A human right to shoes? Establishing rights and duties in the prevention and treatment of podoconiosis

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Abstract (140 words)

Podoconiosis is a debilitating chronic swelling of the foot and lower leg, caused by long term exposure to irritant red volcanic clay soil in highland regions of Africa, Central America, and India. In this paper we consider the human rights violations which cause, and are caused by, podoconiosis in Ethiopia. Specifically, we discuss the way in which the right to an adequate basic standard of living is not met in endemic regions, where the following basic necessities are not readily available: robust footwear, education and health literacy, and affordable, accessible healthcare. Those living with podoconiosis experience disablement, stigma and discrimination, and mental distress, contributing to greater impoverishment and a reduced quality of life. We suggest that while identifying rights violations is key to characterising the scale and nature of the problem, identifying duties is critical to eliminating podoconiosis. To this end, we describe the duties of the Ethiopian government, the international community, and those sourcing Ethiopian agricultural products in relation to promoting shoe-wearing, providing adequate health care, and improving health literacy.

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1. Background

Podoconiosis is a disabling and heavily stigmatised condition characterised by lower leg swelling (lymphoedema) which, untreated, progresses to elephantiasis. It arises in genetically susceptible people who spend most of their lives barefoot and thus exposed to clay soils found in tropical highlands[1,2]. Although the pathogenesis is not fully understood, soil particles penetrate the skin[3], are taken up by macrophage cells[4] and cause a chronic inflammatory process in the lymphatic system of those with genetic predisposition. Lymphatic valvular dysfunction results in steadily progressive bilateral lymphoedema, usually limited to below the knees.[5]

Globally, an estimated 4 million people are affected with podoconiosis, living mainly in tropical Africa, central and South America and Southeast Asia. Recent mapping estimates
suggest that there are 1.5 million people living with podoconiosis in Ethiopia [6] and considerable numbers of affected people in Cameroon [7], Uganda [8], Rwanda, Burundi and the Democratic Republic of Congo. [9] Podoconiosis was reported in the Central American highlands in Mexico and Guatemala south to Ecuador, Brazil, Suriname and French Guiana in the coast of South America [9], but ongoing investigations suggest few affected populations may remain. In Asia, although filarial elephantiasis predominates in India, podoconiosis has been reported from north-west India, Sri Lanka and Indonesia.

Although rarely a direct cause of mortality, podoconiosis disables those affected and leads to significant stigma from the community [7, 10, 11] and health professionals. [12] Social stigma against people with podoconiosis leads to patients being excluded from school, denied participation in local meetings, churches and mosques, and being barred from marriage with unaffected individuals. Studies have documented low quality of life [13], mental distress [14] and depression. [15] Episodes of acute dermatolymphangioadenitis (ADLA – ‘acute attacks’) are among the most severe clinical consequences of lymphoedema, often confining patients to bed during attacks characterised by malaise, fever, chills, lymphangitis, adenitis and eventually skin peeling. These attacks occur frequently (reports vary from 5 [16] to 23 [17] episodes per year), and contribute substantially to the disability and social impact associated with podoconiosis. [15, 16, 18]

The leg swelling and its consequences greatly reduce productivity, patients being half as productive as those with the same occupation but free of podoconiosis. [19] In an area with 1.7 million residents, the annual economic cost of podoconiosis was more than 16 million USD per year in 2005, which when extrapolated to the country as a whole, suggests costs of more than 200 million USD per annum for Ethiopia. [19]

Despite the high impact of podoconiosis on rural farming communities, treatment and control have been hampered by a range of issues. The key challenge faced is lack of awareness that the condition exists and is different from lymphatic filariasis, the other main cause of lymphoedema in the tropics. This lack of awareness is evident among health professionals, academics, and Ministry of Health staff in endemic countries. Intervention is still so new in podoconiosis that challenges exist chiefly in program initiation rather than implementation. Fatalism is rife among health professionals in affected communities. [12] Where treatment is
offered by small non-government organisations, issues such as distance, worries about stigma, illness and misconceptions about treatment are all challenges to patients’ continuing attendance for treatment.[20] All these factors have led to extreme neglect of patients and communities affected by this debilitating disease.

