Managing communication surrounding tungiasis stigma in Kenya

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MANAGING COMMUNICATION SURROUNDING TUNGIASIS STIGMA 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. Stigmatisation of tungiasis sufferers has been identified as a key reason why tungiasis frequently progresses untreated in many parts of the world, however little research has investigated the specifics of tungiasis stigma or the communication strategies sufferers use to manage stigmatization. This article
reports results of focus group and in-depth interviews regarding strategies used
to manage tungiasis stigma from the perspective of persons living with tungiasis
in Murang’a County, Kenya. Most frequently mentioned were withdrawal tactics.
Participants also engaged in refutation strategies to deny responsibility for
their condition. Implications for stigma management communication theory are
discussed.

Keywords: health communication, Kenya, neglected tropical diseases, stigma,
stigma management communication, tungiasis

INTRODUCTION

Tungiasis is a neglected parasitic skin disease common in resource-poor communities
in sub-Saharan Africa, South America and the Caribbean. It is caused by a small
reddish-brown sand flea, Tunga penetrans (T. penetrans), which burrows into the
host’s skin and lays up to a thousand fertilised eggs (Heukelbach and Ogbomoiko
2007; Heukelbach, De Oliveira and Hesse et al. 2001). In most cases T. penetrans
infests the folds of the toes, inter-digital spaces, soles, heels, hands and knees (Chen,
Thong and Jee 2011). In extreme infestations it can infect almost the entire body,
leading to crippling disfigurement and ultimately death.

Besides physical suffering, individuals and family members of persons with
tungiasis suffer from stigma and are often isolated by their societies (Heukelbach and
Ugomoiko, 2007; Njau, Wanzala and Mutugi et al. 2012). Although research has
investigated the pathology and control of T. penetrans (Feldmeier and Heukelbach
2003; Ugomoiko, Ariza and Ofoezie et al. 2007), few studies have addressed
characteristics of stigma in areas where the disease is endemic, or how infected
persons communicate to manage that stigma. This research applied the tenets of
stigma management communication theory (SMC – Meisenbach 2010) to explore
these issues in Murang’a County, site of the highest tungiasis prevalence in Kenya.
SMC predicts communicative coping mechanisms of stigmatised persons on the
basis of their attitudes toward public perceptions of the stigmatised mark and its
applicability to themselves, and provides a broad framework within which to analyse
a range of communicative behaviours.

REVIEW OF LITERATURE

Tungiasis

Like many neglected tropical diseases, tungiasis is prevalent in settings of extreme
poverty, especially among the rural poor and some disadvantaged urban populations
(Hotez and Kamath 2009). An estimated 2.6 million people, mostly rural dwellers,
are infected with tungiasis in Kenya. Seventy per cent of infected persons are children between the ages of 0 and 12 (Ahadai-Kenya-Trust 2010).

Tungiasis is caused by small sand fleas colloquially known in Kenya as ‘jiggers’. As the sites of flea infestation itch and individuals scratch themselves, bacteria enter leading to secondary infection. Chronic inflammation can lead to pustules, ulcerated lesions, loss of nails, gangrene and even disfigurement. Tungiasis is commonly treated by surgical extraction of the flea, but scholars argue that in many resource-poor communities, unhygienic attempts at removal end up causing more harm than good (Feldmeier and Heukelbach 2003). Fleas attach to hosts through contact with the sandy soil in which they thrive, therefore the most effective intervention for tungiasis is considered to be household hygiene (Buckendahl, Heukelbach and Ariza et al. 2010) such as cementing over sandy floors and fumigation, plus antibiotics to treat secondary infections (Heukelbach, Franck and Feldmeier 2004).

**Stigma and stigma communication management**

Besides physical suffering, individuals suffering from tungiasis are often stigmatised (Njau et al. 2012). In an overview of 95 peer-reviewed journal articles on epidermal parasitic skin diseases, Feldmeier and Heukelbach (2003) concluded that stigmatisation was one of the key reasons why tungiasis frequently progresses untreated. By definition, stigmatised persons possess, or are perceived to possess, an attribute (or set of attributes) that marks them as different and leads to their being devalued by others (Smith 2007). Stigmatisation can be understood to arise out of the human impulse for powerful groups in a given social system to define themselves in relation to others. Certain groups become stigmatised as outsiders to the social hierarchy, and have little power to define their own identities (Baumann 1991). Outcomes of stigmatisation can be devastating, impacting health, social relationships, achievement, housing, self-esteem, employment, and nearly every other aspect of life.

