

Imaginations

Journal of Cross-Cultural Image Studies
Revue d'études interculturelles de l'image

IMAGINATIONS

Learning from the Role of Art in Political Advocacy on HIV/AIDS

Steven J. Hoffman, Annemarie Hou, Annie Jones et Julia Woo

Volume 11, numéro 2, 2020

(Immune Nations) Research-Creation at the Intersection of Vaccine Science and Global Health Policy

URI : <https://id.erudit.org/iderudit/1072129ar>
DOI : <https://doi.org/10.17742/IMAGE.IN.11.2.13>

[Aller au sommaire du numéro](#)

Éditeur(s)

York University

ISSN

1918-8439 (numérique)

[Découvrir la revue](#)

Citer cet article

Hoffman, S., Hou, A., Jones, A. & Woo, J. (2020). Learning from the Role of Art in Political Advocacy on HIV/AIDS. *Imaginations*, 11(2), 233–258.
<https://doi.org/10.17742/IMAGE.IN.11.2.13>

Résumé de l'article

Cet essai utilise une approche à méthodes mixtes combinant un examen de la portée, une analyse qualitative thématique et des méthodologies d'études de cas pour identifier les relations entre l'art et le plaidoyer politique dans le contexte de l'épidémie de Sida. Trente-quatre articles pertinents ont été trouvés grâce à une recherche documentaire complète axée sur les analyses scientifiques sociales. Trois thèmes-clés ont été identifiés: lutter contre les stéréotypes négatifs; l'importance de l'éducation; et donner la parole aux personnes touchées par le VIH. L'importance de l'artiste emblématique Keith Haring et de deux œuvres d'art importantes liées au plaidoyer contre le VIH—le Retable de Keiskamma et le Ribbon Project—sont examinées afin d'en tirer des leçons sur le rôle que l'art peut jouer plus largement dans le plaidoyer politique sur les questions de santé mondiale.

All Rights Reserved © Steven J. Hoffman, Annemarie Hou, Annie Jones et Julia Woo, 2020



Ce document est protégé par la loi sur le droit d'auteur. L'utilisation des services d'Érudit (y compris la reproduction) est assujettie à sa politique d'utilisation que vous pouvez consulter en ligne.

<https://apropos.erudit.org/fr/usagers/politique-dutilisation/>

Érudit

Cet article est diffusé et préservé par Érudit.

Érudit est un consortium interuniversitaire sans but lucratif composé de l'Université de Montréal, l'Université Laval et l'Université du Québec à Montréal. Il a pour mission la promotion et la valorisation de la recherche.

<https://www.erudit.org/fr/>



IMAGINATIONS:

JOURNAL OF CROSS-CULTURAL IMAGE STUDIES |
REVUE D'ÉTUDES INTERCULTURELLES DE
L'IMAGE

Publication details, including open access policy
and instructions for contributors:

<http://imaginations.glendon.yorku.ca>

<Immune Nations>

Guest Editor: Natalie Loveless
August 31, 2020

Image Credit:

Kaisu Koski, *Injection Simulator* (2015)

To cite this article:

Hoffman, Steven J., et al. "Learning from the Role of Art in Political Advocacy on HIV/AIDS." *Imaginations: Journal of Cross-Cultural Image Studies*, vol. 11, no. 2, Aug. 2020, pp. 233–258, doi:10.17742/IMAGE.IN.11.2.13.

To link to this article:

<http://dx.doi.org/10.17742/IMAGE.IN.11.2.13>



The copyright for each article belongs to the author and has been published in this journal under a **Creative Commons 4.0 International Attribution NonCommercial NoDerivatives** license that allows others to share for non-commercial purposes the work with an acknowledgement of the work's authorship and initial publication in this journal. The content of this article represents the author's original work and any third-party content, either image or text, has been included under the Fair Dealing exception in the Canadian Copyright Act, or the author has provided the required publication permissions. Certain works referenced herein may be separately licensed, or the author has exercised their right to fair dealing under the Canadian Copyright Act.

LEARNING FROM THE ROLE OF ART IN POLITICAL ADVOCACY ON HIV/AIDS

STEVEN J. HOFFMAN, ANNEMARIE HOU, ANNIE JONES, JULIA WOO

This essay uses a mixed-methods approach combining scoping review, thematic qualitative analysis, and case study methodologies to identify relationships between art and political advocacy in the context of the AIDS epidemic. Thirty-four relevant articles were found through a comprehensive literature search focused on social scientific analyses. Three key themes were identified: addressing negative stereotypes; the importance of education; and giving voice to individuals affected by HIV. The significance of iconic artist Keith Haring and two important artworks related to HIV advocacy—the Keiskamma Altarpiece and the Ribbon Project—are discussed, with lessons distilled for the role that art can play in political advocacy on global health issues more broadly.

