of persons with albinism to be themselves. Popular songs on the album include “I am a Human Being” and “Albino Brotherhood.” Additionally, song-writing workshops are being organised; Ian Brennan encouraged a group of people in Ukerewe Island in Tanzania to write songs about the experiences of persons with albinism using local dialects of *Kikerewe* and *Jeeta*. These are part of the ways in which art are making a difference in the lives of persons with albinism in Tanzania.

Regarding the similar potential role of movies, there have been several movies and comedy skits featuring persons with albinism that illustrate the potential power of the medium to invite new ways to think about persons with albinism. In the Nigerian movie *The Tribunal* (produced and directed by Kunle Afolayan), a man Ifeanyi Imoh (Damilola Ogunsi), believes that he was fired because he of his albinism, and a lawyer decides to represent him in a court case against his former employers. The film is enlightening because it is supported by skilled direction and performances sufficient to elicit discussions about the underlying

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problems associated with prejudice against persons with albinism. Similarly, in Tanzania, Louis Laverdiere's *White and Black: Crimes of Color*, directed by Jean-Francois Mean, addresses the need to end the discrimination and insensitivity faced by persons with albinism and their mothers. The reception of the film suggests that such portrayals can have a dramatic positive impact. After the broadcast of the movie, the murder of persons with albinism in Tanzania, which had been on the increase, dramatically reduced by 90% (Kimaro, 2012). Additionally, Comedy has also been useful in circulating more sympathetic portraits of those with albinism. Recently, there have been persons with albinism getting involved in comedy skits. In Nigeria, among others, we have comedians such as Donald Ernest (Expatriate Comedian) who, via his comedy skits, has been portraying himself to audiences as an individual not be considered as "other."

More broadly, portrayals in art, including photography, may help interrupt and expand dominant ideas of beauty that have helped perpetuate discrimination and violence against peoples with albinism. Regarding the role of aesthetics, it is important to re-orientate people on the need to change their idea of what beauty entails. One might be tempted to ask, what should be the standard of beauty in a continent with persons with albinism? To answer this question, the famous South African photographer Justin Dingwall has produced a collection of portraits in his *Albus* series which explores the aesthetics of albinism and perceptions of beauty. In particular, Dingwall's series is geared towards exploring the aesthetics of albinism in relation to conventional ideas of beauty. He sees his work as inviting greater appreciation of diversity, describing it as:

"not about race or fashion, but about perception, and what we subjectively perceive as beautiful [...] I wanted to create a series of images that resonate with humanity and make people question what is beautiful [...] To me, diversity is what makes humanity interesting and beautiful" (2016).

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### Conclusion

This essay has examined what color specifications entail in sub-Saharan African traditions and the role such concepts continue to play in the experiences of persons with albinism. We have considered the ways in which the skin color of persons with albinism does not have an approximation of the specific colors found in sub-Saharan African traditions, and how this has been used as justification for violating the personhood of people with albinism. We have further considered how indigenous belief systems may also be used to justify discrimination against persons with albinism. Finally, our discussion of representations in the arts has invited us to consider the role these forms may play in re-representing persons with albinism in a manner that is inclusive.


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**Representations and Empowerment of People with Disabilities in  
Selected Nigerian Prose-works**

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**Abstract**

This paper examined the representations and empowerment of characters with disabilities in selected Nigerian prose-works. The study uses the literary sociological approach, and findings showed that the characters with disabilities are empowered with various forms of supernatural abilities which are all grounded in the represented cultures of each prose-work.

*Keywords:* people with disabilities, literary sociological approach, Nigerian cultures

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With its broad influence and its connection to all areas of life, literature no doubt is intimately entwined with our concepts and experiences of disability, for good or ill. Many scholars such as Beauchamp, Chung & Mogilner opine that “literature tells us who we are as a culture; it mirrors our beliefs or challenges them; it helps sell a lifestyle. Literature has been used deliberately to normalize groups of individuals and create social change” (2010). Mbarachi & Igwenyi (2018) add that “literature is said to mirror life (and this) includes the totality of human existence within a given culture or society” (p.30). Likewise, disability studies had had obvious interest in literary representations of disability.

Literature “is a social phenomenon, constantly sensitive to and expressing new aspects of life, current demands and hope giving rise to new social attitude and relationships, which were hitherto unnoticed” (Mkaanem, 2007, p.80). These representations within it also buttress the affinity of literature and the society which is central to the sociological approach to reading literary texts.

With this in mind, the literary sociological approach that this paper adopts, stresses the functionality of literature and re-emphasizes its role as a mirror of society. Obafemi (2008) buttresses this in his assertion that “one of the functions of literature is to serve as an instrument of societal propagation, change, and development” (p.77). The literary sociological approach, according to Aliyu (2013) allows for the examination of “the challenges of living in the society” (p.11).

Furthermore, Kopdiya (2016) states that the literary sociological approach depicts how “literature awakens the feelings and shows the human stories, imagining and showing what the people feel...” (p. 233). An instance of the human stories previously mentioned the by Kopdiya (2016) is in the representation of people with disabilities, the focus of this study. People with disabilities have always existed in African societies, however, creative writers are beginning to pay more attention to the projection to this in their literary works. This

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brings up the significance of the social commitment of African writers which is also an important aspect of the literary sociological approach.

The literary sociological approach emphasizes the social commitment of writers, further reiterating the functionality of literature. The significance of the social commitment of writers is made evident in a statement by Awosika (1997) that, “the socio-political and economic problems confronting the African world today are so over-powering that it would be surprising if the novelists did not show as much awareness of them as they have done” (p.4). Osundare (2007) adds that “the writer by virtue of his ability to transcend quotidian reality, has a duty to relate not only how things are, but how they could or should be” (p.12). This social commitment of writers is encapsulated in the literary sociological approach, and it occupies a major part of this paper, which aims to examine the representations of persons with disabilities in selected Nigerian prose works. This examination would be done using the selected primary texts: Irenosen Okojie’s *Butterfly Fish* (2015), Nnedi Okorafor’s *Sunny and the Mysteries of Osis* (2018), and Abubakar Adam Ibrahim’s “The Whispering Trees” (2012). The analyses of the primary texts would focus on investigating the types and causes of the various forms of disabilities in the selected texts, the attitudes of other characters towards the characters with disabilities, the coping strategies adopted by the characters as well as the empowerment of these characters in the selected primary texts.

### **Representations of Various Forms of Disabilities in the Selected Nigerian Prose-works**

Across the three selected primary texts, various types of disabilities are attributed to characters. Irenosen Okojie’s novel *Butterfly Fish* (2015), which is written within the Benin cultural context, identifies both the physical and psychological disabilities of its central character, Joy. Joy is projected as initially having to deal with mental illness causing her distortions, disturbed sleep, and insomnia (*Butterfly Fish*, 2015, p. 260). Joy experiences

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mysterious events like feeling the presence of spirits, and constantly seeing a spirit, Anon, who accompanies her everywhere she goes, and influences her to attempt suicide. This subsequently results in her sleepwalking into train tracks and the eventual amputation of one of her arms (*Butterfly Fish*, 2015, p. 300). The cause of Joy's deteriorating mental state is attributed to a spiritual source, a brass head, (which is traceable to the indigenous Benin cultural practices), and which ultimately leads to her physical disability.

Another character with a disability in *Butterfly Fish* is Filo, a female character whose type of disability is psychological. The cause of the mental illness that Filo, who is Oba Odion's fifth wife, experiences is a result of her not having a child of her own and the neglect that she experiences from her husband over time. Across many African cultures, especially in past years, women like Filo who experienced the constant loss of their child(ren) tended to be discriminated against. This in turn affects the mental state of such women as some of these women eventually were deemed insane, and the society members, who were the primary causes of this, end up labeling such women using various derogatory terms. Okojie, in an interview with the researcher, buttresses this when she states that, "unfortunately in our culture, if you suffer a lot of miscarriages you tend to be looked down on, especially during the olden days (I. Okojie, personal communication, November 27, 2020). In the novel, *Butterfly Fish* (2015), Filo is described as the fifth wife who:

wore her sadness on her wrists like haphazard bracelets that wounded her skin. Her womb had apologetically born three dead babies, and on days when the air was thick with disdain for all who resided in the royal enclave, she could be found wandering the grounds harassing whosoever she encountered to return her children. (64)

The causes of Filo's mental illness are multi-faceted. In addition to the continuous loss of her babies, she also experiences total neglect and lack of recognition from her husband

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with respect to these losses (*Butterfly Fish*, 2015, p. 64; p. 79). It is stated in the novel that Filo's anger increases due to Oba's refusal "to step in" as he "did nothing to help his forgotten wife" (*Butterfly Fish*, 2015, p. 153). This aspect of the novel illustrates the need for society to stop the tradition of castigating women who experience miscarriages, stillbirths, or any form of child loss. It suggests that, rather than ostracizing such women, there is a need for society, especially the spouses of such women, to be supportive and patiently walk them through surviving such experiences.

In Nnedi Okorafor's *Sunny and the Mysteries of Osis* (2018), the novelist portrays a physical form of disability (albinism), largely based on the Igbo cultural context. The novel's protagonist, Sunny, is portrayed as a teenage girl with albinism. "Albinism is what some classify as a visible disability, perhaps indeed the 'most visible' one. The disability [...] resides in the fact that the character with albinism is treated differently based on the appearance of his/her skin ..." (Lipenga & Ngwira, 2018, p. 1477). Nigeria "is estimated to have one of the highest albinism prevalence rates in the world, which is about 6 million. Children constitute about 40% of this population, spread across all the states in Nigeria" (Aduge-Ani, 2014). The discrimination against people living with albinism is rampant across many African societies leading to their brutal killings in countries like Tanzania where it is believed that their "blood, skin and hair have magical powers" (Adenekan, 2019, p. 1385). With the prevalence of myths and beliefs about albinism, many Nigerians with albinism experience widespread discrimination from families, schoolmates, and peers (Adenekan, 2019, p. 1388).

These prejudices are evident in *Sunny and the Mysteries of Osis* (2018). In the story, Auntie Uju (Orlu's aunty) reacts with disgust upon meeting Sunny. This mirrors broader discrimination of those with albinism in Nigeria. "[I]n Nigerian society, children with disabilities have been incorrectly understood, and this misunderstanding has led to their

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negative perception and treatment” (Eskay, et al., 2012, p. 477). Auntie Uju portrays the typical inhumane treatment experienced by people living with albinism and the perceptions that some members of the larger society have. This is evident in her use of foul words to describe Sunny:

‘Who is this?’ Auntie Uju snapped.

