

## Escaping the Eyes of Empire: Diverting and Embracing Disease Photography

Emma Cardol

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Depicting Africa as a continent ravaged by disease has long been a common practice in Western media. One of the most famous literary accounts of Africa in the late nineteenth century, Joseph Conrad's *Heart of Darkness*, describes African workers as "nothing but black shadows of disease and starvation, lying confusedly in the greenish gloom."<sup>1</sup> With the emergence of portable cameras, textual representations like Conrad's were supplemented with visual depictions, allowing Europeans to "see" Africa for themselves.<sup>2</sup> Photography allowed Westerners without ties to African colonies to visualize the people who lived there and the local conditions, creating a sense of connection between the global West and Africa.<sup>3</sup> Using photography as an educational tool also became appealing, given its perceived ability to surpass biases and represent truth "accurately."<sup>4</sup> This view of photography as the "eye of history," representing reality without interfering with it, diminished as society's knowledge of the practice of photography developed.<sup>5</sup> Nonetheless, stereotypes continue to persist in photographic depictions of African pandemics.<sup>6</sup> In this article, I discuss the conflict between emancipation and domination in photography of disease in Africa, arguing that projects intended to empower their subjects may still reflect colonial trends. To do this, I explore the work of Eric Gottesman and Geert van Kesteren,

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<sup>1</sup> *Heart of Darkness*, 18.

<sup>2</sup> Harrison, "Seeing Health and Illness Worlds," 861.

<sup>3</sup> Du Preez, "Through the Empire's Eyes," 429.

<sup>4</sup> Golden, Weisz, and Comacchio, *Healing the World's Children*, 151.

<sup>5</sup> Ryan, *Picturing Empire*, 16.

<sup>6</sup> Shahidul, "Developing Countries," 60.

two photographers who have sought to capture the lived experience of AIDS patients in Africa, and a project conducted by a number of scholars around a treatment clinic in Uganda.

The creators of these three projects make clear that they aim to empower African people with their work. While this work is not a comprehensive overview of contemporary disease photography, it provides a useful set of case studies to examine how photography can both reconfigure the image of African disease and continue to reinscribe colonial-era ideas. It is important to note that these projects were set in Uganda, Zambia, and Ethiopia, places selected by the photographers for their high level of HIV infection. The colonial trends represented in the chosen case studies are, however, not geographically limited and are reflected in academic analyses about other regions of Africa as well. This article will thus at times refer to African trends rather than Zambian, Ugandan, and Ethiopian trends, since the photographers did not set out to depict local differences but rather seek to convey a sense of commonality across the continent. Both van Kesteren and Gottesman admit that they selected the area they documented based solely on its high percentage of people living with AIDS, without considering other regional specificities. This means that their photography, while based in a specific area, does not engage with questions of regional difference. As Dipo Fayolin stresses in her work *Africa Is Not a Country*, the West drew the borders between African nations during the colonial period without consulting local population groups, and these borders have been reiterated or neglected by Western political forces when convenient. Consequently, framing a photography project as speaking to “African” themes reflects complicated colonial echoes inherent within these projects’ production.<sup>7</sup>

Several academic works inform the analysis of these case studies. Susan Sontag has stressed the importance of depicting tragedies purposefully, warning that repeatedly exposing an audience to representations of disasters without making them feel able to contribute to a solution produces “compassion fatigue.”<sup>8</sup> Empowering photographs, like those that the present case studies

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<sup>7</sup> Fayolin, *Africa is not a Country*, 48.

