

The Social and Economic Impact of Neglected Tropical Diseases in Sub-Saharan Africa

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They are hiding their skin so that people cannot see them. I have not heard of anyone who wants others to know about it. No one will allow them to lead, and many people ignore them. They are considered dangerous. People fear contact with them. I feel sorry for them. Even me, I feared that from staying and meeting them we could get the disease ... They find it hard to marry, and marriages can break because of this condition.
(25-year-old Ugandan woman)

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Abstract NTDs are characterised by several factors, the most common of which is poverty. Attention needs to be given to the socio-economic impact of NTDs and the wide-reaching effects this has on the health and well-being of affected individuals and households. This impact is not uniform as NTDs are linked to poverty and other axes of inequity: vulnerable groups, e.g. gender, disability and ethnicity may become additionally vulnerable. This chapter addresses these issues whilst highlighting the need to focus on illness as well as disease.

Introduction

From Buruli ulcer to trachoma, the illustrative experience of a patient suffering from skin lesions expressed by a 25-year-old woman in an onchocerciasis-endemic village in a study by Weiss (2008) is a typical description of persons suffering from any of the parasitic, bacterial, viral and fungal infectious diseases described in the earlier chapters of this book and known as Neglected Tropical Diseases (NTDs). Together, NTDs affect about 2.7 billion people and kill more than half a million people every year (Hotez et al. 2009). These 2.7 billion are the poorest, disadvantaged and most marginalised people from Africa and some parts of Asia where poverty is high (Hotez et al. 2007a; Molyneux et al. 2005; Brooker et al. 2006; Fenwick et al. 2005, 2006; Ajanga et al. 2006). Sub-Saharan African countries bear the highest burden of NTDs with the number of people afflicted by each of the several NTDs representing up to 90 % of the world's burden for some of these diseases (Hotez et al. 2009; Zhang et al. 2010).

These diseases are characterised by several factors, the most common of which is poverty (WHO 2010a). In sub-Saharan Africa as in other countries where NTDs are present, the poorest of the poor, the most stigmatised and marginalised and those least able to demand services are affected. These often include women, children, ethnic minorities, displaced people as well as those living in remote areas with restricted access to health services.

The economic effects of disease control have been known since the early twentieth century. Research has shown that investment in disease control could rescue the “bottom billion” – those living in some of the world's poorest communities – through its effect on the four key elements of the poverty trap: health, agriculture, education and infrastructure (Sachs 2008; Bleakley 2007). However, attention needs to be given to the socio-economic effects of NTDs and the devastating impact they have on the health of infected households, leading to debilitating physical disability and disfigurement including peripheral neuropathy, cardiac disease from Chagas disease, skin lesions and ulcers from lymphatic filariasis and Buruli ulcer, loss of eyesight from trachoma and onchocerciasis and cognitive impairment from schistosomiasis resulting in a lifetime of disability (Hotez et al. 2007b; Rodrigues and Lockwood 2011). The impact of NTDs on agricultural productivity and education and the infrastructural development in affected communities are wide reaching. The impact is not uniform as NTDs are linked to poverty and other axes of inequity: vulnerable groups, e.g. gender, disability and ethnicity may become additionally vulnerable. Research has established the disability associated with NTDs to be

about 57 disability-adjusted life years (DALYS). However, Hotez (2009), Gyapong et al. (2000a), Babu (2009) and Perera et al. (2007) have noted that these DALYS may actually be higher and that the economic, social and psychological burden of these diseases put together is more extensive than previously calculated. Dr. Margaret Chan in her introduction to the first WHO NTD report succinctly summarised: “The consequences are costly for societies and for health care. Such costs include intensive care for dengue haemorrhagic fever and clinical rabies, surgery and prolonged hospital stays for Chagas disease and Buruli ulcer, and rehabilitation for leprosy and lymphatic filariasis. For some diseases, such as sleeping sickness and leishmaniasis, treatments are old, cumbersome to administer and toxic. For others, especially the diseases that cause blindness, the damage is permanent. Clinical development of rabies can be prevented through timely immunization after exposure, but access to life-saving biologicals is expensive and is not affordable in many Asian and African countries. For most of these diseases, stigma and social exclusion compound the misery, especially for women” (WHO 2010a, p. iv).