‘Auntie,’ Orlu said. ‘This is Sunny. She’s my...’

‘She is *albeeno*’ [sic], she said, her face curling with disgust. [...]

‘Look at this evil girl!’ his auntie shouted. ‘Look at her! Like ghost. She’ll bring illness, poverty, bad luck into the house! Child witch full of witchcraft!’

(*Sunny and the Mysteries of Osi*, 2018, p. 36)

Similarly, other works explore cultural attitudes towards other disabilities, including blindness. For instance, in Abubakar Adam Ibrahim’s “The Whispering Trees” (2012), which is grounded within the Hausa cultural context, Ibrahim considers the character’s struggles being treated as the object of others’ pity. The story’s protagonist, Salim, becomes blind due to an accident at the beginning of the story which causes him to postpone plans to become a medical doctor (“The Whispering Trees,” 2012, p. 46). The character laments the way he is treated by others. “I developed a phobia for eating in front of people. I felt as if they were looking at me, shaking their heads in pity. I hated being the object of their pity” (“The Whispering Trees,” 2012, p. 47). In addition to the personal trauma Salim experienced with a traumatic onset of blindness, he also must endure taunting and indifference from others. In one such case, his sister’s (Jamila) friend, Saratu, teases him for his difficulties dressing himself:

I woke up one morning and came out of my room. Even with my walking cane I still stumbled over the buckets and stools left out of place by the careless Jamila. I was in

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a hurry to get to the toilet. Then I heard someone giggling. I asked, “Jamila, why are you laughing?” It was not Jamila but her friend, Saratu. Saratu said, amidst giggles, “You are wearing your trousers inside out!” Then she cackled, very much like a hen. (“The Whispering Trees,” 2012, p. 48)

### **Empowering Characters with Disabilities in the Selected Literary Works**

In addition to addressing the various types of disabilities and the attitudes of members of the society towards disabilities characters, the writers addressed here also highlight various coping mechanisms adopted by characters. These coping mechanisms identified in the selected texts reiterate the adoption of the literary sociological approach in this study as the writers project coping mechanisms that are true to the reality of people with disabilities.

In addition to realistic depictions, at times authors may adopt other approaches, including use of the fantastical, in their representation. In Okojie’s *Butterfly Fish* (2015), Filo’s position as the “damaged, troubled wife” makes her unhappy, and she gets succor through spiritual means, from the presence of a brass head. The belief in the spiritual efficacy of the brass head is grounded in Benin history and culture. The people of Benin highly regard their arts, which “primarily consists of cast bronze, ivory, brass heads, figurines, brass plaques, large rectangular metal pictures, and carved wood works” (Irabor, 2019, p. 963). Benin City is historically known for its ownership of brass and bronze, as “casting in bronze - or more accurately, brass, bronze, and sometimes copper - began in Benin before the 13<sup>th</sup> century [...]” (Gunsch, 2018, para 3). In addition to the Benin arts being historical artifacts, they also have their spiritual significance. The brass head is spiritually substantial in Benin culture, as it combines the belief in the spiritual essence of the “brass” and the “head.” It is worthy to mention that the human head is highly significant across many African cultures. On this physical and supernatural significance of the human head, Ugochukwu-Smooth (2018)



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asserts:

In many African societies, the human head holds significant symbolism. It is explored at length in forms and performance arts (including masking traditions). Although the human body is equally celebrated as a reliquary that carries the soul in the mortal life and afterlife, the head holds deeper ramifications. It determines the individual as marker of personal identity and physical identification and ties the individual to family, ancestors, extended family, and community. (para 3)

In Benin culture, the combination of the brass and human head (through sculpting) is spiritually significant:

...the Benin [consider] the human head as imbued with spiritual energy (*ehi*) placed by the creator-god Osanobua and his eldest son, Olokun; this energy guides the mortal individual throughout his or her lifetime on earth. Ultimately, the sculptured head is a corporeal memento in honor of revered deceased individuals such as ancestors.

(Ugochukwu-Smooth, 2018, para 3)

In Okojie's *Butterfly Fish* (2015) the mystical effects of the brass head and its connection with Filo are established in the description of the effect of the brass head on Filo. The novel highlights this in the personification of the brass head:

[The brass head] called her, she was unable to resist its slow, rolling whisper. Soft yet insistent, it had folded her lobes before slipping inside her ear drums, saying her name softly, repeatedly [...] Yet behind her raised knees, something inside her locked [...] and Filo decided to stop crumbling beneath her desperation.

(*Butterfly Fish*, 2015, p. 154)

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Okojie elevates Filo from the position of a mere “troubled and damaged wife” to one who sets mysterious events in the palace in motion. In a quest for vengeance, Filo, successfully explores her vulnerability and uses it as a source of strength. Filo explores her pain as a “mother” who has repeatedly suffered the loss of a child, by invoking the spirits of her dead babies and those of the previous kings, all through the help of a medicine man (Kalu) who serves as an intermediary. This act of invoking the dead is a practice established in Benin culture and across other African cultures. The description of Filo’s action is illustrated towards the end of the novel thus:

[Kalu and Filo] continued to meet away from the watchful eyes of the palace and planned the unraveling of the Oba [...] It was Kalu that helped her call the spirits of the previous kings. And it was Kalu who told her what **was deemed to be her weakness was actually her greatest strength** [emphasis added]. Nobody would suspect the mad wife of setting the wheels in motion, of turning them with a sure finger. Filo **sent her babies to cause the very thing her Oba had mocked her for** [emphasis added].

[...]

That bright day, at the palace, her babies came back to her, glorious in the light, speaking the tongue she’d taught them. They ate from her hands, led her past the swirling activities, past the guards they’d left temporarily blind, and into the waiting arms of the day, touching the promises of the future.

And so the small procession of dead babies continues to cluck on the long, dusty trails they followed, telling Filo about the parts they’d played in the fall of a kingdom, changing into their chicken guises when Kalu’s whistles became warning winds.

(*Butterfly Fish*, 2015, pp. 34-341)

Similarly, Okorafor also explores the Igbo belief in the supernatural ascribing specific supernatural powers to the novel's protagonist, Sunny. Although as a person with Albinism Sunny has increased sensitivity to sun exposure (Newman, 2018), ironically Sunny's personal spirit (*chi*) is the Igbo mythic figure, Anyanwu, the sun-god (*Sunny and the Mysteries of Osis*, 2018, p. 1). Before proceeding with this analysis, it is important to mention that the concept of a personal spirit (*chi*) is grounded in Igbo cosmology. The *chi* is integral to the Igbo culture. As Ilogu (1985) explains, "one of the most striking doctrines of the Igbos is that [every] human being has associated with his personality a genius or spirit double known as his *chi*... (as quoted in Nwaezeigwe, p. 9). Arinze (1978) further elaborates about the significance of the *chi* among the Igbos:

Most *Ibos* believe that each individual has a spirit, a genius or spiritual double, his *chi*, which is given to him at conception by *Chukwu* and which accompanies this individual from the cradle to the grave. *Chi* is strictly personal [...] The ordinary *Ibo* man regards his *chi* as his guardian on whose competence depends his personal prosperity. (pp. 88-89)

Sunny's *chi* in *Sunny and the Mysteries of Osis* (2018), the sun god *Anyanwu* (which means "sun"), is a deity worshipped among some Igbo communities with "special and close association with the supreme deity" (Ukwamedua & Edogiaweri, 2017, p. 327). *Anyanwu*'s position as Sunny's *chi* represents Sunny's elevated position in the supernatural realm. *Anyanwu* is regarded among the Igbos as a good spirit whose goodness and revered high status are such that it is:

ignorantly confused with or even identified with *Chukwu*, the supreme being. Some title names for God in different areas include Anyanwu (sun) as AnyanwuChukwuOkike. Anyanwu is regarded in a special way as a deity bringing

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wealth and good fortune to the people (Ukwamedua & Edogiaweri, 2017, p. 323).

The close relationship between both deities (*Chukwu* and *Anyanwu*) in Igbo cosmology is illustrated in Sunny's privileged meeting with *Chukwu*. This meeting is specifically portrayed as a privileged as evident in the description of the reverence of *Chukwu* in the Igbo culture:

Chukwu was the name the Igbo people used for the Supreme Being. The great deity known as Chukwu was so inaccessible to human beings that one didn't even pray to it. If Chukwu gave you audience, you probably would have no idea why and you'd be in such awe, it wouldn't really matter.

(*Sunny and the Mysteries of Osi*, 2018, p. 205)

Okorafor's choice of *Anyanwu* as Sunny's spirit face and *chi* indicates a strong message that people living with albinism are meant to be treated as the humans that they are, respected rather than discriminated against. We have noted that the choice of the sun-god as Sunny's personal spirit is ironic given the sensitivity to the sun experienced by many with albinism (Baker et al., 2010). People with albinism often experience "partial or complete absence of pigment from the skin, hair and eyes...[resulting in lighter] skin, sandy-colored hair, light brown eyes, and [frequently experience] nystagmus, photophobia, and poor visual activity" (p. 169). These experiences are mentioned in the novel with Okorafor specifying ways to manage the situations for people with albinism. It is mentioned in the novel that Sunny had to go for eye exams and resorted to using glasses to improve her sight and protect her eyes from the effect of the direct sunlight (*Sunny and the Mysteries of Osi*, 2018, p. 2). This choice appears to be Okorafor's suggestion that the skin of people living with albinism radiates and shines like the sun, and that as such they could as well stand as honored physical representations of *Anyanwu*, the sun deity.

Similarly, Ibrahim's "The Whispering Trees" (2012) explores indigenous Hausa cultural beliefs as a means of empowering the story's protagonist, Salim. Salim's sudden blindness makes him realize he had previously taken his good health for granted. The first major step that Salim takes as a means of coping with the sudden onset of his blindness is the acceptance of his condition. Salim fully accepts his new state as he starts life afresh by going to the school for the blind and learning to write and read Braille ("The Whispering Trees," 2012, p. 55). His acceptance also guides him towards exploring the possibilities of viewing life from another angle, considering "how it takes being blind to fully understand someone or to see them truly, rather than looking through reality" (Hosking, 2005, p.65). Salim's acceptance results in his exposure to his supernatural ability to read the minds of animate (humans and animals) and inanimate entities ("The Whispering Trees," 2012, p. 60), as well as his ability to interact with the dead (p. 62). The belief that certain individuals can interact with the dead, as well as the belief that inanimate entities have their souls just like humans is traceable to the indigenous Hausa *Maguzawa* religion (Abar, 2019). This religion is still practiced in parts of Sokoto and Zamfara States" (A.A. Ibrahim, personal communication, December 7, 2020). The *Maguzawas* believe that spirits which are referred to as "*iskokai*" (A.A. Ibrahim, personal communication, December 7, 2020) adopt "trees as their dwelling place" (Greenberg, 1941, p. 57). Additionally, *Maguzawas* believe that "spirits can attach themselves to, or acquire the form of, either people, or animals, or inanimate objects (mostly rivers, trees, or mountains (Bala, 2015, p. 11.)