2. Introduction

Political and economic determinants are key to understanding the prevalence and epidemiology of any neglected tropical disease (NTD). Indeed, the category of NTDs is united not by biomedical commonalities, but, as its name suggests, commonalities of geographical distribution and neglect. This neglect has several components. NTDs are seriously under-funded, despite generally being inexpensive to treat. They and their treatments are also under-researched, especially in the pharmaceutical sector, as the populations they affect do not present opportunities for a return on any investment. [21,22] Relatively, and perhaps most importantly, NTDs are under-represented in discourses on disease, mainly because they exclusively affect poor populations and therefore pose little threat to those in Global North contexts,[23] but also because they are over-shadowed by the “big three” diseases of the Global South: HIV/AIDS, malaria, and tuberculosis.

It is therefore unsurprising that NTDs have received little attention in the form of human rights discourses which examine the ways in which these diseases undermine the entitlements of affected individuals. Foremost amongst these entitlements is the right to health, which is trivially undermined in any case of ill-health, but is particularly important in the case of NTDs as it indicates the violation of a more fundamental set of rights due to structural factors.

In this paper we set aside the violation of the right to health in and of itself, and instead turn to its constituent human rights violations. Unmanaged podoconiosis may be a violation of a person’s right to health, but it is more instructive to see it as a symptom of the fact that other rights have been violated, and an indicator that still more rights will be violated. As Mann et al. note, “the extent to which human rights are realized may represent a better and more comprehensive index of well-being than traditional health status indicators.”[24] A major benefit of employing a rights discourse is that it centres the determinants of health, allowing us to speak of entitlements to particular necessities, rather than a vague, elusive entitlement to
good health. And, of course, improving those determinants invariably has beneficial effects which extend beyond good health.

There are two ways of characterising the interaction of podoconiosis with the human rights of those affected. The first concerns the way in which human rights violations contribute to podoconiosis; the second concerns the way in which podoconiosis then contributes to further human rights violations. The second set of violations may be seen as derivative to the first, but given that any strategy must address treatment as well as elimination, both are important.

Arguing that particular human rights have been denied is only the first part of the solution. Rights rely upon a scaffold of duties for their realisation. While rights generally apply to individuals or social groups, duties generally relate to agglomerate stakeholders in the form of governments and international organisations. In the case of podoconiosis, it is important to establish to whom the duties to provide treatments and efforts towards elimination fall. There are two ways of asking this question. One asks who is responsible for the well-being of those affected by the disease; this is a normative question. Another asks who is able to easily provide the necessary resources; this is a pragmatic question.

In the interest of maintaining a clear focus, this paper will only consider podoconiosis in Ethiopia. This ought not to result in significant loss of generality, since many of the rights violations are also applicable in other endemic regions. Given that podoconiosis relies on a specific set of physical conditions and behaviours, much of our discussion will be applicable to other contexts.

This article will be structured as follows: in section three, we describe the determinants of podoconiosis, including inadequate shoe-wearing practices, low health literacy, the remoteness and inadequacy of health facilities, and late diagnoses. In section four, we describe the ways in which podoconiosis leads to a series of additional human rights violations, in the form of restricted health and employment possibilities, and stigma and discrimination. In section five, we describe key strategies for improved treatment and towards elimination, and identify duty-holders in the achievement of these aims. Section six concludes.

3 Determinants of podoconiosis as human rights violations
Those living with podoconiosis are unable to realise their right to those basic necessities that are essential to reaching a standard of living that is adequate for health and well-being. This is despite the fact that low-cost, effective methods of prevention and treatment have been widely noted. In principle, podoconiosis is not a difficult disease to manage or eliminate: it occurs only in select geographies, it is not communicable, it is easily managed if spotted early, it is acquired only through long-term exposure to irritant soils, and its prevention requires neither pharmaceuticals nor large-scale infrastructural changes. Yet in practice, a series of complex, inter-related determinants collaborate to produce prodigious barriers to effective treatment and eventual elimination. It is also relevant to note that because podoconiosis is not transmissible, and tends to result in morbidity rather than mortality, it has been treated as a low priority.\[25\] As such, podoconiosis has been described as the most neglected tropical disease.\[26\]

In this section, we describe the determinants of podoconiosis as violating various human rights instruments.

First, consider that Article 11 of the International Covenant on Economic Social and Cultural Rights (ICECSR)\[27\], which Ethiopia has ratified, recognises the “right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing”. This closely parallels Article 25 of the Universal Declaration of Human Rights (UDHR). Here, we understand that “adequate […] clothing” must be taken to include footwear where its absence results in an inadequate standard of living.