Cet essai utilise une approche à méthodes mixtes combinant un examen de la portée, une analyse qualitative thématique et des méthodologies d'études de cas pour identifier les relations entre l'art et le plaidoyer politique dans le contexte de l'épidémie de Sida. Trente-quatre articles pertinents ont été trouvés grâce à une recherche documentaire complète axée sur les analyses scientifiques sociales. Trois thèmes-clés ont été identifiés: lutter contre les stéréotypes négatifs; l'importance de l'éducation; et donner la parole aux personnes touchées par le VIH. L'importance de l'artiste emblématique Keith Haring et de deux œuvres d'art importantes liées au plaidoyer contre le VIH—le Retable de Keiskamma et le Ribbon Project—sont examinées afin d'en tirer des leçons sur le rôle que l'art peut jouer plus largement dans le plaidoyer politique sur les questions de santé mondiale.

INTRODUCTION

Artists and political advocates share a history of working together to foster awareness, action, and change. Renowned novelist and Nobel Laureate Toni Morrison once claimed, “All good art is political! And the ones that try hard not to be political are political by saying, ‘We love the status quo’” (Nance, 2). Indeed, the expressive nature of art gives artists the ability to stir controversy, shed light on formerly neglected issues, and challenge the status quo in a manner that is more moving and powerful than perhaps any other medium of communication. Therefore, if we seek to catalyze transformative change through the power of art, it would be wise to take stock of available opportunities and learn from past experiences where alliances of artists and advocates have achieved important and enduring changes. In the global health context, there is no better example of a successful partnership between art and political advocacy than the AIDS movement, which has been one of the most successful health movements of the 20th century. Activists employed various strategies to advocate for increased research and funding, lower drug prices, and social justice for people living with HIV—with art being a key strategy. This means that the focus of this special issue of *Imaginations* journal—scaling-up the life-saving potential of global vaccination—would benefit from examining the AIDS movement and understanding how such impactful strategic alliances among artists and advocates were nurtured.

Following the massive public paranoia surrounding what was initially labelled as “gay-related immune deficiency” (AVERT) in the early 1980s, a combination of sweeping scientific discoveries and political advocacy led to approval of the first antiretroviral treatment in 1987. This was followed by the enactment of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990, which increased accessibility of care for low-income, uninsured Americans living with HIV. The establishment of the Joint United Nations Programme on HIV/AIDS (UNAIDS) and various non-profit organizations such as the American Foundation for AIDS Research (amfAR) (focussed on research funding) and ACT UP (focussed on political ad-

vocacy) throughout the 1980s and 1990s accelerated the effort to end AIDS (AVERT). Although the AIDS epidemic continues to pose a debilitating public health threat in many parts of the world, for the first time the majority of people living with HIV are able to access treatment (UNAIDS, *World AIDS Day Report*), people living with HIV have a normal life expectancy (UNAIDS, *World AIDS Day Report*) (Samji et al.; Johnson et al.), and AIDS-related deaths have decreased by 30% since their peak in 2005 (UNAIDS, *Global Report*; AVERT).

The remarkable accomplishments of the AIDS campaign were in no small part supported through the help of art. For instance, in 1990 a photograph of David Kirby, a young man dying from AIDS, was published in *LIFE* magazine (Cosgrove). The haunting image, taken by journalism student Therese Frare, has been seen by more than one billion people around the world over the past three decades and has been described by *LIFE* as “the photo that changed the face of AIDS” (Cosgrove). The picture, taken at the request of Kirby’s family, was quickly reproduced in hundreds of magazines, newspapers, and TV stories worldwide. Another example is the use of art in the mobilization of the Ribbon Project by the Visual AIDS Artists’ Caucus in 1991 (Geoghegan). The red ribbons, which were deliberately not trademarked in order to allow widespread use, quickly became an internationally recognized symbol of solidarity and support for the AIDS crisis. The colour red was chosen for its connection to blood and love, and a ribbon so that it would be easy to recreate and wear (Visual AIDS, “Red Ribbon”). Both the photograph of David Kirby and the Ribbon Project helped to bring visual expression and public representation to the AIDS crisis at a time when awareness that many people were suffering in silence needed to be significantly enhanced for the sake of saving lives.

Although anecdotal examples such as these highlight the importance of art in AIDS advocacy, to date only two papers have looked closely at this relationship. In his 2008 essay on AIDS and artistic politics, Tyrus Miller describes various strategies used by British and American visual artists to advocate for the rights of people living with HIV, providing focussed criticism of mainstream media representations of the AIDS crisis and the use of AIDS exemplars. Similarly, in 2010

Niyi Awofeso and Anu Rammohan published an essay that uses global examples to illustrate the impact artists have had on HIV advocacy, fundraising, health education, combatting misconceptions regarding HIV, and protecting patients' rights through the use of visual arts, multimedia, poetry, and theatre. While both essays are fascinating examples of the power of art in fostering change, they mostly provide anecdotal examples of the role of art as opposed to a comprehensive review of the literature, both published and unpublished. A review such as this would help to create a more complete framework for how art can influence advocacy and lead to the evaluation of the effectiveness of different art modalities and strategies, while also shedding light on how activists from other public health movements can utilize art similarly to advocate for positive change.