<sup>8</sup> *Regarding the Pain of Others*, 91.

present themselves to contain, could be a solution to this fatigue. By allowing an audience to experience the lives of those with HIV or AIDS in a more complex manner, it is possible to move away from the shock that creates compassion fatigue over time and instead creates deeper understanding and empathy. Focusing on complex narratives rather than shock seems more effective in creating compassion, exemplified by the fact that media depictions have increasingly started rejecting the “starving baby syndrome” as a central narrative in their visual storytelling.<sup>9</sup> Lilie Chouliaraki, an influential academic in the field of media and communications, discusses the way that aesthetic choices in visual depictions of tragedies can provide agency to victims or remove their humanity according to the goals the images are meant to serve, which in turn impacts the dignity awarded to the subject of the photograph.<sup>10</sup> Chouliaraki’s work pays close attention to where the camera is placed and how subjects are framed. These choices, Chouliaraki argues, reflect the level of power endowed to the person in the photograph, showing how seemingly innocuous photographs can still be framed in a way that empowers or undermines the subject.

I also draw on Paul Landau and Deborah Kaspin’s idea of “image Africa,” from their work *Images and Empires*, which posits the existence of a version of Africa that has little to do with the lived experience of the local population but is instead entirely made up of Western depictions of the continent.<sup>11</sup> The “image Africa” concept is useful for understanding how Europe and North America instinctively imagine Africa, helping to demonstrate why the photographs analyzed in this article can be considered subversive depictions. The idea of an “image Africa” can be related to Richard Vokes’s argument that colonial powers in the twentieth century became a “regime of seeing,” with the visual representation of the African continent allowing for the continuation of colonial power into the twentieth century, legitimizing and categorizing the continent in order to rule it more efficiently.<sup>12</sup> While this regime did

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<sup>9</sup> Rutherford, *Endless Propaganda*, 125.

<sup>10</sup> *The Spectatorship of Suffering*, 105.

<sup>11</sup> *Images and Empires*, 5.

<sup>12</sup> “On Ancestral Self-fashioning,” 348.

not fall when formal colonial rule in Africa ended, the photographs analyzed in this article show both the desire of some interested parties to move beyond colonial concepts and the difficulties in truly escaping hegemonic trends that continue to structure Western understandings of Africa and experience of African disease.

### **Dominant Photographic Depictions**

The first widespread use of photography to document an African pandemic was during the human trypanosomiasis epidemic prior to the First World War. Photos of patients suffering from the disease were omnipresent in many different Western publications, reflecting the interest in human trypanosomiasis among the European public. This interest arose from a number of different factors. First, the disease was deadly, killing the majority of the population in some areas and making it devastating for the economies of the new colonies.<sup>13</sup> Second, the disease was visually striking, with patients near death becoming emaciated and lethargic, able only to sleep.<sup>14</sup> Finally, the disease emerged at a moment when Europe wanted to be more involved in the welfare of the colonies and saw Western technological “progress” as the way to develop Africa into a “modern” continent.<sup>15</sup> Similar factors motivated Western attention to the early spread of AIDS. AIDS was a disease that primarily affected economically exposed populations, had a high mortality rate, and emerged at a time when television and events like LiveAid had made many in the West interested in the lives of African people.<sup>16</sup> In this article, I argue that the following trends described in this section seen in the media surrounding AIDS have roots in the colonial period, allowing for the perpetuation of a colonial “image Africa” decades after the end of formal colonial rule. The trends briefly discussed in this section are then traced in the case studies selected for this article, either as actively rejected representations or emerging as potentially unintended replications of earlier ideas of disease photography.

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<sup>13</sup> Lyons, *The Colonial Disease*, 73.

<sup>14</sup> Goodwin, “The African Scene,” 112–4.

<sup>15</sup> Neill, *Networks in Tropical Medicine*, 107.

<sup>16</sup> Baughan and Fiori, “Save the Children,” 133.

The first of these trends revolves around the continuously high percentage disease photography depicting children, even with diseases that are not known to primarily impact children. As Kaspin and Landau have argued, the “image Africa” in the West is one in which women and children are omnipresent but men are invisible.<sup>17</sup> Kaspin and Landau argue that this imbalance results from a Western belief that men should provide for themselves while children are emblematic of dependency, innocence, and victimhood.<sup>18</sup> Depicting children can also encourage parental feelings in the audience; seeing a child in need can inspire a desire to help ease the child’s discomforts, be that through donations or other forms of providing support.<sup>19</sup> African adults in colonial photographs were also often described as children by those who took the photographs, stressing their state of dependency on the colonial regime and their supposedly inferior level of development when compared to Europeans.<sup>20</sup> An emphasis on Africa as a land of innocent children has roots in colonial photography but persists in contemporary photographs of Africa.