Article 25 of the Universal Declaration of Human Rights (UDHR):\[28\]

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services […]

Article 7 (b) of the ICECSR\[27\] enshrines the right to “safe and healthy working conditions” as a key realiser of the right to work. This is important in the case of podoconiosis, since the majority of those affected by the disease are farmers working barefoot on irritant soils\[29\]. The African Charter on Human and Peoples’ Rights (ACHPR)\[30\], which Ethiopia has also ratified, likewise calls for the right to work under “satisfactory conditions” (Article 15).
The SCHPR asserts the right to “enjoy the best attainable state of physical and mental health,” for which the state should “take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.” Similarly, Article 12 of the ICECSR recognises each person’s right to “the highest attainable standard of physical and mental health,” which is to be achieved by attending to the rights to:

(b) The improvement of all aspects of environmental and industrial hygiene;
(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

According to the Committee of the ICESCR, in order to realize the right to health, ratifying states are required to ensure that health-care is: available, in the form not only of adequate health facilities, personnel, equipment, and drugs, but also the determinants of health, including adequate water and sanitation; accessible—physically, economically, and informationally—as well as without discrimination; of an acceptable ethical standard, and with due regard to local cultural needs; and of good quality[31].

It is clear that these rights are not being realised with respect to podoconiosis in Ethiopia, where a number of violations of Articles 7, 11 and 12 of the ICECSR, and Articles 15 and 16 of the ACHPR, contribute to the development of podoconiosis. This list of violations is intended to be illustrative rather than exhaustive.

The aforementioned human rights violations stem from inadequacies in:

(a) the availability of robust, suitable footwear in the contexts of work and leisure, and the availability of resources for maintenance of good foot hygiene (e.g. soap, water, bandages, socks);
(b) health literacy;
(c) the accessibility of medical care.

In the following subsections, we describe each of these human rights violations in turn.
3.1 Footwear and foot hygiene

Podoconiosis has been eliminated in endemic regions of North Africa and Europe due to the widespread adoption of shoe-wearing, which is a powerful demonstration of the effectiveness of this single behavioural change. Like many “tropical” diseases, podoconiosis is tropical only in its current instantiation; it was once noted at latitudes as high as Scotland.[9] It is soil-type, rather than climate, that is necessary for the development of the disease. That it is now endemic only in tropical regions is testament to the poverty of those regions. So while the cause of podoconiosis is geochemical, the reasons for its persistence are cultural - lack of shoe-wearing and lack of adequate health infrastructure – are economic, cultural and political.

In endemic regions of rural Northern Ethiopia, there is limited adherence to shoe-wearing. Foremost amongst the reasons for this is poverty, with families prioritising nutrition and education for children above buying shoes. Those who can afford to buy shoes are often not able to replace them when they wear out. Since affordability is key, these shoes are likely to be of low-quality materials and workmanship, which tends to limit their durability, comfort, and suitability for manual work, as well as their degree of coverage, which is correlated with the protection they offer from irritant soils. This leads to inconsistent shoe use, as shoes are made to last by wearing them only intermittently, or only for special occasions.[10] Gender disparities have been reported in the quality of footwear, with fewer women wearing the more expensive leather shoes which offer better protection.[32]

Once swelling sets in due to podoconiosis, it becomes difficult to find shoes which accommodate the larger foot size and shape. Standard footwear is often not appropriate, and podoconiosis patients rely on bespoke shoes designed and distributed by a few non-governmental organisations. However, these shoes are easily identifiable, which can lead to stigma, and an aversion to shoe-wearing.[33]

Stigma plays an important role, with almost a third of those refraining from wearing shoes doing so to avoid violating social norms.[10] In some cases any variety of shoes, along with bandages or visible emollient use, is taken as a marker of disease or disease-susceptibility, so that avoiding shoe-wearing may be a way of averting possible discrimination.[34]
A number of other practical concerns are relevant. A single pair of shoes worn continually in a warm climate without socks causes an unpleasant smell, which again leads to irregular shoe-use, as people attempt to recurrently air their feet. Socks are therefore important in ensuring more comprehensive and comfortable shoe-wearing. Within podoconiosis-prevalent communities, clean water and soap are not always easily accessible, so that foot hygiene can be difficult to maintain.[35]

In addition to shoe-wearing, household floor coverings are also an important mechanism for minimising foot-soil contact and thereby guarding against the development of podoconiosis. The lack of mats or cemented floors is common in endemic regions, largely because the importance of floor coverings is not well-known, [10] and covering household floors presents another expense.