Ibrahim elevates Salim to the role of a "doctor" who could now "treat ailments of the soul" ("The Whispering Trees," 2012, p. 64). Salim can use his newfound ability both for his own good as well as that of others as he helps them solve their life problems. His supernatural ability to treat soul ailments and correct false historical antecedents is illustrated in his ability to unravel the mystery behind the death of one of his childhood friends, Hamza. Salim helps

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to correct the previous impression that Hamza had been killed by the “resident *iskokais* that made the trees whisper” (“The Whispering Trees,” 2012, p. 53). He was able to unravel this truth through his interaction with the soul of his childhood friend, Hamza, who had died when they were young (“The Whispering Tree,” 2012, p. 62). Salim, through his unraveling of the real cause of Hamza’s death, helps heal Tanimu (another childhood friend), who had always believed that he was responsible for Hamza’s death. Tanimu feels relieved after Salim recounts Hamza’s narration of his death, from the realm of the dead. (“The Whispering Trees,” 2012, pp.63-64). Salim’s retelling of the true incidents that led to Hamza’s death results in the liberation of Tanimu’s soul from years of guilt and restores calmness and joy to Hamza’s mother (“The Whispering Trees,” 2012, p. 65). The story ends with Salim’s full acceptance of his blindness and supernatural abilities. Salim then becomes more relevant in the community due to his new role as an intermediary between the realms of the living and the dead, which is a belief grounded in the indigenous Hausa *Maguzawa* practice. Salim’s new role is described thus:

I rediscovered life in serving and I discovered heavenly peace in the Whispering Trees, where I now spend hours listening to the melodies of nature and to the dead. They come once in a while, seeking to reach out to loved ones before taking their final leave.

So it was that I lost my sight to find my vision, I lost my life to find my soul and I lost my vanity to find my purpose (“The Whispering Trees,” 2012, pp. 65-66)

### **Conclusion**

This essay has examined attitudes toward people with disabilities, the suggested

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coping mechanisms for people living with these disabilities, as well as the ways the selected writers may be seen to empower disabled characters by reintegrating them into their larger communities. The paper examined these using a literary sociological approach to analyze the selected primary texts: Irenosen Okojie's *Butterfly Fish* (2015); Nnedi Okorafor's *Sunny and the Mysteries of Osis* (2018); and Abubakar Adam Ibrahim's "The Whispering Trees" (2012).

The selected writers address physical and psychological forms of disabilities experienced by people with disabilities, some coping strategies some employ, and more largely their treatment by others, including discrimination. Sunny is born with albinism in Okorafor's *Sunny and the Mysteries of Osis* (2018). Salim in Ibrahim's "The Whispering Trees" (2012) becomes blind due to an accident, while Filo in Okojie's *Butterfly Fish* (2015), experiences mental illness related to life challenges. Also, the mistreatment of the primary disabled characters represented in the selected primary texts reflect prejudicial attitudes towards people with disabilities more broadly. This is evident in the attitude of Orlu's Auntie Uju towards Sunny due to her albinism, the mockery that Salim experiences from his sister's friend, Saratu, as well as the neglect that Filo experiences from her husband and other members of the palace. The writers project these societal negative attitudes as means of sensitizing and changing the perception of society toward people with disabilities. Various coping mechanisms are also suggested in the primary texts. These include the need to ensure persistent eye check-ups for people living with albinism identified in Okorafor's *Sunny and the Mysteries of Osis* (2018), and the potential to reassess one's relationship to self and community present in self-acceptance in Ibrahim's "The Whispering Trees" (2012).

The selected works addressed here evidence authors empowering disabled characters with various forms of supernatural abilities, all of which are grounded in the represented cultures of each primary text: Benin in Okojie's *Butterfly Fish* (2015); Igbo culture in

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Okorafor's *Sunny and the Mysteries of Osi* (2018); and Hausa culture in Ibrahim's "The Whispering Trees" (2012). These characters all gain empowerment and assistance from the supernatural in different forms. The supernatural empowerment and assistance are for the benefit of the individual characters and the community, re-establishing the communal spirit that exists across many Nigerian cultures. The study, therefore, concludes that the selected writers have succeeded in representing people living with various forms of disabilities in Nigerian societies, by raising relatable issues, establishing the place of these issues within various Nigerian cultural contexts, and proffering solutions.



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## Cultural Etiologies of Disability in Ghana: A Case of Food Taboos in Pregnancy

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### Abstract

In Ghana, most food taboos have their foundations in religious and cultural philosophies which reinforce negative etiologies and understanding of disability. Employing secondary data and personal experience; this article examines food taboos across three ethnic groups in Ghana and their cognitively held correlation with disability in unborn children and infants.

*Keywords:* disability, food Taboos, pregnancy, Africa

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Ghana is rich in culture, religion, and philosophical values made up of animate, inanimate, and numerous unforeseen forces (Nyangweso, 2018; Abudu and Imafidon, 2019). These interact and help form the reality and worldview for many Ghanaians, helping explain and define what is expected in life (Abudu and Imafidon, 2019). This suggests that views and understandings of disability are similarly rooted in cultural, religious, and general societal perceptions with justifiable rationale and/or beliefs that are neither homogenous nor static (Roberts and Lindsell, 1997; Nyangweso, 2018). This article aims to draw attention to an overlooked perspective when it comes to consideration of disability in Ghana. This article will highlight some of the cultural underpinnings of disability in pregnancy with key references to food taboos. The contextual scope will be based on three (3) ethnic groups in Ghana: *the Ga-Adangbe, the Akans, and the Ewes*.

I draw my definition of disability from the International Classification of Functioning, Disability, and Health (ICF) model under the World Health Organization (WHO). This is because it is the definition adopted by the Ghana Statistical Service (GSS) during the 2010 population and housing census in Ghana<sup>iv</sup>. The ICF model<sup>iv</sup> defines disability as “*the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)*” (WHO 2001:213).

Disability is therefore perceived as functional limitations and restrictions (Cobley 2018). Under this definition, three (3) components of functioning are considered: *body function and structure, activities, and participation*. The *body function/structure* correlates to the health condition/impairment such as vision or speech impairments, whereas the *activities’* function relates to the constraints in undertaking daily activities such as eating and walking. Lastly, the *participation* function comprises constrictions in aspects of life such as schooling and employment (Banks, Kuper, and Polack, 2017; Cobley, 2018; Cobley and Bezzina,

2019). The interaction of these three functions coupled with personal factors such as age, gender, and environmental factors such as inaccessible infrastructure and negative behaviors determines the extent of disability.

This article is structured into three broad sections. The first section titled *an overview of disability, food taboos, and ethnicity* presents some background information on disability, food taboos, and ethnicity in Ghana and other parts of sub-Saharan Africa. This is followed by exploring perceived different disability-associated food taboos during pregnancy. The last section highlights some ways of addressing these purported disability-associated food taboos during pregnancy.

## **An Overview of Disability, Food Taboos, and Ethnicity in Ghana**

### ***Background of Disability in Ghana***

In the 2010 population census, it is estimated that 3% of Ghana's population have some form of disability (GSS, 2013, 2014)<sup>iv</sup>. Out of this percentage, 52.5% are females, whereas the remaining 47.5% are males (ibid). In Ghana, three (3) main religions are dominant: *Christian (71.2%), Islam (17.6%) and Traditional (Indigenous - 5.2%)*. Mirroring the religious structure of Ghana, 69.5%, 13.7%, and 7.8% of persons with disabilities (PWDs) are Christians, Muslims, and Traditionalists respectively. Concerning ethnicity, there are predominantly eight (8) ethnic groups in Ghana. In descending order are the *Akan (47.5%), Mole-Dagbani (16.6%), Ewe (13.9%), Ga-Adangbe (7.4%), Gurma (5.7%), Guan (3.7%), Grusi (2.5%), Mande (1.1%) and others (1.4%)*. Like the religious structure, the ethnic structure of PWDs in Ghana mimics the national pattern. 40.80% of PWDs are Akan, 18.5% Mole Dagbani, 18.4% Ewe, 5.7% Ga-Adangbe, 4.9% Gurma, 3.9% Guan, and 1% Mande ethnic groups (GSS, 2012, 2013, 2014). As indicated earlier, this article will focus on the Akan, the Ewe, and the Ga-Adangbe ethnic groups. The choice of ethnic groups is

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primarily based on the availability of secondary data.

The understanding of disability in Ghana is rooted in cultural and religious beliefs that are mostly negative and discriminatory in their conceptions of disability (Abudu and Imafidon, 2019; Leshota and Sefotho, 2020; Naami, 2015; Nyangweso, 2018; Ocran, 2019; Opoku et al., 2019). For instance, the Ashantis sub-ethnic group (from the Akan ethnic group) killed infants born with physical differences such as six (6) fingers<sup>iv</sup> upon birth (Rattray & Christaller, 1969). Again, children with Down syndrome, autism and other neurodivergent spectrum were seen as “animal-like” and would often be abandoned by the riverbanks or near the sea so they return to what is believed to be “their kind” (Bayat, 2014; Nyangweso, 2018).

In exceptional cases, where the discriminatory behaviors are reversed, PWDs are deified and idolized, rarely affording them the opportunity of living like everyone else (Abudu & Imafidon, 2019; Nyangweso, 2018). For example, the Gas sub-ethnic group (from the Ga-Adangbe ethnic group), revered neurodivergent individuals with awe and wonderment as they were believed to be a reincarnation of a deity (Field, 1937; Nyangweso, 2018); hence they are treated with immense kindness, gentleness, and patience.

### ***Food Taboos***

Taboo is a bigger concept than sacred or secular and clean or unclean (Douglas, 2002; Salihu et al., 2019; Sigmund, 2003). It means any ritual prohibition to which an automatic sanction is attached (Douglas, 1966, 2002). Taboos exploit an innate, irrational fear in the human psyche (Sigmund, 2003). According to Douglas (1970, 2002), taboos are screaming headlines, and one should be wary of imputing latent and rational functions to taboos, for example, medical reasons for the Judeo-Islamic taboo on pork (ibid).