The disease-specific chapters in this book use aspects of the medical model of disability (Carson 2009; Yokotani 2001) (an individual’s disability) which views physical problems as needing to be cared for and cured by medicine, through a focus on the basic biology, life cycle, disease presentation, epidemiology and burden of disease and distribution, available control tools and strategies, challenges of programme implementation, further research for control and an outlook for the next decade of NTDs. This chapter focuses on the socio-economic impact of NTDs using aspects of the social model of disability (Yokotani 2001) (an unequal relationship within a society in which the needs of people with some form of disability are often given little or no consideration especially when they are the poorest of the poor and have no voice). It firstly highlights lay perceptions and understanding of NTDs, followed by an overview of NTDs gender as well as the stigma, the quest for therapy in the event of contracting an NTD and the economic burden of having an NTD on the individuals, households, and society. Additionally it highlights the importance of action to address female and male genital schistosomiasis, which have been neglected to date. The chapter finishes with a discussion on the cross-cutting themes with respect to the social and economic impact of NTDs and the need for further action.

Disease Versus Illness: Lay Perceptions of NTDs

The distinction between disease and illness has been well described. Whereas disease defines a pathophysiologic process, illness is defined by the complete person: physical, psychological, social and cultural (Eisenberg 1977; Helman 1981). Illness represents an individual’s unique and personal experience of being unwell. People often rationalise their illness experience through a complex web of personal encounters, experiences and belief systems shaped by their cultural and social world. As expressed by Kleinman (1980), individuals would usually develop a personal (or adopt an existing) “explanatory model” that represents their personal conceptualisation of the cause, course and consequences of their illness. For each of the NTDs being discussed in this volume, there is a classic medical description, researched

and acceptable causes and tried and tested treatment options. The conditions according to medicine are either bacterial infections, worm infestations or vector transmitted (mosquito, a fly, etc.). In some instances, there is no clear-cut cause. On the other hand, many people in African societies rationalise their experience of ill health through complex personal experiences and belief systems (sociocultural and/or religious) ingrained in their cultural and social world. An explanation of ill health or physical manifestations, be it by the patient or the people in his or her society, would usually be representative of their personal conceptualisation of the cause, course and consequences of their illness (Green et al. 2002). Patients' perceptions about a disease, its effective treatment and the socio-economic dislocation caused by the illness and related symptoms generally have a significant impact on when and where to go for diagnosis and treatment. Beliefs about the cause and transmission of a disease vary considerably from culture to culture; however, there are some general traits that permeate many cultures. They can be dynamic in that the prolonged nature of a condition and the long period and difficulty of a healing process can lead to assumptions of mystical involvement even for people who attributed their ill health to natural causes at the onset of symptoms. As Peeters Grietens et al. (2012) state, the same condition can also have double causality. In other words, a particular disease may be attributed to natural/medically known causes and simultaneously to mystical causes. Therefore, whilst medical science describes a malfunction in the body, lay perceptions of disease causation relate to their experience with their ill health.

According to Peeters Grietens et al (2012) in Benin, plots of land on which crops are grown are protected by charms to prevent theft, so, in that country, Buruli can be attributed to a charm as a result of trespassing on another person's land thereby disrupting a social order. In Ghana, amongst other causes, Buruli is attributed to a curse "if your mouth is strong", in other words if a person uses powerful words to curse or witchcraft because someone hates you (Renzaho et al. 2007; Stienstra et al. 2002).

In sub-Saharan Africa, there is a dearth of information on perceptions of lymphatic filariasis. Even in Ghana where studies on the subject have been conducted in the Northern and Southern part of the country, there are multiple differences in perceptions of aetiology. Whilst in Southern Ghana the belief is that one gets the disease because of an imbalance in the body's constitution and other physical and sometimes spiritual causes, in the Northern part of the country, the perception is that it is due to external forces like witchcraft or a curse (Gyapong et al. 1996a; Ahorlu et al. 1999).