3.2 Health literacy

Misconceptions concerning the causes of podoconiosis, and preventative-behaviours, are common within endemic communities.[10,36,37] Various symbolic explanatory models for the disease circulate within endemic communities, including the idea of podoconiosis as a form of religious punishment, or as a result of “magic,” often believed to be caused by stepping on dead animals.[34,36] As well as posing barriers to preventing onset of the disease, these beliefs can lead to patients seeking treatments from symbolic healers, which is not only costly and ineffective, but sometimes leads to patients being advised against attending podoconiosis clinics.[34]

Non-symbolic misconceptions also abound. There is the mistaken yet widespread belief that podoconiosis is infectious, which, coupled with the above symbolic beliefs, leads to considerable stigma around the disease. Other misconceptions include the idea that the disease is transmitted by insects, [10] by blood, or by affected individuals.[36] One study showed that only 41.4% of a podoconiosis-endemic community knew that the disease could be treated. [10]

Health literacy in relation to podoconiosis within endemic communities is low, with the average disease-knowledge of women quantified as half that of men.[10] Given that women’s beliefs are typically more determinative of children’s beliefs and behaviours, the effects of low
health literacy in women are particularly concerning.

3.3 Healthcare

Misconceptions amongst health professionals regarding podoconiosis are high, with one study reporting that 98% of respondents were ill-informed about the causes of podoconiosis.[12] More than half believed that it was transmitted by insects, and half of respondents believed it to be infectious. Stigma towards podoconiosis patients was high, and 86% of health professionals surveyed did not feel competent to treat podoconiosis.[12] Further, 70% of the same group of health professionals reported lacking the basic resources (i.e. emollients, bandages) to provide treatment. Clearly, healthcare is held back as a result of inadequacies in both training and resources.

Even where healthcare is available, in rural areas there are issues with accessibility, with patients citing distance from clinics and the need to meet other commitments (e.g. care-work, other labour) as major reasons for discontinuing attendance.[34] Some patients must travel long distances on foot to reach clinics, which is physically challenging, while others rely on public transport, which is financially challenging. Those who live particularly far from clinics are also often deterred by the cost of an overnight stay.[34]

4. Effects of podoconiosis as human rights violations

Podoconiosis has a major impact on the enjoyment of human rights of patients. Human rights are interrelated and interdependent, so that violation of one right generally entails the violation of others. Neglecting the health vulnerabilities of those in disease-endemic regions eventually hampers social and economic opportunities, and leads to further vulnerability.

Research conducted in endemic communities reveals that podoconiosis confers social, psychological and economic burdens on patients.[15,19] Patients also experience absenteeism and reduced working hours due to frequent disease-related acute attacks.[17,18] Podoconiosis therefore poses a considerable threat to education and employment opportunities. In this section, we discuss three human rights violations in particular: the right to education, the right to work, and protection against discrimination.
4.1 The right to education

The ICESCR formulates the most comprehensive and detailed provision on the right to education. [27] Article 13 enjoins that primary and secondary education should be “available and accessible to all by every appropriate means.” Those living with podoconiosis are deprived of this right to education on various fronts. Patients often have limited access to education due to disease-related acute attacks, as well as stigma and discrimination. Disease-related acute attacks have a serious impact on school enrolment and completion, in addition to affecting attendance and performance. A recent study indicated that pupils with podoconiosis may lose a considerable number of school days, drop out, under-perform, and lack concentration as result of disease-related illness.[38] Schools in endemic rural areas are often located in remote villages. Students must therefore walk long distances on foot, which is especially difficult because of the disabling effects of podoconiosis. Thus, lack of accessible educational facilities coupled with the physical effects of the disease hamper learning opportunities.

Students with podoconiosis often experience isolation, discrimination, verbal abuse, and harassment by peers within educational settings. As a result, school attendance falls, as families protect their children from exposure to stigma and discrimination.[38] This experience aligns with the findings of a previous study, which indicates that avoidance is a common coping strategy amongst podoconiosis patients.[11] Coupled with financial constraints, physical inaccessibility, and disease-related discomfort, stigma and discrimination pose major barriers to enjoyment of the right to education.

Although podoconiosis patients may appear to have the same notional access to education as unaffected individuals, the conjunction of these factors produces serious inequity. A particularly concerning by-product of the lower level of education experienced by podoconiosis patients is the effect this has on health literacy, and the ability to effectively manage the condition.

