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Patients' experience with tuberculosis and healthcare in sub-Saharan Africa

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Visual ethnography: bridging anthropology and public health

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The last scene of the film ends. The room remains dark and quiet. Someone switches on the light showing the audience of (public) health scientists digesting the story of six tuberculosis patients. One person remarks, 'Now I finally realize what your research is about.'

The ethnographic film presented in the scene above (*TB in Town 2*, the Academic Medical Center, Amsterdam, the Netherlands, 2015) was part of an interdisciplinary anthropological health study about patients' experience with tuberculosis (TB) in South Africa. Ethnography calls for immersion into the lives of research subjects by fostering in-depth interactions and relationships with them over an extensive period of time, aiming for a holistic understanding of the nuances and complexities of respondents' lives.¹ Through ethnographic health research, public health practitioners can be informed about patients' experiences of illnesses and health, potentially leading to improved health care programmes. Anthropologists have for many years played a significant role in public health as cultural brokers mediating between the variety of clinical realities and experiences of patients, clinicians, and policy makers.² However, anthropologists' actual contribution to the formation of health policies within the public health domain remains marginal.³

In the context of an interdisciplinary TB research at the Academic Medical Center (AMC) in Amsterdam, the anthropologist on the team (Cremers) aimed for a synergy of anthropology and public health while navigating differences between the disciplines. Scholars have discussed divergent scientific agendas: anthropological research often leads to context-bound specific findings and detailed, nuanced manuscripts, whereas public health research aims at generalizable extrapolation in the format of short, concise articles.⁴ Various scholars have written about the exploratory, question-driven character of anthropological research versus the formulation of hypotheses in public health research aimed at health recommendations.⁵ Another often-mentioned contrast is the use of qualitative versus quantitative methods.⁶ Public health researchers rely predominantly on quantitative techniques, and their limited use of qualitative techniques tend to depend heavily on researcher-defined categories. Consequently, the value of these methods has been criticized because it would yield data that may differ significantly from respondents' perspectives.⁷

Although the literature sufficiently mentions the disciplinary differences and contributions of anthropology and public health,⁸ there is a need to elaborate how these disciplines can benefit from each other, creating an effective synergy. We suggest that the use of visual ethnography can potentially bridge anthropology and public health, serving both disciplinary agendas while communicating ethnographic details to represent the voices and experiences of respondents within an academic and applied sphere. Potentially, this can contribute to theories on patients' experience with

illness and care, and hence, a deeper understanding of the functioning of care programmes.

VISUAL ETHNOGRAPHY

Over the past twenty years, visual anthropology was officially established as a sub-discipline of anthropology engaging in the making of ethnographic films (and photographs).⁴ Similar to ethnographic methods, these films are not directed by predetermined matrices but are gradually developed through discovery and collection of visuals of respondent's everyday lives over time.⁹ Ethnographic film captures the sensation of lived experiences evoking the idea of moving, seeing, and hearing.¹⁰ Visuals can additionally convey much deeper dimensions of experience: *'experience [...] is made up of ideas, emotions, sensory responses, and the pictures of our imagination'*.¹¹ Whereas the written word can inform the reader about 'thoughts' of respondents' experiences, visuals can additionally make someone empathetically understand patients' experiences.¹² The combination of space, gestures, emotions, attitudes, facial expressions, interactions, composition, and context communicates meaning and directly engages the audience in a complex representation of this experience. The boundaries between the audience, film subjects, and researcher become blurred, leading to a sense of shared experience.

SYNERGISTIC POTENTIAL OF VISUAL ETHNOGRAPHIC HEALTH RESEARCH

Visual methods can connect applied and academic anthropology to other disciplines, creating linkages and contributing to a wider interdisciplinary framework.⁴ Nevertheless, in medical sciences, scientific thoughts are generally confined to the printed and spoken word with the exception of some health campaigns and applied anthropological health research.¹³ Moreover, visual methods in health research have often been criticized for their limited use as illustrative materials for non-academic pursuits.¹⁴ A similar critique was mentioned in earlier debates on the value of visuals for academic anthropology, during which anthropologists advocated for a more significant role for ethnographic film.¹⁵ Film can generate forms of knowledge that are very different from written work and communicates messages that may be unsatisfactory to scientists who desire more clarification, contextualization, or more specific study results. The scientific value of ethnographic health films can be constructed through suggestion, reference, ambiguity, and implication without forming an explicit statement.¹⁰

