

Changing the narrative: visual methods can reinforce or reduce disease-related stigma

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Health conditions have often been associated with stigma and exclusion, leading to social marginalisation and discrimination. Historical references demonstrate how individuals affected by skin diseases were considered 'defiled', ostracised and compelled to reside outside the community.¹ Although stigma is associated with a number of diseases including HIV/AIDS, tuberculosis and mental health disorders, skin diseases are particularly susceptible to stigma due to their visible nature. Stigma manifests through misunderstandings, entrenched superstitions and fear, leaving those affected vulnerable to judgement, prejudice and social exclusion. Skin diseases can intensify feelings of shame and self-consciousness, limiting a person's opportunity to fully participate in society.² Leprosy-related stigma is often described in the literature, but similarly, individuals affected by other skin conditions, like albinism, psoriasis and vitiligo, may also face societal stigma and discrimination impacting mental health, basic human rights and opportunities for marriage and employment.^{3 4} In the case of albinism, the deep-rooted prejudices, myths and misconceptions can be life-threatening and result in violence, mutilation and even murder.⁵

A range of community engagement strategies has been developed to address disease-related stigma, each tailored to specific objectives and target audiences. While some approaches concentrate on increasing community awareness about a disease to reduce fear and misperceptions, others focus on nurturing empathy. Initiatives with patients and their relatives, such as peer-led counselling for people affected by leprosy,⁶ can improve self-confidence and resilience. It is equally relevant to engage with healthcare professionals, as addressing any stigma they may hold towards patients can mitigate

SUMMARY BOX

- ⇒ Participatory visual methods (PVMs) involve individuals or communities who create visual representations using tools like photography, video, drawings or mapping to express their experiences and perspectives. These methods empower participants, promote dialogue and improve understanding of complex health issues in research, advocacy or community engagement.
- ⇒ When using visual methods in research or community engagement, it is important to conciliate the wish to raise awareness while maintaining integrity and inclusivity in visual representations of people affected by skin diseases.
- ⇒ Ethical considerations associated with the use of PVMs include obtaining informed consent, ensuring privacy and confidentiality, using images that are equitable and considerate of the individuals represented and which respect the participants' cultural beliefs and traditions, which is particularly important for vulnerable populations in resource constrained settings.
- ⇒ Guidelines should be developed for the use, storage and dissemination of visual data to protect participants' rights and interests in the current era of internet, social media and artificial intelligence.

discrimination and dismantle barriers to healthcare access.⁷

This commentary aims to explore the potential caveats and benefits of utilising visual methods for engagement addressing stigma associated with skin diseases.

THE POWER OF GLOBAL HEALTH PHOTOGRAPHY

Imagery is a powerful communication tool. From portraying personal perspectives to highlighting the situation of a community, imagery provides a uniquely impactful vehicle to communicate narratives with broad social and environmental context, which can compel and connect the viewer. Participatory visual methods (PVMs) involve the use

Box 1 Case study 1

We conducted a photovoice project among persons affected with leprosy, their family members and healthcare workers to explore community health and social issues around leprosy in Papua province, Indonesia. Participants were encouraged to take photographs capturing their daily lives. Through facilitated group discussions, they were guided to provide narratives for each photograph. Participants selected their preferred images, which were displayed at a photo exhibition in a public venue on World Leprosy Day 2022 with the aim to improve public perception of leprosy and stimulate engagement with the public, local government and other stakeholders (<https://www.youtube.com/watch?v=IYDTwt7vnRs>).⁸

of visual tools and techniques to engage and empower participants and enhance understanding of complex health issues in research or community-based projects. These engagement methods invite collaborative learning and allow individuals to express their feelings, values and perspectives in a creative way using photography, video, drawings or plays.⁸ PVMs can help to overcome language and literacy barriers and give a voice to disadvantaged populations.⁸ It provides a platform to share stories, challenge societal misconceptions and promote dialogue among different stakeholders, including healthcare providers, policymakers and the general public. Participants can use visual representations to portray themselves as they wish to be seen, but also to convey the impact of stigma on their lives.

Indonesia has the third highest leprosy caseload in the world with over 17 000 new individuals diagnosed every year.⁹ We conducted community engagement projects in two leprosy endemic areas in eastern Indonesia using PVM that focused on the lived experiences of people affected by leprosy, with the aims of empowering those affected, raising awareness and encouraging tolerance and inclusivity within the community^{10 11} (boxes 1 and 2).

THE PITFALLS OF PHOTOGRAPHY

Despite good intentions, the use of visual methods in portraying people with skin diseases can have unintended negative consequences and may reinforce stigma. Historically, images, hand-drawn or photographs, have often been utilised to instil fear, evoke sympathy or

Box 2 Case study 2

We organised a photo exhibition 'Letter from the hills: The invisible burden of leprosy in Sumba' by Yoppy Pieter, who is an award-winning Indonesian photographer, in 2022 and 2023 across different cities in Indonesia. The exhibition featured the narratives of seven individuals affected by leprosy in Sumba, a remote island in eastern Indonesia, illustrating their daily challenges, resilience, vigour and dreams. Through the exhibition, we aimed to enhance public knowledge, increase empathy and challenge prevailing stereotypes associated with leprosy (figure 1).⁹ The website is also available online through www.invisibleburdenofleprosy.com.



