

The Association of Beliefs About Heredity with Preventive and Interpersonal Behaviors in Communities Affected by Podoconiosis in Rural Ethiopia

Desta Ayode, Colleen M. McBride,* Hendrik de Heer, Emi Watanabe, Tsega Gebreyesus, Getnet Tadele, Abebayehu Tora, and Gail Davey

College of Social Sciences, Addis Ababa University, Addis Ababa, Ethiopia; Social and Behavioral Research Branch, National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland; Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland; Department of Sociology, Wolaita Sodo University, Sodo, Ethiopia; Brighton and Sussex Medical School, Falmer, Brighton, United Kingdom

Abstract. Little is known about how beliefs about heredity as a cause of health conditions might influence preventive and interpersonal behaviors among those individuals with low genetic and health literacy. We explored causal beliefs about podoconiosis, a neglected tropical disease (NTD) endemic in Ethiopia. Podoconiosis clusters in families but can be prevented if individuals at genetically high risk wear shoes consistently. Adults ($N = 242$) from four rural Ethiopian communities participated in qualitative assessments of beliefs about the causes of podoconiosis. Heredity was commonly mentioned, with heredity being perceived as (1) the sole cause of podoconiosis, (2) not a causal factor, or (3) one of multiple causes. These beliefs influenced the perceived controllability of podoconiosis and in turn, whether individuals endorsed preventive and interpersonal stigmatizing behaviors. Culturally informed education programs that increase the perceived controllability of stigmatized hereditary health conditions like podoconiosis have promise for increasing preventive behaviors and reducing interpersonal stigma.

INTRODUCTION

The contributions of genomics to health and disease are gaining global attention.^{1,2} Scientific leaders suggest that genomic discovery may hold particular promise for improving global health.^{3,4} For example, advances in the understanding of the genomes of insect vectors likely will inform the development of more effective vaccines that may lead to widespread improvements in the prevention and control of many infectious diseases in the developing world.⁵ Similarly, emerging genomic knowledge is also improving understanding of the complex interplay of genetic susceptibility and environmental exposures that underlie most chronic diseases. This knowledge could inform new health education approaches that convey the importance of reducing exposures to environmental risk factors. When targeted to those individuals most susceptible to environmental harms, these health education programs may heighten the impact of public health interventions at reduced cost.⁶ However, many posit that realization of these benefits will be challenged by lay audience's beliefs about the role of genetics and the difficulties of conveying information about complex gene-by-environment influences on disease.⁷ Adapting this information for global contexts characterized by low literacy and diverse cultural norms will also increase the challenge.

The link between causal beliefs and behavior change. There is considerable conceptual support for the necessity of educating lay audiences about the role of genes and environment in disease causation as part of comprehensive health promotion interventions.^{8–10} For example, the Common Sense Model of Self Regulation asserts that individuals' "illness representations" (that is, their beliefs and perceptions about the causes of illness) can be important catalysts for what, if any, actions individuals take to remediate health threats.^{11–13} Moreover,

these beliefs and perceptions are inherently social in that they often represent shared beliefs about illness that are maintained through interpersonal communication in social contexts.¹¹ Thus, illness representations or beliefs, derived from a variety of sources, including cultural beliefs,^{14,15} are important to consider in promoting preventive actions.

The specific structure and content of commonsense understandings of the causes of illness are also thought to influence preventive actions.¹⁶ For example, beliefs that a health threat is caused by violations of moral or religious taboos likely prompt different preventive actions than beliefs that disease is an organic response to an environmental exposure.¹¹ Especially germane for the case of genetics is if individuals believe that heredity renders health conditions unavoidable—strong endorsement of heredity as the disease cause would be expected to negatively influence preventive and interpersonal actions.^{13,17,18}

Evidence of effects of causal beliefs on behavior. The empirical evidence to date shows mixed findings for an association of beliefs about heredity as a cause of disease with preventive and interpersonal behaviors. Interventions that make linkages between genetics and disease risk have had very little influence on some preventive actions (e.g., smoking cessation, weight loss, and increasing physical activity),¹⁹ whereas for others (adherence to cancer screening in high-risk families), genetic risk information has consistently shown benefit.²⁰

The majority of research evaluating the influence of genetic causal beliefs on interpersonal behavior (e.g., stigmatizing behaviors) has been in the area of mental illness. A recent review of 32 studies shows that beliefs in biogenetic explanations of mental illness did not seem to lessen stigmatizing behaviors such as social distancing; indeed, there was some evidence that it may increase these behaviors.²¹ Studies of other conditions indicate that personal genetic information may influence a range of other interpersonal behaviors. For example, in one small study of families at high risk for Huntington's disease, family members reported an array of changes in family relationships in response to genetic risk information, including dissolution of marriages, decisions not