Furthermore, ethnographic film can function as a platform on which various respondents can represent their ideas, experiences, and culture. All visual production is more or less created through collaborative and reflexive processes between the researcher and respondents, and herein, the filmmaker/researcher

and respondents can be considered active agents in the social construction of meaning.¹³ Tailored to issues of health and disease, patients may be empowered by this so-called communication competence¹⁴ in which they can express themselves while knowing that someone is paying attention to their words and experiences. Moreover, it can give voice, and a face, to those who are often under-represented in public discourse.¹⁶ Ethnographic film has the added value of communicating a message about larger structures of inequality or asymmetric power structures. Engaging policymakers in a process in which they are not only informed but also immersed in the patient's world, could enhance empathetic understanding, and consequently inform health strategies.¹⁴

INTERDISCIPLINARY STUDY ABOUT TUBERCULOSIS

With the ambition to draw from both the disciplines of public health and anthropology, we explored a variety of methods combining ethnography in three different sites with one or more other methods. In South Africa, we conducted visual ethnographic research and experienced its synergistic potential. The present article draws on the visual aspects used during this study.

Cremers served as director, camera operator, and researcher conducting visual ethnography about TB within the community of Town 2 in the township Khayelitsha, South Africa, in close collaboration with the University of Cape Town. South Africa faces one of the worst TB epidemic and highest HIV rates in the world with a TB incidence of 834/100 000, 61 percent TB-HIV co-infection, and 8.5 percent drug resistant TB (DR-TB).¹⁷ (DR-)TB treatment is available for free in Khayelitsha, but side effects are often aggressive (e.g., nausea, dizziness, psychosis) and especially severe on an empty stomach.

The aim of this sub-study was to enhance our understanding of how the complex relations between TB patients, community members, treatment, and the highly developed TB health programme in this township play out in everyday treatment compliance, that is, continuing TB treatment without interruption (Cremers et al. n.d.) For five months, Cremers worked with her local research assistant, Maqogi, a respected pastor and social activist of the community. They found respondents via the snowball technique. Six respondents, all TB patients, a pastor and community care worker were approached for the visual ethnographic part and consented with a long-term, intensive engagement during which they shared their experience of TB, care, and death embedded within the social structures of a South African township, characterized by high levels of poverty, unemployment, and crime.

AN ETHNOGRAPHIC HEALTH FILM

Cremers' request to film during interviews and participant observation and the presence of the camera seemed to work as a catalyst, as respondents reacted

positively and explained they hoped their struggles while being on TB treatment would reach beyond this research. They guided the visual data collection by explaining and showing intake of treatment, visits to the clinic, the way their family and community members supported or discriminated them, their living circumstances and neighborhood, and several funerals. After establishing a confidential relationship between researcher and researched, they shared not only the practicalities of having TB but also their TB-related difficulties, pains, fears, and hopes during interviews and informal conversations with Cremers, Maqogi, family, and friends.

The respondents' statements and the context in which they were filmed shows how treatment compliance is not exclusively the product of care programmes or patients' struggles but rather shows flexible and creative processes of survival, coping strategies, and the existence of social networks leading to supportive and stigmatizing actions. It gives the audience insight into social moments, the state of patients' bodies and minds, their emotions, the impact of extreme poverty and hunger, the mundaneness of death, and how this shapes the shifting agencies of TB patients navigating tuberculosis and treatment.

Cremers' position within this research field and her influence on what was being filmed became clear through the conversations she had with respondents (Photo 1). In a later stage of the filming process, many scenes happened unexpectedly, for example, as seen during an informal discussion with three tuberculosis patients about the consequences of taking TB medication: *'I just took my pills, I don't know what will happen. Maybe I will go mad. I think you [Lianne] should go now. Like now now.'* Or a patient who throws her medication in the bin explaining to Cremers: *'I am not going to take these pills, Lianne. The food is finished. I will go mad!'* illuminating the patient's fear of psychosis behind so-called 'non-compliant behavior'. The latter scene communicates how the relationship between Cremers and respondents did not necessarily trigger socially desired answers regarding treatment compliance or an ideal type representation of the 'good patient.' This could be linked to how respondents viewed Cremers: because of her long-term presence in the field, they may presupposed a certain degree of understanding that might give them the feeling of not being judged as irresponsible. The importance of this mutual respect was also visible during an interview with a respondent who had ceased TB treatment, amongst others because of side effects. She told Cremers that the camera gave her the feeling of being taken seriously and started crying because the attitudes of nurses made her 'not feeling human anymore'.

The film was co-produced by the key-informants who actively influenced the camera's orientation and the film's thematic content. The primary goal was to make TB patients' experience come to life for both a fundamental and applied research audience within the spheres of public health and anthropology.