Therefore, in this study we sought to undertake a scoping review and qualitative thematic analysis of social scientific literature on the role of art in political advocacy in the AIDS movement. Specifically, we hoped to expand the current understanding of the relationship between art and political advocacy by (1) undertaking a focussed attempt to explore a representative cross-section of the arts, including poetry, visual art, music, film, and theatre; (2) conducting a comprehensive literature search; (3) using examples from available time periods as well as different geographical regions; (4) examining peer-reviewed literature such as quality assessment studies, randomized controlled trials, cross-sectional surveys, and case studies, along with the grey literature; and (5) consolidating findings from the literature search to create a framework on how art can influence political advocacy. Readers from art, art history, and visual culture will note the absence of a body of work on art and AIDS from their disciplinary perspectives. A review of the significant body of literature in those fields exceeds the scope of this essay. Rather, our overall aim was to use the AIDS movement as a case study in order to gain a better understanding of how art can be used in global health advocacy.

METHODS

The wide scope of the literature on the topic of art and AIDS advocacy calls for numerous forms of evidence to be analyzed, from randomized controlled trials and quasi-experiments to case-control studies, ethnographic analyses, and cross-sectional studies. To encompass such a wide variety of article types, we decided to use a mixed-methods approach by performing a scoping review followed by a qualitative thematic analysis and an examination of three short case studies. We believed that combining these three methodologies would allow us to bring together a variety of study designs and create as comprehensive a framework of the literature as possible.

Scoping Review

A literature search was conducted in April 2016 using five electronic databases: Google Scholar, Web of Science, EbscoHost, Proquest, and Sage Pub. The generic search string used for each database is shown in Figure 1.

```
(“Human Immunodeficiency Virus” OR “Acquired Immune Deficiency Syndrome” OR “HIV” OR
“AIDS”)
AND
(“Visual art” OR “Photography” OR “Media art” OR “Performance art”
OR “Community art” OR “Theatre” OR “Theater” OR “Street art”
OR “Art exhibit” OR “Graffiti” OR “Photography” OR “Artistic”
OR “Artwork” OR “Poetry” OR “Poem” OR “Music” OR “Song” OR “Drama” OR “Dance”)
AND
(“Lobbying” OR “Lobby” OR “Advocacy” OR “Advocate” OR “Policy” OR “Change”
OR “Policy change” OR “Policymaking” OR “Activism” OR “Activist” OR “Educate”
OR “Education” OR “Awareness” OR “Stigma” or “Funds” OR “Fundraising” OR “Knowledge”)
```

Figure 1: Generic search string.

A chain sampling technique was used, whereby we searched the reference lists of relevant articles to identify further literature. Web of Science was also used to search for others that have cited the relevant articles, consistent with the pearl growing method, which is the process of growing additional sources from a few initial grains. To ensure that

this review included grey as well as peer-reviewed literature, we also searched Google for blog entries, civil society or government reports, and any other potentially relevant web pages.

Articles were included in the review if they discussed the role that particular forms of artwork or artists have played in advocating for the AIDS movement in a political context. As noted earlier, the definition of art used is any medium with a visual element, including photography, visual art, theatre, poetry, writing, spoken word, music, and dance. Political advocacy was conceptualized as any activity aimed at changing HIV/AIDS-related policy by influencing (1) elites, policy makers, or policy networks, (2) civil society, and/or (3) the general public. While we were open to articles in languages other than English, we did not come across any in our searches. No exclusion criteria were applied in terms of the year of publication or the country in which the artwork was created.

Qualitative Thematic Analysis

Following the literature search, a qualitative thematic analysis was conducted to identify recurring themes in the literature. Two investigators (AJ and JW) independently read through each study and extracted key themes about the role of art in HIV/AIDS political advocacy. In other words, after reading each study the investigators asked themselves, “How do the findings of the study relate to the relationship between art and policy making on HIV/AIDS?” This was followed by a reconciliation process, in which the investigators discussed any disagreements and decided on a final set of overarching themes.

Case Studies

In addition to the scoping review and qualitative thematic analysis, three artworks were separately identified as well-known examples that highlight the role of art in political advocacy throughout the AIDS movement. These examples were chosen to help discuss further the overarching themes of the literature in a more accessible, relatable manner.