Food taboos simply mean the avoidance of certain foods based on personal, religious, cultural, and health reasons. Food taboos could broadly be categorized into two (2) groups:



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*temporal* and *permanent*. Temporal food taboos are foods that are generally consumed but, due to certain activities or situations such as religious fasting, pregnancy, etc. are not consumed (Arzoaquoi et al., 2015; Asi & Teri, 2016). Permanent food taboos are foods that should never be consumed mainly because such foods may cause serious health issues (such as allergies resulting in death) or such foods are seen as sacred (for instance, totems, [some of the totems of the Lafe sub-ethnic group under the Ewe ethnic group are the antelope ‘se’ \[in Ewe\] and sparrow ‘atsutsrœ’ \[in Ewe\]](#)) (Chakona & Shackleton, 2019; Kuzma et al., 2013).

The avoidance of certain foods could have positive or negative implications. For instance, an individual avoiding peanut, groundnut, and other types of nuts due to established allergic reactions ensure the safety and health of that individual. Alternatively, abuse of human rights occurs when food taboos are imposed against the wishes of individuals within a sub-ethnic group (clan) or ethnic group. For instance, a pregnant woman from the Ga-Adangbe ethnic group is asked (sometimes openly or through implied customs and practices) not to eat mudfish because she is pregnant. This limits her agency and instills fear and anxiety as the consumption of mudfish during pregnancy is purported to lead to health impairments of the foetus. These food taboos and others will be discussed further in this article.

Food taboos (in both written and unwritten social rules) exist in one form or another in every society. Religion, culture, and health stipulate foods that are fit and unfit for human and animal consumption. Food taboos, among other beliefs and practices, have a long history and are based on centuries of trial and error (Gadegbeku et al., 2019). On a comparative basis, many food taboos seem to make no sense at all, as what is declared unfit by one group may be perfectly acceptable to another (Meyer-Rochow, 2009). Food taboos are conscious actions taken to avoid certain foods based on causal explanation – logical, supernatural, or difficult to explain rationally. According to Meyer-Rochow (2009), one ought to expect a

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sound explanation for the existence (and persistence) of certain dietary customs in each culture. Food taboos are part of complex attitudes relating to the sense of taste, feelings, and abstentions which are concerned with the creation and maintenance of cultural differences, male authority, and gender inequalities (Whitehead, 2003). This article presents some of the gendered dynamics of food taboos related to disability among pregnant women in Ghana. The original link between people and land produces traditions and practices in specific environments, and in this instance, food taboos and other held beliefs and practices concerning pregnant women (Shorter, 1998).

In Ghana, the understanding of disability and its formation is deeply rooted in religion and culture. Disability in Ghana is understood and defined within the realms of spiritual forces – test of faith, unique gift, curse, and punishment. For instance, ancestral violations of social norms such as incest and breaking food taboos are deemed to result in the birth of children with atypical and neurodivergent developments such as autism and dyslexia (Gadegbeku et al., 2019; Nyangweso, 2018). In Ghana, Christians and Muslims alike combine Christianity and Islamic practices with some Indigenous (Traditional) practices. For example, outdoorizing new babies and new mothers are typical amongst most ethnic groups in Ghana. This practice takes place on the eighth day after birth and involves formally presenting a newborn baby to the gods, society, and ancestors. Before the eighth day, it is not permitted for the newborn to be brought outside to avoid negative influences that may adversely affect the health of the child. After this and other Indigenous (Traditional) practices, a Christian family will later take the newborn to church for baptism.

This mixture of religions sometimes reinforces positive attitudes, behaviors, and practices or exacerbates negative ones. In Ghana, a pregnant woman is seen as a treasure, a demi-god, and at the same time vulnerable. In some cases, pregnant women are expected to behave in certain ways to ensure that it does not affect the unborn baby.

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I have experienced some of these dynamics during my own pregnancy. An encounter in 2016 in a market in Ghana demonstrates some of the contradictory associations (both negative and positive) assigned pregnancy. I had wanted to buy two fingers of plantain. I, therefore, asked the plantain seller if she would divide the five fingers of plantain she had arranged and give me two. During that time, her back was facing me. She said “No,” and I gradually turned around to leave while she turned to face me. Realizing I was pregnant (by then I had a big belly and some swollenness on my face), she immediately retracted her earlier stance of “No” and said, “please come and get the two fingers before you go and steal it (because you are craving for it) and make your unborn baby suffer a bad omen or curse me.” Clearly this evidences some of the contradictions associated with pregnancy in Ghana.

Lastly, monumental situations of life such as pregnancy and childbirth continue to be notoriously surrounded by food taboos relating to disability and good health (Gadegbeku et al., 2019; Getnet et al., 2018). Moreover, these foods are linked to the same or similar food taboos across sub-Saharan Africa, affirming the centrality, gendered and cross-cutting nature of the neglect of food taboos linked to disability among pregnant women in Ghana and other parts of sub-Saharan Africa such as Nigeria, Cameroon, Ethiopia, and South Africa (Asi & Teri, 2016; Chakona & Shackleton, 2019; Ekwochi et al., 2016; Getnet et al., 2018).

### ***Ethnicity and Culture***

The classification of ethnic groups in Ghana is provided by the Bureau of Ghana Languages (BGL) and has been used since the 1960 census (GSS, 2013). Ethnicity refers to a sense of kinship, solidarity, and common culture (Hutchinson & Smith, 1996) which often nurtures positive feelings of belonging to a cultural group (Guibernau & Rex, 1999).

In Ghana and most parts of Africa, human groups created their societies and traditions within environments which represented multiple adaptations to different and similar

ecosystems (Shorter, 1998). These ethnic groups were categories of interaction, representing clusters of groups and dialects, masking together (ibid). Centuries of trade and slavery “ethnicized” groups with colonialism politicizing them further, resulting in radical or structural change within these ethnic groups (Dwyer & Drakakis-Smith, 1996; Guibernau & Rex, 1999; Hutchinson & Smith, 1996; Shorter, 1998). Ethnic groups remain classifications of interaction and distribution with old and new fields of application in both pre and post-colonial states (Shorter, 1998). Ethnic groups are seen as a whole society, having a high degree of self-sufficiency, politically autonomous, with their distinctive language, culture, and identity such as the Asante kingdom within the Akan ethnic group (McCaskie, 1995; Shorter, 1998).

Ghanaian traditional ethnic societies and other parts of sub-Saharan Africa are often associated with a mentality that differs from the science of modern societies (Shorter, 1998). Different labels have been given to this mentality – primitive morally and culturally, unable to differentiate between subject and object, magical, impervious to logic, etc. (ibid). Nonetheless, these ethnic groups continue to foster a sense of belonging and development within communities.

### **Ghanaian Ethnic Groups (In Focus)**

The ethnic groups under discussion comprise 11 out of 16 regions in Ghana. These ethnic groups found across 11 regions are situated within the southern and some parts of the middle belt of Ghana represented in regional map depicted in Figure 1 below.

**Figure 1***The Map of Ghana*

Source: [Ghana Districts, 2019](#)

For the Akan ethnic group; nine (9) regions broadly fall under this: Brong Ahafo, Bono East, \*Oti (parts of the Oti region), Ahafo, Western North, Western, Central, Ashanti, and \*Eastern (parts of Eastern regions), Ashanti, Eastern, Western, Central, and Brong Ahafo regions. Secondly, the Ga-Adangbe ethnic group encompasses two (2) regions: Greater Accra and parts of the Eastern region. Thirdly, the Ewe ethnic group is situated mainly in the Volta

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and parts of the Oti region. Almost all important aspects of these three (3) ethnic groups: *Akan*, *Ga-Adangbe*, and *Ewe* have been documented by several authors and credible web pages<sup>iv</sup> (Agbodeka, 1997; Kissi et al., 2017; Lawrance, 2005; R. S. Rattray & Christaller, 1969). The duplication of their work is not necessary; however, a brief overview would provide readers with some background information and context to the article.

### ***The Akan Ethnic Group***

The Akan people constitute the largest ethnic group in Ghana (GSS, 2012, 2013). About 44% of the Ghanaian population speak Akan as non-native speakers (Agyekum, 2006). The Akans occupy a greater part of the southern sector of Ghana, precisely 9 out of 11 southern regions. Some Akans are also found in Cote d'Ivoire as well. One major food among the populace is boiled pounded cassava and plantain ("*fufu*") with green or tomato soup served with bush meat.

### ***The Ga-Adangbe Ethnic Group***

The Ga-Adangbe make up about 7% of the Ghanaian population (GSS, 2012, 2013). Some Ga-Adangbe's are also found in Togo and Benin (Dakubu, 1972). They live primarily in the Greater Accra region and some parts of the Eastern region. Fermented blended and moulded boiled corn ("*kenkey*") and fried fish served with hot and spicy chilli sauce are common food found among the Ga-Adangbes.

### ***The Ewe Ethnic Group***

Constituting about a tenth of the Ghanaian population (GSS, 2012, 2013), the Ewes occupy predominantly the Volta region and some parts of the Oti region. The Ewes could also be found in Togo and Benin (Agbodeka, 1997; Lawrance, 2005). Cornmeal ("*akpele*") and okra sauce or soup served with fish or meat is a common meal found with the Ewes.

## **Disability-Associated Food Taboos During Pregnancy**

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### *Ghanaian Disability-Associated Food Taboos During Pregnancy*

In Ghana, there is a widespread belief that pregnant women should refrain from eating certain foods or risk giving birth to children with disabilities. I discuss below broadly three (3) food taboos in the form of snails (among the Ga-Adangbe ethnic group), bush meat (duiker (antelope) and greater cane rat (grasscutter) (among the Akan ethnic group) and mudfish (among the Ewe ethnic group).

#### **Snail**

Snails are herbivores found in most parts of West Africa, Spain, France, Portugal and a few other countries and are seen as one of the cheapest sources of proteins in West Africa (Adeyeye et al., 2020; Fagbuaro et al., 2006). Snails have a 37 to 51% protein content compared to guinea pig (20.3%), poultry (18.3%), fish (18%), cattle (17.5%), sheep (16.4%) and pig (14.5%). They are also low in fat and are a source of iron, magnesium, calcium and zinc (Adeyeye et al., 2020; Eton, 2022). Zinc is involved in body processes which helps to reduce fatigue, and promote good skin and a healthy heart (Eton, 2022). Although snails are among the rarest foods to produce allergies and health complications (de la Cuesta et al., 1989), there are however snail-borne parasitic diseases, such as schistosomiasis, which causes immune reactions and progressive damage to organs (Lu et al., 2018; WHO, 2022). Schistosomiasis is an acute and chronic parasitic disease where people become infected when the larvae of the parasites (released by freshwater snails) infiltrate the skin during contact with infested water (WHO, 2022); it is very prevalent in areas without access to safe water and adequate sanitation.