Another hallmark of the pictures taken during pandemics in Colonial Africa is the lack of local surroundings. Rather than show patients within their communities, photographers isolate their subjects against non-descript backgrounds. This trend was particularly popular during ethnographic studies by colonial powers in the nineteenth century, but in many disease photographs the white background persists.<sup>21</sup> Photographing patients as if they exist in a vacuum is widely criticized by various patient advocates, who see the practice as removing a patient’s humanity, leaving behind only their diseased body.<sup>22</sup> While certain diseases require the isolation of patients, as we have seen during the recent Covid-19 pandemic, the apparent isolation of patients in disease photography has been used to convey an impression of the represented

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<sup>17</sup> *Images and Empires*, 4.

<sup>18</sup> Zarzycka, “Save the Child,” 30.

<sup>19</sup> Nathanson, “The Pornography of Poverty,” 105.

<sup>20</sup> Landau and Kaspin, *Images and Empires*, 3.

<sup>21</sup> Gilman, *Disease and Representation*, 259.

<sup>22</sup> Squiers, *The Body at Risk*, 156.

population as primitive or uncaring, unwilling to take care of their sick and dying.<sup>23</sup>

In analyzing a photograph, Chouliaraki suggests, it is essential to consider the positioning of bodies within the frame. Patients photographed lying down appear helpless, unable to pose or otherwise engage with the camera.<sup>24</sup> Patterns of gaze are equally important in eliciting a response from the viewer, with patients with lowered eyes or the photographer looking down on their subject suggesting a submissive attitude, while direct eye contact is meant to evoke a feeling of urgency in audiences.<sup>25</sup> Contrasting a Black patient and a white doctor also has a long history as a technique to imply a hierarchy of power in which the patient is helpless, as seen in representations of white male doctors towering over local patients.<sup>26</sup> Photographs where a caregiver hovers over a patient, standing tall while the patient is lying down, evoke a sense of domination even if care is provided when the picture is taken.

The following case studies show both the perpetuation of these trends as well as active resistance against them. The photographs selected for analysis are, according to the leaders of the projects in which they appear, intended to break with dominant narratives and offer an alternative perspective on disease in African countries. I argue that while the photographs achieve this goal to a certain extent, echoes of earlier ideas remain visible, showing the difficulty in moving beyond colonial discourses in the representation of disease.

### **Mwendanjangula!**

Geert van Kesteren's project *Mwendanjangula!*, based in Zambia, is an example of a project that sets out to promote empowerment while still reinscribing colonial trends. Van Kesteren is a Dutch photographer who has worked for various media outlets including Newsweek and the Dutch broadcasting network NOS.<sup>27</sup> In 1999, he

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<sup>23</sup> Lydon, "Behold the Tears," 42.

<sup>24</sup> Bleiker and Kay, "Representing HIV/AIDS in Africa," 141.

<sup>25</sup> Mittelman and Neilson, "Development Porn?," 377.

<sup>26</sup> Lynteris, *Visual Plague*, 25.

<sup>27</sup> Van Kesteren, "Short Bio."

traveled to Zambia with journalist Arthur van Amerongen to report on the impact of AIDS on Zambia's population. *Mwendanjangula!* is the book that emerged from this project. Mwendanjangula, the name of a demon in Zambia related to AIDS, is shown in Van Kesteren's work as an omnipresent interference in the lives of patients—rather than seeking to photograph only disease, Van Kesteren states he wants to capture the larger societal context.<sup>28</sup> He collaborates with sculptor and AIDS activist Clement Mufuzi, who seeks to break the stigma that still exists surrounding the disease in Zambia.<sup>29</sup> The book contains interviews with the local population, who tell their stories about how being HIV positive or having AIDS impacts their lives. The book's back cover describes the work as “a blood-curdling reportage about love and death, hope and despair, and the daily life that, despite everything, continues.”<sup>30</sup>