In the Democratic Republic of Congo, the mode of transmission and dramatic sequelae following sleeping sickness are very well known and recognised by community members (Mpanya et al. 2012). In addition, serious prohibitions (complete rest for 6 months) are linked to those with diseases with severe consequences for individuals if they are not seen to be adhered to. Although considered shameful, having the disease signifies a shift in societal position rather than rejection by the family and community. Guinea worm in Ghana is seen as a normal part of the human anatomy. The worm is not seen as an alien presence. It is normally in people's blood and shows up from time to time (Bierlich 1995).

In Table 1 we show that lay perceptions of these conditions differ sometimes significantly from what is medically known.

Table 1 Lay perceptions on disease causation

Condition	Lay description	Reference
	Perceived cause	
Buruli	Unknown, witchcraft, drinking unclean water, unhygienic practices, playing with an infected person and infraction against social order	Renzaho et al. (2007), Stienstra et al. (2002), Peeters-Grietens et al. (2012), and WHO (2013a)
Dracunculiasis (guinea worm)	Poor drinking water	WHO (2013b) and Sisay (2012)
	Drinking water infected by people with the disease	
Human African trypanosomiasis (sleeping sickness)	The fly, eating the amaranth plant and eating pork	WHO (2013c) and Mapanya et al. (2012)
Leishmaniasis (kala-azar)	Sandflies, dirt, washing in a canal, eating and drinking with patients	WHO (2013d)
Leprosy	Hereditary, witchcraft breaking of a taboo	WHO (2012) Gender and leprosy case studies 2009
Lymphatic filariasis	Hydrocele “fever scrotum”, elephantiasis, “elephant leg”, these are as a result of a curse, poor body constitution and/or are hereditary	WHO (2013e), Gyapong et al. (1996a), and Ahorlu et al. (1999)
Onchocerciasis	Bite of the blackfly causing itching, Several worms in the body, eating improperly cooked leaves	WHO (2013f) and Aninakwah-Boahene et al. (2014)
Schistosomiasis	Sign of growth, hereditary	WHO (2013g)
Soil-transmitted helminths (ascaris, whipworm and hookworm)	No information found	WHO (2015)
Trachoma	Normal part of childhood	WHO (2013h) and Desmond et al. (2005)
Yaws	Poor personal hygiene and sanitation	Anecdotal reports from Ghana

NTDs and Stigma: The Impact on Gender Roles and Relations

Many if not all NTDs discussed in this book cause impairment, disfigurement and sometimes permanent disability, leading to stigma and social discrimination. Many studies on stigma refer to leprosy, and this may be due to the fact that rejection as a result of leprosy dates far back to biblical times to depict a mark of disgrace or physical disorder (to such an extent that sufferers of leprosy subjected to their own mock funeral prior to banishment from their families and communities). In some cases, they endured torture and execution (Roueche 1986) and rejection either for physical or social reasons (Weiss 2008; Goffman 1963). The concept of stigma can

be either enacted (when the affected person faces rejection, discrimination or physical abuse by others) or perceived (when the affected person thinks he or she is or can be stigmatised because of their physical condition). In many cases, the perceived stigma can be worse than that enacted and may lead to known attempts of suicide, emotional stress, depression and anxiety (Heynders 2002; Hyland 1993; Scambler 1998; Van Brakel 2003). Stigma as an important mediator of social burden can lead to invisibility and marginalisation of infected people, emotional distress and delayed diagnosis and treatment even to the extent that free treatment at health facilities is not sought to avoid a public appearance because of the disease (Perera et al. 2007; Pépin et al. 2002).

Discrimination and stigma heighten people's vulnerability to ill health. In all countries of the world, the burden of disease is disproportionately borne by vulnerable and marginalised groups, who often suffer from other social inequities as well as discrimination (United Nations Special Rapporteur 2003: para. 59). It can also be an obstacle to prevention and treatment. This form of discrimination against people living in poverty can be reinforced by other forms of discrimination, such as on grounds of sex or race, which further increase vulnerability to neglected diseases. For example, the status of women in many countries, including their lack of ownership of resources, affects their access to prevention and treatment and means they may well be more vulnerable to stigma and the impact of stigma.