For stigmatised persons, information control regarding their condition is a fundamental issue. Scholars have proffered lists of strategies individuals use to manage stigmatising communication (see Ashforth, Kreiner and Clark et al. 2007; Goffman 1963; Smith 2007), the most comprehensive of which is Meisenbach’s (2010) stigma management communication theory. Synthesising literature on occupational taint, health and disability stigma and image repair, Meisenbach posits that the strategies individuals choose to manage stigma depend on several aspects
of the stigma itself. First, the type of stigma – physical, moral or social (Goffman 1963) – can affect the response of others to the marked person. Second, the degree of stigma influences response by non-stigmatised persons. Individuals whose stigmatised traits have not yet been revealed (discréditable persons, Goffman 1963) employ different strategies from individuals whose stigma is visible (discrédited persons). Drawing on Smith’s (2007) stigma communication theory, Meisenbach also notes that stigma can be divided with reference to societal perception of whether membership in the stigmatised group is volitional. If those in the stigmatised group are to blame for choices they made, and such choices put the community at risk, their isolation is heightened (Schwartzer and Weiner 1991; Weiner 1993). Furthermore, how perilous the stigma is considered to be for the community, the societal labels affixed to possessors of the stigmatised trait, and the presence of the mark itself, may affect how stigmatised persons communicate about their condition. The theory is graphically displayed in Figure 1.

Figure 1: Model of stigma management communication (Meisenbach 2010)
Meisenbach’s unique theoretical contribution is to posit that these factors converge to influence stigmatised individuals’ attitudes about a) public perceptions of a stigma generally, and b) the applicability of the stigma to themselves in particular. Their attitude toward either of these factors may be one of acceptance or challenge. The theory maps communication strategies by crossing these possibilities (see Table 1). Strategies identified by the theory include rhetorical strategies such as apologising, claiming defeasibility, highlighting logical fallacies and using humour; purposeful avoidance of communication, such as ignoring and avoiding; and more strictly behavioural approaches, such as hiding the stigmatised mark, stopping stigmatised behaviour, and bonding with other stigmatised persons.

Table 1: SMC strategy typology

<table>
<thead>
<tr>
<th>Acceptance of societal understanding of stigma</th>
<th>Acceptance that stigma applies to self</th>
<th>Challenge that stigma applies to self</th>
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<tr>
<td>I. Accepting</td>
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<td>Passively accepting</td>
<td>Displaying of stigma</td>
<td>Hiding/denying stigma</td>
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<td>Apologising</td>
<td>Apologising</td>
<td>Avoiding stigma situations</td>
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<td>Using humour</td>
<td>Blaming stigma for negative outcomes</td>
<td>Stopping stigma behaviour</td>
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<td>Isolating self</td>
<td>Isolating self</td>
<td>Distancing self from stigma</td>
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<td>Bonding with other stigmatised persons</td>
<td>Bonding with other stigmatised persons</td>
<td>Making favourable social comparisons</td>
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<th>Challenge of societal understanding of stigma</th>
<th>III. Evading responsibility</th>
<th>IV. Reducing offensiveness</th>
<th>V. Denying</th>
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<tr>
<td>III. Evading responsibility</td>
<td>Claiming provocation</td>
<td>Refocusing on non-stigma attributes</td>
<td>Simply denying</td>
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<td>IV. Reducing offensiveness</td>
<td>Asserting defeasibility</td>
<td>Refocus on minimal harm caused by stigma</td>
<td>Discrediting discreactors</td>
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<td>V. Denying</td>
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<td>Providing evidence</td>
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<td>VI. Ignoring/displaying</td>
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<td>Highlighting logical fallacies</td>
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**Tungiasis stigma in Murang’ a County, Kenya**

Murang’a County, the site of this research, is located in central Kenya. Ethnically, the population is predominantly Agikuyu. Primarily rural with one major town, the primary sources of foreign exchange for the region have historically been tea and coffee production. However, these agricultural commodities have faced stagnation and declining world prices in recent years, creating financial challenges for farmers.
Stephen Kimotho, Ann Neville Miller and Peter Ngure

(Nyaga 2007). The poverty rate in Murang’a County is estimated at 29.9 per cent (UNDP 2009).

Murang’a County is also believed to have the highest tungiasis prevalence rate in Kenya (Ahadi Kenya 2010; Kenya National Assembly 2010). In a cross-sectional study of children 5–12 years of age, Njau and colleagues (2012) found a prevalence rate of 51.7 per cent among sampled individuals. Anecdotal evidence from non-governmental organisations has suggested the condition is stigmatised by community members (e.g. Ahadi Kenya Trust 2008; Ali 2009; Njeri 2011; Wangui 2008).