The case studies were not identified through a literature search. Rather, during the design phase of the study, investigators brain-

stormed what famous visual artworks or artists came to mind when they thought of art in the context of AIDS. When a set of key artworks were identified, three were chosen based on their well-documented nature and their iconic status in the AIDS movement. A brief literature search was then conducted to explore the design and impact of each artwork.

RESULTS

Scoping Review

Thirty-four relevant articles were identified from the literature search. 25 (74%) of the articles were published in peer-reviewed journals, eight (24%) were grey literature, and one (3%) was a book. The most common article types were case studies (n=7) and analytical essays (n=4), followed by ethnographic analyses (n=3), pre-post studies (n=3), qualitative studies (n=3), reports (n=3), art exhibition reviews (n=2), dissertations (n=2), post-intervention surveys (n=2), randomized controlled trials (n=2), books (n=1), and newspaper articles (n=1). Case studies often involved analyzing the general impact of a particular artwork or artist, without formally assessing the artist or audience members. Similarly, analytical essays involved discussing the general role of art in HIV advocacy using evidence from the literature as well as examples of relevant artworks.

12 (35%) of the artworks were based in Africa and another 12 (35%) were in North America, followed by Europe (n=5), Asia (n=4), and international (n=2). The most common art modalities were theatre (n=21), visual art (n=11), photography (n=4), poetry (n=4), and music (n=4). Visual art was more likely to be used in Europe and North America, whereas theatre was more commonly found in Asian and African regions. The target audience of the 32 artworks was the public (91%), with five (32%) and one (3%) of the artworks targeted towards civil society or policy networks, respectively.

Case Studies

Case Study 1: Keith Haring

As one of the most influential artists of his time, Keith Haring's works helped to place the experiences of individuals living with HIV on the public's radar and provided powerful symbolism to the AIDS movement. The theme of HIV/AIDS began to appear midway through Haring's career, first due to the loss of his friends' lives to the illness and later to his own HIV diagnosis (Haring).

Following his diagnosis in 1988, Haring made it a personal goal to use his art to help provide funding and imagery to AIDS organizations (Keith Haring Foundation). This is illustrated in one work from 1988 (Figure 2), in which a large, horned sperm is shown as a personification of HIV. The sperm is hatching from an egg strapped to a man's body, highlighting the oppression and devastation experienced by individuals with the virus (Melcher). The contrast between the monstrous appearance of the sperm and the fragility of the man's body reminds us that HIV was far from being considered "treatable" at the time, often leaving patients with a sense of despair and hopelessness.

In addition to shedding light on the challenges faced by people living with HIV, Haring, through his artwork, also called out the public's indifference and disdain towards the AIDS movement. *Silence = Death* (Figure 3) shows a group of figures covering their ears, mouths, and eyes, highlighting the fact that most people were forced to suffer in absolute silence, rejected by their own communities (Melcher). A pink triangle is shown in the background, an emblem that had once been a symbol used to signify homosexual individuals during the Holocaust. Haring's use of the pink triangle in his works helped gay and HIV/AIDS rights activists re-appropriate the symbol as a pro-gay, HIV rights icon throughout the 1980s (Melcher).



Figures 2 and 3: Keith Haring, *Untitled*, sumi ink on paper, 76 x 57 cm, 1988 (left); Keith Haring, *Silence = Death*, silkscreen on paper, 99 x 99 cm, 1989 (right). © Keith Haring Foundation

Case Study 2: *Keiskamma Altarpiece*

One of the most influential and powerful pieces of AIDS-related artistic advocacy is the intricate beading that makes up the *Keiskamma Altarpiece* (Figure 4). This piece of art, measuring approximately 4 by 6.5 metres (14 by 22 feet), was created in 2006 over the course of six months in Hamburg, South Africa, by 130 women whose small coastal town was nearly decimated by the AIDS epidemic (“*Keiskamma Altarpiece*”). Established as part of the Keiskamma Trust under the direction of Dr. Carol Baker, a local physician and artist, the underlying aim of the project was to provide the community members with a visual representation of their experiences and communal resilience at the height of the AIDS epidemic (Ress).

While a significant historical precursor, the *Isenheim Altarpiece*—a 16th-century artwork from Alsace, France, that inspired the *Keiskamma Altarpiece*—depicted the horrors of ergotism, its 21st-century successor focuses instead on the devastation of the AIDS epidemic (Chalmers). The piece is divided into three sections, with the outermost layer representing the death, pain, and void left by the epidem-

ic in South African communities, represented through images of orphans, broken families, funerals, and empty streets. This panel operates in sharp contrast with the middle layer, which uses extremely vivid, colourful images to portray hope, life, and the beauty of South African culture. Finally, the outermost images show black-and-white images of three grandmothers whose grandchildren have been affected by or lost to AIDS-related illnesses (Chalmers). These brave women are described as “the saints of today and the guardians of the future, struggling to raise their own grandchildren and those of others” (Chalmers 1338).

