Stigmatizing Beliefs, Stereotypes and Communication Surrounding Tungiasis in Kenya

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Stigmatizing Beliefs, Stereotypes and Communication

Surrounding Tungiasis in Kenya

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Abstract

Tungiasis is a neglected parasitic skin disease widespread in resource-poor communities in sub-Saharan Africa, South America, and the Caribbean. Besides physical suffering, individuals and family members of persons with tungiasis suffer from stigma associated with the condition and are often socially excluded. Review of literature shows that, little research has investigated the specifics of tungiasis stigma in tungiasis endemic areas. This article reports results of focus group and in-depth interview research on beliefs, stereotypes, and stigmatizing communication surrounding tungiasis from the perspective of persons living with tungiasis in Murang’a County, Kenya. The analysis and description of the nature of stigma communication associated with tungiasis were based on stigma communication theory (SCT). The findings of this study suggest that, besides stigma messages (mark, label, peril and responsibility) attributes provided by SCT, the nature tungiasis stigma communication would be understood best as an intersection of two other major components—tungiasis stigma beliefs and stereotype associated with tungiasis—that intersect during stigma communication processes and shaped tungiasis stigma communication in distinct ways in the sampled community. Causes of tungiasis identified by interviewees included curses and witchcraft. Sufferers of severe infestations were stereotyped as lazy and unhygienic, and as possessing “jigger-attracting blood.” Both physical deformity and moral stigma were associated with tungiasis.

Keywords: sub-Saharan Africa, neglected tropical diseases, stigma, stigma communication theory, tungiasis, stereotypes, beliefs.
Introduction

Tungiasis is a neglected parasitic skin disease widespread in resource-poor communities in sub-Saharan Africa, South America, and the Caribbean. Besides physical suffering, individuals and family members of persons with tungiasis suffer immensely from stigma associated with the condition and are often socially excluded (Heukelbach & Ugboomboiko, 2007; Njau, Wanzala, Mutugi, & Ariza, 2012). By definition, stigmatized persons possess, or are perceived to possess, an attribute or set of attributes that marks them as different and leads them to being devalued by others through the use of negative evaluations and stereotypes (Major & O’Brien, 2005; Smith, 2009). The creation, reinforcement, and management of tungiasis stigma, like any stigma, is tied to communication, in a process called stigma communication (Meisenbach, 2010; Smith, 2009; Smith, Ferrara, & Witte, 2007).

Though significant research has been done on T. penetrans, many studies have focused on case reports of travellers and tourists with limited infestation (e.g. Chen, et al., 2011; Hager, Jacobs, Orengo, & Rosen, 2008). Dermatologists and epidemiologists have also studied the morbidity, genetic variability, morphology, pathology and control of T. penetrans (Feldmeier & Heukelbach, 2003; Eisele et al., 2003; Heukelbach et al., 2007; Ugboomboiko, et al., 2007).

Although scholars agree that the symptoms of tungiasis lead them to be devalued and stigmatized by others (Bronder, 2010; Collins et al., 2009), the beliefs or stereotypes as well as the nature of stigmatizing communication underpinning stigma associated with tungiasis have received limited attention from scholars.

Tungiasis in Kenya

Also known as jigger, funza, ndutu, among many other names, tungiasis is a parasitic skin disease now endemic in many parts of Kenya. According to Kimani, Nyagero, and Ikamari (2012) about two million cases of T. penetrans infestation had been registered between 2008 and 2010 by nongovernmental organizations helping in the control of the spread of T. penetrans in Kenya. According to the recently published National Policy Guidelines on Prevention and Control of Jigger Infestations in Kenya, an estimated 1.4 million Kenyans translating to 4 percent of the total population suffer from jigger infestation (Ministry of Health, 2014). Cases of stigma associated with tungiasis and adverse effects of such stigma in Murang’a County have also been regularly
reported by media reporters and non-governmental organizations (e.g. Ahadi Kenya Trust, 2008; Ali, 2009; Gikandi, 2009; Njeri, 2011; Wangui, 2008; Wanjala, 2010), but this evidence is almost exclusively anecdotal.

Tungiasis creates substantial social and financial burdens for individuals, families, communities, and even nations (Heukelbach, De Oliveira, Hesse, & Feldmeier, 2001; Ugboroiko, Ariza, Ofoezie, & Heukelbach, 2007). Our study focused on the presence of the disease in Murang’a County, which has been reported as the site of the highest tungiasis prevalence in the sub-Saharan nation of Kenya (Kimani, Nyagero, & Ikamari, 2012; Karuga, 2011; Kenya National Assembly Report, 2010; Ministry of Health, 2014).

Understanding the stereotypes and stigma associated with tungiasis is essential for maximizing effectiveness of health and health communication interventions for this neglected tropical disease, as stigmatization may erect substantial barriers to health information seeking and treatment. The purpose of this research, therefore, was to investigate these issues in Murang’a County.

Review of Literature

Tungiasis

Tungiasis is a neglected tropical disease (NTD) caused by the smallest known sand flea, Tunga penetrans, or the chigoe (jigger) flea. Like many NTDs, tungiasis is prevalent in settings of extreme poverty, especially among the rural poor and some disadvantaged urban populations (Hotez & Kamath, 2009). It is estimated that over 1.4 million people are infested with T. penetrans in Kenya with the most at risk population cohorts being children 5 to 14 years, the elderly, and the physically and mentally disabled persons (Ministry of Health, 2014), and most live in rural areas.