In a previous report (Kimotho, Miller and Ngure forthcoming), we described deep stigmatisation of tungiasis sufferers in Murang’a County. Signs of their condition were obvious even to the casual observer – ulceration, loss of fingernails and toenails, and difficulty in walking to the point that some could barely manage to totter to neighbours’ houses a few metres away, to take part in focus-group discussions. Furthermore, stigmatising labels were so embedded in the social lives of the community that they were found in jokes, stories and songs. Respondents stated that community members flatly told them they were responsible for their own condition. By their description, interviewees were ostracised, taunted, and refused employment or lost jobs because of their symptoms. Their children dropped out of school, and in some cases families stopped seeking treatment for other ailments for fear that hospital personnel would castigate them for their infection.

In the initial presentation of her model, Meisenbach (2010) called for research from an interpretive perspective that offered insight into how individuals use multiple and potentially contradictory communication strategies to manage stigma. In addition, she noted that lack of research on stigma management techniques in non-Western contexts constituted a weakness in generalisability of the theory. In response to this call, we used Meisenbach’s typology of communication strategies to guide an interpretive investigation into the following question regarding tungiasis in Murang’a County, Kenya:

RQ1: To what extent are the categories provided by stigma management communication theory useful for understanding communication strategies tungiasis sufferers use to manage stigma?

METHOD

This study was approached from a descriptive-interpretive research paradigm which posits that knowledge is constructed not only by describing an observable phenomenon, but also by taking into consideration people’s subjective beliefs, values and attitudes (Creswell 2007). The assumptions central to this study were based on perspectives outlined by Creswell (2007) and Schreier (2012). Descriptive-interpretivists are guided by the belief that multiple realities of a phenomenon exist and can only be understood by interrogating people in depth. Therefore, our study
design entailed conducting four focus-group discussions (FDGs) and 12 in-depth interviews with tungiasis sufferers from Gitugi location in Murang’a County. Ethical permission was obtained from Daystar University’s Centre for Research, Publication and Consultancy, and from the Kenya National Council for Science and Technology.

Sample and population

The sample was drawn from Gitugi location in Mathioya constituency of Murang’a County. With the help of the trained personnel at Gitugi Jigger Help Centre, four sub-locations were purposefully sampled: Chui, Runyeki, Mihuti and Karunge. The first author also visited the Gitugi location area chief and the sub-chiefs to explain the nature and objectives of the research, and to request permission to access respondents.

Focus groups

The four focus groups had six to 12 participants each. Eligible participants were: 1) between 18 and 60 years old, 2) identified by staff of Gitugi Jigger Help Centre as suffering from tungiasis, 3) conversant with Gikuyu or English language, and 4) willing to spend one hour discussing issues around tungiasis. Participants were evenly split between genders. As a result of the Karunge Jigger Help Centre being some distance from certain respondents’ homes, focus groups were held in the homesteads of selected participants.

Procedure. The first author moderated the discussions. Research assistants operated recording equipment and took care of logistics. Participants were welcomed and then reminded of the purpose of the discussion. They were asked which language(s) (English and/or Gikuyu) they would be comfortable using during the discussion. Informed consent for participation and audio recording was obtained and confidentiality was guaranteed prior to discussions. The discussions lasted about one hour. At the end, participants were thanked and provided with lunch and a token of appreciation of Ksh 500 (about US$5.95), which is equivalent to basic minimum consolidated wages for unskilled labourer per day (Labour Institution Act 2012).

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

In-depth interviews

In-depth interviews were conducted to provide triangulation of focus-group findings and to elicit information about stigmatised individuals’ experiences that may have been difficult for the tungiasis sufferers to talk about in a group.

Participants. The staff at Gitugi Jigger Help Centre helped identify a purposive sample of ten households from which 12 respondents were obtained for in-depth interviews. The same inclusion criteria were used for interviewees as for focus-group participants.

Procedure. Interviews were held in the respondents’ homes in Gitugi location. After an introduction and having established a rapport with the family members, participants were informed of the purpose of the research, and oral informed consent was obtained prior to the commencement of the interview sessions. Interviews were held in a private place with one respondent at a time. Research assistants offered soda and packed cakes or cookies during the course of the meeting. Afterwards interviewees were thanked for their participation and provided with a gift pack containing maize flour, a bar of soap and a small bottle of antiseptic liquid.

Instrumentation. The same interview guide was used as for the focus groups.

Pilot testing of research instruments

Pilot testing was done at Ngutu, a sub-location in Gitugi location. With the help of a village elder, two households were sampled and four respondents were interviewed. Based on the results, a few words on the interview schedule were changed to reflect the local dialect.