This work was not well received among AIDS activists. Van Kesteren's own website makes no mention of the project, suggesting that he no longer finds the work worth promoting. Van Kesteren originally intended for *Mwendanjangula!* to be part of a 2000 exhibition by the International AIDS Conference, but in the end the committee rejected his work in favor of exhibitions that promoted “living openly.”<sup>31</sup> AIDS activist groups took issue with the reinforcement of negative stereotypes in his work, which shows African AIDS patients as Black, helpless and either nearing death or already dead.<sup>32</sup> According to Lynn Dalrymple, a South African AIDS activist, there is no need for photography to further stress the physical horrors of AIDS because the general public is acutely aware of this aspect of the disease. According to Dalrymple, it is more important to focus on how patients live with the disease than on the many tragedies that it causes.<sup>33</sup>

*Mwendanjangula!*, as its back cover promises, covers many facets of Zambians' lives and the manner in which they cope with AIDS. Photographs in the book show church services for those who

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<sup>28</sup> Van Amerongen and Van Kesteren, *Mwendanjangula!*, 83.

<sup>29</sup> *Id.*, 10.

<sup>30</sup> *Id.*, back cover.

<sup>31</sup> Von Stauss, “Representations and Objections,” 47.

<sup>32</sup> *Ibid.*

<sup>33</sup> *Ibid.*

have died of the disease, billboards urging the public to “stay faithful to one partner” to avoid spreading AIDS, and condom distribution by activists. However, the book also contains numerous pictures taken in hospices, pictures of bodies covered in cloth in a morgue, and even a close-up image of the face of a deceased man. The many photographs included in *Mwendanjangula!* do indeed show the lives of patients outside of their final moments, but they portray those lives in a very specific and at times limited way. Van Amerongen’s extended section on exorcisms and traditional healers, and the title of the book, referencing the “AIDS demon,” suggest a level of “otherness,” emphasizing the idea that medical treatment for AIDS in Africa is fundamentally different than in the United States or Europe due to the local population’s attitudes.<sup>34</sup> The book also contains an extensive section on prostitution and the supposed promiscuity of Zambian people, echoing Western perceptions that AIDS especially affects Black people due to their supposed hypersexuality.<sup>35</sup> This narrative of AIDS being more prevalent in Africa due to the supposed promiscuity of the “Other” not being disputed by this book, even if there is little empirical evidence to support these claims.<sup>36</sup> Van Amerongen also conducts an interview with a traditional healer, whom he describes as being “dressed in all her finery: a get-up of feathers, beads, monkey skulls animal skins and other indefinable bits and bobs.”<sup>37</sup> While they never express a negative opinion of traditional healing outright, Van Amerongen and Van Kesteren depict it in a manner that stresses its “strangeness.”<sup>38</sup> The text describes a meeting with the traditional healer as follows: “Her eyes begin to roll, her body shakes and she produces sinister sounds that slowly merge into a sort of cackle.”<sup>39</sup> This alien display is contrasted with an interview with a Dutch doctor, David Koetsier, who is photographed for *Mwendanjangula!* at work in a hospital in fig. 1. Van Kesteren and Van Amerongen

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<sup>34</sup> Egawa, “Social Construction of AIDS,” 15.

<sup>35</sup> Gilman, *Disease and Representation*, 263.

<sup>36</sup> Treichler, *How to Have Theory in an Epidemic*, 254.

<sup>37</sup> Van Amerongen and Van Kesteren, *Mwendanjangula!*, 83.

<sup>38</sup> *Id.*, 84.