4.2 The right to work

The right to work is essential for realizing other human rights, and is a core source of personal
development, as well as a facilitator of economic and social inclusion. The ICESCR enshrines the right to work under articles 6, 7 and 8. Since podoconiosis is so often caused by labour, in the form of barefoot agricultural work, it is particularly lamentable that the disease frequently threatens a person’s ability to work, both through physical impairment, and through the effect of discrimination. Those whose education is disrupted as a result of podoconiosis may also find themselves less able to work by virtue of lacking necessary skills. The right to work is therefore undermined by virtue of violations of the right to healthcare, the right to healthy working conditions, the right to education, and the right to adequate footwear.

Podoconiosis patients experience rights violations in relation to access to, or continuation of, employment, which may occur due to disease-related complications or due to discrimination as a result of widespread stigma. Podoconiosis patients are often denied job opportunities, are unfairly dismissed, and may experience mistreatment in the workplace.[37] As with education, some podoconiosis patients avoid employment as way of minimizing stigmatization. [11] Many podoconiosis patients are unable to work due to physical impairment related to both ongoing lymphoedema (leg swelling) and acute attacks.[18] Podoconiosis patients and their dependents are accordingly more likely to be poor, and less likely to afford medical care. Podoconiosis is therefore a cause of economic loss, low productivity, and reduced working hours in disease-endemic communities.

4.3 The right to protection from discrimination

The right to protection from discrimination recognises the effect of stigma and discrimination on the social and economic opportunities of individuals, and the resulting increase in vulnerability. Stigmatizing attitudes continue to delimit the social and economic well-being of podoconiosis patients. This stigma is largely a result of low health literacy within endemic populations, including amongst health-workers. As such, it may be traced to a violation of the right to accessible information with regard to health issues.

Studies have demonstrated that podoconiosis patients face stigma and discrimination in both the public and private realms. Both felt stigma (perceived fear of actual stigma) and enacted stigma (including unfair dismissal or school drop-out due to discrimination), have been documented.[39] Stigma towards podoconiosis patients is often manifested through differential
treatment at social events, isolation from the community, limited marriage prospects, reduced access to education, and limited job opportunities.[37,39]

5. Duties regarding treatment and elimination

As we have demonstrated in the previous two sections, podoconiosis is enabled by the violation of a set of human rights. The subsequent development of the disease violates a second set of rights. In this section we reflect on these right violations, which constitute the determinants and effects of podoconiosis. Articulating rights violations paves the way for the identification of duty-holders and recommendations in relation to those rights. We begin by describing some extant initiatives which have been successful in tackling podoconiosis (5.1), following which we identify duties which must be met in order to address human rights violations (5.2), before exploring the rightful duty-holders (5.3).

5.1 Promising interventions

At present within Ethiopia, non-governmental organisations (NGOs) play a key role in offsetting these rights violations. The most prominent of these are: International Orthodox Christian Charities (IOCC), Action against Podoconiosis Association (APA), Ethiopian Catholic Secretariat Social and Development Commission (ECC-SDCO), and Mossy Foot International (MFI, formerly Mossy Foot Prevention & Treatment Association).[25] These organisations have provided programmes focussed on lymphedema management, awareness-raising, and shoe-distribution. As such, they provide health-care, health literacy campaigns, and footwear, thereby responding neatly to the key human rights violations we have identified. However, their resources are understandably limited and unpredictable, and their geographical coverage is incomplete.

One particularly promising initiative is that led by the MFI, in which patients who have been successfully instructed in the management of their own podoconiosis (via shoe-wearing and foot hygiene) are trained to act as “Community Podoconiosis Agents” within their local communities, inducting others into effective management of the disease, and leading

awareness-raising sessions and clinics in public spaces.[40] This has been a highly effective scheme, and has the benefit of being patient-led, which promises greater cultural sensitivity and credibility. (Note that this also meets the ICESCR requirement that the right to health be met in a “culturally acceptable” manner.) It also addresses the issue of patients travelling long distances to reach clinics, by devolving good quality, tailored care into each community. A related suggestion is to employ these expert patients in bridging the divide between biomedical healthcare and traditional healing.[34] This could have the dual effect of increasing adherence to clinic treatments as well deploying the epistemic role of traditional healers in providing medically-sound advice, without undermining their source of income.