In addition to providing communities with the means of earning money and coping with their loss, the creation of the *Keiskamma Altarpiece* has helped to raise funds and support for the local AIDS movement as a whole (Schmahmann). For instance, the unveiling of the piece was used as an opportunity to raise funds for projects such as the Keiskamma Trust and the Keiskamma AIDS Treatment Project, which are aimed at serving the medical and educational needs of local communities while also fostering creative and artistic endeavours by community members (“Keiskamma Altarpiece”). In addition, since its unveiling, the altarpiece has been travelling worldwide and has helped to raise international awareness of the poverty and void left by AIDS in South Africa (Schmahmann). Due to its far-reaching impact on bringing local as well as international attention and support to the AIDS epidemic, the *Keiskamma Altarpiece* has been described as a “contemporary icon of how the human spirit can rise above adversity and create art of enduring strength and beauty” (Jeng).



Figure 4: Artists of Keiskamma Art Project, *The Keiskamma Altarpiece* (open),
Humburg, Eastern Cape, South Africa, 2005. Mixed media, 4.15 × 6.8 m © Keiskamma
Art Project. Image courtesy of The Keiskamma Trust.

Case Study 3: The Ribbon Project

While there are now dozens of celebrity-endorsed activist projects, the Ribbon Project is one of the most powerful examples of how celebrities can bolster political movements and promote change. Inspired by the yellow ribbons used to support the US army in the Gulf War and to protest the Iranian hostage crisis in 1979–80 (Houghton), the now-iconic twisted red ribbon was developed by Visual AIDS artists in 1991 as a way to simply yet meaningfully “show support and compassion for AIDS victims and their caregivers” (Visual AIDS, “About Us”).

The rise and success of the project were intimately connected to celebrity culture from the very beginning. In fact, the red ribbon first caught the media’s attention when actor Jeremy Irons was seen wearing it at the 1991 Tony Awards (Geoghegan). Soon, the Visual AIDS volunteers were being approached by Hollywood reporters, and demand skyrocketed to a point where supply of the ribbons had to be outsourced to external organizations. Beloved celebrities, including Eliz-

abeth Taylor, Bette Midler, and Richard Gere, began to proudly wear and openly discuss the ribbons in public, creating what was called the “ribbon-sporting culture” among actors (Geoghegan).

The support from Hollywood helped to bring the project into everyday American life, with schools and churches holding their own ribbon-making collectives (Geoghegan). In effect, the red ribbons had altered the public’s perception of the illness, from a mysterious, unknown phenomenon taking place in the shadows to a tangible, real issue that deserved to be discussed and addressed publicly. In previous years, the White House of the United States has displayed a beautiful 28-foot red ribbon at the North Portico on World AIDS Day—symbolizing the government’s commitment both to end the AIDS epidemic and to support the people, families, and communities affected by HIV/AIDS (Phillips).

In addition to bringing the AIDS epidemic from the shadows into the mainstream media, ribbon-making initiatives also became a meaningful way of raising funds and support for the cause in developing countries; numerous collectives around the world began to create, sell, and wear the ribbons, with all proceeds going towards supporting people affected by the epidemic (Grünkemeier).

Many have pointed out that the red ribbon is only a symbol and not a real solution, questioning the extent of the project’s impact in the HIV/AIDS rights movement. However, one cannot deny the fact that the red ribbon helped to bring a sense of solidarity and unity to a highly stigmatized, misunderstood epidemic. Sir Nick Partridge, a prominent AIDS activist, described the meaning of the ribbons for people living with HIV/AIDS and their families: “A number of people living with HIV really appreciate seeing other people wearing the red ribbon. They realise they’re not alone and recognise that the majority of people wearing them probably don’t have HIV themselves, and that sense of support and solidarity is very, very important” (Geoghegan).

DISCUSSION

Through the results of the scoping review, we identified three key themes regarding the role of art in AIDS political advocacy: addressing negative stereotypes, education, and voice for individuals affected by HIV/AIDS.

Theme 1: Addressing Negative Stereotypes

One cannot ignore the highly political nature of HIV/AIDS that distinguishes it from other public health epidemics such as diabetes and malaria. One of the reasons behind its political nature is that at the beginning of the AIDS epidemic, the disease was touted as a “plague” that could only affect the gay community (Noland et al.). This misconception, combined with persistent discrimination against the LGBTQ community, led the public to respond to the epidemic with disdain and indifference.