In any society, different roles are assigned to men and women as a result of either culture or religion. This disproportionately affects the extent to which men and women and boys and girls are exposed to and infected by any of the NTDs being discussed and shapes whether infected patients experience enacted (a discriminatory experience as a result of being labelled with a disease) or felt stigma (an imagined social reaction that can change a person's identity) (Crinson 2007). It also affects their perception and health care-seeking behaviour in the event the disease.

Allotey and Gyapong (2005) argue that all functioning societies are built on the abilities of individual members to adopt specific roles and responsibilities. The roles that are assigned to males and females by culture and society, how they are played out and how they relate to each other at the individual and broader sociopolitical levels are described by the concept of gender. That there are gender differences is not in dispute; the problem arises with the different values placed on the various roles and responsibilities and the consequences of this in creating and sustaining disadvantage and inequities. Gender roles and relations shape how individuals and societies operate, the effects of the disadvantage created, and permeate all aspects of life, from production, allocation and distribution of resources to exposure to disease and health-promoting services.

But does all this add value to health-related outcomes, and do these need to be addressed in responses to NTDs? At the very least, retaining a gender focus on any agenda provides information on new ways of approaching health issues and identifying points for specific interventions to address specific issues. On the basis of the conventional health indicators provided through quantitative methodologies, current data are not strong enough to support a definitive response. Data quality are poor and often draw largely on biased samples; sex disaggregated data are often

not available and, when available, are not always used to inform responsive policy. In addition, qualitative data usually focuses on women without reference to the interaction with men within their societies or the dynamics of gender relations. There is little information to proffer explanations of gender differences from male perspectives.

It must be noted that in spite of cultural or religious diversity, the expression or experience of stigma is similar worldwide. It affects mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious functions, and the depth and detail of how stigma is experienced is linked to gender, roles, relations and expectations (Van Brakel 2003).

In the case of sleeping sickness and leishmaniasis, men generally tend to contract the disease more than women probably as a result of occupational hazards and general exposure to the vector; however, women tend to be more stigmatised from the consequences of contracting the disease and can experience complications such as amenorrhoea, infertility and miscarriage (WHO 2010a).

In the DRC, women appeared to be more knowledgeable about the disease than men due to their role as caregivers which means they are more exposed to health education messages when they send sick family members to a health facility (Pépin et al. 2002; Mpanya et al. 2012). Within this context, having sexual relations when one has the condition is a taboo, and gendered norms mean that women have to leave their matrimonial homes to avoid sex whilst their male counterparts seek other women for sexual interactions (Mpanya et al. 2012).

Both men and women are susceptible and probably equally infected by onchocerciasis, schistosomiasis, soil-transmitted helminths and sleeping sickness with women suffering more of the consequences during pregnancy as a result of anaemia and iron deficiency due to heavy infection (WHO 2010a).

Urogenital schistosomiasis also referred to as female or male genital schistosomiasis (FGS and MGS) is common in Africa. Adolescent girls and women with FGS can experience bleeding and unpleasant discharge from the vagina, genital lesions and nodules in the vulva general discomfort and pain during sex. FGS is a cause of subfertility and miscarriage and can affect vulnerability to HIV and the human papillomavirus, all of which arguably have wide-reaching social and economic consequences, although how women experience symptoms indicative of FGS, their treatment-seeking pathways and the impact on their livelihoods and well-being are poorly understood. Symptoms of MGS in adolescent boys and men include bleeding and egg deposition within semen, yellow discoloration in semen and lumpy semen, the implications of which are poorly understood (Mbabazi et al. 2011).

FGS and MGS are sensitive, private and possibly stigmatising conditions. Messaging therefore needs to be geared to the realities of females' and males' gendered experiences. This requires in-depth qualitative research to explore the context and community discourse surrounding FGS and MGS symptoms and the development of appropriate referral and treatment strategies that are accessible to all women and girls and men and boys, regardless of where they live or how much money or resources they can access.