<sup>39</sup> *Ibid.*





Figure 1: Photograph by Geert van Kesteren titled “Dr. David Koetsier, tropical-medicine specialist, at the Kaoma District Hospital, 1999.”<sup>40</sup>

paint a vivid picture of Koetsier’s work, noting that his hospital rarely has running water or electricity. Koetsier himself says that he feels pride about what he can do in “wretched conditions,” praising his local staff, who always retain a sense of optimism.<sup>41</sup> His final quote tells us why he stays in Zambia even though its conditions are not optimal for saving patients’ lives: “Poverty has its own beauty. But I can’t bear it indefinitely.”<sup>42</sup> This quote is reminiscent of earlier colonial beliefs about people in Africa, which, as Sabine Wilke argues, present a sense of beauty in simplicity or destitution, an idea of African individuals being somehow untouched by modernity.<sup>43</sup> Koetsier also radically separates himself from both his patients and the local population in this quote, stating that while he cannot stand this life for long, they never seem to lose their optimism.

The photo of Koetsier in fig. 1 echoes this sentiment—he appears overwhelmed, crouching beside a lifeless Black body. He is not physically positioned above the patient in this photo, but he is

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<sup>40</sup> *Id.*, 99.

<sup>41</sup> *Id.*, 56.

<sup>42</sup> *Ibid.*

<sup>43</sup> “Romantic Images of Africa,” 288.

undoubtedly the subject of the photograph, with the patient being a secondary concern. In this image, colonial trends can be seen, with the patient lying incapacitated on the table. The photograph is a visual representation of a narrative that was often used to justify colonial intervention, where Europeans needed to “save” the people of their empire. Koetsier, the white doctor, seeks to help the local population but is unable to do so due to poor infrastructure and a lack of resources. The Black patient, helpless and dying, is placed mostly outside the frame and out of focus, emphasizing Koetsier’s moment of emotion. In Van Kesteren’s photograph, the agency and life of the patient is secondary to the white doctor and his pain. This photograph pairs well with the quote that Koetsier provided about his working conditions. When Koetsier, Van Kesteren and Van Amerongen are eventually too overwhelmed to continue looking at the Black patients in front of them, they can leave. The Zambian people they photograph will likely not be given this same option.

Van Kesteren’s photography does not fall neatly into the category of shallow “poverty pornography” as described by academics involved in the humanitarian space like Janice Nathanson. According to Nathanson, poverty pornography compresses suffering into a distorted view of an area.<sup>41</sup> Van Kesteren and Van Amerongen traveled with an activist and interviewed Zambian people; their book’s photographs do not depict Black suffering only as colonial imagery presented it. However, that does not mean that echoes of earlier colonial imagery have disappeared from their work. Western medicine is portrayed with more nuance than traditional healers, who are portrayed as animalistic and wild. The helplessness of the locals is repeatedly stressed, and the doctor they photograph states he never intended to stay there. The voices of the local population continue to be filtered through Western perceptions in *Mwendanjangula!* Van Kesteren and Van Amerongen’s work repeatedly stresses the exotic nature of the local population, shows that Zambians know little about the disease they are struggling with, and indirectly blames the local population for the disease by stressing sexual promiscuity as its leading cause. Rather than breaking from stereotypes, Van Kesteren and Van Amerongen

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<sup>41</sup> “The Pornography of Poverty,” 104.

use similar visual representations to those seen in colonial photography. Rather than question the global West's sense of African disease, they stress its accuracy. The picture of Koetsier exemplifies this idea: a white man does what he can with the resources provided to him, but he cannot save the local population from themselves. This image is strongly reminiscent of the writing by colonial officers a century before.<sup>45</sup>

### **“I am a Kid”**

Despite the continuation of certain trends in photography of disease in African communities, various projects and some countries increasingly resist these stereotypes. Uganda, for instance, forbade photographers in the early years of the AIDS pandemic to take photos of its citizens suffering from AIDS due to suspicion of exploitation inherent in these projects.<sup>46</sup> Many African scientists pushed back against the common Western idea that the proximity between African people and monkeys made Africa the source of AIDS, arguing that this belief only reinforced negative Western stereotypes.<sup>47</sup> While Western media has a strong idea of their “image Africa,” there are local projects that show a sense of resistance against this characterization, for example explored by Kylie Thomas, who analyzes various different local art projects surrounding AIDS and its representation.<sup>48</sup> These projects attempt to reject colonial trends, seeking to complicate the West's image of disease in Africa. Even so, the trends previously mentioned have continued to reemerge in the photos meant to empower the local population, suggesting the trends' continuing power.