Fleas live two to five centimetres deep beneath sandy soil, and humans are infected when they walk or otherwise come into contact with the infested ground. The female flea burrows into an individual’s skin, increases its volume by a factor of roughly 2,000–3,000, frequently reaching a diameter of up to 1 cm, expels about 100 eggs over a two–week period, and then dies (Collins, McLeod, Konfor, Lamnyam, Ngarka, & Njamnshi, 2005). In most cases T. penetrans infests folds of the toes, inter-digital spaces, soles, heels, hands, and knees (Chen et al., 2011; Hakeem, Morris, Bhattacharyya, & Fox, 2010). The sites itch and victims normally start to scratch, promoting the entry of bacteria. Persistent inflammation can lead to ulcerated lesions, loss of nails, and gangrene. Extreme infestations may result in crippling disfigurement and,
ultimately, death.

Extraction of the flea surgically with a sterile instrument is the commonly recommended treatment, but that requires a skilled hand and good eyesight, and scholars argue that in many resource-poor communities attempts at surgical removal cause more harm than good (Feldmeier & Heukelbach, 2003). The most effective intervention for tungiasis is considered to be household hygiene (Buckendahl, et al., 2010) in combination with antibiotics to treat secondary infections (Heukelbach, et al., 2004).

Murang’a County, Kenya

Murang’a County, the site of this research, is located in central Kenya and is predominantly occupied by the Agikuyu community. It has a population of nearly one million people, about 30% of whom live in poverty on less than $1 per day (NEMA, 2009). Much of the population depends on subsistence farming, with tea and coffee production historically being the major source of foreign exchange. These commodities have faced stagnation and declining prices in recent years, creating financial challenges for farmers (Nyaga, 2007).

Severe tungiasis has been reported in almost all the seven constituencies in Murang’a County, that is: Kigumo, Kangema, Kandara, Kiharu, Gatanga, Mathioya and Maragua. In a cross-sectional study aimed at describing the prevalence of tungiasis and associated risk factors in a sentinel group (children 5-12 years of age) in Murang’a County, Njau and colleagues (2012) found a prevalence rate of 51.7% in the sampled individuals. This means that slightly more than half of the respondents who participated in that study were infested with T. penetrans.

Stigma Associated with Tungiasis

In a review of 95 refereed journal articles on epidermal parasitic skin diseases, Feldmeier and Heukelbach (2003) concluded that stigmatization was one of the key reasons why tungiasis frequently progresses untreated in many parts of the world. Stigma refers to an attribute that is profoundly degrading, reducing the individual that possesses it from a whole, socially accepted person to a disparaged and discredited one (Goffman, 1963).

Most research on stigma finds its theoretical base in Goffman’s (1963) seminal work on the topic. In his classic definition, stigma is “an attribute that is deeply discrediting” (Goffman, 1963, p. 3); a mark of shame, of spoiled social image. Stigmatized persons are viewed as possessing characteristics that are a legitimate basis for excluding them or avoiding them, or even treating them as non-persons (Leary & Schreindorder, 1998). This act of ostracizing, or othering
members of outgroups, has been viewed as a means by which communities displace negative emotions raised by a threatening situation, exercise power over the people marked with the stigma, increase the security of their own group, and enhance homogeneity among the non-stigmatized (Devine, Plant & Harrison, 1999; Gilmore & Somerville, 1994; Parker & Aggleton, 2003). At its most basic level, stigma is a powerful discrediting and sullying social label that radically alters the way individuals view themselves and are viewed by others as persons.

Goffman (1961) described three general types of stigma: 1) physical deformities, 2) moral transgression, and 3) membership of a despised social group. Diseases like tungiasis may involve more than one type of stigma, as physical deformities are associated in the minds of community members with non-adherence to certain community values.

To actually stigmatize refers to the action and the process of assigning stigma to an individual. This stigmatization process is effected in several steps (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2002). First, human differences are separated out and named by society, with some differences caused by diseases like leprosy, schizophrenia, and tungiasis considered to be defining social characteristics. When such traits are viewed negatively, the stigmatizing mark becomes content cue that highlights the danger that a stigmatized group poses to the rest of society (Devine, Plan, & Harrison, 1999; Parker & Aggleton, 2003). Characteristics are then given labels associated with the negative stereotypes, and a rationale is constructed for devaluing, rejecting, and excluding those who possess them. As a result, labelled individuals are separated from the rest of society, and experience discrimination and loss of status.

Link and colleagues (Link, 1987; Link, Cullen, Streuning, Strous, & Dohrenwend, 1989; Link & Phelan, 2001) have argued that people are socialized to associate stigmatized groups with stereotypes, to devalue stigmatized people, and to discriminate against them through interpersonal communication and other platforms of interactions including mass media (Link & Phelan, 2001). The degree of isolation stigmatized individuals undergo depends in part on society’s perception of whether their membership in the group is volitional. Put differently, if those in the stigmatized group are to blame for the choices they made, and such choices put the community at risk, their isolation is heightened. Stigmatization, therefore, becomes implicitly or explicitly a socially sanctioned process. Link and Phelan (2001), observed that this separation of “us” from “them” is not only carried out by unlabelled members of society towards labelled persons, but is also a social process that is
sometimes purposefully and sometimes unconsciously carried out by the labelled persons themselves. The outcomes of stigmatization can be devastating, impacting health, social relationships, achievement, housing, self-esteem, employment, and nearly every other aspect of life.