*Address correspondence to Colleen M. McBride, Social and Behavioral Research Branch, National Human Genome Research Institute, Building 31, MSC 2073, 31 Center Drive, Room B1B54, Bethesda, MD 20892. E-mail: cmcbride@mail.nih.gov

to marry or have children, and interpersonal conflict that stressed familial relationships.²² Additionally, adults who learned that they were at genetically high risk for Alzheimer's disease (AD) were significantly more likely to report having purchased long-term care insurance, presumably, in part, to spare family members from burdensome care responsibilities.²³ Findings among children showed that, across a variety of heritable health conditions, children perceived that carrier status information would influence their marriage and parenting choices.²⁴

Although this prior research suggests that individuals' beliefs about the role of heredity in disease causation may influence a variety of preventive and interpersonal behaviors, results may not generalize well to the global health community. All of these studies were conducted in developed countries where study populations had relatively high literacy. These studies most commonly assessed beliefs of individuals and families who were offered genetic testing for rare conditions, a context in which environment has less influence on disease risk. Additionally, most of the studies were conducted with samples that were recruited in high-risk clinics with individuals who received extensive genetic counseling. These study structures contrast with the developing world, where target populations have low literacy (i.e., many are illiterate); additionally, the majority live in rural settings, where educational and clinical genetic resources are limited.²⁵ Thus, consideration of endemic causal beliefs about locally relevant disease, in which both heredity and environment have important causal roles, is needed in the developing world. Understanding the association of these beliefs with preventive and interpersonal behaviors could inform the development of genetics education interventions for research recruitment and health promotion.

To this end, we describe sources of participants' beliefs about the causes of podoconiosis (also known as mossy foot disease), their perceptions of the role of heredity in the condition, and how these perceptions influenced their preventive and interpersonal behaviors. This study was conducted in rural Ethiopian communities affected by podoconiosis, a geochemical (nonfilarial) elephantiasis caused by the absorption of ultrafine silica particles from the soil through the skin of the feet.^{26,27} Evidence suggests that heightened susceptibility to soil exposure clusters in families,²⁸ with estimates of heritability at 63%.²⁷ The disease is entirely preventable if genetically high-risk individuals consistently protect their feet from exposure to irritant particles by wearing shoes starting at a young age.²⁶ Recent evidence indicates that shoe-wearing prevalence is low and inconsistent²⁹ and that the majority of school-aged children in these rural settings in Ethiopia wear inappropriate shoes that do not adequately protect the feet from exposure to the soil (e.g., flip flops).³⁰

Prior work in these communities has shown that those individuals affected by podoconiosis are apprehensive about participating in genetic research³¹ and that they avoid social events (e.g., church and school) to cope with a stigmatizing environment.³² In this report, we describe more recent qualitative assessments of adults that focus on whether and how beliefs about the role of heredity in podoconiosis influence individual preventive actions and interpersonal stigmatizing behaviors (e.g., selection of marriage partners).

MATERIALS AND METHODS

Study setting. The study was conducted in the Wolaita zone of southern Ethiopia with an estimated population of 1.7 million people. Ethiopia is among the poorest countries in the world, ranking 174 of 187.³³ Accordingly, more than 75% of the population lives on less than \$1 per day. The majority makes their living in farming and animal rearing. Overall literacy in Ethiopia is 18% for adult females and 42% for adult males.³⁴ Approximately 45% of the population is under the age of 15 years.³⁵ The prevalence of podoconiosis in the Wolaita zone is estimated at 6% of the general population.³⁶ This finding means that efforts aimed at primary prevention of podoconiosis would need to target an estimated 46,000 children at genetically high risk to consistently wear shoes.

Mossy Foot Treatment and Prevention Association. A local nongovernment organization (NGO), the Mossy Foot Treatment and Prevention Association (MFTPA), provides health education and treatment in Wolaita to approximately 30,000 individuals affected by podoconiosis and their families per year through a structured system of 14 outreach clinics geographically dispersed throughout the Wolaita zone. The MFTPA staff provides health education through oral presentation along with free shoes and socks two to three times annually to children (aged 1–5 years) of affected individuals, and parents are shown how to wash children's feet.³⁷ Treatment of affected individuals comprises foot hygiene, bandaging where indicated, use of socks and shoes, exercises to improve lymph flow, and elevation of the legs while sleeping, and treatment seems effective in improving clinical outcomes and quality of life.³⁸ Accordingly, the MFTPA orally delivered health education curriculum emphasizes the importance of wearing shoes and properly cleaning feet each day. The curriculum has not included any emphasis on improving understanding of the causes of the condition.