Although the prevalence of lymphoedema and elephantiasis is higher in women than in men when hydrocele is taken into consideration, more adult men than women appear to have severe chronic consequences of lymphatic filariasis. The consequent disfigurement results in the infected person experiencing stigma, social and psychological distress with women having a far less chance of finding a spouse than men and suffering more problems and general discrimination (WHO 2010a, b).

Clemmons et al. (2002) report that with regard to decision making for MDA for onchocerciasis control, men are the key decision makers. Women are not invited to meetings where issues are discussed and are not given feedback on the major decisions taken. They are informed about CDTI activities by word of mouth just before drug distribution. There are also gender differences in community-based providers: in this context relatively few ivermectin distributors (21 %) are women. Although they receive less support than their male counterparts, female distributors are just as willing to continue ivermectin distribution in the community, and they perform as well or better than men in this regard (Stienstra et al. 2002).

The perception in the Ashanti region of Ghana is that more women have Buruli ulcer than men because of prostitution. However, like lymphatic filariasis, both sexes appear to be equally discriminated against since they are avoided in public places due to fear of contracting the disease, have less chance of being appointed into leadership positions and have problematic marriages and less chance of getting a spouse (Stienstra et al. 2002). Breiger et al. (1998), in their study in Nigeria, documented some issues around stigma related to onchocerciasis from individual survey respondents. Examples of responses are as follows:

“I am embarrassed because my whole body is covered with Onchocerciasis”, “It is shameful for having tough skin like a frog”, “I am embarrassed because it has destroyed my body”, “I am ashamed when it itches me in the midst of a crowd”, “It embarrasses me” “I use a long wrap whenever I go out”, “It causes disrespect when one scratches in public” “People laugh at him”, “People won't want to be close to someone with Onchocerciasis”, “Onchocerciasis leads to disrespect because it causes blindness and destroys the skin”.

All these expressions, the ways in which perceived and enacted stigma are experienced, depict physical, mental and social attributes, self-hate, self-depravation and lack of social acceptance and stress of illness experience as described by Goffman (1963). The complex ways in which stigma is experienced affect health care-seeking behaviour in many ways. Weiss (2008) suggests some key interventions to address stigma. These are (1) support, (2) enactment of laws and (3) awareness creation in order to challenge sociocultural norms and behaviour.

The Quest for Therapy in the Event of NTDs

Over the last 10 years or so, there have been important advances in the development of diagnostics and massive support from pharmaceutical companies to supply drugs for the treatment of the NTDs. Available treatments are either for free or cost less than a dollar a day, and studies have shown that an integrated MDA using a combination of medicines to prevent or treat the seven most prevalent NTDs yields the best return (Hotez et al. 2007a).

With the exception of guinea worm, the NTDs being discussed in this book can be effectively treated with drugs and the majority through mass drug administration (MDA), provision of clean water, vector control and proper sanitation. Through health education and massive campaigns, NTD control programmes in sub-Saharan Africa have succeeded in treating people over many years; however, the response to attempts at treatment and control varies from disease to disease and depends on the approach used. In the DRC, low attendance at screening sessions for human African trypanosomiasis (HAT) was attributed to, amongst other things, mistrust of mobile team nurses (who were perceived to leave the disease in people's blood with the use of injections), unannounced arrival of staff for screening exercises, fear of lumbar punctures, fear of unsolicited HIV/AIDS tests, other economic priorities and the lack of confidentiality during the screening procedure itself (Mpanya et al. 2012). Side effects, the timing of MDA, the type and attitude of the distributor (community distributor or health worker) and experience with adverse events have also affected MDA for lymphatic filariasis and onchocerciasis, although the expelling of worms after drug administration has been found to be a motivating factor (Abanobi et al. 2011; Abd Elaziz et al. 2013; Babu and Babu 2014; Gyapong et al. 2000b).