Smith (2007) examined the specific communicative means through which the social construction of stigma takes place in her stigma communication theory. Stigma communication refers to the mechanism through which stigma messages are created, reinforced and maintained through a communication process and how such messages spread through communities to teach their members to recognize the disgraced (i.e., recognizing stigmata) and to react accordingly (Smith, 2007). Smith has argued that four types of communication content (marks, labels, responsibility, and peril) play critical roles not only in eliciting particular cognitive and affective responses but also in shaping the development of particular stigmatizing attitudes, isolation and removal of stigmatized people, and sharing of stigma message with others in the society. These four types of content provide cues: a) to distinguish people (marks), b) to categorize these distinguished people as a separate social entity (labels), c) to link this distinguished group to physical and social danger (peril), and d) to imply a responsibility or blame on the part of the stigmatized for their membership in the stigmatized group and their linked peril (responsibility). The model is graphically displayed in Figure 1.

Figure 1. Model of Stigma communication

Stigma communication theory addresses the problem of stigma from a communicative point of view and underscores the inextricable nature of communication in stigma formation, maintenance and management. We therefore employed it as the guiding theoretical framework for this investigation into the characteristics of tungiasis stigma.

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Based on the components of the theory, the following research questions were posed regarding stigmatization of tungiasis sufferers in Murang’a County, Kenya:

RQ1: What are marks that distinguish tungiasis sufferers from the community?
RQ2: What labels does the community assign to tungiasis sufferers?
RQ3: What threats do these marks signify to the community?
RQ4: How do community members assign responsibility for these marks?

We also inquired into the results of tungiasis stigma in the lives of suffers:
RQ5: What outcomes do tungiasis sufferers experience as a result of stigma?

**Method**

A descriptive phenomenological research design was employed to investigate the experiences of individuals and families within a circumscribed geographic location who are affected by tungiasis. A qualitative approach was deemed appropriate for the study as it facilitated in-depth understanding, and afforded flexibility to respond to unexpected and new development in the data (Yin, 1994).

Four focus group discussions (FGDs) and 12 in-depth interviews with tungiasis sufferers from Gitugi location in Murang’a County were used to collect data. FGDs were deemed suitable for the study because they are helpful in the preliminary investigations (Onwuegbuzie, et al., 2009) and provide a non-threatening social environment that facilitates interaction among participants (Onwuegbuzie, et al., 2009). In addition FGD bring out a wider range of experiences as individuals stimulate each other’s reflections and build on one another’s narratives (Schulze & Angermeyer, 2003).

In-depth interviews were conducted to provide triangulation of focus group findings and to elicit information about stigmatized individuals’ experiences, opinions and feelings that could have been difficult for the individuals suffering from tungiasis to talk about in a group (Morgan, 1997).

Ethical permission for the project was obtained from the Daystar University’s Centre for Research, Publication and Consultancy and post graduate Board (CRPC& PB) in Nairobi and from the National Council for Science and Technology.

**Participants**

The research was conducted in Murang’a County. The sample of the
study was drawn from Gitugi location in Mathioya constituency. According to the Kenya Bureau of statistics (2010), Mathioya constituency has a population of 88,219 of which 38% live in Gitugi Location. Gitugi location comprises Runyeki, Kambara, Chui, Ngutu, Gitugi, Karunge, Mihuti, Nyakianga, Gikoe and Gatunguri Sub–Locations. All the sub-locations share climatic and cultural characteristics but they have not been affected by tungiasis in same way (Ahadi Kenya Trust, 2010). With the help of the trained personnel at Gitugi Jigger Help Centre, we purposefully sampled four sub-locations: Chui and Runyeki, where cases of tungiasis were most prevalent; Mihuti where the rate infestation is moderate; and Karunge where the rate of infestation is low.

Participants for the focus group discussions were purposively sampled in accordance to the following sampling criteria which was used in deciding the eligibility of the respondents.

Eligible participants were: 1) between 18 years and 60 year old and currently living within Gitugi location, 2) identified by the trained staff of Gitugi Jigger Help Centre as suffering from tungiasis, and exhibits symptoms of tungiasis as described by Feldmeier, Kehr, and Heukelbach (2006), 3) conversant with Gikuyu or English language and, 4) willing to spend one hour discussing issues about tungiasis.

The staff at Gitugi Jigger Help Centre helped identify a purposive sample of 10 households for in-depth interviews. The goal was to get at least 12 respondents from among the 10 households. Staff applied the same inclusion-exclusion criteria used for the focus groups to locate in-depth interview participants.

**Procedure**

**Focus groups.** Four focus groups discussions were held with 6-12 participants each. Gitugi Jigger Help Centre (situated at Karunge sub location) where the focus group discussions were to take place, was quite a distance from most of the respondents’ homes and some respondents were too severely infested with tungiasis to walk for long distances. Therefore, focus groups were held in selected homesteads of tungiasis sufferers.

The first author moderated the discussions. Research assistants were also present and operated recording equipment besides taking care of logistics. Participants were welcomed and then reminded of the purpose of the discussion. They were asked what language(s) (English and/or Gikuyu) they would prefer for the discussion. Oral informed consent for participation and for audio recording was obtained before commencement of the interview sessions.
In-depth interviews. In-depth interviews were held in the respondents’ homes in Gitugi location. After introduction and establishing rapport with the family members, participants were informed about the purpose of the research at the beginning of the interview. Field-notes were also taken. Interviews were held with one respondent at a time, with the selected respondent led to a private place for the interview. A semi structured interview guide was used to guide the discussions.