Eric Gottesman is an American photographer who sought to reimagine photography of AIDS in Africa. In his first project, titled *If I Could See Your Face I Would Need Food*, he covered the faces of AIDS patients in different ways, showing the continued stigma surrounding the disease.<sup>49</sup> His second project, *Sudden Flowers*,

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<sup>45</sup> Neill, *Networks in Tropical Medicine*, 126.

<sup>46</sup> Hooper, *Slim*, 48.

<sup>47</sup> Chirimuuta and Chirimuuta, *AIDS, Africa and Racism*, 122.

<sup>48</sup> *Impossible mourning*, 28.

<sup>49</sup> Gottesman, “If I Could See Your Face I Would Not Need Food.”

depicts the disease in Ethiopian children. Ethiopia at the time of this project had the second-highest population of “AIDS orphans” in the world and many children without housing suffering from the disease.<sup>50</sup> Gottesman gave selected children a camera and some loose guidelines and assignments for what they should try to capture, but he was otherwise uninvolved with the staging of the photos that the children produced.<sup>51</sup> The pictures that resulted from Gottesman’s project, which were shown at temporary exhibitions around Ethiopia, show an entirely different side to living with disease. These pictures show the children’s families, future aspirations, and daily lives.

One photograph from the *Sudden Flowers* project is known as “I am a Kid.” Tenanesh Kifyalew, the girl in this photograph, garnered a lot of attention from Gottesman due to her enthusiasm for photography and this project. Tenanesh, who was twelve years old when Gottesman met her, was born with HIV; her doctors had predicted that she would not make it past seven. She died nine months after the project was completed.<sup>52</sup> Tenanesh played an integral role in the exhibitions that Gottesman set up throughout Ethiopia, which were titled “Abul Thona Baraka.”<sup>53</sup> The exhibitions set up in Addis Ababa included not only photographs taken by the children, but also letters and postcards Tenanesh had written. The audience was encouraged to create a dialogue with the work by adding letters to the photos on display, creating a new form of communication surrounding HIV/AIDS. By engaging the audience in the design of the exhibition, allowing them to alter it through their own words, the project became part of the community rather than simply seeking to depict AIDS sufferers as isolated and diseased individuals.

In “I am a Kid,” Tenanesh poses with a poster of Jesus on her wall. She is centered in the photograph, looking at the camera as if she seeks to show off her living space. On the floor, there are

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<sup>50</sup> Bleiker and Kay, “HIV/AIDS in Africa,” 151.

<sup>51</sup> *Sudden Flowers*.

<sup>52</sup> Mengiste, “Sudden Flowers.”

<sup>53</sup> Gottesman, “Abul Thona Baraka.”