Sampling. The current study involved 4 of 14 communities served by the MFTPA. The four sites were selected to represent the diversity of communities served with respect to size, duration of the relationship with MFTPA, and distance from the offices of the MFTPA (Table 1). For the overall study, participants were identified from six target groups: (1) adults affected with podoconiosis (that is, individuals who have been treated by the MFTPA for the condition), (2) children of affected individuals, (3) unaffected adults, (4) children of unaffected adults, (5) leaders of community groups (e.g., idirs [social insurance groups]), and (6) religious leaders. Participants were recruited using convenience and snowball sampling. Oral consent was obtained from all adult participants by a trained research assistant using procedures developed and evaluated in the work by Tekola and others.³¹ Parental consent was obtained from children to participate in study

TABLE 1
Characteristics of clinic sites affiliated with MFTPA

	Site 1	Site 2	Site 3	Site 4
Number of podoconiosis patients registered with MFTPA	1,754	2,420	2,233	868
Duration of relationship with MFTPA (years)	11	7	12	8
Distance from MFTPA headquarters (km)	35	36	15	20

activities. Briefly, these procedures involved contact through an MFTPA staff member, who referred prospective participants to the research assistant; the research assistant then provided information about the study and obtained individual consent. Institutional Review Board approval was obtained for all study procedures from the National Ethical Review Committee of the Ethiopian Science and Technology Ministry and the National Human Genome Research Institute.

Data collection. A research assistant (D.A.) spent up to 3 weeks in each of the four communities conducting focus group discussions, semistructured in-depth interviews, and extended case studies with research participants to explore study themes. For this report, we focus on adults' beliefs about heredity as the cause of podoconiosis and their effects on individual preventive and interpersonal stigmatizing behaviors. Focus group discussions were comprised of both heterogeneous and homogenous groups of men, women, community leaders, and individuals affected with podoconiosis. The groups lasted approximately 90 minutes and generally included 8–12 individuals. Individual interviews were conducted in participants' homes or convenient public locations. Interview guides for the adult focus groups and semistructured individual interviews assessed identical themes that included attitudes and beliefs about the causes of podoconiosis (e.g., "what do you think causes podoconiosis?"); general child health promotion practices (e.g., "what kind of traditions does the community have to protect the safety of children?"); family roles and functioning (e.g., "who is more influential on children's behavior: mothers, fathers, or someone else?"); attitudes and beliefs about shoe wearing (e.g., "are shoes considered to be valuable in your community?"); role models for adults and children (e.g., "who in the community might be a good role model for children to look up to?"); and optimal settings for podoconiosis prevention activities (e.g., "where would be a good place for children to learn about podoconiosis?"). All data collection was conducted in either Amharic or Wolatigna and audio-recorded.

Data coding and analysis. The audio recordings of focus groups, semistructured interviews, and case studies were first transcribed in the language in which they were conducted (either in Amharic or Wolatigna). Translations of transcripts were checked for consistency to evaluate accuracy of important concepts. To maximize the breadth and depth of the analysis, four coders, including two Amharic speakers, were involved in developing the coding structure and coding the data. The coding structure was based on the four interview themes, and subthemes were created under each of the four themes as the coders reviewed the transcripts. The transcripts were also retranscribed into English by T.G. to evaluate accuracy of important concepts. All coders coded multiple data sources and overlapped with each of the three other coders. One-third of all transcripts was coded by at least two coders. To ensure adequate intercoder reliability, every inconsistency between coders for a given source (e.g., the transcript of a focus group) was resolved. In addition, in weekly meetings, any suggested categories or themes to add were discussed and agreed on by all coders. N-Vivo-9 (QSR International Inc., Cambridge, MA) qualitative data analysis software was used to assess the major themes in the transcripts. Generated codes were used to identify mentions of heredity as a cause of podoconiosis, link these mentions to endorsement of preventive behaviors, and when appropriate, produce counts for

comparison across subgroups. In that the interview guides for the focus groups and semistructured interviews were thematically comparable, we report these results collectively but denote the source of each example quote.