Instruments

Questions invited participants to explore their lived experience with tungiasis. We did not impose categories suggested by our theoretical framework, but asked broad open-ended questions about their approach to stigmatization. Discussion questions inquired into participants’ knowledge and experience about \textit{T. penetrans} infestation, the nature of stigma communication associated with tungiasis, their attitudes towards stigma beliefs of the larger society, and outcomes of tungiasis stigma communication for them. For each topic the first author as facilitator solicited specific narratives of tungiasis sufferers own experiences. Questions were composed in English and translated to Gikuyu by the first author, in consultation with other Gikuyu-speaking researchers.

Pilot testing of the interview guide was done at Ngutu, sub-location in Gitugi location, Mathioya constituency. Like the other sub-locations, Ngutu is inhibited by Agikuyu people, many of them living in abject poverty and depending on subsistence farming. Tungiasis prevalence in Ngutu is also high. With the help of a village elder from Ngutu sub-location, two households were purposefully sampled and four respondents were interviewed. Based on the results, a few words on the Gikuyu interview schedule were changed to reflect the local dialect.

Data analysis.

Focus groups and interviews were conducted in the Gikuyu language, and translated into English during transcription, resulting in 501 pages of double-spaced raw data. Data analysis was based on Miles and Huberman’s (1994) inductive process: data reduction, data display, drawing conclusions, and verification. Initial categorizations were shaped by the pre-established questions, then data were then broken down into meaningful pieces or codes, and labelled. The bits of coded material were later clustered together under code headings. This process was repeated until no additional significant new insights emerged (Blanche, et al., 2006; Miles & Huberman, 1994). The data
reduction stage was followed by the data display stage which involved transforming information into appropriate and simplified configurations. Finally, the verification entailed testing the emerging meanings by looking for alternative or competing themes, reviewing outliers, and self-reflection. An audit trail was established and the first author also kept a reflective journal in which he recorded daily information about research process, his reactions, and research findings (Lincoln & Guba, 1985; Sririvasta & Hopwood, 2009).

**Results**

**Marks**

Research question one asked what marks identified person infected with tungiasis as a member of a stigmatized group. Interviewees described marks associated with tungiasis as including ulceration, pain, loss of fingernails and toenails, and difficulty in walking among others. It became clear that in severe cases, tungiasis is a grotesque and disfiguring disease, patently evident to even the most casual observer. For example, one mother described the ritual she and her husband had to go through to care for their severely infested children:

Before leaving our home for casual jobs in the neighbourhood, we had to literally carry them like small babies to their grandmother who constantly played the role of a caretaker. The kids were so severely infested. Their feet had become so inflamed and had multiple ulcers. My husband would carry one and I would carry the other. They are three kids. One had to wait for the second round. They couldn’t walk . . . back to our house which was less than fifty meters from their grandmother’s house.

One man summarized dolefully, “A person with severe infestation like me gets so much preoccupied with scratching the various itchy parts of his body that my whole mind becomes preoccupied with the itch and pain from the inflamed skin. I lose the appetite and I cannot eat.” The desperation some respondents described at times of extreme infestation was almost unimaginable. Here, for example is one woman’s story.

I remember one day I decided to go and see my sister because I didn’t have food and I was starving because I couldn’t work and no one would employ me as a casual labourer. I had gone for a few days without food . . . . I walked with a lot of difficulties and pain all the way to Kanoorero to see my sister who lives there (about 3km). I was weak, severely infested with jigger fleas, and hungry. . . . I would walk for few meters and sit down to rest. When I got near my sister’s home, I was totally exhausted. I couldn’t walk
anymore. I began to crawl like a baby towards my sister’s house. My sister couldn’t believe her eyes when she saw me. She cried.

Not only did interviewees describe the physical marks and effects of tungiasis to us, we saw them for ourselves. At the hour the first focus group was to commence at the Gitugi Jigger Help Centre, we learned that the tungiasis sufferers who were to participate were so severely infested they were unable to walk to the Centre. We had to revise our plans so as to meet at a central homestead. We were met by a village elder who informed us that several participants could not walk even the short distance to their neighbours’ home. Their feet were so ulcerated and infected with *T. Penetrans* that walking was agonizing. The first author drove to each home to transport participants to the venue. Flies hovered over their inflamed, open wounds throughout the interview and they waved them off with their hands. This scenario was replayed at all four focus groups.

Children in interviewees’ homesteads, their small feet infested with fleas, limped as they played in the red soil that harboured tens of thousands of *T. penetrans*. Some scratched lesions on feet that were strangely twisted by the disease. One six-year-old child was so heavily infested that he was reduced to crawling. “All he does is to cry and scratch his inflamed feet all the day,” his father commented. Many of these individuals told us they rarely ventured out of their homesteads because of the evidence of tungiasis on their bodies. Some scheduled interviewees, in fact, decided they were too embarrassed to be seen by visitors and refused to come out of their houses when we arrived.

**Labels**

Research question two asked what labels were assigned by the community to persons infected with tungiasis. The polite way of referring to tungiasis sufferers in everyday Gikuyu language is *mändũ urĩna ndutu* (“a person suffering from tungiasis”). However, respondents mentioned a list of derogatory terms used by the non-stigmatized individuals: *nyandutu, wamatutu, wamage, nyamatutu* or *wanyari*. All these labels are variants of “jigger owner(s)” or “jigger possessor.” Sometimes the term *nyandutu* was used to connote “jigger man” or “jigger woman.” For instance, one mother recounted how a teacher publically humiliated her children in front of their fellow students and labelled them *wamatutu*.

