

Using ethnographic film in tackling podoconiosis

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Background: Ethiopia has one of the worst podoconiosis rates in the world, affecting >1.5 million patients. We present our ethnographic film ‘Tigist, the story of a girl with podoconiosis’ and its potential use in tackling podoconiosis.

Methods: We conducted visual ethnography, consisting of video-recorded participant observations and interviews with seven patients, three healthcare workers and two podoconiosis experts.

Results: We acquired video recordings of social moments, the state of podoconiosis patients’ bodies and minds, their emotions and the impact of poverty.

Conclusions: Our film allows for an intensified understanding of patients’ daily experiences with podoconiosis, potentially impacting care, awareness and medical teaching programs.

Keywords: ethnographic film, patient experience, podoconiosis, stigma

Introduction

‘My family loves me, but couldn’t do anything because they had not treatment. My mom told me to wait with school until I recover. I am often bullied by other kids because of my legs. When I go to school, my friends are spitting on me. When they insult me, when they run away...I feel very sad. I just feel that I live alone’. —Interview with Tigist

This is one of the moving scenes of our short ethnographic film ‘Tigist, the story of a girl with podoconiosis’ (photo 1). This film was created during a visual ethnographic study on podoconiosis in Ethiopia. Through the sharing of visual knowledge, we aim for novel ways of reflecting on this public health theme and engage a wide range of audiences into the daily lives of podoconiosis patients.

In Ethiopia, >1.5 million people are affected by podoconiosis.¹ This disease is unique in being entirely preventable and non-contagious, with the potential to be eliminated. Prevention strategies such as regular foot hygiene and using footwear seem straightforward, yet remain unattainable as most patients are either unaware or do not have the financial means.²

Podoconiosis is a severe disabling disease with enormous physical, social, psychological and economic implications. Various studies show that patients are often stigmatized, leading to prejudice; discrimination; intimate partner violence; social exclusion from schools, local meetings and churches and prohibition to marry into affected families.^{3,4} The disease leads to a low quality of life, depression and reduced economic productivity and subsequently increases poverty.⁴ Prevention and treatment of podoconiosis are therefore of great importance to patients to break the stigmatization and disease–poverty–disease cycle.

However, the biggest obstacles to podoconiosis control in Ethiopia are poverty, limited access to primary healthcare, low prioritization, scarcity of allocated resources and policy makers’ and practitioners’ lack of understanding of the disease.² To increase understanding of this neglected disease and to underscore the urgent need for action, we conducted visual ethnographic research and made a short ethnographic film. Visual ethnography enables the sharing of knowledge that both engages yet also transcends medical and scientific rationales.⁵ With our film (17 min) entitled ‘Tigist, the story of a girl with podoconiosis’, we offer an alternative way of understanding and explaining patients’ complex experiences with podoconiosis while engaging the viewer on deeper dimensions made up



Photo 1. Tigist receives podoconiosis care for the first time in her life at the health centre Mossy Foot Project, Sodo, Ethiopia.

of space, interactions, emotions, attitudes, facial expressions, composition and context.

Methods

One visual anthropologist (director, camera operator, editor), three medical doctors (interviewers, observers) and five local research assistants (community health workers, translators, guides) conducted visual ethnographic research in a highly endemic rural area and an urban area in Ethiopia in October 2017. Participant observation was done for 14 d during care practices at the Mossy Foot Project (MFP) health centre (Sodo, Wolaita region), the St. Giuseppe Health Centre (Addis Ababa) and during daily activities at patients' homes (eating, farming). This generated rich data regarding the cultural and social context and interactions between practitioners, patients, family and community members. Using a convenience sampling technique, seven podoconiosis patients, three health workers and two podoconiosis experts were recruited for semi-structured in-depth interviews (1.5 h). The questions covered podoconiosis perceptions and experiences, care, poverty and stigma. Interviews were conducted in local languages and translated into English. All participant observation and in-depth interviews were audio and video recorded. The video camera did not seem to hinder interaction between researchers and respondents, as the camera was handheld or in a corner on a tripod. The unstructured character of participant observation and interviews allowed for an active role of respondents, who guided the camera's orientation and the thematic content. Visual and audio recordings were screened

multiple times (Premiere Pro, Adobe Creative Cloud), translated into English, transcribed, coded into meaning units, divided into categories and subcategories and analysed for structures, meaning and context (ATLAS.ti, 7th edition; Scientific Software Development, Berlin, Germany). Findings and analysis were repeatedly discussed with all co-authors. We received permission from the local clinics and local community leaders. All respondents agreed to the lack of anonymity that is associated with research captured on film and provided their written informed consent. Additionally, we received informed consent from the parents or guardian of minor participants.

Results and discussion

We created a film 'Tigist, the story of a girl with podoconiosis' (17 min). This ethnographic film captures two patients' experiences with podoconiosis and additionally presents the perspectives of two podoconiosis experts. In total, we interviewed three female and four male patients (ages 13–70 y), all were or had been farmers, four lived in a rural area and three had moved to Addis Ababa and all had a low socioeconomic status.

Link trailer: <https://vimeo.com/431039486>

Link ethnographic film: <https://vimeo.com/447785513>

In sum, patients were unable to walk or work due to their swollen and painful feet. Podoconiosis aetiology, prevention and treatment was unknown to most patients; some explained that worms or witchcraft could cause podoconiosis. All patients had delayed seeking medical care for years (5–20 y). Patients, health workers and the podoconiosis experts explained that delays were

caused by ignorance about the disease and the availability of treatment or financial constraints. Such barriers to care have been reported in a study about podoconiosis challenges globally.² All patients faced financial problems due to the inability to work. Patients reported facing stigmatizing attitudes in their social environment, with people discriminating against or isolating them and blaming them for having the disease, or fearing contagiousness. These findings resonated with two studies in this area.^{3,4} Health workers and patients in urban areas explained that podoconiosis patients often migrate from rural to urban areas to avoid stigmatization.

Visual ethnography empowers patients and health workers, providing them with an innovative tool for expressing their experiences with podoconiosis. It gives them a voice, and a face, that is urgently needed as podoconiosis often remains under-represented in public discourse, meanwhile communicating a message about larger structures of inequality.⁵ Our film not only informs but also immerses a variety of audiences (e.g. policy makers, health workers, patients, researchers, the lay public) in the world of people affected by podoconiosis. Consequently this film may be used to support synergies between these multiple stakeholders for improved podoconiosis programmes. The film can also be used for sensitizing patients and a broader public about this neglected tropical disease. Future research may look into the impact of visual ethnographic research on diverse audiences and their responses.

Conclusions

This visual ethnographic study aimed to inform, but also immerse diverse audiences in the world of podoconiosis patients, highlighting the extremely high burden of disease as well as the usually completely reversible nature of podoconiosis by relatively simple measures. Overall, we argue that our ethnographic film can play a crucial role in enabling a greater understanding of patients' daily experiences with podoconiosis, potentially impacting care, awareness and medical teaching programs.

Authors' contributions: ALC, BJV and EB conceived the study. ALC, BJV, ZG and EB designed the study protocol. ALC, BJV, ZG, MB, EM, JA and EB carried out the data collection. ALC filmed, edited and directed the ethnographic film. ALC, BJV and EB drafted the manuscript. ZG, EM and MvV critically revised the manuscript for intellectual content. All authors read and approved the final manuscript.

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