RESULTS

Overview. A total of 307 participants were recruited across the four sites (range = 72–84 per site), comprising a total of 38 individual interviews, 28 focus group discussions, and seven case studies. This report focuses on adults ($N = 242$) who participated in the data collection activities and had demographic identifiers noted. A total of 147 adult participants were males, and 94 adult participants were females (one individual's gender was not noted). Virtually all adults who participated were parents. A breakdown of data collection approaches completed with each target group is shown in Table 2. Thus, we present results summarized across all sites and target groups. Wherever noteworthy differences by gender or target group were observed, they are indicated. In the following sections, we describe the sources of information about causes of podoconiosis, the scope of beliefs about heredity as a cause of podoconiosis, and the associations between beliefs about heredity and engagement in preventive and interpersonal behaviors.

Sources of information. The majority of participants reported that their beliefs about the causes of podoconiosis were based on oral traditions and rumor.

"I have acquired knowledge about the cause of this disease from hearsay and rumors in the community. We have not proved this, but from practical experience of my life, the rumor has some truth." (Male, age 67 years, affected, focus group.)

"Everybody talks about this disease. I have also heard from my father, grandfather, and other old people in my neighborhood talking to each other about the problem. Some patients also give us information about the cause of the problem when we discuss with them." (Female, age 34 years, unaffected, individual interview.)

Additionally, a number of individuals also reported that their beliefs were based on direct observation of individuals and families who were affected by the podoconiosis.

"We knew about the disease not from anywhere but only from those who are affected by the disease. In our day to day life, we see some people suffering from such disease, and when we go to visit them, they tell us the cause of their illness and how it happened to them, how they are feeling." (Female, age 26 years, unaffected, focus group.)

Beliefs about the role of heredity as a cause of podoconiosis. Heredity was spontaneously and frequently mentioned in participants' renditions of the cause of podoconiosis to an equal extent in focus groups and individual interviews. Three

TABLE 2
Number of adult participants by target group and data collection approach

Target group	Focus group	In-depth interview	Case study	Total
Affected	55	12	1	68
Unaffected	107	21	0	128
Unassigned	0	0	2	2
Leaders	39	5	–	44
Total	201	38	3	242

Adult participants who had demographic information available ($N = 242$).

common themes emerged in these descriptions: (1) heredity is the sole cause, (2) heredity is not a causal factor, and (3) heredity is one of multiple causes. We compared the number of times that heredity was mentioned by group as shown in Table 3. Unaffected individuals were consistently more likely to mention heredity in relationship to podoconiosis than affected individuals. Community leaders were also more likely to mention heredity than affected individuals. However, it is notable that, compared with affected individuals, unaffected individuals and community leaders were more likely to endorse heredity both as an important cause of podoconiosis and deny it as an important causal factor.

A relatively small number of adult participants believed heredity to be the sole cause of podoconiosis, making the disease inevitable and unavoidable. Individuals who readily acknowledged this belief tended to belong to families who were unaffected by the conditions, which is illustrated in the quotes below.

“The disease reproduces itself from one generation to another. If anyone in the bloodline of your family had this disease in the past, it is inevitable that the disease repeats itself in the generations to come. It is, however, very difficult to know which person in that family line could be affected.” (Male, age 41 years, unaffected, individual interview.)

“It is hereditary. Anyone who has the disease in the bloodline of the family can pass it on to the children born from that person.” (Female, age 23 years, unaffected, focus group.)

There was a second and sizable group of participants who actively disputed heredity having any role in the development of podoconiosis; instead, they endorsed beliefs about various environmental exposures as the cause of podoconiosis, such as walking on cold ground or areas of open defecation and animal carcass disposal as well as poisons in the soil derived from snake or insects affecting the feet.

“This disease is not a hereditary disease. The main cause, in my assumption, is walking barefoot. Various types of poisons spread into the ground by certain worms and insects could affect our feet unknowingly.” (Male, age 35 years, unaffected, focus group.)

“We have learned and understood from our life experience that this disease is not hereditary. By chance, only one person could be affected in a family without other family members being affected. Let me give you one example that I know very well. In my neighborhood, there is a poor person who was always barefoot and was not taking care of his personal hygiene. His feet were normal until he became matured adult. Suddenly, he became sick with mossy foot disease. This poor

guy became victim to the disease due to hunger and poor sanitation, not because of hereditary predisposition.” (Male, age 52 years, unaffected, focus group.)

Moreover, individuals who attributed it solely to environmental causes were more inclined to see the condition as contagious.