Data analysis. Interviews and focus groups were conducted in the Gikuyu language, and translated into English during transcription, resulting in 501 pages of double-spaced raw data. Transcriptions and field notes were organised and stored in separate folders in the NVIVO 10 database. Data analysis was based on Miles and Huberman’s (1994) inductive process: data reduction, data display, drawing conclusions, and validation. Initial categorisations were shaped by SMC, but repeated passes through the data yielded additional themes. An audit trail was established and the first author also kept a reflective journal totalling 37 pages (Lincoln and Guba 1985; Srivastava and Hopwood 2009).
RESULTS

Stigma management communication theory predicts that the strategies used by stigmatised individuals should align with their attitudes toward public perceptions of a stigma generally, and the applicability of the stigma to themselves (see Table 1). The preferred strategies described by participants, however, did not readily align with the model. Therefore, although some specific tactics identified by the model did emerge in the data, the tactics are organised below by the following emergent categories: withdrawal, refutation, denial/ignoring and aggressive strategies. The withdrawal and refutation categories were mentioned most frequently, denial/ignoring and aggressive approaches rarely.

Withdrawal strategies

Among our interviewees the most frequently described responses to stigmatising communication from neighbours or other community members involved some sort of withdrawal from social interaction.

Isolation. Most commonly mentioned was isolation. Most interviewees had succumbed to self-isolation from any sort of public forum such as funeral ceremonies, weddings or dowry payment ceremonies. The following comment was representative:

I have stopped going to many social occasions like church services because of shame and fear. I feel embarrassed about the jigger wounds and wobbling when I walk. I fear that someone will ask me about it. I don’t want to get into an argument with people … I do not participate in social gathering or such meetings. I cannot attend such school meetings because I fear they may humiliate me … I also don’t attend chief’s baraza [meetings]. I have decided to stay away rather than … get embarrassed.

Several respondents reported avoiding attending church, a major societal institution in rural Kenya. The explanation of one 19-year-old woman who was severely infected with tungiasis encapsulates many of these issues:

The boys make fun of me! They tell me, ‘get out of the way, Nyandutu (jigger girl) is passing.’ Then they whistle and make fun of me as I pass. They laugh loudly and taunt me. Nowadays I do not go to the roads. I stay here at home. My friends don’t want to see me too. They don’t want to talk to me anymore. I don’t talk to them either. I keep to myself. I think they hate me … I used to go to church when I was not infested with jigger fleas. Nowadays I do not go. I feel better that way.

Some respondents reported having disengaged from almost all forms of social interaction, often remaining locked indoors to avoid stigmatising encounters. One woman, for instance, explained of her husband: ‘He thinks people might say he is useless … My husband prefers to stay alone in his small house. He is too embarrassed to face people.’ Another woman complained: ‘I do not have friends in this region and
I do not attend social functions around this place because I realized that every time we meet they want to pass some rumours about me .... I have decided to stay alone and mind my own business.’

**Hiding the trait.** Hiding a stigmatising trait is most appropriate when an individual is discreditable (Goffman 1963), that is, when it is still possible to conceal that they possess the stigmatised attribute. Participants having been selected by village elders or personnel at the Gitugi Jigger Help Center, most were heavily infected and thus already discredited. However, some still attempted to hide the signs of their condition, while others narrated stories of past (perhaps less intense) infestations during which, for example, they wore shoes to hide the tungiasis on their feet. This was not always easy, as one woman explained:

> You know even if I have jigger fleas infestation I often wear shoes when visiting the public places. And that way, many people may not notice the infestation. I have to look smart anyway like the others ... jigger fleas are such a nuisance ... you will have to scratch so that the fleas can stop biting you. But because you are in the public you will do it carefully over the shoes.

One mother’s narration of her trouble in coming up with money for shoes for her infected children underscores the importance of this strategy to tungiasis sufferers:

> I feel embarrassed and therefore resolved that they need not attend the Sunday services when their feet look so bad. You see I cannot afford a pair of shoes for them even if it costs only Ksh 100 [US $1.10]. I cannot afford it. I hope that one day God will give us enough money to buy shoes and hide this shame. You know a pair of shoes to wear when attending church service ... 

One man we interviewed recalled his parents’ approach to concealment:

> If an important person – like a teacher – visited the family, my parents would tell us to hide in the next room, to avoid embarrassing the family. My mother would shout at us ‘eheria ii ndutu haha mütiraigua mügeni’ [get the jiggers fleas out of here, can’t you hear a visitor is at the door]. We were young and we never felt offended. In fact we scrambled out giggling and ran into the next room. We got used to it such that, every time a visitor came, we did not wait for our mother to remind us.