... There was this teacher who would tell my kids to remove their shoes and then, he would parade them in front of the other kids. The teacher would then call the rest of the class, “come and see Mary and Jane, they have big jiggers on their feet, they are dirty girls, and we will call them...
wamatutu.” . . . The teacher then said, ‘I want you to imagine of the parent ... the mother or the father of this kid. Hasn’t he or she failed in his or her duties?’”

Interviewees reported also, being compared with animals. One man related an incident when he was confronted by a fellow villager in the road who asked him, ‘Do you consider yourself a man or a monkey? Even monkeys are better they know how to take care of their feet.”

Two additional labels associated with tungiasis emerged from the data, both of which contravened closely held values in the Gikuyu community: tungiasis sufferers as dirty or negligent, and tungiasis sufferers as lazy or irresponsible.

*Tungiasis sufferers as dirty or negligent.* All respondents that we interviewed had on several occasions been labelled dirty or blamed for neglecting their personal hygiene by those who were not infected with tungiasis. They were also accused of keeping unhygienic houses or compounds. This led to exclusion of tungiasis sufferers by many non-stigmatized people in the community. “They don’t want to come near us,” one respondent said of non-infected neighbours. “They call my family mucii wa ndutu (the jigger family). They believe we are dirty.” A woman echoed her story, “I once heard a woman from the neighbourhood say some bad things about my family. She said, ‘Jigger fleas visit the dirty ones.”

Communities punish more heavily those perceived to have chosen attitudes or actions that contribute to the stigmatizing attribute, than those who act involuntarily (Smith, 2007). Interviewees made it clear that non-infected persons accused them of being culpable for their own condition. “They always blame me for neglecting my own health and hygiene,” one man stated. “They look at jiggers as something I have brought on to myself. They accuse me of neglecting my basic roles like cleaning my body.”

*Tungiasis sufferers as lazy.* The other prominent label that emerged from the perception that tungiasis sufferers were lazy and irresponsible. Laziness is a trait that is abhorred among the Agikuyu people and the society generally reprimands those perceived to possess it. Interviewees reported being the subject of public accusations. One woman narrated a stigmatizing encounter with some neighbours:

I was once stopped by two women from the village and they demanded to know why I am embarrassing the women folks. “Why are you embarrassing us in the village with your laziness. We are very disappointed with you. Why have you neglected your own children? No wonder you couldn’t get a husband from

this village to marry you.

Although women reported being subjected to this type of verbal aggression more than men, a 56-year-old man also described how he was confronted men from his village:

As you can see... I don't have some of the fingernails [displaying his hands]. Once, some non-infested men noticed this and rebuked me, “Go away lazy one, wangage! [Jigger owner]. You have let the jigger flea infest your whole body!” You are so lazy! You are of no good. Nyandutu uyu [You jigger man].

Responsibility

Research question three asked how community members understood responsibility for causing these marks. Four main beliefs emerged during data collection: tungiasis as a curse, tungiasis as caused by witchcraft, tungiasis as a premonition of death of a relative, and tungiasis as caused by “jigger-attracting blood.”

Tungiasis as a curse. Three variants of this belief emerged: tungiasis as a curse from God, tungiasis as a parental curse, and tungiasis as an ancestral or generational curse. Some tungiasis sufferers believed that tungiasis was caused by kirumi (a curse) from God. They were not able to explain why God had cursed them, but they deeply believed that God was displeased with them as individuals or as families. All that the sufferers who subscribed to this belief could do, then, was to plead with God for healing or leniency. One woman lamented, “Sometimes I ask myself, what sin, did I commit against God? Or maybe God has cursed me and that’s why I go through all this kind of torture.” A man recalled, “I even told God, that ‘God it is apparent you want to take these kids away from me. But Lord make it a bit honourable and less torturous for them.”

More commonly, respondents explained that mistreatment of a parent or grandparent by his or her child could lead to a parental curse. Cases of tungiasis that were traceable to parental curses could be identified by the fact that fleas attacked the individual on virtually all parts of the body, not just feet and hands, which is more typical of the disease. One man expounded:

People in this community believe that if you mistreat the elderly persons like our grandfathers or grandmothers who are infested with jiggers: For instance... your grandfather may request you: “Son, please extract this jigger flea from my foot because I cannot see it. My sight is failing.” So if you refuse to help such an elderly man, as he painfully scratches the jigger
fleas infested feet, he will keep on cursing you saying, “May you get worse jigger fleas infestation than these!” Once you get such an infestation, you cannot get healed—not even in the modern hospitals. No matter what you try the infestation will keep on getting worse and worse.

In contrast to parental curses, which were invoked in response to specific failures of filial duty, respondents also described another type of curse, *gitigo*, as spanning several generations such that living members of a family might not even know where it had originated. A disgruntled relative might have pronounced a curse not only on an immediate offender, but on succeeding generations in the family line. As one man explained:

I remember how I got heavily infested with jigger fleas to a point that I couldn’t move around. My sons tried hard to extract jigger fleas from my feet. I tried to dip my feet in a pesticide solution, but the infestation only got worse. So every known remedy failed and people in the village started talking of the tungiasis condition as *ndutu taciakiũndũ*—jigger fleas possibly brought by a curse—and people would say that tungiasis in our home was a curse. So they [people not affected by tungiasis] would shout at me, *ehera haha ici ndutu ciaku nĩtaciakiũndũ [kĩrumi]* (move away from us, your jigger flea infestation is strange, you are cursed).