“All we know is that walking barefoot on a cold land is the main cause. I do have a son with mossy foot . . . I guess he was exposed to the disease by sharing the same bowl of water with me to wash his legs.” (Female, age 40 years, affected, focus group.)

A third group of participants perceived the condition to be multifactorial and include heredity, which is illustrated in this quote.

“Likewise, the cause of this disease is multiple. It is caused by cold weather. Other cause is physical injury by sharp things while walking barefoot here and there . . . when the foot is affected due to such causes showing swelling below the ankle . . . then it becomes hereditary.” (Male, age 50 years, unaffected, Catholic church leader, focus group.)

Individuals who included heredity in their beliefs about the multiple causes of podoconiosis often cited inherited sensitivity to the environment as they mused about the multiple factors that caused the condition.

“The disease affects only some individuals, because not all human beings are the same. Some have strong resistance to any disease while others not. That is why it affects some and not others. If my skin is weak and has low resistance, then the same holds true to my children.” (Female, age 42 years, affected, focus group.)

“The disease is hereditary. But it can be preventable through shoe wearing. But lack of money to purchase shoes has been exposing people to hereditary contraction of the disease.” (Male, age 38 years, unaffected, focus group.)

Other participants framed the multiple factors in terms of environmental deprivation that induce a constitutional susceptibility (as opposed to heredity) that increased the risk of developing podoconiosis.

“Our locality is prone to drought due to weather change, and therefore, we face shortage of food. As a result, people will not get breakfast, lunch, and dinner, properly. This causes much fluid in their body, which will cause their leg to swell.” (Male, age 54 years, community leader, focus group.)

Some participants also believed that the multicausality suggested that there were different types of podoconiosis: one caused by heredity and the other related to injury by various objects as indicated in the following quote.

“In fact, the cause differs from one individual to another. In some cases, it is hereditary. If it is hereditary, the person carries the disease in his blood unnoticed until he reaches adulthood. However, there are also many other causes that bring on the disease. Some are affected by snake bite and others hit or pierced by sharp objects.” (Male, age 55 years, individual interview.)

Association of beliefs about heredity with preventive behavior. Generally, participants’ beliefs about whether heredity caused podoconiosis were associated with the perceived importance of taking preventive actions as illustrated by the quotes below.

“In my view, the cause of the disease matters in order to say it is preventable or not. We can prevent it if it is not hereditary. Nobody can prevent a hereditary disease. Only

TABLE 3
Number of mentions of genetics by target group

	Adults			
	Affected (N = 68)	Unaffected (N = 128)	Leaders (N = 44)	Unassigned (N = 2)
Disease is in bloodline or hereditary	1	14	4	0
Genetic determinism: nothing can be done about it	0	14	3	0
Genetics as a cause mitigated by hygiene or footwear	2	3	1	0
Genetics is not important in disease development	3	9	4	1

God can prevent it.” (Female, age 30 years, unaffected, focus group.)

“It depends on what caused the disease. I don’t think it is possible to cure mossy foot that which is transmitted through heredity. If the disease develops from factors other than heredity, it could be cured through treatment.” (Male, age 40 years, unaffected, individual interview.)

Additionally, participants’ beliefs about environmental causes of podoconiosis suggested using folk cures to remedy the condition.

“Our elders perceived that the disease is caused by cold, and therefore, they insist us to use garlic.” (Male, age 45 years, affected, focus group.)

We further explored whether beliefs about heredity influenced adults’ perceptions about the importance of specific preventive and interpersonal behaviors.

Shoe-wearing behavior. Consistent shoe wearing and foot washing are the primary behaviors that reduce affected families’ risk of developing podoconiosis. Beliefs about the role of heredity as a causal factor influenced participants’ views of what actions were appropriate to take to reduce risk. Individuals who perceived that podoconiosis was hereditary and as such, unpreventable tended not to endorse foot wear as important.

“However, if the disease is there in ancestors of a given family, wearing shoes cannot help preventing it.” (Female, age 30 years, unaffected, individual interview.)

The flip side of the perception that podoconiosis is hereditary and unpreventable played out with those individuals who perceived themselves as having no hereditary risk (i.e., the disease did not run in their family) reporting that wearing shoes was unnecessary.

“To tell you frankly, there is nothing I intentionally do to prevent the disease. I do not worry about it, because I know that there is no such disease in the bloodline of my family. Before getting married to my ex-wife and the present wife, I proved that no one is affected by this disease in the history of both families. I have no doubts that in this regard and therefore, do not bother about taking any measure with the intention to protect myself and my children from podoconiosis disease.” (Male, age 45 years, unaffected, individual interview.)