Another interviewee, a woman, confirmed this practice, but added a note of explanation:

> Tungiasis is a disease of shame ... the kids might embarrass the whole family scratching the jigger wounds in front of the respected visitor. Or it might disgust the visitor. So the parents send the kids into the other rooms of the house. If the mother is the one welcoming the visitor and she is infested too, she looks for something to carefully cover her feet to hide the infestation from the visitor. That time she cannot scratch her feet no matter how intense the itch could get.
T. penetrans also infests other parts of the body like fingers, palms, elbows and knees. This kind of infestation was deemed more embarrassing than the infestation on the feet, and required innovative solutions. Interviewees mentioned wearing long-sleeved shirts and other clothing to hide their wounds. One young man explained: ‘Sometimes I would wear a pair of socks, like gloves on my hands to hide the jigger flea infestation on my hands and attract less attention from people in public forums.’

One interviewee described even lying to a doctor about her condition:

I was very ashamed of my condition and couldn’t bring myself to tell the doctors that I had gone to hospital because of jigger fleas. So I told the doctor that tiny pieces of thorns had pierced my feet. But when the doctors examined my feet, he looked at me angrily and asked, ‘Why are you trying to lie to us? Who can’t see these big jigger fleas embedded on your feet? Speak the truth ... say you have been unable to manage tungiasis and we will treat you.’

**Bonding with other stigmatised persons.** Parents in our sample mentioned that their severely infested children in primary school tried to socialise exclusively with other infected children. ‘My children stay, talk or play only with those who are like them: those with jigger infestation,’ one mother explained. ‘That way they are able to counter stigma from others and protect one another from the rude boys who harass the small ones.’ A father of three described a similar situation:

My children have been object of crude jokes or ridicule from other kids. They tell me that some kids would step on the jigger fleas infested feet, just to provoke them and then run away. Of course my jigger fleas infested kids cannot run after them. The aggrieved children would just curse them or stay away in the class dejected while others are out in the field playing. My kids and others who suffer from tungiasis stay together and they don’t want to mix with the other kids because the kids who are not infested with jigger fleas will joke or ridicule them .... As they go home, my children and other the kids infested with jigger fleas will often wait until all the other pupils have gone home and then they can walk home.

**Refutation strategies**

In contrast to withdrawal strategies, a number of participants railed against the unfairness of stigmatisation. Some explicitly described incidents in which they had engaged these tactics with non-stigmatised individuals; in other cases it was difficult to determine whether their rhetoric had extended beyond our own interviews. These techniques included making favourable comparisons between themselves and uninfected persons, claiming defeasibility, and pointing out logical fallacies in stigmatisers’ condemnation.

**Making favorable comparisons.** Many persons we interviewed minimised their stigma by making favourable comparisons of their families with others. One severely infected woman explained her response to criticism from her neighbours:
I once heard a woman from the neighbourhood say some bad things about us. She said, ‘Jigger fleas visit the dirty ones. If people cannot clean themselves they will get even their faces infested with jigger fleas.’ I felt very bad and answered back, ‘Some people are very foolish and ignorant. Why can’t you ask yourselves why my aunt who sweeps her house daily has a more severe infestation than us?’

Another participant defended herself: ‘I see that neighbour of mine there. He is an elderly man. He has his kinsmen who look after him. But you can see that he still suffers from tungiasis. He is more affected than any of my children.’

The legitimacy of stigma was also challenged by some of our interviewees, in what Meisenbach refers to as discrediting of the discreditor. ‘Do you think you are any better because you are not infested with tungiasis? You are very stupid,’ one of our interviewees reported saying to one of his tormentors. ‘Your father, whom we buried the other day, will never talk to you again! And for such disrespect on me from you, I join your father in this and I will never talk to you.’ Several women asserted that they cleaned their houses as often as those who stigmatised them: ‘Actually, many people argue that jigger fleas are brought by dirt or because we are dirty, or because of neglecting personal hygiene ... those who say so are not any cleaner than us.’ ‘Think before you talk,’ another interviewee reported telling a man who refused to sit next to him because the interviewee was severely infected with tungiasis. ‘You are very foolish! You may not like me but you should respect everyone. If you were the god that provides cure for all diseases in this world, I would prefer to die than come to you for cure.’

Claiming defeasibility or unintentionality. Many interviewees deferred agency or control away from themselves. That is, they claimed defeasibility. One way they did so was by attributing tungiasis to curses – curses from God, generational curses, and parental curses. The following description by one man of his son’s extremely severe tungiasis is illustrative:

The jiggers have attacked virtually all parts of his body – the hands, feet, knees, elbow, buttocks every part. And not the usual attack. I extract up to 30 jigger fleas from one finger, very many from his feet. Every time I extract the jigger fleas from the feet of the boy, he simply becomes crippled. He cannot walk because of the pain caused by the jigger flea wounds. He sometimes can only crawl. Now that is when I observed that this kind of infestation with jigger fleas is not normal. Nĩtaciakũndũ [they are caused by a curse]. Now what can I do with this magnitude of infestation?