The snail taboo is being discussed within the Krobo sub-ethnic group which falls under the Ga-Adangbe. This taboo although prominent among the Krobo people is largely acceptable among pregnant women in Ghana and elsewhere in West Africa such as in Nigeria

(Arzoaquoi et al., 2015; Ekwochi et al., 2016; Gadegbeku et al., 2019). Snails' prohibition as food during pregnancy has been motivated by their association with poor saliva control and the dribbling mouth of a baby whose mother ate snails during pregnancy. It is widely accepted that the consumption of snails during pregnancy by the expectant mother could lead to cerebral palsy, intellectual disability, and other neurological impairments (ibid).

### **Bushmeat (Duiker [antelope] and Greater cane rat [grasscutter])**

The duiker (antelope) and greater cane rat (grasscutter) form part of a wider group of animals referred to as "bushmeat." The antelope and grasscutter are omnivores and herbivorous animals respectively and are seen in most parts of sub-Saharan Africa (Animalia, 2022a, 2022b). Bush meats are generally expensive in West Africa but similar to the snails, have very high protein content (Jori et al., 1995; Niyi, 2014). In addition, the feces of the greater cane rat taken directly from the caecum and colon are also used in soups and sauces due to their high iron and mineral contents (Jori et al., 1995). The feces could be compared with nutritional contents in cocoyam leaves (called "*kotomire*" in Ghana) or spinach. Bush meats have been linked to endemic cases of diseases from animals spread to human beings such as the Ebola Virus Disease (Onyekuru et al., 2020; Subramanian, 2012).

Bushmeat is a common delicacy among the Akans and rapidly growing in popularity in Ghana and across sub-Saharan Africa (van Vliet et al., 2011). The greater cane rat (grasscutter) is seen as a totemic animal for twins among the Akuapims sub-ethnic group of the Akan ethnic group (Arzoaquoi et al., 2015; Gadegbeku et al., 2019). Pregnant women and twins are prohibited from eating greater cane rat as it is believed to cause intellectual and other developmental disabilities (Gadegbeku et al., 2019). In addition, the Akuapims also believe that the duiker (antelope) causes leprosy (ibid). Therefore, people who belong to the Akuapim sub-ethnic group, including pregnant women, are prohibited from consuming duiker (antelope). Unlike the snail food taboo, there seems to be no explanation directly



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linked to the food itself, rather than its totemic symbolism.

### **Mudfish**

Mudfish (also known as bowfin in some parts of the world) is present in the waters of West Africa, the Americas, Asia and Australia (Cleaveri, 2003). Mudfish is high in protein, iodine, omega-3 fatty acids and minerals (Amegovu et al., 2017; Weyant, 2022). Similar to other finned fish such as tuna, and salmon, mudfish can trigger fish allergies such as hives, nausea, indigestion, diarrhea, asthma and in extreme cases anaphylaxis—a life-threatening reaction that impairs breathing (ACAAI, 2022). These allergies can be managed through strict avoidance and medication, as with other allergies with nuts, lactose, gluten, etc.

The Ewe ethnic group forbids pregnant women carrying twins and twins from eating mudfish. This is because it is believed to cause mental health issues such as schizophrenia and bipolar disorders (Gadegbeku et al., 2019), although there is no explanation for this food taboo based on the literature reviewed. Is it possible that the prohibition is attributed to the name of the fish (“mud”) with the homophonic word “mad”? This question is worth exploring to contribute to the accumulation of Ghanaian knowledge on gendered food taboos and disability.

As indicated earlier, food taboos exist in almost all ethnic groups in Ghana. For instance, the Grusi ethnic group prohibits the consumption of animal (cow) hide (called “*wele*” in Ghana) (Arzoaquoi et al., 2015; Gadegbeku et al., 2019). The Grusi ethnic group are mostly found in Northern Ghana. In Northern Ghana, when chiefs and kings are enskinned, the treated and dried animal hide is a symbol of chieftaincy and kingship. Although there are controversies surrounding the nutritional values of “*wele*” such as negligible protein content (Agbeka, 2020), “*wele*” is a Ghanaian local delicacy present in foods such as tomato sauce, green sauce, okra sauce, soups, etc. (This is incidentally a

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personal favorite of the author: I consumed [and continue to consume] in pre-pregnancy, during pregnancy and post-pregnancy phases.) It is believed to cause miscarriage during pregnancy and delay to the detachment of the umbilical cord, thereby posing health complications for both the unborn baby and expectant mother (Gadegbeku et al., 2019; Getnet et al., 2018; Whitehead, 2003). Food taboos associated with disability continue to exist among pregnant women in Ghana and other sub-Saharan African countries.

### **Sub-Saharan Africa Disability-Associated Food Taboos During Pregnancy**

Food taboos are enshrined in cultural and religious heritage and cut across sub-Saharan Africa. Briefly presented in this section are disability-associated food taboos during pregnancy across sub-Saharan Africa. In East Africa, Ethiopia (Awabel District) specifically, *bananas* are prohibited foods among pregnant women because they are believed to produce a uniquely shaped head of a fetus (Getnet et al., 2018). In other parts of West Africa such as Nigeria (Enugu, South Eastern), snails are food taboos among pregnant women because they are believed to trigger poor saliva control causing intellectual and other developmental disabilities similar to the Ghanaian case (Ekwochi et al., 2016). Furthermore, in Southern Africa, precisely South Africa (Kat River Valley-Eastern Cape), orange or orange juice is a prohibited food among pregnant women because it is believed to produce yellow skin, yellow pimples/rash, yellow eyes, and cracked lips resulting in albinism (Chakona & Shackleton, 2019). Lastly in Central Africa, with particular reference to Cameroon, the meat of wild animals such as leopards, crocodiles, and monkeys are food taboos among pregnant women as are believed to cause mental and behavioral health conditions such as schizophrenia, bipolar disorder among others (Asi & Teri, 2016). These disability-associated food taboos are prevalent in the African continent and particularly within ethnic and other cultural groups in sub-Saharan Africa. The shared experiences and customary practices inherent in our African culture and religion continue to promote the understanding of disability within the space of

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pregnancy food taboos.

### **Implications of Food Taboos for Disability**

Food taboos are generally monopolistic and skewed mainly towards females, in the case of pregnancy. If a pregnant woman has sexual relations with a partner who consumes these forbidden foods, does it also cause disability? I have more questions than answers about the gendered dimension of these food taboos. Additionally, these food taboos are deeply rooted in cultural beliefs passed on from one generation to another and are prevalent in both rural<sup>iv</sup> and urban areas, although a bulk of cases are found in the rural areas. Currently, there is no data to confirm the perceived disability associated with food taboos in pregnancy. This brings to the fore the culturally gendered perspectives of disability in Ghana and other parts of sub-Saharan Africa and the need to claim rightly the understanding of disability and disability justice by researching and disseminating information on disability-associated food taboos during pregnancy. Again, these also unearth the geographical dynamics of food taboos associated with a disability during pregnancy.

Some food taboos prevent pregnant women from accessing a well-balanced diet, resulting in a high prevalence of low birth weight and harm to mother and baby (Asi & Teri, 2016; Kuzma et al., 2013; Whitehead, 2003). Therefore, one could argue that in upholding or strictly adhering to food taboos during pregnancy, unborn babies face a greater risk of health issues that could lead to impairment rather than the reverse.

Further, the typology of disability-associated food taboos during pregnancy differentiates between disability typologies. This affirms the African disability typology proposed in “The Handbook of African Philosophy of Difference,” edited by Imafidon (2019). From this book, two broad African disability typologies exist: “*persons with universal disabilities*” such as the visually impaired and the physically challenged who fall

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within the categorization of common or widespread human difference; and “*persons with particular disabilities*” such as persons living with albinism and persons with angular kyphosis who fall within the categorization of uncommon human difference and perceived as “mysterious beings with special powers” (persons within this category are mostly slain and maimed to amass wealth in the spiritual realm) (Abudu & Imafidon, 2019, pp. 395–398). These disability typologies associated with pregnancy food taboos fall broadly under particular disabilities.

### **Recommendations and Conclusion**

#### **Way-Forward for Disability-Associated Food Taboos During Pregnancy**

The typology of food taboos comprises homogenous and heterogenous foods across Ghana and other parts of sub-Saharan Africa (national/continental issue). Different approaches will be needed for different food taboos and different geographical spaces.

- i. Education through sensitization and communication through the dissemination of disability and disability-related research could be a way to go. For instance, national institutions, civil societies, Non-Governmental Organizations (NGOs), religious institutions, educational institutions, think tanks, etc. need to periodically sensitize and share information on disability and its causes. Using where possible the lived experience of PWDs such as Farida Bedwei (<https://www.weforum.org/people/farida-bedwei>), a Ghanaian software engineer with cerebral palsy, could help people understand disability better.
- ii. At the community level, engagement with traditional and religious leaders as facilitators are key. They are the custodians of traditions and customs. A transformative approach is important here, which takes time; this is because culture and perceptions are not easily broken; education needs to emanate from community leaders and members themselves with support from experts.

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- iii. Disability sensitization activities and programs should not only target persons with disabilities but persons without disabilities as well as men and women.
  - iv. Health services centers such as reproductive health clinics, ante-natal, and post-natal services are good hotspots for discussing issues of disability. Pregnant women (with and without disabilities), new mothers (with and without disabilities), men (with and without disabilities), etc. could serve as facilitators depending on the local context to discuss issues further.
  - v. It is important to encourage women (with and without disabilities) to share their pregnancy journeys. This will take time as this is very uncommon in Ghana and many parts of sub-Saharan Africa due to the myths and traditions surrounding pregnancy and childbirth.
  - vi. There is the need for periodic and several medical research pieces to debunk the disability-associated-food taboos in pregnancy. Funding would be a key catalyst to ensuring its materialization.

## Conclusion

The understanding of impairments and disability deeply rooted in beliefs translated into myths, stories, and folktales needs to be rejected as it produces mental health issues such as anxiety, inferiority, self-consciousness, fear, marginalization, exclusion, etc. (Wright, 1960) among pregnant women. The experiences of PWD in Ghana and other regions of sub-Saharan Africa are of serious concern. And their being stigmatized and marginalized, etc. is rooted in cultural and religious beliefs (Nyangweso, 2018).