People with limited resources, particularly those living in rural areas, invariably seek medical help first from the least expensive, closest and most trusted sources. Treatment may also be sought simultaneously or sequentially before going to a hospital. The first time a person experiences a feeling of being unwell, they ask what is wrong, and then often they will deploy the wait and see what happens next approach. As soon as the condition is prolonged for longer than expected, the "why" questions begin to set in. Why is this happening to me or my family or that person at this time and what can be done about it? This leads to a quest for therapy as described by Kleinman (1980) and Helman (1981) where people irrespective of their socio-economic, religious or cultural background seek traditional and cosmopolitan care simultaneously. Kleinman propounds that when a person is sick, there are three interlinked health sectors that are available for use: popular, folk and professional sectors. In all societies these sectors are available and create a pluralistic health care system with a wide range of options for care seekers to choose from in times of ill health. The popular sector is usually the first point of call and is usually at the home level where advice is sought from relatives and friends. Communities and parents' past experience informs practice at this stage: for example, self-medication is practised with leftover drugs from the home and drugs borrowed from friends or purchased from local drug shops. Conditions like hot body, chills, general

discomfort and malaria, which are considered mild, are dealt with easily within this sector. The folk sector has the more traditional type of healing, and treatment is sought from traditional healers, spiritualists, faith healers, herbalists and traditional birth attendants. This sector can be visited as a first option but in most cases are contacted when the first health-seeking attempt within the household or community does not work. However, the popular and folk sectors may be used concurrently. The professional sector is the more formal sector that has people with formal professional training like doctors, nurses and pharmacists. Others however may rush or be rushed directly to a health facility depending on what they perceived to be the cause of their condition. Due to cost and other factors, it may be the last point of call when all other options have failed by which time the condition would have progressed severely (Fig. 1).

In Benin, Buruli ulcer patients can access home treatments (salves, antibiotics and analgesics), traditional medicine (herbs, divination, incantations) and hospital treatments. Over 70 % of patients interviewed at home and in hospital used traditional and hospital medicine interchangeably (Peeters Grietens et al. (2012). The availability of a pluralistic health care system in African settings, the cost of care, fear of stigma and “mutilation” after treatment are some of the reasons for delay in seeking health care. Interestingly the perceived cause of the disease did not contribute to a delay in care seeking for Buruli ulcer patients in Cameroon (Stienstra et al. 2002). Similarly in the Greater Accra and Ashanti Regions of Ghana, Buruli patients had multiple sources of care available to them and acted in the same way as their counterparts in Benin and Cameroon, applying salves to their nodules and “boils” at

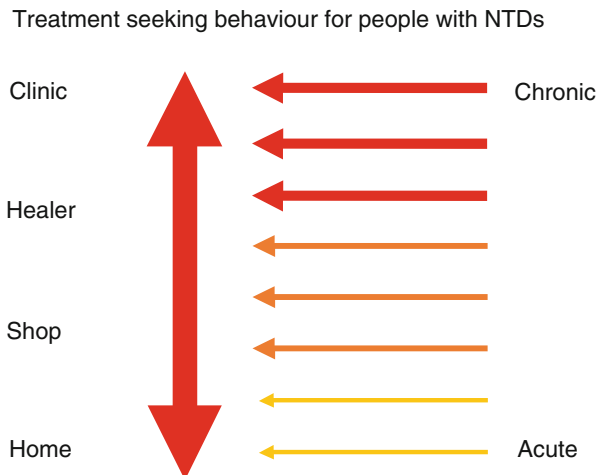


Fig. 1 Treatment-seeking pathway for NTDs (Source: Gyapong and Theobald, unpublished data). A patient suffering from, for example, elephantiasis, has multiple options available for seeking health care which they will use simultaneously depending on what they perceive to be the cause of their problem, what they can afford, what they believe in or advise/pressure from family and friends

home, seeking treatment from a traditional healer and then finally using the hospital as a last resort (Renzaho et al. 2007; Stienstra et al. 2002).

The Economic Impact of Having NTDs

Apart from the physical and psychological suffering caused by NTDs to people in endemic societies, the disease also inflicts an enormous economic burden on the individual, the household, the community and the society at large. For many sufferers, there is a loss of productivity, school absenteeism and high costs from long-term stay in formal and non-formal health care institutions which further exacerbate the entrenched cycle of poverty and ill health for disadvantaged populations (Hunt et al. 2007).