Such a scheme can only be successful at larger scales if health professionals are themselves adequately educated and resourced to be able to diagnose and treat podoconiosis, as well as promoting positive health behaviours amongst high-risk patient groups. At present, podoconiosis-endemic regions are not only deprived of the necessary resources for prevention and management (shoes, water, soap, bandages, and emollients), they are critically deprived in an epistemic sense. These epistemic lacunae are common in both patients and health professionals, and provide fertile ground for the misconceptions which undermine comprehensive shoe-wearing and promote stigma. As we have shown, this stigma is a substantial barrier to the right to education for affected children, which then in turn limits the capacity for employment and health literacy of those living with the disease. Whilst shoe-wearing will be the key to eliminating the disease, one cannot expect the practice to become widespread and enduring if it is not founded on an improved understanding of the disease.

The key area that is ripe for intervention is increasing the accessibility of durable, comfortable, protective shoes. A recent study demonstrated that almost three-quarters of those surveyed in Northern Ethiopia were willing to pay for footwear.[32] For the quarter that were unwilling to pay for footwear, the most important factor was poverty. Deribe et al. suggest that subsidised shoe distribution schemes may be effective in ensuring more comprehensive shoe-wearing. [41] While working alongside public health efforts towards increased health literacy and the importance of consistent shoe-wearing, these schemes must capitalise on recent shifts towards shoe-wearing as a sign of respectability and fashion, especially amongst younger people.[42] Given the increasing desire for shoes, and the fact that the majority of people are willing to pay for them, there is clearly a desire for affordable footwear which must be treated as a public
health priority rather than a mere market opportunity. One way of meeting this need within the communities themselves is to extend schemes designed by MFI, in which podoconiosis patients are trained to produce suitable footwear for sale or distribution within their communities.[43] Another option is for governments to collaborate with shoe companies in order to fund subsidies.[44] Partnerships could be formed with justice-oriented companies such as TOMS, which currently provides a free pair of children’s shoes for every pair purchased, or Oliberté, which manufactures its shoes within the first Fair Trade certified footwear factory, based in Ethiopia.

5.2 Identifying duties

Synthesising the previous sections, the following interlocking changes are necessary to the realisation of human rights which will facilitate the elimination of podoconiosis, and minimise its effects on existing patients:

I. The right to health:

(a) Rural communities should have access to affordable healthcare services within walking distance, either via the establishment of permanent local clinics, or via the regular presence of mobile clinics.

(b) All curricula for health professionals working in endemic areas should include training on the pathogenesis, identification, and treatment of podoconiosis, and the physical resources for treatment should be readily available.

(c) Health professionals should be tasked with training expert patients, and working with traditional healers, in order to improve health literacy within endemic populations.

(d) Federal and regional government should create cross-sectoral opportunities to raise awareness about podoconiosis in the wider community, through for example, the agriculture, education, and development sectors.

II. The right to adequate clothing/footwear:

Comfortable, affordable, long-lasting, protective footwear should be readily available within endemic populations for people of all ages. Promoting shoe-wearing should be an important part of the training recommended in I (b) and (c).

III. The right to safe and health working conditions:

Podoconiosis should be seen as an occupational health priority amongst farmers, and robust
footwear must be provided to workers as a health and safety measure, and shoe-wearing enforced.

As well as addressing violations of human rights, these recommendations respond to the aims of the UN Sustainable Development Goals[45], which call for: the elimination of neglected tropical diseases, universal access to high-quality medical care, improvements in the financing and training of health professionals, and safe working environments for all.

5.3 Identifying duty-holders

At the outset, we drew a distinction between the normative question of who is responsible for the well-being of those affected by podoconiosis, and the pragmatic question of who is able to easily facilitate the necessary changes. Whilst NGOs have thus far played an important role in podoconiosis management, particularly in developing innovative techniques for management, much larger-scale, better-resourced efforts, based on more extensive data, will be needed in order to bring about elimination.

The primary duty for preventing human rights abuses and seeking elimination must lie with the government of Ethiopia, who have sovereignty over the nation’s land, one-fifth of the soils of which can cause podoconiosis.[46] In this regard, it is critical to note that agriculture is the cornerstone of the Ethiopian economy, and accounts for almost half of the gross domestic product (GDP), and 80% of the workforce.[47] This productivity is partly accounted for by the tremendous fertility of the soil, which is largely due to its volcanic origins.[48] Coffee-growing, which contributes 41% of the country’s export earnings and 15% of the population’s livelihood,[49] is particularly reliant on these fertile volcanic soils. In other words, the principal cause of podoconiosis is also a principal contributor to the nation’s economic viability. Many of those affected by podoconiosis are coffee farmers, or live in coffee-producing regions.[50]