Art was one of the ways in which activists tried to combat this misunderstanding. For instance, Laurien Ward studied the effects of a play designed to show how AIDS can spread to individuals outside traditional risk groups. Audience reports from professional, community, and business organizations showed an increased understanding of modes of HIV/AIDS transmission and greater sympathy for those with the illness (Ward). Similarly, Mary Stuart Petty used interviews, observations, and analysis of media archives to examine how Philadelphia communities used visual art in combating mainstream depictions of HIV/AIDS. Community members described using art to depict patients with AIDS that do not necessarily fit the stereotypes surrounding the diseases—to illustrate that AIDS can affect anyone, not simply the gay community or the sexually promiscuous (Petty). This gradual perception shift—from viewing AIDS as primarily a disease of the gay community to one that can affect the general public—eventually led to more calls for action from the public rather than just LGBTQ rights advocates (Middelkoop et al.).

Another factor that contributed to the political nature of the AIDS epidemic were the social taboos against discussions of sex and safe sex practices. Therefore, advocates tried to encourage more candid dis-

cussions around safe sex through art (Petty). For instance, in India, Thukral and Tagra's *PUT IT ON!* and *PUT IT ON AGAIN!!* interactive art exhibits have used colourful, attention-demanding graphics to tackle the social insecurities and stigma surrounding sex education (Thukral and Tagra).

Lastly, perhaps more so than individuals with other debilitating illnesses, patients with HIV/AIDS have long been perceived as abject, helpless victims, leading to further alienation and discrimination (Campbell). Based on analyses of photographs of those with HIV/AIDS since the 1980s, David Campbell reported that more recent activities have been using photography to convey more balanced portrayals of individuals living, not dying, with HIV/AIDS—thus helping to destigmatize the illness in popular culture (Campbell). Similarly, a report on United Nations Development Programme's artistic campaigns in China found that projects that tended to be the most well-received were the ones that led viewers to accept patients as capable of leading normal, happy lives as friends and family, not simply as victims deserving sympathy (Xiaopeng and Settle).

Theme 2: Education Regarding HIV Prevention, Testing, and Treatment

Various art modalities have been implemented to disseminate health information in an accessible, easy-to-understand manner. For instance, in 2002 a collaboration between the Tanzania Theatre Centre and Bagamayo College of Arts used a participatory theatre method to allow local officials, leaders, artists, youths, and community members to identify key factors contributing to HIV transmission and brainstorm potential prevention strategies (Mabala and Allen). Performance-based educational methods have been shown to increase participants' knowledge about HIV prevention among 13- to 16-year-old youth in London, UK (Campbell et al.). Similarly, the use of drama production has led to increased attendance of AIDS counselling programs by persons living with HIV, their partners, and their families in the United States (Ward). On the other hand, a randomized controlled study by Elliott et al. found that compared to a standard health education seminar, theatre production did not have a significant impact on HIV

knowledge, attitudes, and risk behaviour among youth in Glasgow, Scotland.

While there are conflicting findings on the effectiveness of art modalities in HIV education, the aforementioned studies demonstrate how artists and scientists can work together in public health advocacy. The variety in education methods as a result of scientist and artist collaboration is particularly powerful in communities where literacy and numeracy skills may be limited, and where individuals may not identify with the understanding and coping mechanisms of the HIV/AIDS epidemic that exist in other cultures. For instance, eMPathy Trust is an organization based in South Africa led by writers and leading researchers aimed at advancing public understanding of the illness (Rabinowitz). Following a needs assessment, eMPathy Trust produced a children's book titled *Staying Alive Fighting HIV/AIDS* (Rabinowitz). The book uses powerful imagery and simple language to convey biological facts about HIV/AIDS transmission and management, to counter the myths surrounding HIV/AIDS (Rabinowitz). By using words, symbols, and stories derived from the local communities, the book illustrates how art can present scientific information in a more approachable, culturally appropriate manner to the public (Rabinowitz).

Theme 3: Voice for Individuals and Communities Affected by HIV

Art has also been a powerful tool to shed light on the grave realities of those affected by HIV/AIDS, thus helping to highlight unmet needs, low access to treatment, and potential areas for policy intervention. For instance, one study found that by asking youths with HIV/AIDS to compile and share poems and stories about their own experiences, local activists were better able to identify areas of needs that had previously gone unnoticed in public health efforts—such as support groups and family education (Mitchell). Similarly, Roland Bleiker and Amy Kay found that providing patients with cameras to document their own experiences with the illness was an effective way of exploring difficult-to-access services and barriers to treatment.

Beyond simply identifying issues, art can also empower patients and communities to intervene on those issues directly. In a case study,

Kennedy C. Chinyowa describes how integrated popular theatre has been used in Africa to inform public policy debate. Following local performances about the community's experiences with HIV/AIDS, participants got the opportunity to discuss their experiences with advocacy organizations, local policy makers, and grassroots activists. This was followed by a tour of nearby villages and wards in the district, allowing for the sharing of diverse experiences across communities (Chinyowa, "Helping Them"). Similarly, based on a 21-month ethnographic analysis, Susan Pietrzyk reported that civil societies often use art such as dance, music, poetry, and theatre to inform policy makers of emerging areas of need.