Similarly, a woman specifically identified the curse upon her family as a generational curse – probably invoked by someone long dead, but persistently following the family tree to every leaf and twig, as it were.

I think our current generation is being affected by a jigger fleas spell cast on to us by some family members or by a disgruntled parent who died many years ago. What can we do now? We have tried medicines, hospitals and all traditional concoctions. But these jigger fleas
Interviewees also declaimed responsibility by attributing tungiasis to witchcraft. Witchcraft in the Agikuyu context refers to the manipulation by malicious individuals of powers inherent in spiritual entities and substances, to cause harm to others (Ashforth 2001). According to our respondents, the motivation behind witchcraft in their own situations was typically jealousy. People with a grudge against them could act in mysterious ways with the 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. One woman reasoned: ‘I think that tungiasis can be as a result of a spell cast by a person who practices witchcraft. I have done everything. I have swept the house, poured water everywhere, fumigated the house, and treated the infested feet and yet the tungiasis problem persists.’

Even though respondents drew from a culturally approved repertoire of external causes to explain their infestation, they also stated that community members flatly told them they were responsible for their own condition. Many interviewees went to great lengths in conversations with us to explain that, in contrast to accusations by non-stigmatised onlookers, they had not intentionally allowed themselves to be infected. They insisted they had worked tirelessly to extract the embedded fleas, treat their infections with various drugs, and maintain high levels of hygiene. ‘I have tried extracting these jigger fleas from her feet. I have tried types of medicines brought to me. I have applied even diesel fuel on her feet, but the jigger fleas are still adamant,’ a frustrated mother stated. ‘I have pesticide and fumigated the house countless numbers of times.’ Another woman claimed: ‘As for me I always sweep my compound whenever I am around, I clean well.’

**Highlighting logical fallacies.** More commonly, interviewees refuted the societal assumption that individuals with tungiasis were lazy or unhygienic by arguing that tungiasis infestation was not a price anyone would willingly pay – lazy or not. As one man argued:

A single jigger infestation in your toe is such an incessant nuisance .... You can hardly sleep with just a single infestation. What about someone who has tens or hundreds of jigger flea infestations? It is pure torture for such a person. And so when I hear such accusations – that tungiasis sufferers are dirty, irresponsible or lazy ... accusations borne out of ignorance – I feel bad. I don’t believe there is any tungiasis sufferer including me who can neglect their hygiene or allow jigger fleas to feast on them.

Similarly, another woman we interviewed described the way poverty amplified the difficulty of dealing with tungiasis in her family:

Many people say that I have neglected my children. They cannot understand why I do not extract jigger fleas from my children’s feet. Such people always get it all wrong .... Because in my right mind I cannot allow jigger fleas to torment my kids as I watch. They
don’t understand that sometimes I have so many problems here .... Sometimes I don’t have anything I can serve them for lunch or supper. My husband will leave in the morning to look for employment. He may get something to do or not. I have to look for something for the kids ... I leave in the morning and come in the evening only to find that there is no water or firewood in the house. So the few hours before dusk cannot be spent extracting jigger fleas. I have to go out again. So by the time I am coming back into the house, it’s already dark.

Denial and ignoring strategies

Denial. Two among our interviewees denied that stigma existed at all. For example, when asked whether those who are not infested with tungiasis invite him to social functions and if he is stigmatised, one interviewee asserted: ‘No ... they don’t stigmatise me. Why would they stigmatise me? I am still their relative and will remain a member of this village even though I am infested with jiggers.’ Another man explained that many people in his village had tungiasis and they all joined together to assist and support one another:

If we get a word that you are sick or someone is sick from your family with tungiasis or other diseases, we try very much and visit the troubled family. Sometimes we will contribute some money that is given to such a family or is used to take the person to hospital .... In our village we don’t have that kind of a problem of stigma.

Ignoring. Similarly, a small number of interviewees mentioned ignoring stigmatising messages. They narrated incidents in which they were taunted, but kept quiet. Typical of this approach was one man’s story about a chance meeting with fellow villagers:

After casual greetings they asked me, ‘Why have you allowed jigger infestation on yourself and now you are a grown-up. You are so useless ... You can’t even take care of yourself. You have left yourself to the jiggers and you are a grown-up.’ I didn’t say anything to them. People have been saying such things and now they don’t bother me.