Some individuals talked about how their direct experiences with the condition changed their views about whether hereditary podoconiosis could be prevented by wearing shoes. A 30-year-old patient who received free shoes from the MFTPA best illustrates the effect of this experience.

“Now, my foot is completely in normal shape. I was not wearing shoes before my foot happened to be like that. That incident gave me good lesson, and since then, I made my children wear shoes, thinking that, otherwise, they may also develop the disease ... (Do you think your children may develop podoconiosis?) Yes, I do have worries, because my grandmother and my mother were affected by the same disease. Hence, I am a bit worried that it could be transmitted through hereditary predisposition. My mother’s foot is showing some changes after she started to wear shoes. That is why I am strict in encouraging my children to wear shoes.” (Male, age 30 years, affected, wearing shoes, individual interview.)

It is noteworthy that perception about the link between wearing shoes and preventing podoconiosis often was linked to observed behaviors. Whether participants were

wearing shoes during data collection activities was routinely noted. Among those individuals who endorsed wearing shoes to prevent podoconiosis, considerably more adult men were wearing shoes than adult women. Virtually all religious and community leaders were wearing shoes at the time of their interview.

Finally, beliefs about heredity supported individuals taking precautions other than footwear that were perceived to reduce the risk for contracting podoconiosis as well.

“Realizing that the disease is in my bloodline, as much as possible, I am trying my best to feed my children sufficiently. If they go hungry, their body would become so weak and easily exposed to the mossy foot disease. Therefore, I never let them go hungry.” (Male, age 40 years, unaffected, individual interview.)

Beliefs about heredity and interpersonal interactions. Participants perceived that being affected by podoconiosis and having concerns about developing the condition influenced a number of interpersonal interactions from marital relationships to involvement in various social activities.

Marital relations. Beliefs that podoconiosis was a hereditary disease had a profound and widely acknowledged influence on partner selection and marital stability. Many individuals acknowledged the difficulties that members of affected families had in finding a marriage partner. The case of an ex-patient illustrates how beliefs about heredity influence marrying behavior. This man had married an unaffected woman while he was being treated for podoconiosis. However, for him, the pathway to find a marriage partner was not easy. For fear of heritability of the disease, his marriage proposals were turned down by women that he approached, including his present wife.

“When I was 25, neighbors arranged a marriage proposal to a girl. However, she quickly and angrily turned down my proposal, responding to the elders that she would not like to marry from a kitta (podoconiosis) family ... Then, God gave me the power not to give up hope. A church leader arranged marriage with another girl. This woman also denied my proposal. However, they tried to convince the woman for 3 months, telling her that my sickness is natural thing and it can happen to anybody at any time. Finally, she agreed ... That was surprising news for many people. Some were happy about my marriage, while others, including her relatives, were commenting in bewilderment, saying how dare this woman get married to this kitta? She herself must be a patient.” (Male, age 35 years, affected, case study.)

Participants commonly reported situations where men divorced their wives when they realized that the woman was affected by podoconiosis. Males ended marriages with affected women and found new wives in the interest of avoiding the disease in their family. For example, one woman, aged 40 years, reported that her husband divorced her when she developed podoconiosis after giving birth to children. She speculated that the reason for divorce was her sickness and that her husband could not bear the challenge of leading a family affected by podoconiosis.

Participants also reported occurrences where men divorced wives when the disease appeared in one of the children. The assumption was that the woman was the carrier of the disease. Another case study illustrates the familial pressure and conflict generated by the occurrence of podoconiosis within a family.

“I made a wrong decision in divorcing my ex-wife, because I was pushed by my blood relatives. They considered it as a curse from God and would become hereditary . . . When I got married to the present wife, I consulted elders about the presence of the disease in her bloodline. I chose her as my wife after proving all her blood relatives are free from the disease. However, the case of Abraham (his son with his second wife who developed podoconiosis) created confusion again in my life. He is my son, and I like him as equally as my other children. I wonder what other people say about this condition. They might have thought this disease exists in the bloodline of my relatives. The thought of such views gives me some discomfort.” (Male, age 55 years, unaffected, case study.)

Participation in social gatherings and community events. Individuals described that it was commonplace for those individuals affected by podoconiosis to be excluded from social gatherings such as weddings, funerals, and school and church attendance. The explanation for these exclusions often included perceptions that podoconiosis was a hereditary condition.