Furthermore, by giving voice to those with HIV/AIDS, art modalities can allow patients to better advocate for themselves in a medical setting. In their pre- and post-intervention study, Johanna Shapiro and Lynn Hunt found that theatrical performances about AIDS were an effective way to increase medical students', residents', physicians', and faculty's empathy for patients and insight into patient care—showing that art could be integrated into medical education. Furthermore, at an HIV/AIDS outpatient clinic in the United States, murals by staff, patients, and their families were used to foster a stronger sense of community and build support systems (Kaimal and Gerber). Participants were able to relate to one another over shared challenges; physicians could gain insight into aspects of their patients' experiences that they may not be able to discuss during their short clinic visits, while patients and families were pleasantly surprised to see that their physicians were often facing struggles and dilemmas similar to their own (Kaimal and Gerber).

An important step for any individual or community affected by an epidemic of any proportion is the grieving process. To allow grieving to take place is to allow individual or communal expression through any means that may resonate or provide closure; and communities across the world use theatre, poetry, photography, embroidery, and other art modalities to allow those affected the opportunity to voice their lived experiences (Black; Hanna; Petty). In Addis Ababa, Tanzania, asking local residents of a heavily HIV-affected village to show their experiences through photography generated multiple representations of HIV

and allowed viewers to “recognize that the process of representation is inherently incomplete, and thus inevitably political” (Bleiker and Kay, 141). As such, personal experiences of people living with or affected by the epidemic can provide a reality displaced from popular opinion, potentially affecting a shift in demand on political attention.

Geography and Art Modalities

While these three themes exemplify the main messages delivered through the methods of political advocacy that we discovered, we must also look at the ways in which geographical location affects the scope of messages. For instance, many of the studies found in the scoping review noted that African advocacy efforts centred around local experiences as opposed to national or international (Mabala and Allen; Black; Chinyowa, “Emerging Paradigms”). Further, the *Keiskamma Altarpiece* is an excellent example of political advocacy imbued with local perspectives that affected the international community through its power and emotion. This altarpiece travelled around Canada and the United States, winning awards and praise for its depiction of local struggles with the AIDS epidemic of South Africa (Schmahmann).

In contrast, the United States began advocacy efforts of an international scope through the development of the Ribbon Project. Through this project, the focus of advocacy efforts shifted from a local perspective to the much larger international influence due to ease of mobilization (Moore). As well, the 2005 American musical *Rent* examined local New York City perspectives on life with HIV for both people affected directly and indirectly, perspectives that could then be applied to both the national and international spheres of experience through a shared understanding of the impact of HIV/AIDS on the lives of people affected (Schrader).

Another way to examine the political advocacy efforts of artists around the world would be through the focussed utilizations of the various art modalities employed. American artists David Wojnarowicz and Keith Haring as well as activist group Gran Fury presented their opinions and voices through the medium of art that could be displayed either on the street or in museums. In Tanzania, it was noted that due

to high levels of illiteracy, verbal art through the forms of song, poetry, and theatre are favoured to convey advocacy and health communication efforts (Askew). In Thailand, theatre was a successful mode of AIDS advocacy and education delivery (Cahill), and in India, art exhibits and radio shows were predominant (Nambiar et al.). These examples demonstrate that artists' work is based on different cultural and political objectives.

The Impact of the AIDS Movement on Global Health Funding

Lastly, it is important to discuss the significant impact the HIV/AIDS movement has had on the way in which global health epidemics are funded. In fact, all of the three aforementioned themes—addressing stigma, education, and voice for patients—helped to shed light on the gravity of the epidemic and thus promote more funding and support for affected individuals.

To date, there have been 35 million deaths worldwide from HIV, and at the end of 2016 there were 36.7 million people living with HIV (Joint United Nations Programme on HIV/AIDS, “Global HIV & AIDS Statistics—2018 Fact Sheet”). By combatting the perception of HIV/AIDS as an illness affecting only select marginalized populations, artists and advocates helped to raise awareness of the widespread nature of this epidemic and thus bolster more public mobilization (Campbell). This has led to the backing of new, high-profile global health funders such as the Bill and Melinda Gates Foundation. As a result, annual spending on AIDS research and treatment has reached into the billions of dollars. Increased funding has also fostered the development of dedicated organizations for the fight against HIV/AIDS, including the Global Fund to Fight AIDS, Tuberculosis, and Malaria and Gavi, the Vaccine Alliance, and paving the way for the development of mass immunization and treatment frameworks of other global health epidemics (Cohen).