In the Global North, particularly the UK, the medical model<sup>iv</sup> of disability which defines impairment and disability as a medical or health condition has been greatly criticized by several authors (Michael Oliver, 1990; Finkelstein, 2001; Mike Oliver and Barnes, 2006; Morris 2001; Garland-Thomson, 2017; Shakespeare, 2016). At the same time, perhaps it may

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be leveraged for evidence-based explanations into the ontological perspectives of impairments and disability in Ghana and other parts of sub-Saharan Africa. In strategically applying some aspects of the model, conscious efforts must be made to ensure that disability is not viewed as a personal/individual or family tragedy or issue but rather as shared social responsibility (Barton & Oliver, 1997; Imhoff, 2017; Nyangweso, 2018; Shakespeare, 1997).

These restrictive etiologies need to be questioned through evidence such a model may arguably present. Understanding disability is key to ensuring inclusivity. Such an understanding in Ghana and elsewhere in Africa is deeply rooted in culture. Culture and ethnic identity are basic aspects of what it means to be human. As such, they are wedded to basic human rights (Wagner, 1981) in Ghana and Africa as a whole. Moreover, through disability-associated food taboos in pregnancy, a system of acculturation in the form of cultural aggression and domination occurs. Addressing such abuse of human rights for both pregnant women and PWDs requires continuous research, sensitization, and dissemination; all are key to debunking the negatively held correlation (or otherwise) between food taboos and disability during pregnancy.

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### Endnotes

<sup>iv</sup> I draw on statistical and non-statistical data from the 2010 Ghana population and housing census conducted by the Ghana Statistical Service.

<sup>iv</sup> The ICF Model does not go without criticism. Disability is perceived as functional limitations and restrictions (Cobley, 2018). Some authors argue that persons with disabilities should have the freedom of achieving functioning feasible to them- act, participate or live on behalf of what matters to them; something currently absent from the ICF model (Mitra & Shakespeare, 2019; Sen, 1999; Whiteneck, 2006).

<sup>iv</sup> In contrast, the 2011 world report on disability puts the disability prevalence rate at 12.8% (WHO, 2011). This disparity is largely due to how disability was measured. The 2010 Ghanaian census adopted a binary (yes or no) format in measuring the disability prevalence

instead of using the recommended Washington Group Short Set -WG-SS (WG, 2021).

Although the WG-SS is without criticism, it can expand the scope to capture more aspects of disability. In the just-ended 2021 census, Ghana however used the WG-SS (GSS, 2021).


Preliminary reports from the 2021 census push this percentage to 8% (GSS, 2022). The issue of measurement goes beyond the scope of this article; however, it is an important driver.

<sup>iv</sup> Polydactyly (individuals with extra fingers/toes) is present in 1 in 1000 births globally, with a higher incidence of 1 in 150 births in the black population (Rathjen et al., 2017).

<sup>iv</sup> Some of these web pages include GhanaWeb ([www.ghanaweb.com](http://www.ghanaweb.com)), Ghanadistricts ([www.ghanadistricts.com](http://www.ghanadistricts.com)), Britannica ([www.britannica.com](http://www.britannica.com)), among others.

<sup>iv</sup> Rural areas are geographical locations where most persons with disabilities live. In Ghana, 3.3% of PWDs live in rural areas compared to urban areas (2.7%).

<sup>iv</sup> The model sees disability as something to be cured and/or treated by health professionals. Disability is seen as emanating from biological or physical or neurological imperfections. The medicalization of disability has been criticized in terms of its individualization of disability, among other criticisms.

 **Cultural Etiologies of Disability in Ghana: A Case of Food Taboos in Pregnancy** by Francisca Adom-Opare  
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## Employment of People with Disabilities in the Hotel Sector in Zimbabwe: Challenges and Opportunities

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### ABSTRACT

This study sought to establish the extent to which people with disabilities (PWD) are employed in the hotel sector in Zimbabwe. The study was motivated by the continued emancipation of PWDs globally and industry's increasing acceptance of the contributions PWDs can make. Using a qualitative approach (interviews with hotel managers), this study revealed that PWDs are not employed in Zimbabwe's hotel sector. Stigma, lack of information/knowledge about disabilities, and supposed costs related to accessibility are the main challenges to the employment of PWD in the hotel sector.

*Keywords:* Disability, Employment, Hotels

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People with disabilities (PWD) globally have often been relegated to socio-economic peripheries. However, with the continuous calls for emancipation of minority groups, legislations have been enacted in many countries to help ensure PWD, like other minority groups, enjoy the same rights as their non-disabled counterparts. One such fundamental right is the right to equal employment opportunities (Kalargyrou, 2015). A glance at the tourism and hospitality industry in Zimbabwe, particularly in the hotel sector, shows that people with physical disabilities are almost completely excluded from employment. Obvious questions include why? Does it mean that PWD are not interested in working in the hotel sector or the industry is not availing opportunities to such candidates? What are the prospects of employment for PWD in the hotel sector?

PWD (including physical, sensory, and cognitive) constitute about 15% of the world population (United Nations 2018). This number has been increasing in recent years partly due to aging of baby boomers. Their number is expected to grow exponentially by 2050 (Eurostat 2005; Chikuta 2016). Access to equal employment opportunities is obviously a right for all, including PWD (UNCRC, 2006). At the 20<sup>th</sup> session of the UNWTO General Assembly, 2013 Agenda item 14 was Accessible Tourism for All (UNWTO, 2013). Unfortunately, a vision for accessible tourism for all may remain a dream if the industry does not employ PWD; do so can help pave the way to accommodating tourists with disabilities. In many countries, exclusion from tourism remains one way many PWD are socially and excluded (Chikuta & Kabote, 2018; Chikuta, 2017; Choruma, 2007).

The intention of this study is to address a series of questions:



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1. What is the percentage of employees with disabilities among hotel employees in Zimbabwe?
  2. What positions do employees with disabilities hold in the hotels?
  3. How are hotels benefiting from employing PWD?
  4. What challenges are the hotels facing in trying to employ PWD?

### Literature Review

Disability can be defined as any restriction or lack (resulting from an impairment) of ability that one encounters which hinders them from performing an activity in the manner or within the range considered as normal for a human being (United Nations, 2008). According to the CDC (CDC, 2021), disability is any condition of the body or mind (impairment) that makes it more difficult to do certain activities and interact with the world. Types of disabilities may include mobility, hearing, vision, communication, cognitive (memorizing, mental health, learning, thinking) and social (Disability & Health, 2017). Degree of impairment can obviously impact daily management of life.

The United Nations' (2006) Convention on the Rights of People with Disabilities (CRPWD) states that PWD have a right to access services from all areas of citizenship. The CRPWD was developed from a social model approach to disability recognizing the ways in which social, political, and economic barriers may participate in creating a "disabling" environment (Hyde et al., 2010; United Nations, 2006; Michopoulou et al., 2015). According to Bizjack et al. (2011) the USA, Europe, and Australia were among the first regions to develop statutory and legal instruments to ensure adherence to the provisions of the CRPWD and its protocols.

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## PWD in the Workforce

In the working environment, PWD's ability to participate and contribute in the workforce may be doubted by their non-disabled counterparts (Zakaria et al., 2020) resulting in employment discrimination (Zakaria et al., 2020). While opportunities exist, PWD often experience discrimination, segregation, and social exclusion (Darcy, 1998; Burnett and Bender-Baker, 2001).

Percentage of PWD varies by country. Mirroring the UN's estimate we previously considered, the World Health Organisation (WHO) estimates that approximately over a billion persons globally have some form of impairment, about 15% of the global population (United Nations World Health Organisation International Classification of Functioning Disability and Health (WHO, 2018). The reported average rate of disability varies from 10% to 20% of the population in Western developed countries, while in China around 6% of the population are officially estimated to have disabilities, representing roughly 83 million people, estimated to rise to 85 million to 87 million in 2030 (China Disabled Persons' Federation, 2013), as cited in Chikuta (2017) and Chikuta and Kabote et al. (2017). In the EU, 28 member states, the employment rate of people aged 15 to 64 years with disability was documented at 47.3%, with the highest employment rate reported for PWD in Sweden, and the lowest in Hungary (Eurostat, 2014).

In comparison, in the USA, according to the U.S. Census Bureau, there is an estimated 56.7 million persons with disabilities, 18.7 percent of the total 303.9 million U.S. population (Brault, 2012). The 9.9 million workers with disabilities in the U.S. make up 9.1 percent of the U.S. working-age civilian non-farm workforce, which totals 129 million people aged 21 to 64. The U.S. leisure and hospitality industry employs a similar percentage of workers with disabilities, an estimated 846,000 workers with disabilities, 9.2 percent of the

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total 9.22 million people working in the leisure and hospitality industry (Brault, 2012, Houtenville & Kalargyrou, 2014).

A spectrum can be seen in other countries. In Hungary, almost half a million individuals are reported to have disabilities, with that expected to reach 1 million by 2021 (RHS (2018) as cited in Berend (2018)). The employment rate of PWD in Hungary was low at 23.7%. According to 2011 data from the Hungarian Central Statistical Office (KSH), 2,416 persons with disability were employed in the food and accommodation industry. Also, in Malaysia, about 2.4 million people are employed over a decade. However, only 3,523 out of that 2.4 million are disabled employees, and those are mainly in a private sector (Hooi, 2001). Per Ms. Norani Hashim, the Director of Disability Development Department of Malaysia, since 2008 only about 581 people with disabilities have been employed in the public sector. This clearly suggests the majority of PWD are being accepted by the private sector rather than the public sector. Malaysia's only special law on equality and anti-discrimination is the Persons with Disabilities Act 2008 (Wahab & Ayub, 2016). The act protects employees with disabilities from prejudice, dangerous working conditions, wrongful dismissal, and discrimination in the workplace as well as in daily life.

### **Disability and Employment in Africa: A Tourism Perspective**

Despite many African countries being signatories to the UNCRPD (Chikuta & Kabote, 2018), there is a long way to go towards ensuring equity for people with disabilities. South Africa is lagging behind in domesticating legislation as guided by the UNCRPD and Optional Protocol established in 2006 (Dube, 2007, Makuyana & Saayman 2018). The 2011 South African census recorded 7.5% of the population with a form of impairment (Statistics South Africa, 2014). 68% of those are working age but not employed due to inaccessibility of workplaces and disabling education systems (Statistics South Africa, 2014). Clearly, South

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Africa has not yet fully incorporated the UNCRPD into the domestic legal framework (Dube, 2007; Makuyana & Saayman 2018).