Photo 1 Interaction between Cremers and her respondents in the township Khayelitsha, Cape Town, South Africa (written informed consent obtained from all visible respondents).

Consequently, the two-folded aim was to inform public health policies about patients' experience with TB and care and to reflect on theoretical debates on illness experience, treatment compliance, and care.

The preliminary study results of our South African sub-study were presented with the film *TB in Town 2* at a meeting for social scientists and public health practitioners in Cape Town (February 2015), the weekly scientific meeting for (public) health researchers at the Center of Tropical Medicine and Travel Medicine of the AMC in Amsterdam (April 2015), and at a meeting for anthropologists at the University of Amsterdam (April 2015). *TB in Town 2* embodied innovative means of communicating this study's ethnographically informed public health messages to different audiences. Various people were visibly touched by the audio-visual stories and reported to have gained better understanding of the complex decision making processes in which TB patients engage while being on treatment. One public health practitioner explained, '*I now realize that even for myself, I might choose to stop TB treatment in this situation.*'

We argue that visual ethnographic film can be a powerful source of detailed data, a quick and efficient way of conveying and evoking deeper understanding of patients' experience, and engaging diverse audiences, while sharing interdisciplinary knowledge.

ETHICS IN VISUAL ETHNOGRAPHIC HEALTH RESEARCH

During this collaborative visual ethnographic research process, it is important to consider various ethical implications. The most visible one is that respondents cannot participate anonymously in this kind of research; otherwise important data would be lost. This foregrounds a particular informed consent process in

which ethics of filmic representation and the loss of personal privacy should be discussed. Moreover, film is a medium that in modern technology is easily spread over the Internet, reaching different audiences. Respondents cannot always foresee different interpretations by audiences. Audience reactions are seldom discussed within visual anthropology,¹⁸ let alone the related task of the anthropologist to deal with this adequately. We argue that visual anthropologists should facilitate full information about the ethics and practices of filmmaking to respondents,⁴ both at the beginning and end of fieldwork, and discuss potential audiences and their reactions. This was extensively discussed with respondents of our visual ethnographic study.

Another often-voiced dilemma in the field of visual anthropology is the fear of reinforcing ethnocentric notions and stereotypes. Since the sixties, visual anthropologists have debated the effects that film can have on different audiences related to the idea of different ways of seeing.¹⁴ To some extent, we see literally, but we also look conceptually, linguistically, and metaphorically as informed by our cultural conditioning.¹¹ A tension can exist between different forms of seeing, but additional interaction occurs during which ‘meaning shapes perception, but in the end, perception can refigure meaning, so that at the next stage this may alter perception once again’.¹¹

Visual anthropology must confront how ethnographic films can misleadingly communicate the idea of an objective representation of reality.¹⁹ Visual anthropologists have a great impact on the message and meaning through the assembling of the film; selective emphasis, camera position, secretiveness, and the order in which scenes are presented all create meaning.¹⁰ Preventing the audience from thinking they are watching an unmediated reality, the researcher should share throughout the film how the visuals are collected, what the relationship was with respondents, and what influence the researcher had on events. This approach was used in the ethnographic film *TB in Town 2*. If the positionality of the researcher is integrated into the story, the viewer gets a clearer idea how this ‘reality’ is produced.

CONCLUSION

Our study elaborated how public health and anthropology may benefit from each other. After exploring a wide variety of data collection methods in three different study sites, we argue that visual ethnography has enormous synergistic potential. An intensive visual ethnographic collaboration between researcher, local research assistant, and key respondents was aimed at creating an in-depth, nuanced view of TB patients’ everyday experiences with TB and care in Khayelitsha, the largest and fastest growing township of Cape Town, South Africa. Visual methods fostered the interdisciplinary process by communicating ethnographic knowledge and engaging various public health and anthropological stakeholders of both fundamental and applied research fields.

The impact of previously made ethnographic health films²⁰ suggests that this method is likely to synergize these two disciplines and enhance interdisciplinary research. Further research is needed to address methodological questions such as informed consent and the avoidance of perpetuating stereotypes that may arise from this approach.

There are various approaches in which visual ethnography can be embedded, such as the multimedia approach – a combination of new media, printed words, photographs, and film in an integrated, relational structure.^{19,21} The variety of media gives the viewer extra sensorial layers of sound and sight to immerse themselves in a mediated reality produced by researchers and participants. A non-sequential organization of study results enables the viewer to independently make links between ideas and explore the subject. Another approach is the creation of an interactive platform in which the researcher, patients, medical practitioners, public health scientists, and the general audience can communicate with each other.

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