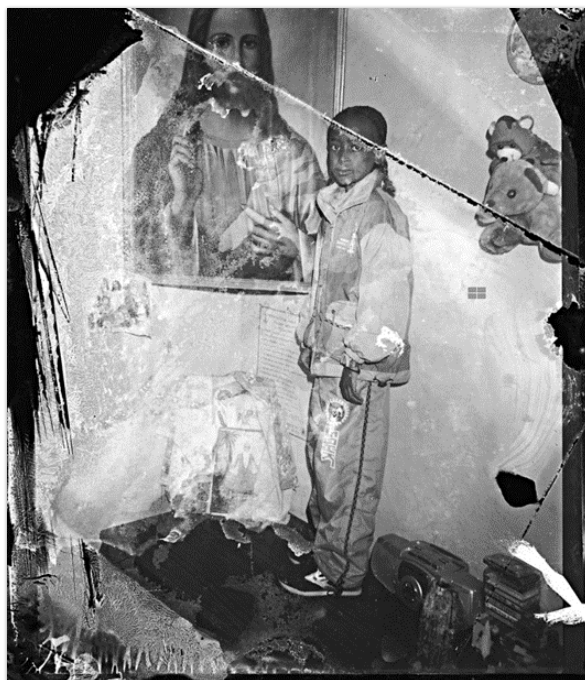


Figure 2: Photograph by Tenanesh Kifyalew titled “I am a Kid.”<sup>54</sup>

cassettes and a stereo, and stuffed animals are visible on the wall next to her. Tenanesh is deeply connected with her surroundings, and the blank void of early colonial photography is replaced here with the clutter of the subject’s daily life. The World Health Organization encourages photographing children in a “dignified” manner, which includes enduring that they are wearing sufficient clothing. Tenanesh’s photograph appears to achieve this goal. She appears to be in complete control of her surroundings and her body.<sup>55</sup> The scene represented in “I am a Kid” is entirely ordinary: a child showing off items and ideas which are important to her, including her Christian identity, her toys, and other forms of entertainment. Rather than being placed in a scene by a photographer, this photograph allows us to see her in the way she perceives herself. However, this photograph still reflects some

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<sup>54</sup> Gottesman and Kifyalew, “I am a Kid.”

<sup>55</sup> Black, “WHO Photography Expectations.”

trends in photographic documentation that emerged in the colonial period.

Gottesman deliberately focused on the experiences of children in *Sudden Flowers*, likely knowing that a child suffering from disease evokes more sympathy than an adult in the same position. While the children and the communities were involved in the design and execution of the project, Gottesman eventually published the book and had final editorial power, not the children. Ultimately, Tenanesh could not have taken the photo that she did without being selected for the program that Gottesman designed.

“I am a Kid” represents the tensions that continue to exist in disease photography in Africa, allowing for more agency and power for the subject of the photograph while still containing a power imbalance between the Western gaze and the African subject.

### Dagie’s Candle

Tenanesh’s photograph seems to have a generally positive tone—although she is not smiling, the photograph does not directly allude to the hardships that she may have faced as an HIV-positive child in Ethiopia. Other photographs, however, both within the *Sudden Flowers* project and beyond it, have allowed African youth to address the darker side of living with HIV and AIDS. A 2020 photography-based study produced through the collaboration of numerous scholars from a variety of different backgrounds sought to allow young people in Uganda to depict the stigma that they faced as HIV-positive young people.<sup>56</sup> These teenagers, aged between 12 and 19, were part of a support group near their treatment clinic and in an active treatment program at the time of their participation in the study.<sup>57</sup> The goal of this study was to represent the social hardships that these young people continued to face even as they received healthcare. The emotional turmoil stemming from an HIV diagnosis is a key theme in the photographs that emerged from this photography project. Fig. 3 is a photograph taken by Dagie, a 17-

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<sup>56</sup> Kimera *et al.*, “HIV-Related Stigma.”

<sup>57</sup> *Id.*, 3.



Figure 3: “Because people tell me that I can die anytime, I fear darkness and I have to light a candle every day before I sleep. This also is very dangerous because one time I almost got burnt while asleep, yet I stay alone in my room.’ (Dagie, 17-year-old boy).”<sup>58</sup>

year-old boy who participated in this photography study. The picture is not a portrait, but it is still deeply personal, giving a glimpse into the fear that continues to be part of the lives of many people living with HIV. In this, the photograph contradicts the notion that only faces can evoke emotion in a crisis situation.<sup>59</sup> The photograph, containing a candle seen through a wired fence, conveys Dagie’s fear of death and his need to leave a candle burning at all times because he is unable to sleep in the dark. The physical barrier present in the picture also conveys a feeling of Dagie’s isolation from the rest of his surroundings. This feeling of isolation is frequently seen in photographs surrounding stigma.<sup>60</sup> Many participants in the study communicated to the researchers that they felt ostracized in their social circle, being present but not being afforded the ability to

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<sup>58</sup> Kimera *et al.*, “HIV-Related Stigma,” 10. Both the caption and the photograph are included in the original text.