*Tungiasis as caused witchcraft.* Witchcraft in the Agikuyu context typically refers to the manipulation by malicious individuals of powers inherent in persons, spiritual entities, and substances to cause harm to others (Ashforth, 2001). Among the Agikuyu and indeed many African communities, witchcraft related illnesses are perceived as spiritual attacks. Modern health healthcare and remedies for witchcraft-related illness, therefore, are considered redundant or, at best, secondary to traditional rituals, medicines and sacrifices (Ashforth, 2005).

According to our respondents’ narratives, the motivation behind witchcraft in their own situations was typically jealousy. People with a grudge against them could act in mysterious ways with intent to cause harm, which would take the form of *T. penetrans* infestation so severe that it would result in prolonged suffering and sometimes death.

Respondents made this attribution of cause to witchcraft after all known methods to them of fighting jigger fleas had failed. They described themselves as victims of malice and undeserved suffering. The following excerpt from one man’s comments exemplifies this perspective:

My kids would hardly sleep at night. They would cry the whole night. Once you extract one jigger flea, three or more jigger fleas embed in the same
hole the following day... What we are experiencing here is strange! It is like a witch, an evil person poured them here in my compound. I am about sixty now and I have never seen a person immobilized by jiggers. But my son can’t walk now... the jiggers in this home are not going away. It is like they are reproducing in thousands in the house.

**Tungiasis as premonition of death.** Some respondents believed tungiasis to be premonition of death of a loved one, and were convinced that the infestation would not be subdued until someone in the family died. A 47-year-old mother of seven recalled:

I remember this time they had attacked my family and they were as severe as they are this time. Yes, they were severe and we really suffered. Then one day, a young man and a relative from the neighbouring ridge died. Immediately after his death the jigger fleas started disappearing. We buried the young man on a Saturday afternoon and by Sunday afternoon there was not a single flea in the house. They disappeared completely...I have been praying to God not to let the jiggers take away anyone from my home. . . .Such jigger fleas nĩcia gũthetha mûndû [they are a foreboding of death of a person]. They come to take someone away to God.

**Tungiasis as caused by “jigger attracting blood.”** Some respondents believed that tungiasis is not a disease that affects everyone, but is unique to particular families or individuals in the area because they possess “jigger attracting blood.” This stereotype did not allude to tungiasis being a genetically transmitted disease. Rather, in some undefined way, tungiasis was recognized as endemic in some families by virtue of having been in the family tree for a long time. Many respondents challenged this notion and argued that such claims were inaccurate. One interviewee asserted:

Well some people believe that the tungiasis in this home is a "family thing" they make sweeping comments like “the family of so and so has thakame ya ndutu (the jigger attracting blood) or they would simply call us “the jigger family.” But that is not true...You know the jiggers are as common today as they used to be in the past when almost every family had the infestation.

However, several tungiasis sufferers reported that they believed in this stereotype. One woman mused over the issue, “Sometimes I think there are certain family that are more susceptible to jiggers than others. Or maybe it is in the blood of family tree — there could be families that have blood type that is liked by jiggers more than others. You can’t tell what is wrong with such a family!” Another woman stated that even within a family, jigger fleas appear to be selective and attack only those with “jigger attracting blood.” She gave an
example of a homestead in which all other members of the family were affected by jiggers except a grandmother. “Eeh... sometimes you can do nothing about tungiasis. You see there is . . . a grandmother who is not infested with the fleas yet the other members of the family are infested with jiggers. How would you explain how the jiggers skip this member of the same family?”

The first author happened to visit the family and was able to investigate these statements. During the visit he established two important things. First, the grandmother, who was about 70 years old, did indeed have minimal infestation compared to the other members of the family. She also had very good interpersonal and story-telling skills, and had a number of grandchildren around her constantly listening to her stories. She explained that the children extracted fleas from her feet as they listened to her stories. This extraction was regular feature of the social activities during the story telling sessions. She then applied a mixture of Dettol disinfectant, Vaseline jelly and traditional herbs—mainly juice from ndũra fruits (Solanum incanum)—to her feet, to keep off the fleas and heal the wounds. Other members of the family did not make such efforts.

Peril

Research question four asked what peril, or threat, these marks signified to the community. Two forms of physical peril were associated with tungiasis as reported by our interviewees: the spread of the disease in compounds where infected persons visited, and transmission via infected water and food. Non-infected persons in the community were concerned about the presence of jigger eggs, commonly referred to as ngee, on the tungiasis sufferers’ bodies. Villagers feared that the stigmatized individuals could spread tungiasis by dropping the numerous jigger eggs on the floor of the house they visited. The fear of getting T. penetrans after interacting with tungiasis sufferers was apparently potent. For instance, a severely infested tungiasis sufferer told us that, “The neighbours do not allow me into their houses. They tell me to wait outside the house so that I don’t drop the jigger eggs in their house.”

Non-infected members of the community were also reported to be afraid that tungiasis sufferers could easily contaminate foods and drinks if they were allowed to handle them during social events, by dropping flea eggs into the dishes from their flea infested hands. Consequently, many tungiasis sufferers were not allowed to take up roles like cooking and serving food at social functions like wedding and dowry payment ceremonies. Typical was one woman’s description of how people refused to eat food that she served.
You see in one occasion, I served people with food. You see when the people look at my hands and all they imagined of the *ngee* (jigger eggs) dropping into the food tray. . . . They declined to eat the food. One of them said, “Even though I am hungry, I cannot take this food served by *moko ma ndutu* (jigger hands)!” ... Someone declining to take food served by me in public was very embarrassing for me. You see, I was serving very many people and they were watching what was going on. Those I had already served also put the plates down and refused to eat the food when they got the message that my hands had *ngee* (jigger eggs).