“People show a disgraceful outlook towards mossy foot patients. They gossip against them as if the family is cursed by God and suspect all their tribe/clan as a potential threat.” (Male, age 41 years, unaffected, individual interview.)

“It is really disgraceful to the family if the child is found sick in the same family where one of the parents is a podo patient. People assume that family as dangerous, prone to the disease, and they look down on them.” (Female, age 40 years, unaffected, focus group.)

A recovered patient and religious leader similarly expressed his experience.

“Some individuals receive the disease from their fathers and forefathers. (Do you believe in it?) I am not sure, but it is believed by the general community that it is hereditary. Whatever the cause, some people assume that it has hereditary nature. That is really painful. When you feel the symptom, you worry not about the pain but the reaction of the community, which is heart-breaking. That was exactly what I had experienced.” (Male, age 50 years, affected, individual interview.)

The influences of beliefs about the role of heredity as a causal factor in podoconiosis had generally negative influences on how affected individuals were treated by others. Numerous participants commented that beliefs that podoconiosis was hereditary resulted in families being stigmatized.

“The community members devalue patients, assuming that the disease is hereditary.” (Male, age 55 years, unaffected, focus group.)

By contrast, beliefs that the condition was not hereditary resulted in more empathic and compassionate perceptions of affected individuals.

“There are people with bad attitude concerning the patients; there are also people who have good understanding and compassionate to them. We hear such people saying that this disease is not inborn; it is rather accidental . . . They allow patients to participate in social groups, and they also eat together. They understand this disease is common for all men and indiscriminately affect everyone by chance.” (Male, age 47 years, idir leader, focus group.)

Some participants reported that social interactions were improved for affected individuals who received medical services from MFTPA. The availability of treatments was

perceived to have changed community perceptions by showing the curability and preventability of podoconiosis, irrespective of etiology of the disease as indicated in the comments below.

“There is a person I know who, I don’t want to mention his name here, is a healthy person, but four of his children’s feet swelled up because the disease was there in the bloodline of his wife. People, therefore, hesitate to get mixed with persons in such bloodline. However, after the intervention by mossy foot organization, such problem is gradually dwindling.” (Male, age 60 years, unaffected, focus group.)

Affected adults talked about the effect of their disease on their children’s social interactions and its negative impact on social opportunities, such as school.

“For fear of insults, our children refrain from going to school. They stay outside of school and come back home as if they were coming from school.” (Male, age 55 years, affected, focus group.)

DISCUSSION

We examined whether beliefs about heredity as a cause of podoconiosis were associated with preventive and interpersonal behaviors among members of four podoconiosis-endemic communities in rural Ethiopia. Participants reported few standardized sources of health information about podoconiosis. Instead, their understanding of the causes of the condition was based on lived experiences and observations in the community. Individuals readily provided their direct observations of podoconiosis affecting multiple family members, leading some to conclude that it is an entirely inherited condition. Alternatively, others’ observations of affected families, in which some developed the condition and others did not, led them to dismiss heredity altogether and conclude that contagion and other causes (e.g., cold) were at play. A third group believed in multiple causes of the condition, explaining that individuals differed in their tolerance to the many environmental deprivations experienced in rural Ethiopia. Some of these individuals included heredity in this conceptualization.

Participants’ descriptions suggested that their beliefs about heredity did influence actions taken (or not taken) and influenced preventive and interpersonal behaviors. Consistent with numerous social cognitive theories of health behavior,^{11–13} the association of beliefs about heredity with preventive and interpersonal actions was mediated by beliefs about the controllability of hereditary conditions. Individuals who misunderstood that heredity made podoconiosis inevitable tended to downplay the importance of taking preventive actions, such as wearing shoes, if no one in their family was affected and feel negatively about marrying individuals from affected families. By contrast, those individuals who believed that heredity had no role in the condition tended to endorse the importance of wearing shoes to prevent the condition. However, they also expressed concerns that the condition was contagious, which in turn, increased their belief that interactions with affected families should be avoided.

Taken together, our results suggest that prevention interventions should acknowledge what individuals observe to be true (that podoconiosis clusters in families), while emphasizing that the condition is not inevitable. This information must be accompanied with efforts to deepen understanding of individual variation in susceptibility, a concept acknowledged by

many participants but only superficially understood. A genetic education program that uses relevant metaphors to depict how podoconiosis arises from an interaction of hereditary susceptibility and environmental exposure could have several potential advantages. First, as with many social contexts in the developing world, efforts to increase consistent use of footwear are hampered by poverty. Hence, the MFTPA has resorted to a service delivery model in which they direct their limited infrastructure to distribute free shoes to genetically high-risk families. Although this approach may be justifiable and could have considerable public health benefit, without appropriate health education programs that help the community understand the rationale for these steps, these approaches could backfire. In this sample, shoes were perceived to be a valued resource regardless of risk status, which is indicated in this quote.