<sup>59</sup> Chouliaraki, *The Spectatorship of Suffering*, 106.

<sup>60</sup> Moletsane *et al.*, “Image of Stigma,” 66.

participate.<sup>61</sup> One participant even remarks that she feels that people in her area want HIV-positive people to be separated from the rest of society, a feeling represented by another photograph taken of a fence.<sup>62</sup> Candles are a common way to memorialize the dead and have been used as a metaphor for life's fragility in many different forms of media, a famous example being the "tomorrow, and tomorrow, and tomorrow" speech in William Shakespeare's *Macbeth*, which states that life is nothing more than a "brief candle."<sup>63</sup> The photographs produced by these Ugandan youth show that they are constantly confronted with the possibility of death even as they are being treated against further progression of their HIV into AIDS. The candle in Dagie's photograph is meant to drive away the dark, but at the same time, a physical barrier keeps this candle away from the audience. As Dagie explains in his caption, a candle has the potential to burn the person who most finds comfort in it. In this photograph, the lived experience of an HIV-positive youth in Uganda is captured. Rather than depicting dying bodies, the photograph shows the fragility and fear in their lives indirectly.

Dagie's photograph does not include a human subject, so the early colonial trends that emphasized the physicality of disease are not seen in his work. This can be seen as an implicit rejection by the photographer of the colonial focus on the African photographic subject as a body rather than a person with an internal life. Despite the considerable differences between the projects from which they emerged, Tenanesh and Dagie's photographs have this in common. Dagie and Tenanesh represent their relationship with AIDS as more than a physical reality, instead focusing on their individuality. As a result, the viewer receives a sense of Dagie and Tenanesh as people, not as patients. The researchers who organized the project in which Dagie participated employ the photovoice practice, which seeks to gather information about participants' lives through their photography, researching *with* the participants rather than simply researching them.<sup>64</sup> While Gottesman is not a researcher, allowing

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<sup>61</sup> Kimera *et al.*, "HIV-Related Stigma," 11.

<sup>62</sup> *Id.*, 8.

<sup>63</sup> *Macbeth*, 53.

<sup>64</sup> Kimera and Vindevogel, "Youth Living With HIV/AIDS in Uganda."



children to tell their own stories allowed him to gather glimpses into the children's lives that go beyond their diagnosis and health condition. Both these photography projects serve the goal of broadening general understanding of the lives of children living with AIDS.

### **Conclusion**

Photography of and around disease in Africa has changed significantly since photography first became a tool of the colonial order. The "regime of seeing" and the "image Africa," which afforded the global West all agency in determining the way that Africa was seen, has started to become less all-encompassing, allowing for the lived sensations of African people to emerge visually. That said, colonial trends can still be found in disease photography that seeks to empower the photographed subject. In van Kesteren's work, agency was given to the European doctor instead of the anonymous Zambian patient, reaffirming pre-existing power hierarchies even within a work that sought to explore AIDS in a more complex manner. Gottesman's project makes a more conscious effort to escape from colonial trends by allowing Ethiopian children with AIDS to self-represent. However, Gottesman still belongs to a power system that allowed him final editorial discretion. By focusing on children, moreover, Gottesman repeats a long-running trope of African disease photography. Finally, Dagie's photograph allows him to speak about the inner fears he experiences as an HIV-positive teenager in Uganda, depicting the social experiences of those with the disease and proving that resistance to colonial tropes can be found in many different forms, as can be seen in all projects analyzed here in different ways. This study has analyzed photographs that defy the "image Africa" imposed in the early twentieth century and complicates our understanding of disease in Africa by showing the people behind the medical labels they receive. The analysis has shown that fully discarding these trends is more difficult than it may initially appear because a larger power imbalance between the global West and Africa continues to structure audience understandings of photographs from Africa. As mobile phones and inexpensive camera equipment continue to broaden the possibilities for visual

representation, it will be interesting to see whether colonial trends will finally be put to rest or if they will continue to haunt disease photography in the years to come.

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