One woman described a similar situation that had occurred as recently as that day, when she was on her way to the focus-group discussion:

A few women met me on the way to this place and asked me scornfully. ‘It seems like you are having jiggers party today in the neighbourhood! Or what is going on? It seems like you will no longer work, maize flour gets to you at home courtesy of these jiggers!’ I didn’t tell them anything. I know they despise me and wanted me to pick a quarrel with them. They try very hard to stigmatise me but I cannot give in.

Reducing offensiveness. It is difficult to reduce the offensiveness of a patently obvious ailment like tungiasis, but several of our interviewees were keen to impress upon others that they could live independently without inconveniencing anyone. In the following extract, one man complained about the verbal abuse he received from his fellow villagers:
... but you see, my condition does not prevent anyone from doing whatever they want in this village. I do not beg food from them because of my condition neither do these people come to help me. I am not seeking for any help from them. So I just leave them alone and I would be happy if they left me alone too.

Aggressive strategies

Physical confrontation. In addition to strategies provided by SMC, several of our respondents narrated stories of getting into fights at school or in the neighbourhood with people who taunted them about their tungiasis. A 27-year-old man we interviewed explained how he was occasionally physically aggressive with would-be stigmatisers:

I remember once a young man told me to move jiggers away from him claiming he was getting disgusted by my jigger wounds and was also afraid of the tiny white ngee [jigger eggs]. The others laughed. I didn’t find it funny. We were several of us in a group and I felt that such a joke was so extreme. I felt so humiliated and I grabbed him by the collar and before the others could realise what was going on, we were rolling on the ground fighting. Of course we were separated by my friend, but I wanted to teach him a lesson.

A woman described expressing her anger more passively when she petitioned a politician to help her get employment:

When he looked up and saw me, he was shocked. He stood up and told me that his office does not entertain people of my type .... I was very angry and embarrassed by his remarks. I stormed out of his door and banged it furiously behind me, which called the attention of almost all the people in the adjacent offices. I met some employees in the corridors who were sympathetic and asked me what had happened but I did not answer them.

Threats. One participant recounted using threats to stop fellow villagers from abusing them. In the following excerpt, a man described his approach to a teacher who had stigmatised his tungiasis-infected children:

I had to go to school to confront this teacher. I went there and told the teacher not to label my kid wandutu ‘jigger girl’. I threatened him that, he should never call my daughter that name again; otherwise I would do something he would live to regret. The teacher stopped that behaviour.

DISCUSSION

Guided by the predictions of stigma management communication theory (Meisenbach 2010), this study investigated the means by which individuals infected with tungiasis in Murang’a County, Kenya, managed stigmatising communication from community members. SMC postulates that characteristics of the stigmatised condition identified
in previous literature – among them a) depth of stigmatisation, b) type of stigma (physical, moral or social group), and c) controllability of stigmatised trait – come together to influence stigmatised individuals’ attitudes towards their own condition. The theoretical contribution of SMC is in conceptualising these attitudes as a cross between stigmatised persons’ acceptance and challenge of the societal view of the stigma, and acceptance and challenge of its application to them personally. The four combinations of these two attitudes predict the strategies stigmatised individuals will bring to bear in managing their stigmatisation.

In the case of tungiasis stigma in Kenya, depth, type and controllability of the stigmatising mark did indeed appear to be key influences in shaping respondents’ communication about their condition. With respect to depth of stigma, inflamed, ulcerated wounds, twisted toes, laboured walking – all of these physical signs blatantly mark tungiasis sufferers as outcasts, discredited within their communities. Only in cases of mild infestation can people with tungiasis hope to manage a ‘discreditable’ state (Goffman 1963). Thus, few of our interviewees challenged the application of tungiasis stigma to themselves.

When it comes to type of stigma, the physical disfigurement of tungiasis qualifies it as what Goffman (1963) terms an ‘abomination of the body’. This type of stigma consists of various physical deformities, disabilities and chronic diseases. Like leprosy (Nations, Lira and Catrib 2009) and other skin conditions (Weiss and Utzinger 2008), tungiasis sufferers stated they were perceived as dirty and disgusting. As a result of the visceral response by community members to their condition, tungiasis sufferers often withdrew into isolation.

In addition, the distinction between controllable versus non-controllable origins of tungiasis infestation was at the core of interviewees’ active struggles against stigmatisation. The overriding belief of the community at large, as reported by interviewees, was that tungiasis was volitionally caused by laziness and poor hygiene, a particularly offensive combination because cleanliness and industriousness are key virtues in Agikuyu society (Kimani, Nyagero and Ikamari 2012). Interviewees firmly resisted these internal attributions, and almost all the refutation strategies in our interviews were designed to counter them. They argued that no sane person would undergo the suffering of tungiasis – or watch their children suffer – if they had control over the matter, that they were no less hygienic than their neighbours, and that whatever their condition they deserved to be treated with dignity and respect.