Globally, the burden of disease concept first published by Murray and Lopez (1996) has been used to quantify the burden of premature mortality and disability for major diseases or disease groups. The NTD burden is expressed through disability-adjusted life years (DALYs) that is the years of healthy life lost because of disability or premature death. NTDs constitute the fourth largest disease burden of all communicable diseases and account for 46–57 million DALYs lost (Murray and Lopez 1996; Hotez 2009). NTDs in sub-Saharan Africa (SSA) account for the highest DALY lost affecting about 21.2 million people (Hotez and Kamath 2009).

Hotez and Kamath (2009) estimated DALYs for STH infections and schistosomiasis by adjusting ranges of global estimates according to the percentage of the total number of cases that occur in SSA. Other NTD burdens were quoted directly from WHO estimates. From their analysis, they determined that the total burden of NTDs in SSA is as high as one-half of the disease burden caused by malaria and twice the disease burden caused by tuberculosis in SSA, suggesting that NTDs represent a formidable public health challenge in the region (Hotez and Kamath 2009).

Studies show that the burden of lymphatic filariasis is likely to be underestimated due to stigma, where an affected individual avoids public life and may abandon work (Norris et al. 2012). A study by Gyapong et al. (1996b) in northern Ghana found the mean duration of an ADL episode to be 5.1 days and the mean period of total incapacitation to be about 3 days. This affects family income negatively especially during the rainy season when these subsistent farmers need to be on their farms to till their lands. Marginalised populations are the most affected, and already impoverished, and the impacts of NTDs are likely to be catastrophic. The figures on DALYs – presented above in Table 2 – do not capture or reflect the impact of illness and health care seeking on individuals and households, and this needs to be better understood in order to develop more responsive health services. It is estimated that with chronic conditions, an acute episode of the disease can cause an individual to lose up to 5 days of work per episode (Norris et al. 2012). More than half of Guinea worm patients are unable to leave their beds for about a month, which generally coincides with the peak season of agricultural activities, when labour is in maximum demand. This can lead to malnutrition amongst children in households whose able members are affected. For this reason, in Mali the disease is tellingly called “the disease of the empty granary”. Children miss school

Table 2 Disease burden (DALYs) in sub-Saharan Africa resulting from NTDs

Disease	Estimated global disease	Estimated % disease	Estimated SSA disease	Reference
	Burden in DALYs	Burden in SSA (%)	Burden in DALYs	
Hookworm	1.5–22.1 million	34	0.5–7.5 million	Hotez et al. (2008) and Bethony et al. (2006)
Schistosomiasis	1.7–4.5 million	93	1.6–4.2 million	WHO (2004) and Hotez et al. (2008)
Ascariasis	1.8–10.5 million	21	0.4–2.2 million	Hotez et al. (2008) and Bethony et al. 2006
Lymphatic filariasis	5.8 million	35	2.0 million	WHO (2004)
Trichuriasis	1.8–6.4 million	27	0.5–1.7 million	Hotez et al. (2008) and Bethony et al. 2006
Human African trypanosomiasis	1.5 million	100	1.5 million	WHO (2004)
Trachoma	2.3 million	52	1.2 million	WHO (2004)
Onchocerciasis	0.5 million	99	0.5 million	WHO (2004)
Leishmaniasis	2.1 million	18	0.4 million	WHO (2004)
Leprosy	0.2 million	14	0.02 million	WHO (2004, 2008)
Dengue	0.6 million	<1	0.005 million	WHO (2004)
Total NTDs	≤56.6 million	15–37	8.6–21.2 million	Hotez et al. (2008)

Source: Hotez and Kamath (2009)

when they have guinea worm and when they substitute for sick members of their households (Ruiz-Tiben and Hopkins 2006: 275–309). A study in Ghana indicates that caregivers and adult patients lost a total of 535 productive days seeking Buruli ulcer care and school-going children lost 365 days to the disease and confirms that its treatment poses significant 45 % economic burden on households (Amoakoh and Aikins 2013).