"I see a shoe as an essential material for everybody."
(Female, age 40 years, affected.)

Thus, social welfare programs to distribute public health interventions to those individuals at genetically high risk will require community buy in that may be facilitated by improved understanding of the role of heredity in the development of debilitating conditions such as podoconiosis. To achieve this aim, interventions then must include the broader community of individuals, even if they are not personally affected by the condition.

Second, our results suggest that increased understanding that hereditary susceptibility to podoconiosis among affected families can be remediated may be an effective strategy to both increase shoe wearing and decrease negative interpersonal behaviors. Combining this information with specific examples of affected individuals being cured could further illustrate the preventability of the condition, and its amenability to treatment could prevent interpersonal stigmatizing behaviors. The use of graphical metaphors for susceptibility that can be described orally to minimize literacy demands will be essential. For example, the work by Peay and Austin³⁹ used the metaphor of a mason jar depicted as holding different amounts of colored marbles to indicate environmental and hereditary contributors to illustrate the joint effects of heredity and environment in the context of mental illness. Such approaches could be adapted to convey how heredity can be overcome by preventive behaviors such as shoe wearing.

Our use of multiple qualitative strategies with multiple target groups also highlighted some considerations for selecting optimal venues to deliver genetics education. Groups that include affected and unaffected individuals in discussing the role of heredity as a cause of podoconiosis may not be optimal for conveying information about the combined role of heredity and environmental influences on podoconiosis. Instead, educational sessions in intergenerational households or neighborhoods of related individuals that enable individuals to feel at ease in these discussions may increase the opportunity for more detailed explanations of gene and environmental contributors to the conditions.

Based on these findings, our study team is currently developing a community-based intervention that will include genetic susceptibility information to illustrate the preventability of podoconiosis. We are targeting unaffected and affected households with education about the role of heredity in podoconiosis as a means to promote social environmental support for shoe wearing among genetically high-risk children. Although currently in development, we plan to

involve lay health educators, who will visit households in communities served by MFTPA shoe distributions. The intervention activities are planned to begin in the fall of 2012.

Although this qualitative study had an unusually large and diverse sample, generalizing the outcomes to other cultural contexts may be limited. Our results are supported by at least one study conducted in Ghana suggesting that perceiving a filarial elephantiasis to be hereditary resulted in social distancing in the form of restricted marital partner selection.⁴⁰ However, our findings for potential benefits of improved understanding of heredity as a prevention approach for podoconiosis may not necessarily generalize to other disease contexts or communities. Our partnership with the MFTPA in conducting the study may have resulted in some social desirability bias in responses.

In conclusion, recent genome-wide association studies showing the genetic underpinnings of podoconiosis⁴¹ support the need for vigorous public health efforts to consider how best to apply this new knowledge to promote health. Indeed, the case of podoconiosis offers a valuable example of the challenges of using genetic information for risk stratification and targeting scarce resources to those individuals at highest risk for negative health outcomes. Results of this project suggest the critical role that genetic education strategies can play in promoting health and reducing the stigma of preventable hereditary health conditions.

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Authors' addresses: Desta Ayode and Getnet Tadele, College of Social Sciences, Addis Ababa University, Addis Ababa, Ethiopia, E-mails: destaayode@yahoo.com and getnett2001@yahoo.com. Colleen M. McBride and Emi Watanabe, Social & Behavioral Research Branch, National Human Genome Research Institute, National Institutes of Health, Bethesda, MD, E-mails: cmcbride@mail.nih.gov and watanabee@mail.nih.gov. Hendrik de Heer, Department of Physical Therapy and Athletic Training, College of Health and Human Services, Northern Arizona University, Flagstaff, AZ, E-mail: hendrik.deheer@nau.edu. Tsega Gebreyesus, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, E-mail: tgebreye@jhsph.edu. Ababayehu Tora, Department of Sociology, Wolaita Sodo University, Sodo, Ethiopia, E-mail: abezed@yahoo.com. Gail Davey, Brighton and Sussex Medical School, Falmer, Brighton, United Kingdom, E-mail: G.Davey@bsms.ac.uk.

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