Considering the political economy of soil in Ethiopia suggests an important moral link between the nation’s economy, which is currently in a period of promising growth, and some of its most neglected populations. It seems problematic for the nation’s economy to benefit so disproportionately from its agricultural sector, while those living within podoconiosis-endemic agricultural communities are unable to access a “standard of living adequate for […] health
and well-being [...], including food, clothing, housing and medical care and necessary social services.”[28] Failing to provide adequate healthcare and access to footwear is tantamount to environmental classism,[51] with the rural poor being tied—both culturally and economically—to the land which is harming them, without the means to prevent those easily avoidable harms. In other words, the right to safe and health working conditions is being violated for specific sectors of the population which is a stark violation of Article 2(2) of the ICESCR, which repudiates discrimination based on “social origin, property, birth, or other status.” This should also be cast as a pressing occupational health issue, which links back to the way in which podoconiosis impacts on the right to work.

Care-models such as that currently used by the MFI are highly effective, and could be scaled up in an attempt at elimination, provided the requisite resources and data are made available. As the principal duty-holder, the government of Ethiopia must provide these missing links in order to militate against the violations of human rights as delineated in the instruments the state has ratified. Indeed, ratification entails an obligation to respect, protect, promote and fulfil these rights, and while progressive realisation is an acceptable interpretation of this obligation, it is not clear that any notable progression has been made in reducing reliance on NGOs in managing and reducing podoconiosis. While there is a cost to implementing the improvements listed in section 5.2 in endemic areas, this must be weighed against the 45% of working days lost each year,[19] and the increased health-care costs of non-adherence to inadequate care options. An under-resourced public-health strategy must be particularly intelligently conceived in order to optimise scarce resources. Clearly, a rigorous, well-resourced, shoe-wearing campaign, coupled with podoconiosis-specific training to existing and incumbent health-care workers, will be more cost-effective than managing the needs of an otherwise growing number of patients.

Of course, one cannot ignore the fact that healthcare provision in Ethiopia is weak, with the capacity to provide healthcare to only half of the population, and with a disproportionate share of healthcare funding, per capita, focussed on curative healthcare for urban populations, to the detriment of public health measures for rural populations. Only 42% of those in rural areas have access to healthcare facilities within walking distance. The right to health of rural populations is patently not met. Until recently, efforts to treat podoconiosis had been led solely by NGOs, who recently partnered with the Ethiopian Federal Ministry of Health and advocated
for the integration of podoconiosis into the National Master Plan for NTDs. This promises to introduce lymphedema management services into government clinics and improve staff training, but the scheme is under-resourced (and still reliant on external donations), and government health care facilities do not serve all endemic rural populations [25]. This is perhaps unsurprising, given that only 4.9 percent of Ethiopia’s GDP is spent on healthcare [52].

The poverty of Ethiopia must be seen relative to the wealth of the Global North; specifically, the capacity to provide vital services to Ethiopian people is hamstrung by the requirement that the state prioritise servicing high interest debt to the Global North states and institutions. Ethiopia has undergone a programme of structural adjustment since 1992, resulting in a diminished public sector[53], under-resourced health care services, and a growing reliance on NGOs to make up the shortfall. This is not to absolve the government of Ethiopia of its aforementioned human rights duties, but to be realistic about its capacity to deliver on those duties in light of its unrelenting economic dues. Ethiopia is not necessarily able to set its own priorities within a global economy that is hostile to the health needs of its population. Yet as the General Comment on Health within the ICESCR notes[31]:

[I]nternational financial institutions, notable the World Bank and the International Monetary Fund, should pay greater attention to the protection of the right to health in their lending policies, credit agreements and structural adjustment programmes.

Reforms to debt repayment in light of this consideration, or, more radically, some form of debt relief may be the most robust way of advancing Ethiopia’s capacity to improve its health provision and devote the necessary resources to rural settings to tackle podoconiosis.

In addition to debt, Ethiopia has a considerable problem of illicit financial flows.[54] Much of this is due to trade-mispricing, in which sales and purchases of goods take place at prices which do not match those of the market, facilitating tax avoidance, largely by multinational enterprises whose subsidiaries are distributed globally.[55] Curbing illicit financial flows by increased global tax transparency and accountability will be key to ensuring that nations like Ethiopia can stem the tide of capital flight and thereby finance initiatives for the improved healthcare, education, and specific resources (i.e. footwear) that are necessary to eliminate podoconiosis and prevent further losses, both economic and social. Given the way in which the
soil *mobilises* export products even as it *immobilises* those who work on it and with it, perhaps one narratively coherent suggestion for funding the necessary public health improvements could be through export taxes on agricultural products.