Thus, the antecedent factors identified in the SMC model from previous literature were useful for understanding how respondents managed communication surrounding their particular stigma. However, the strategies of communication that emerged from interviewees did not cluster under the four attitude combinations provided by SMC. We refer readers to Table 1 for this portion of the discussion. Most participants would have mapped onto Quadrant III of the two-by-two matrix, because they accepted the application of stigma to self and at least partially challenged societal
understanding of stigma. (Exceptions were the two interviewees who selected denial and ignoring strategies, that is, Quadrant IV.) This should have predisposed them to the communication strategies listed in that quadrant: tactics relating to evading responsibility and reducing offensiveness. Contrary to the model, few instances of reducing offensiveness emerged. Rather, among the more than 40 participants who did not appear to reject both the individual and societal application of tungiasis stigma, other tactics from all four quadrants were regularly reported. From Quadrant III participants described claiming unintentionality. They claimed defeasibility by appealing to socially accepted explanations of heavy tungiasis infestation like witchcraft and curses (Steinsträ et al. 2002). Many, however, spoke of discrediting discreditors and highlighting logical fallacies (Quadrant IV). Several interviewees made favourable social comparisons; even more commonly interviewees reported withdrawing instead of actively engaging purveyors of stigma (Quadrant II). Infected feet, hands and elbows were hidden under shoes, socks-cum-gloves and long-sleeved shirts. When hiding was impossible, participants withdrew from successive spheres of social interaction (Quadrant I). Small children were banished into the back of the house when guests came, school-going children congregated with similarly afflicted classmates. Indeed, the round peg of data was so resistant to being inserted into the square theoretical hole provided by SMC that we eventually organised our results by means of the emergent categories of withdrawal, refutation, denial/ignoring and aggressive strategies.

In sum, attitudes of the stigmatised toward societal stigma and the appropriateness of its application to self – the central explanatory mechanism of SMC – were less valuable as a heuristic for data analysis than characteristics of stigma identified in earlier theorising (Goffman 1963; Weiner 1993). One reason may be that in tungiasis all three antecedent factors converge, making stigmatisation more extreme than many types of stigma on which current Western theorising is based. Unlike occupational stigma, for example, which may be shed in certain social situations, tungiasis stigma is constantly evident. Unlike HIV/AIDS, tungiasis is not concealable from early days of infection. There is also the uncertain duration of tungiasis. Although some families struggle for years with severe infection, for others infection may wax and wane. Sufferers are aware that if they can manage their condition for a few weeks or months, next year they may take their place again among the non-stigmatised. Individuals’ desperate readiness to deny personal liability, and also isolate themselves and make favourable social comparisons – strategies that in Meisenbach’s model represent separate approaches to stigma management – serve as complementary means of holding a temporary stigma at bay.

A final issue may be cultural differences between the American and the Kenyan view of the relationship of self and community. Within highly individualist and affluent American society, the stigmatised may in some sense be able to refashion their identity. If stigmatised individuals choose to deny or refuse to accept their
stigma, they may be respected for their stubborn determination to reject societal norms. In many African societies, however, community norms are more binding. Stigmatised persons may have neither the desire nor the ability to redefine their condition. In other words, categorising stigma management communication through an acceptance of a societal worldview about the stigma, may not be relevant.

This research involved two methodological limitations that should be mentioned. First, we relied on self-reported accounts of tungiasis sufferers regarding stigmatisation by non-infected community members. Their perspective would inevitably differ from that of other community members. Second, we investigated the experiences of individuals and families within one county in Kenya. These experiences cannot be considered representative of individuals in other parts of the world, or even other ethnic groups in Kenya.

CONCLUSION

Tungiasis stigma remains a serious challenge and impediment to health seeking and the utilisation of health facilities among many poverty-stricken Kenyans. In the lives of our respondents, especially those whose infections were severe, tungiasis stigma was a crushing burden added to a painful, debilitating condition. The stigma management of the infected individuals we interviewed often consisted of withdrawing from society, or asserting defeasibility to an audience who did not accept their claims. Such tactics make cure of this treatable disease, and prevention of future infestations, even more difficult (Buckendahl et al. 2010; Heukelbach et al. 2004). That is, tungiasis sufferers’ strategies for managing stigma were likely at worst to exacerbate their condition, and at best to simply assuage their own guilt. Further research is needed to test alternative stigma management techniques that have worked for community members facing similar stigma situations, as well as interpersonal communication strategies by non-stigmatised persons that can be most effective at providing support. Failure to do so will see tungiasis remain 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.

REFERENCES