Similarly, since the government of Botswana is not a signatory to the UNCRPD of 2006, PWD face barriers to exercise their rights, including rights to employment opportunities (Mukhopadhyay and Moswela, 2020). The government of Botswana has made some efforts to create an office to assist PWD within the Office of the President. However, this has been widely criticized because the approach is rooted in social welfare (care). This approach tends to emphasize care of PWD who are perceived to be a “social burden” requiring social welfare support (Mukhopadhyay & Moswela, 2020). In addition, the approach has been criticized for delaying the recognition of the rights of PWD and enacting disability-specific legislation to protect their rights.

Elsewhere, in Zambia, about 2 million people or 15% of the population, have a disability (World Health Organization, 2012). Most live in rural areas where there is limited access to services such as health and care. In 2005, the employment rate of PWD showed limited opportunities for PWD: 45.5% of the population compared to an employment rate of 58% among persons without disabilities. Zambian Central Statistical Office 2000 Census reported that many PWD are self-employed mainly in the agricultural sector (World Health Organization, 2012). Generally, the report indicated that most Zambians with disabilities live in poverty, with a literacy rate low compared to people without disabilities. As a result of poverty, many PWD turn to street begging to survive. Generally, the government of Zambia has made some efforts to adopt some legislations to protect PWD. Some of the rights enshrined in their constitution include the right to equal opportunities to employment and basic services; however, enforcement is lacking (Zambia Central Statistical Office, 2000).

The Government of the Republic of Namibia (2015) suggests that the actual

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percentages of PWD are slightly higher than the global estimations of 15.0% of the population. This is so because there are no reliable statistics of PWD in Namibia. In Namibia, PWD are not happy with disability policy shortfalls negatively affecting their life experiences (Haidula 2016; Chichaya et al., 2018). Other stakeholders in disability services also indicate they are not happy about what the government is doing to protect the rights of PWD. Moreover, there is the need for the government to review the disability policy which has not been reviewed since its inception in 1997 (Government of the Republic of Namibia, 2017a).

In Zambia, similar issues may be seen. Zimbabwe is blessed with many tourist attractions, e.g., the majestic Victoria Falls, Eastern Highlands, Kariba dam and national parks such as the Hwange national park, Gonarezhou, among others. Zimbabwe has done well in terms of visitor numbers since independence in 1980. In 2018, the country received over 2.5 million tourists: 80% from the region, 9% from Europe and 5% from the United States of America. Tourism employment also contributed about 5.2%, with 7.2% contribution to Gross Domestic Product (GDP) (Zimbabwe Tourism Authority, 2019). While there has been a general growth in number of visitors into the country, the issues of universal accessibility have not been on the tourism sector's agenda (Chikuta, 2015; Chikuta & Kabote, 2018; Chikuta et al., 2021). As a result, PWD have not been prioritized or given opportunities to play a role in the development of tourism in Zimbabwe. This includes equal opportunity to employment. Authorities in Zimbabwe have done very little to alleviate this (Khupe, 2010.) The government has only enacted the Disability Persons Act in 1992, amended in 1996. There is also a lack of government budgetary allocations towards disability affirmative action. There are no reliable disability related statistics in Zimbabwe, but there are an estimated 1.5 million PWD, about 10% of the total population (Choruma, 2007). Data on the employment of PWD in Zimbabwe is also very scarce.

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### Perceived challenges of PWD

Despite aspirations to be employed, many PWD often experience challenges and barriers, including discrimination. This is frequently because of the assumed difficulties of hiring PWD (Lysaght et al., 2012; Kalargyrou, 2014). In contrast to this, in the United States, the rights of PWD to non-discriminatory employment practices are protected under the Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act (ADAAA) of 2008, primary U.S. laws regarding disability (Houtenville & Kalargyrou, 2014). Some perceived barriers to employing PWD include perceptions of the shortage of resources and related costs, lack of skills, and supervisors' concerns about managing PWD (Houtenville & Kalargyrou, 2011; Lengnick-Hall et al., 2008; Kalargyrou, 2014).

Negative perceptions towards disabilities by both the employers and the patrons or visitors is also another challenge negatively affecting the employment of PWD in the hotel sector. According to Patterson (2021) and Stanley and Stanley (2015), elements such as decoration, furniture, and the appearance of restaurant service personnel provide important cues for customers to make purchase decisions and evaluate service performance. It is against such perceptions that the physical appearance of hotel employees comes under scrutiny by employers during the recruitment process, often placing many physically disabled PWD at a disadvantage when employers select potential employees. Studies in the retail and hospitality industries in the United Kingdom examining perceptions of personal appearances in employment (Warhurst et al., 2000). Nickson et al., (2005) concluded that appearances and self-presentation skills of customer-facing employees were more important to employers in the hospitality industry than technical skills. In this regard, because of discrimination, PWD may be placed at a disadvantage in hospitality employment.

Another key challenge of employing PWD is the provision of specialized

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accommodation. According to Sharma et al., (2019), employees with disabilities often require specialized equipment, facility modifications, adjustments to work schedules for them to perform their professional tasks efficiently. Telwatte et al., (2017) suggests that many employers believe in providing additional support to employees with disabilities, if required, to enhance their professional effectiveness in the place of work. The general challenge is the perceived high costs involved in providing reasonable accommodation for employees with disabilities (Chikuta et al., 2021; Groschl, 2012; Sharma et al., 2019; Telwatte et al., 2017). This is despite the fact that employers can practically convert costs incurred in training individuals with disabilities into long-term investments as it is believed that such employees are loyal and committed to their employers for a longer duration (Groschl, 2012).

### **Perceptions of hotel managers in Zimbabwe towards PWD: a review of empirical literature**

Employing PWD may assist in attracting more tourists. As such, it may be considered an effective marketing strategy by hotels in Zimbabwe as they stand to benefit for the tourist market of tourists with disabilities. Tourism enterprises that take steps to employ PWD create new business opportunities for growth (Mubaiwa, 2021) and play a positive role in advancing an inclusive tourism society. Despite this, in Zimbabwe, PWD face multiple attitudinal, environmental and institutional barriers that prevent them from having equal access to employment opportunities (Choruma, 2007). The lack of a national disability policy in Zimbabwe limits employment opportunities for disabled persons within the economic sectors (Khupe et al., 2022) including in tourism. This lack of a national disability policy cascades to individual organizations including hotels and manifests in lack of human resources policies that cater for disabled persons as potential employees. The silence in HR policies of hotels about PWD limits opportunities, relegating PWD to the periphery. This is especially true as

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many hotel managers in Zimbabwe often appear to perceive PWD as incapable of handling many labor-intensive tasks within the hotel industry.

Discrimination against PWD (Khupe et al., 2022) leading to their marginalization is compounded by long-held cultural beliefs associating PWD with bad omens, curses or punishment from God or ancestors for family crimes (Khupe et al., 2022; Marongwe & Mate, 2007). This may further lead to stigma and discrimination in employment. Moreover, Lang and Charova (2007:7) stated that “It is a common perception within Zimbabwe that disabled people are passive and economically unproductive, and therefore constitute a burden upon society.” Thus, there is a predominant negative attitude towards PWD leading to exclusion from employment in tourism. The perception of hotel managers in Zimbabwe generally reflects larger societal perceptions. Consequently, there are very limited numbers of PWD employed in the hotels in Zimbabwe and, there appear to be no disabled persons holding managerial or senior positions in organizations (Khupe et al., 2022).

### **Benefits of employing persons with disabilities**

Despite the relatively small number of PWD in full-time employment in the hotel sector, there appear to be a range of benefits of recruiting PWD. Houtenville and Kalargyrou (2011) found that reduced turnover and increased retention and productivity ranked high among the reasons persuading companies to recruit PWD. Subsequent research has also shown that PWD remain in an occupational position the same amount of time or longer than their non-disabled counterparts (Kalargyrou, 2014). In a study by Hernandez and McDonald (2010), employees with disabilities stayed at the job 4.26 months longer than employees without disabilities. Laabs (1994) as cited in Kalargyrou (2014), reported that the Chicago Marriott also experienced lower overall turnover after it began hiring PWD. Its turnover rate was 32% per year vs. the typical turnover rate within the hotel industry of 50%.



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This research about the benefits of employing PWD has also been supported elsewhere (Kalargyrou, 2014; Kaletta et al., 2012; Jasper and Waldhart, 2013; Houtenville and Kalargyrou, 2011). Research supports the benefit of employing PWD since they exhibited lower turnover and absenteeism rates than those without disabilities. These findings for the hospitality industry are consistent with those for all industries (Kalargyrou, 2014). Low turnover has a benefit of reducing brain drain, costs associated with recruitment, selection, and training of newly hired employees.

As such, employers need to acknowledge that developing well-designed accommodations will not only benefit employees with disabilities but have many other benefits for employers as well. This includes the fact that structural and technologically upgraded facilities may also attract customers with disabilities (Sharma et al., 2019). In addition to attracting customers with disabilities, hiring PWD may also help create a positive brand image. A study in the USA found that 92% of consumers felt more positively towards companies employing PWD (González & Fernández, 2016; Siperstein et al., 2006). Additionally, customers with disabilities also prefer to patronize hotels they see as the reducing the unemployment rate for PWD (Gonzalez & Fernandez, 2016).

Moreover, attracting customers with disabilities can be extremely profitable. The total market for travel for PWD is expected to increase exponentially by 65% from 2005 with market value of 53.5 billion pounds to 88.6 billion pounds in 2025. In addition, there is high demand for accessibility in Europe, and the demand is expected to reach an approximated 160 million people by the end of 2025 (Botwell, 2015). This is quite a lucrative market for Zimbabwe's hotel sector to consider tapping into to benefit economically. Currently, Zimbabwe receives most of its international visitors from Europe (8%), the US (4%), and Asia (4%) (Zimbabwe Tourism Authority, 2019). These statistics suggest a lucrative market

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for Zimbabwe's hotel sector.

### **Methodology**

This study adopted a qualitative approach with interviews being the data collecting technique. Study participants were conveniently selected managers of star rated hotels in Zimbabwe. Due to Covid-19 pandemic induced travel restrictions and the need to avoid unnecessary face to face interactions, the interviews were conducted online. The interviews were conducted in January and February 2021 using telephone, WhatsApp Video Calling, Google Meet, Zoom and Skype, depending on what was convenient to the respondent. With the consent of the respondents, all interviews were recorded. The interview questions were derived from literature, guided by the research questions. Twenty hotel managers or their representatives were interviewed. The sample size was guided by the saturation concept as proposed by Konstantina et al., (2018) and Creswell (2009).

