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 alumuno-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 heath 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 CESCR**,** 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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