An additional set of potential duty-holders may be identified by considering the beneficiaries of Ethiopia’s agricultural products. Since podoconiosis is so often an occupational health issue, those situated on the product supply chain must be responsible, at least in part, for the well-being of farmers. Three of the world’s wealthiest nations – Japan, Germany and Saudi Arabia – are the leading importers of Ethiopian coffee [49], while prominent multinational brands like Illy and Starbucks are major suppliers. Global North consumers, nations and their multinational suppliers should be conscious of the working conditions of Ethiopian coffee farmers, many of whom are at high risk of developing podoconiosis, or are living and working with the disease. There is considerable potential for ethical consumerism to assist in the elimination of podoconiosis by requiring shoe-wearing amongst farmers, and, crucially, by providing appropriate footwear. While multinational coffee companies do not employ Ethiopian farmers directly, those sourcing and consuming Ethiopian coffee could push for these products to be acquired according to “Fairtrade” standards, thereby promising decent working conditions for farmers, in the form of shoe distribution and shoe-wearing. At present, Starbucks claims to source almost all of its coffee ethically, ensuring “safe, fair and human working conditions, such as protecting workers’ rights, providing adequate living conditions” [56]. In Ethiopian coffee-growing regions, these baseline working conditions can only be realised by shoe-wearing amongst farmers. There is no evidence that Starbucks, or any other coffee company, has considered this particular occupational risk. Many consumers would resist buying products whose farming disables workers. In the Global North, coffee (particularly premium varieties, such as those varieties that are regionally trademarked within Ethiopia) has relatively inelastic demand,[57] so that high prices (as a result of say, providing footwear to workers) can easily be passed on to the consumer. Similar arguments may be made about corporate and consumer responsibility with regard to other Ethiopian agricultural exports.

In a globalised world there are also global responsibilities for global health issues, and podoconiosis should not be taken as an exception to this simply because of its geographical specificity, lack of mortality, and lack of transmissibility. If the government of Ethiopia (and, *mutatis mutandis*, the governments of other endemic regions) is to be successful in eliminating
podoconiosis, it will require the assistance of other bodies. As Ooms and Hammonds [58] point out, growing wealth inequality between nations [59] determines the ability of Global South states to invest in health-related goods. Since the determinants of NTDs are so inter-linked, and tend to overlap geographically in their endemic regions, tackling podoconiosis should be part of a multi-NTD strategy of improved health-care and improved literacy. [60] This must be viewed as a global responsibility; it is not something Ethiopia can, or should, be left to address on its own.

6. Conclusion

Podoconiosis is a disease which could readily be eliminated but persists through failures to provide the basic necessities which are jointly required for its elimination. It is caused by inadequacies in: access to appropriate footwear, resources for foot hygiene, health literacy, and healthcare. These constitute violations of the right to a standard of living adequate for health and wellbeing. In turn, once podoconiosis has developed within an individual, further rights violations occur in the form of stigma and discrimination, and adverse effects on education, employment, and social participation.

Paul Farmer and Louise Ivers describe the quandary raised by easily eliminable diseases such as podoconiosis as the “dilemma of global health in the 21st century: finally, we have the tools for prevention and diagnosis and care; what we lack is an equity plan linked to a delivery system.” [61] In the case under consideration, the solution could not be simpler: comprehensive shoe-wearing would eliminate podoconiosis within a generation. Yet of course, the “right to shoes” is in fact a complex bricolage of other rights, and poverty currently undermines their joint realisation.

Increased efforts towards health literacy and shoe-wearing initiatives will be critical to ensuring enjoyment of the right to an adequate standard of living, and for the eventual elimination of podoconiosis, while improved access to health services is vital to those already living with the disease. Implementing these improvements is the duty of governments of endemic regions towards their own citizens, but without broader structural changes to (say) stem illicit financial flows, and liberate funds for healthcare, Global South nations cannot be expected to finance
the robust, abiding public health measures needed. Podoconiosis may pose no health threats to those on safer ground, but a disease of poverty is also a disease of wealth, and there is a global duty to prioritise elimination, and thereby secure the rights of those in endemic regions.

References


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