Somewhat surprisingly, despite these societal fears, tungiasis was often not classified as a disease, by either infected or uninfected members of society. Persons infected with tungiasis were embarrassed of lining up to see the clinicians with other sick people whom they perceive to have truly serious diseases like malaria, typhoid among others. The “jigger” problem simply did not fall into the category of ailments for which one would seek medical treatment. One of our interviewees clarified:

Of course I go to hospital because of other health problems but I have never gone to hospital specifically because of tungiasis. You know everyone believes that tungiasis is not a disease. So . . . it would be hard for me to imagine myself lining up with people who have other health problems at the health centres. I believe in extracting the jiggers.

**Effects**

Research question five asked what outcomes persons infected with tungiasis experienced as a result of stigmatization. Interviewees reported a wide range of negative psychological, social, educational, socioeconomic, and healthcare-related outcomes.

*Psychological and social effects of stigmatization.* Among psychological outcomes of their condition mentioned by respondents, embarrassment was most common. “I wouldn’t want to carry my kids along to social functions. It is going to be a very shameful episode if I do that. People will keep on staring at them. . . . I feel so ashamed about my family and my children,” one young mother stated.

Others got angry. One interviewee described fighting over his father’s reputation, “At some point ...my dad was the most affected. He couldn’t walk properly and we felt bad. So when someone made a joke out of it. I obviously got very angry and a few of such incidences ended up in fist fight.”
Other respondents described extreme alienation, isolation, and near despair:

You know when the neighbour’s children prepare to go to church, my children feel bad. They feel left out. They cannot accompany the neighbours’ children to church because of jigger infestation. Sometimes I look at myself and it is hard to imagine that such things are happening to me and my children. I also feel left out. I feel like I don’t belong to this village. It’s such a lonely life.

A number of interviewees described the progress of such social isolation. As the disease and attending stigmatization progressed, they withdrew further and further from village life. The following excerpt was typical of many respondents’ described experience:

Tungiasis is a bad disease. Tungiasis destroy our relationship with other people in the village. They cannot respect us if we have jigger fleas. I cannot feel confident when addressing them. They once shouted at me, “Wee ūrīgitwo nī wandutu niūyū ūkūhota” [Now look at you. If you cannot extract jigger fleas from your feet, what advice can you offer here?].

People disregard us and act as if we don’t exist. That is how we feel. Now if you feel like that, will you attend meeting where people are giving their ideas? Will anyone listen to your ideas? You often keep to yourself like other tungiasis sufferers

Educational, socioeconomic, and healthcare-related effects of stigmatization. According to our respondents, stigmatization led to discrimination and loss of employment opportunities. “Another employer told me that I am lazy and he cannot give me work,” one woman recounted. “He said, 'If you cannot extract jigger fleas from your own body, how can you convince me that you can do other things well.'” Another confirmed, “You know how people in this place hate lazy people ... so they really dislike me and accuse me of not going out to seek for casual jobs... they say I stay at home all the day and yet I cannot manage the jigger problem in my family by at least extracting them from the kids’ feet.” One woman narrated how she lost her job as a household maid:

I was working for a certain family and after a few days, I was told to stop. When I asked the other employees why the employer stopped me from working in his compound, they told me that they heard him saying, mūtimia wa ndutu [that jigger woman] is so infested with jiggers. I don’t think she will do any good job here. She is dirty and she will just drop ngee [jigger eggs] all over the compound.
Similarly, a man we interviewed explained how he was denied the opportunity to work in an urban hotel when potential employer recognized his illness:

I remember when we were young men and like all other young men in the village we had jigger fleas infestation on our feet and hands. One time we had gone to look for employment and set off for Nairobi city. We had been promised jobs by a small hotel owner in the city. But we were all turned away because our fingers were severely infested with jigger fleas.

For infected children, tungiasis minimized educational opportunities. Several families among our interviewees reported that their children had dropped out of school because of stigmatization and ridicule. “It happened to my daughter too,” one man stated. “She was nicknamed wandutu (jigger girl). The students and teachers said she was dirty and lazy. She was an adolescent then. She was very affected. She cried many times. I tried to encourage her to face them and not be cowed by them but she was very hurt and she dropped out of school.” One of our adult interviewees gave an account of her own school years:

When I was a student other student taunted and made fun of us [tungiasis sufferers] because we had jigger fleas infestation. In addition, the teachers would sometime gather all the kids suffering from tungiasis and line them up in front of the other students. The teacher would then scold them for being dirty and untidy and cane the jigger infested fingers or toes. It was very embarrassing and painful. We would then be ordered to go and wash our feet and extract the jigger fleas, right in the school.

Stigmatization also led to reduced access to healthcare. According to our interviewees, health workers also communicated their irritation at the supposed laziness of tungiasis sufferers when they sought treatment in hospitals. Several reported feeling offended and humiliated, and vowed never to seek medical care for tungiasis again. One woman explained that she could not seek treatment from the local health centre because she feared being embarrassed in front of the other patients by health workers. “I don’t take my children to hospital because of jiggers. I will only be inviting insults from the doctor. Doctors don’t take this as a disease. They argue that the children are infested with jiggers because I am lazy and irresponsible or have chosen to neglect my responsibilities.”
Discussion

Guided by stigma communication theory (Smith, 2007) this research investigated mark, label, responsibility, and peril in stigmatizing communication about tungiasis. Tungiasis is a grotesque and disfiguring disease, patently evident to even the most casual observer. Marks of the stigma as described by participants included pustules, ulceration, and debilitating sequel, such as loss of nails and difficulty in walking or sitting. Tungiasis is a grotesque and disfiguring disease, patently evident to even the most casual observer. Children of interviewees limped through flea-infested sand and scratched lesions on twisted, inflamed feet even as we conducted our data collection.