According to WHO, about 65 % of the global infection of lymphatic filariasis occurs in Southeast Asia (WHO 2013e). India alone spent an average of \$1 billion every year on lymphatic filariasis as a result of treatment and productivity lost (WHO 2013; Chu et al. 2010; Norris et al. 2012). The treatment cost within an endemic population is estimated to cost \$2 lost per patient per year, and a single dose of treatment per year costs \$0.03 per person (Chu et al. 2010; Norris et al. 2012; Ramaiah et al. 2000). In Ghana the average cost of treating Buruli ulcer was estimated to be US\$ 780 per patient during 1994–1996, an amount that was greater than the per capita that the government earmarked on health. In 2008 the disease accounted for 25 % of households' yearly earnings on hospitalisation costs in Cameroon, whilst the median total cost of hospital treatment was identified as

€126.70 in the same country (WHO 2013a). An indirect cost valued at US\$1,378.67 with a mean of US\$21.88 for Buruli ulcer was identified as a cost burden to a household member with the disease in Ghana (Amoakoh and Aikins 2013).

Discussion

NTDs are diseases of poverty and are themselves impoverishing, disproportionately affecting people living in poor or marginalised communities. Hotez (2009) and Person et al. (2009) suggest that women are often particularly isolated and marginalised by stigma-associated NTDs. These diseases play out in multiple ways and across the generations. Children, for example, are withdrawn from school due to financial constraints on older people with disabilities. Vulnerability to different NTDs, ability to access treatment and social and economic impact of NTDs affect different people in multiple ways, and this in turn is dependent on contextual factors. There is a real need for intersectionality (Tolhurst et al. 2012) and approaches that analyse the interplay between gender, poverty, ethnicity, disability, sexuality, religion and age. Additionally adopting an intersectional approach is useful in terms of influencing policy as it provides an inclusiveness, which is often missing when health policies are developed.

There is clear and complex disconnect between biological cause/medical model explanation and social understanding and aetiology of disease. What is important for health promotion is that dialogue needs to be tailored to the understandings and realities of different communities. This is not straightforward, but community-embedded cadres such as community health workers and community-based drug distributors have embedded knowledge that can support interventions. The focus for action needs to go beyond community messaging, to ensure that resilient health systems are developed that are responsive to the needs and realities of socially and economically disenfranchised citizens.

There is also need for qualitative research. The value of qualitative research to better understand the lived realities of affected communities as well as the ability and challenges faced by health systems to appropriately address these is often overlooked when addressing NTDs. However, increasingly those working on NTDs are aware there is a gap in data, which can only be filled by research methods which enable the depth and detail of affected communities and health providers' experiences and challenges to be better understood. For example, through qualitative and participatory approaches, the needs and priorities of frontline providers and volunteers can be documented to ensure these feed into policy and practice to support sustainable and equitable human resource strategies for integrated NTD control.

The social and economic impacts of NTDs go beyond the health sector.

- There is a need for intra- and inter-sectoral action, i.e. links within the health sector itself as well as between the health sector and other sectors like education, agriculture and sanitation. For example, action to address FGS will require new

partnerships within the health sector between NTDs and maternal and sexual and reproductive health as well as strategies at the community level to build links with relevant formal or informal providers (e.g. women who might seek help in the case of infertility).

- New partnerships beyond the health sector, for example, with Ministries of Education, and Gender, Youth and Community Services will be essential in any discussions or action on FGS. Generating and making evidence on interventions that work need to be accessible to stakeholders who should use it in the course of their work, which requires new ways of working together within and across sectors and with stakeholders.
- Poverty alleviation actions are also necessary to address the catastrophic social and economic effects of NTDs on women and men and girls and boys.

Conclusion

In a time when maintaining the integrity of the art of medicine is of critical importance, we are instead witnessing its devaluation due to the current counterposing forces in health care. Disease has become the focus of the technologic and market-driven medical system, whilst illness and the sociocultural aspects of medicine have blurred into the background. Yet, the healing tools and instruments of science are blunt and ineffective when used blindly in ignorance of the complex meaning and context of a patient's illness and the impact of this on their livelihoods and well-being. We need to foster attitudes, values and communication skills that focus on illness, not just disease, to prepare ourselves for the challenges ahead.

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