Figure 1 A compilation of four photographs, including individual quotes from visitors, displayed during the photo exhibition 'Letter from the hills: The invisible burden of leprosy in Sumba' by Yoppy Pieter, which was held in 2022 in Jakarta and in 2023 in Malang, Indonesia. The appropriate rights/permissions have been sought. The original names of the people affected by leprosy have been changed. Visitors shared their impressions: (A) Toru with her younger sister. 'The photos of Toru radiate resilience: she's a strong character with a fighting spirit'; 'The images were powerful and moving, capturing a deep sense of optimism and humanity.'; 'Despite her physical limitations, Toru shows an eagerness to learn and embrace life.'; 'Her resilience is truly inspiring'. (B) Robertus working in the field together with other people in his village. 'The images show the impact of leprosy without romanticising the condition itself. The photos are able to frame social interaction and togetherness of the people.' (C) Rada washing her feet under the close attention of her son. 'This photograph is about family and adaptation to leprosy. It reflects the pain and strength she endures as a woman, a wife and a mother'. (D) A girl on the lap of her mother. 'The photo conveys a mother's unwavering determination, layered with emotional complexity. Its visual portrayal of her daily life with leprosy, capturing both the personal burden and broader social reality'; 'This photo expresses the story of an unstoppable mother'.

sensationalise diseases, by showcasing extreme presentations of conditions to garner financial support.¹² Leprosy, for example, conjures up images of highly contagious individuals with deformities, while, in reality, the vast majority of people exposed to the bacterium never develop the disease. Leprosy is also curable: most people with leprosy experience subtle symptoms, which can be managed effectively. The representation of diseases in visual media influences public perception and, in some instances, reinforces negative stereotypes and power imbalances. In the 19th century, images of disease were used in an imperial context to reinforce the moral superiority of Europeans over non-Europeans, perpetuating racial hierarchy.¹³ During the recent Mpox outbreak, clinical images frequently depicted individuals with brown or black skin, even when referencing cases from countries where the majority of the population

has white skin. Whereas medical textbooks have historically predominantly illustrated skin diseases on white skin, sexually transmitted infections, like syphilis, have been over-represented on brown or black skin,¹⁴ further contributing to stereotypes and racial injustices. These examples highlight the importance of providing unbiased information in global health, ensuring accuracy and inclusivity.

PVMS CAN BE EMPOWERING

PVM are aligned with the principles of collaborative learning and empowerment. PVM may shift or balance power dynamics in a research project by enabling participants to generate or co-create knowledge. Where, how and with whom the outputs of PVM are shared depends on the wishes and consent of the participants. Nonetheless, it is important to be aware of the limitations, as numerous steps in the process are controlled by the researchers.¹⁵ Researchers should acknowledge these methodological limitations and seek to maximise empowerment and democratisation of the processes. In our photovoice project (box 1), we attempted to achieve this by enabling participants to take their own photographs and selecting their 'favourite' images to be exhibited to the public. The task of the facilitator was to guard against the display of images that potentially could negatively impact participants in the future in a way the participants could not have foreseen at the time the project was executed (e.g. exclusion from government facilities).¹⁵

INFORMED CONSENT PROCEDURES IN MARGINALISED POPULATIONS

Ethical considerations associated with the use of PVM include obtaining informed consent from participants, ensuring their privacy and confidentiality, and respecting local customs and traditions. In rural communities, the notion and practice of 'informed consent' is more challenging and related to limited access to healthcare, low health literacy, cultural beliefs and language barriers. Participants might consent to projects without fully comprehending the potential implications this may have for themselves or their communities, especially if they have limited access to internet or experience with research.¹⁵ In our photo exhibition (box 2), we used dynamic consent procedures.^{8 15} By seeking consent during various stages of a project, this approach ensures informed decision-making and acknowledges the evolving perspectives and attitudes of individuals towards participation.

THE WIDER IMPACT OF ARTIFICIAL INTELLIGENCE AND PHOTOGRAPHY

The uncontrolled use of imagery on the internet and social media, and the rapid developments in artificial intelligence (AI) databases often using public images, raises significant ethical and legal concerns, particularly

regarding confidentiality and security.^{16 17} A particular concern is the use of facial recognition technology, as AI algorithms can link faces to personal identities, raising risks of misuse or unauthorised access to personal information, which could compromise an individual's anonymity. Personal identifying features like tattoos, birthmarks or unique physical traits may be captured and stored in databases. This further amplifies the risks associated with imagery of individuals affected by skin diseases in research or engagement, as participants may unknowingly have their personal information exposed or exploited. It is therefore important to establish guidelines for the use, storage and dissemination of visual data to protect participants' rights and interests, especially considering the amplified impact of imagery in the digital era.^{8 12} Charani *et al* recently developed a good-practice framework for the use of imagery in global health in which global health actors are encouraged to rethink their intentions in using imagery in their communications ensuring they are relevant, considerate of the individuals portrayed, accompanied by informed consent, and equitable in representation.¹²

CONCLUSIONS

Efforts are being made globally to reduce stigma and discrimination associated with specific health conditions through education, awareness campaigns and promotion of inclusive policies. These initiatives aim to dispel myths and misconceptions that drive stigma and play a key role in addressing the deeply ingrained challenges faced by those affected. The ethical considerations associated with PVM, especially in the context of skin diseases, require a vigilant approach that prioritises the rights and well-being of the people involved. For instance, obtaining dynamic informed consent and ensuring participants understand how their images and stories will be used, as well as their right to withdraw their consent at any time. Scientists bear the responsibility to engage with participants as active collaborators to shape the project and to carefully consider the use of imagery, ensuring that it neither perpetuates stigma nor compromises the standards of good practice. The rapid advances in AI and machine learning pose additional ethical and legal challenges and underscore the need for comprehensive discussions on these matters. The establishment of customised context-specific guidelines that adapt to local societal norms for the selection, storage and utilisation of imagery will be imperative to protect individuals' rights and interests, ensuring responsible and respectful use of visuals in community-based research and engagement.

Correction notice This article has been corrected since it published online to correct the author name to Yoppy Pieter.

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