Physical disfigurement of tungiasis qualifies as what Goffman termed an “abomination of the body,” a type of stigma consisting of various physical deformities, disabilities, and chronic disease. These same bodily characteristics, however, also conferred a moral stigma on tungiasis sufferers (Walker, Payne, Jarrett, & Ley, 2012). Like persons with leprosy (Nations, Lira, & Catrib, 2009) and other skin conditions (Weiss & Utzinger, 2008), participants said they were perceived as dirty, lazy, and disgusting. These issues were associated with blemishes of character: sufferers had failed to uphold key virtues of the Agikuyu society of cleanliness and industriousness (Kimani et al., 2012).

Stigmatizing labels associated with tungiasis were dual-pronged. They were not only derogatory in their meaning but also denoted that the labelled person was the disease and a member of a separate group from the rest of society, a feature observed in stigma communication process associated with other diseases like epilepsy (Smith, 2007).

With respect to responsibility, findings revealed a complex combination of attributions of tungiasis to both internal and external causes. Consistent with Stienstra et al.’s (2002) findings about Buruli ulcers in Ghana, we noted that where course and outcome of the ailment worsened, or the sufferers tried unsuccessfully to treat the disease, the conviction that curses or witchcraft were a probable explanation became more salient to them. This attribution enabled them to declaim culpability, assigning blame for their condition to outside forces beyond their control (Fottrell et al., 2012). Non-stigmatized individuals, however, were said to regard even curses as the sufferers’ fault because their families must have erred somehow to deserve a curse in the first place.

With respect to peril, our participants revealed several common types of misinformation among community members at large. Fears that tungiasis
sufferers would spread the disease by touch, and that infected persons would spread flea eggs when handling food are exaggerated, given that literature on the epidemiology of tungiasis (Feldmeier, et al., 2004; Heukelbach et al., 2007).

Among our findings, the belief that seemed to have the most far-reaching implication on health seeking behaviours was respondents’ avowed belief that tungiasis is not a serious disease. This belief, reported to be shared by non-stigmatized community members as well, was based on the recognition that tungiasis had been a fact of life for many generations in the community and was therefore unworthy of medical attention in a modern hospital. It was a minor problem that should not divert medical resources from treating more serious conditions (Kimani et al., 2012). Consequently, persons living with tungiasis did not seek medical help. With respect to health communication interventions in Murang’a County and similar locations, messages focused on labelling tungiasis as a disease may decrease marginalization of sufferers, but more importantly legitimize seeking treatment.

Theoretically, although SCT proved helpful for framing our investigation, we found it to be limiting particularly in the sense that it did not offer explanations for social phenomena, or allowing insight into social processes as it would normally be expected of a theory. SCT is more of a set of typologies. Mark, label, responsibility, and peril, the components on which we focused, are characteristics of stigmatizing communication that are useful as topics to explore, but the theory gives no guidance on what a knowledge of these issues should tell us about the stigmatizing process, specific outcomes for stigmatized persons, or potential points of intervention for health communication interventions. Indeed, to develop interventions, additional information is needed about beliefs of the community regarding the nature of health and illness in general, beliefs about the disease in question in particular, and values and practices related to interconnectedness and responsibility of community members to one another. Within highly individualist and affluent American society where the theory was originally proposed, and where many international health efforts are strategized, some of these issues may seem less critical. In many African societies, however, community norms are binding and characteristics of stigma must be understood in the light of them.

Several limitations should be noted about this research. First, we relied on self-reported accounts of tungiasis sufferers regarding stigma, beliefs, and communication about tungiasis from non-infected community members. Their perspective would inevitably differ from that of other community members. Furthermore, we investigated the experiences of individuals and families within a circumscribed geographic location: Murang’a County in Kenya. These
experiences cannot be considered representative of individuals in other parts of
the world, or even of other ethnic groups in Kenya. Furthermore, although
findings of this study suggest that tungiasis stigma may permeate educational
institutions and may also be a feature of some interactions with health care
professionals, our study was not designed to consider those contexts. Future
research, ideally observational studies, should explore the outworking of stigma
in educational and healthcare setting and test approaches to minimizing stigma
communication there.

The findings suggest that ignorance about the etiology and epidemiology of
tungiasis is a key reason behind the proliferation of the tungiasis stigma
communication. Therefore, culturally appropriate and sensitive anti-tungiasis
stigma campaigns that would increase knowledge of tungiasis, through multiple
media, targeting individuals suffering from tungiasis and general public were
highly recommended.

In conclusion, we note that although many urban Kenyans consider
tungiasis a somewhat obscure disease of up country folk, it remains an
important health problem that is responsible for horribly disfiguring not only
the physical appearance, but also the social lives, of thousands of rural
residents. Tungiasis sufferers are ostracised, discriminated against, excluded
from social events and openly taunted by both children and adults. The labels
of tungiasis sufferers are so embedded in the social lives of the community, that
they are found in their jokes, stories, and songs. Tungiasis stigma remains a
serious challenge and an impediment to health seeking and utilization of health
facilities among many poverty-stricken Kenyans. More research is needed to
test alternative stigma management techniques that have worked for community
members facing similar stigma situations, as well as possible health
communication interventions to communicate that tungiasis is a disease that
can be effectively treated in health care facilities.

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