Creswell's (2009) six steps of qualitative data analysis were adopted by the researchers. First the researchers were mainly dealing with transcribing the data from recordings into text data as well as organizing and preparing data. Secondly, for researchers to develop deeper understanding about the data from hotel managers before analyzing it, they had to read the data several times. The data was then coded into different categories such as images and text. Themes for analysis were then generated from the coded data. The next step involved outlining how themes were to be presented qualitatively, and finally data interpretation was done. Thus, data was analyzed thematically and presented as per research objectives. Table 1 below shows the profile of the respondents.

#### **Table 1: Profile of respondents**

Respondent	Designation	Organizational type	Gender	Age	Experience	Location
R1	Hotel Manager	3 Star Hotel	Male	45	15 years	Masvingo
R2	Hotel Manager	4 Star Hotel	Male	42	14 years	Harare
R3	Human Resources Manager	3 Star Hotel	Female	48	16 years	Harare
R4	Hotel Manager	2 Star Hotel	Male	38	10 years	Masvingo
R5	Hotel Manager	2 Star Hotel	Male	35	9 years	Mutare
R6	Hotel Manager	3 Star Hotel	Female	37	11 years	Kariba
R7	Hotel Manager	4 Star Hotel	Female	44	18 years	Victoria Falls
R8	Hotel Manager	4 Star Hotel	Male	44	12 years	Victoria Falls
R9	Hotel Manager	3 Star Hotel	Male	41	13 years	Masvingo
R10	Hotel Manager	3 Star Hotel	Male	42	15 years	Bulawayo
R11	Hotel Manager	2 Star Hotel	Male	40	12 years	Beitbridge
R12	Hotel Manager	1 Star Hotel	Female	38	10 years	Kwekwe
R13	Human Resources Manager	2 Star Hotel	Male	34	9 years	Gweru
R14	Hotel	2 Star Hotel	Male	39	14 years	Nyanga

	Manager					
R15	Hotel Manager	3 Star Hotel	Female	40	15 years	Harare
R16	Hotel Manager	2 Star Hotel	Male	39	14 years	Harare
R17	Hotel Manager	3 Star Hotel	Male	43	16 years	Bulawayo
R18	Hotel Manager	2 Star Hotel	Female	41	15 years	Victoria Falls
R19	Hotel Manager	3 Star Hotel	Male	35	11 years	Harare
R20	Hotel Manager	1 Star Hotel	Male	40	14 years	Masvingo

### Findings and discussions

This section presents the results of the in-depth interviews that were carried out with the twenty hotel managers. The results are presented following the dominant themes that emerged from the thematic analysis as well as the research questions. Where possible, interview excerpts from the study participants are shown for emphasis.

#### Percentage of employees with disabilities in the hotel sector in Zimbabwe

Participants were a bit skeptical about revealing the profile of their employees in their organizations. However, the results of the study suggest there is a limited or even zero number of employees with disabilities in the hotel industry of Zimbabwe. Some of the below statements by participants suggest discrimination against PWD by some employers in the hotel sector.

*R1: "Truly speaking our job here requires physical fitness, so all our employees must pass*

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*the fitness test before being employed."*

*R10: "Our facilities do not cater for PWD including staff."*

*R15: "Well, we have never received job applications from PWD since we opened this hotel."*

*R8: "Here we do not have any of our staff with physical disability."*

Thus, the results suggest that hotels in Zimbabwe do not have employees with visible disabilities. The findings are supported by Khupe (2010) who blamed the authorities of Zimbabwe for doing virtually nothing to alleviate the challenges being faced by disabled people. The unemployment for PWD is a significant challenge in the hotel sector in Zimbabwe, including because of employment discrimination (Kalargyrou, 2014).

#### **Positions held by PWD in the hotels**

Division of work and specialization is central to achievement of organizational objectives. All respondents to the study revealed that they do not have employees with disabilities within their hotels. However, this result is somehow contestable because respondents might not be aware of certain hidden impairments within their staff especially the cognitive and hearing impairments as illustrated below:

*R1: "Well, since we do not have staff with physical disabilities, it means none of the positions is occupied with PWD."*

*R6: "Honestly speaking all our positions here require physically fit and abled people."*

*R14: "I do not think disabled people can cope with the demands of hotel work."*

Results of the study suggest that hotels in Zimbabwe are yet to employ PWD and this requires serious consideration to achieve inclusive growth and development of the hotel

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industry. This finding squarely validates the contention advanced by Zakaria et al., (2020) that PWD are considered as unable to participate in working environments, and as a result they experience discrimination in terms of employment opportunities. Some of the recurring statements by the respondents are clearly discriminatory.

### **Perceptions of advantages of employing PWD**

Asked about advantages or benefits of employing persons with disabilities, hotel managers had this to say:

*R7: "If we can employ PWD it can give us an opportunity to make our facilities accessible and friendly to PWDs customers."*

*R11: "Employing PWD may help to address inequalities that presently exist within our society and the employment profile as well as landscape."*

Despite the absence of employees with disabilities in Zimbabwe hotels, respondents revealed that there are indeed benefits in employing PWD. One prominent benefit raised by participants was that employing people with disability can also attract visitors with disabilities hence more business to the hotel. For example, *R4: "Yes, I feel if as a hotel we can employ PWD, I think we can also attract customers with disabilities as like attracts like."* As previously stated, this aligns with Sharma et al., (2019) and Kalargyrou et al., (2018) who posit that developing well-designed accommodations will not only benefit employees with disabilities, but such structural and technologically upgraded facilities will also attract customers with disabilities. Gonzalez and Fernandez (2016) also added that one of the reasons why hotels which employs PWD also attracts visitors with disabilities is that they know that employing PWD reduces the unemployment rate for persons with disabilities. This is despite the fact that this study's results suggest there are no PWD employed in the hotel

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sector in Zimbabwe.

Additionally, literature has identified other benefits of employing PWD in the hotel sector. These include reduced workplace risks (Lengnick-Hall et al., 2000, Kalargyrou, 2014), reduced time lost due to disabling injuries, reduced turnover and increased retention (Houtenville & Kalargyrou, 2011; Kalargyrou, 2014), reduced absenteeism due to employee loyalty. These factors in return increase productivity Kalargyrou (2014); Kalargyrou (2015). Overall, the literature suggests clear benefits for the Zimbabwe hotel sector.

### **Challenges of employing PWD for hotels**

Respondents revealed a host of challenges faced by PWD in Zimbabwe in the tourism industry, including discrimination. For example, reflecting negative perceptions of PWD, participant R10 made the statement *"I think it's not fair to employ PWD. These people must be assisted financially whilst they are at home."* This perception is consistent with the dominant charity model of disability which states that disability is a charity case which require societal sympathy and alms (Oliver, 1996). Hountenville and Kalargyron (2015) and Lysaght et al. (2012) also cited discrimination of PWD as one of the dominant challenges PWD face.

Another dominating concern raised by the respondents was negative attitudes by potential employers towards PWD. Participants had negative attitudes about employing PWD in the hotel sector in Zimbabwe. One respondent, R25, said *"It's difficult to employ PWD because they also need to be assisted when doing their job."* These findings are consistent with Lysaght et al., (2012) and Kalargyrou (2014) who cited that PWD often experience challenges and barriers such as negative attitudes by employers that impede their ability to secure employment.

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Among these, this study revealed that most employers believe it is expensive to employ PWD. For instance, R07: *“To be honest with you my brother, it is expensive to hire a person with disability in the sense that you may need to provide facilities such as toilets and accommodation for the person to use so it becomes expensive.”* The perceptions are consistent with Sharma et al., (2019) and Chikuta et al., (2021). This study also suggests employers in the hotel sector in Zimbabwe are not prepared to employ PWD. The findings suggest that most employers have a strong negative attitude towards employing PWD. Below is one of the dominant responses by managers:

R 21: *“PWD require special treatment, my brother. That's why our government can employ the second person who is able bodied to assist their employees with disabilities and pay two people in the process.”*

### **Prospects of employing PWD in the hotel industry of Zimbabwe**

There are abundant opportunities for employing PWD in the Zimbabwe hotel sector. There are clearly multiple benefits. This is reflected in a respondent statement: R16: *“Employing PWD means there is an opportunity to build a great brand and reputation. Some hotels in the United States are already doing that.”* The findings corroborate studies by Kalargyrou (2014) suggesting there is competitive advantage in employing PWD due to employee loyalty and employees exceeding expectations with lower turnover and better attendance.

As established, there are clear benefits from employing PWD in the tourism industry. R9: *“looking at the profile of the tourism market, I honestly think that the disabilities market is a lucrative niche market that deserves serious consideration.”* These results are consistent with Buhalis et al., (2005), and Chikuta (2017) who have suggested PWD have become a



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significant consumer market for tourism players including hotels.

### **Conclusion**

Clearly, the hotel sector in Zimbabwe can employ more PWD. The hotel sector seems to be uninformed about the potential of the labor market of PWD. Hotel managers seem to be unprepared to accommodate employees with disabilities in their hotels, and this seems to be as a result of both lack of knowledge as well as discrimination. Some hotel managers however seem to be aware of the benefits of employing PWD which include a good public image and attracting the accessible tourism market. However, managers feel there is a need for awareness within the industry of the need for employing PWD. Moreover, they have the often-erroneous view that hiring PWD is expensive and involves refurbishing facilities and purchasing additional assistive equipment. Given enough education, the managers are likely to employ PWD in the future. The growing disability market and increased disability advocacy present opportunities for employment for PWD.

### **Recommendations**

While Zimbabwe ratified the UNCRPD in 2013, there has not been enough effort to ensure that the provisions of the convention are enforced in all sectors of the society and economy. There is therefore the need for the government of Zimbabwe, through the Ministry responsible for the tourism and hospitality industry, to spell out accessibility requirements for any hospitality business. This will benefit both employees and customers with disabilities. It is also recommended that the Zimbabwe Tourism Authority take issues of accessibility more seriously as it grades and accredits hotels and other designated tourist facilities. More affirmative action is required to better empower PWD, and this should begin with equipping them with the skills required to qualify to work in the hotel industry. There is also need for a

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deliberate move by the tourism industry to include PWDs in employment. As suggested previously in the literature review, employing PWD not only empowers the employed individuals but also puts the organization at a competitive advantage as it is viewed as a good corporate citizen. Hotel managers should realize these benefits along with others, including that employing PWD will reduce labour turnover and will help the organization attract tourists with disabilities.

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