The second way in which creative arts have affected HIV/AIDS funding is through the partnership between artists and researchers. In addition to helping to convey research findings to the general public, art modalities have also been a powerful tool to raise funds for research efforts. For instance, Visual AIDS is an organization that utilizes visu-

al arts to support HIV-positive artists, as well as raise funds for HIV/AIDS treatment and research (Visual AIDS, “About Us”). At the same time, physicians and researchers have also helped to add legitimacy to arts-based AIDS advocacy movements. Activist groups—particularly ACT UP—were able to influence AIDS research far more effectively due to arguments strengthened by physician involvement than had they relied on less technical and more argumentative discourse from the general public (Fabj and Sobnosky). With the rising number of medical professionals and scientists joining AIDS activist groups, the messages the groups conveyed were more concise and medically factual, solidifying the grounds of the demands made by the organizations, which in turn spurred much-needed funding to advance research efforts (Epstein).

Third, the efforts of AIDS activists and artists highlighted both the delay in drug development and the “vast inequities between rich countries and those too poor to afford powerful anti-HIV drug cocktails” (Cohen, 163). Art has particularly been a powerful way of raising funds in poor communities that may have limited access to other means of mobilizing public interest and support. For instance, as mentioned previously, the *Keiskamma Altarpiece* has allowed local communities to raise funds for local medical and educational HIV/AIDS-related projects (Visual AIDS, “About Us”).

Strengths and Limitations

In providing case studies as well as discussion on the three main emergent themes from our research, this analysis has not only presented a broad base of evidence but also specific cases where the AIDS movement has used art in its political advocacy. As can be seen from the research, a strength of the scoping review is the breadth of results discovered from the initial searches. However, as previously mentioned, an obvious limitation is the lack of research that emerged in languages other than English. In addition to references from other disciplines such as art history and visual culture, it is entirely possible that there is a large body of social scientific research that did not appear in our searches, as our terms were presented in English, despite the fact that we were open to including publications in other languages. Another

limitation is the number of terms used to describe visual art in the search strategy; there are many other terms that could have been included, such as “graphic design.” However, we chose a specific subset that we thought would be captured in most research studies.

Future Research Directions

While a large amount of research was identified on the use of participatory theatre, grassroots local activism, and individuals who contributed to AIDS political advocacy, there was a noticeable gap in the research: the lack of research on the quantifiable *impact* of specific artistic interventions, modalities, and efforts, such as those organized by organizations such as UNAIDS, ACT UP, and Gran Fury. In this essay, we have emphasized the centrality of art to the AIDS movement as a whole, and the prolific use of art, signage, community protests, and lobbying; however, we have also found that there is a lack of social scientific research assessing the impact of art as political intervention—including how it affected the AIDS movement as a whole.

Finally, no research was found that quantitatively documents the shift in public perception of AIDS from its explosive beginning to the eventual development of antiretroviral therapy and government-subsidized treatment access programs. While this might be a rather daunting task, it would be useful to the field of AIDS research, as it would show the transition of the disease to a global epidemic, and how the response grew on multiple continents. Further, an in-depth look into the way artistic expression may have influenced the speed of development of antiretroviral therapy drugs over the years and the politics surrounding local and international access and distributions would be a helpful endeavour. In future iterations of this research we would hope to address this gap as well as examine what research into the role(s) of art in the AIDS movement might offer analysis of other global health phenomena.

WORKS CITED

- Askew, Kelly M. "'Eat Squid Not Fish': Poetics, Aesthetics, and HIV/AIDS in Tanzania." *Journal of African Cultural Studies*, vol. 27, no. 3, Sept. 2015, pp. 255–76, doi:10.1080/13696815.2015.1042432.
- AVERT. *History of HIV and AIDS*. 13 July 2015, www.avert.org/professionals/history-hiv-aids.
- Awofeso, Niyi, and Anu Rammohan. "Kindred Paradigms: Community Arts and Health Advocacy in HIV/AIDS Activism." *Hektoen International: A Journal of Medical Humanities*, vol. 2, 2010, pp. 26–31. *Google Scholar*, www.hektoeninternational.org/index.php?option=com_content&view=article&id=562.
- Black, Steven P. "The Morality of Performance: HIV Disclosure in Speech and Song in South Africa." *Ethos*, vol. 43, no. 3, Sept. 2015, pp. 247–66. *Web of Science*, doi:10.1111/etho.12090.
- Bleiker, Roland, and Amy Kay. "Representing HIV/AIDS in Africa: Pluralist Photography and Local Empowerment." *International Studies Quarterly*, vol. 51, no. 1, Mar. 2007, pp. 139–63. *Web of Science*, doi:10.1111/j.1468-2478.2007.00443.x.
- Cahill, Helen. "Withholding the Personal Story: Using Theory to Orient Practice in Applied Theatre about HIV and Human Rights." *Research in Drama Education: The Journal of Applied Theatre and Performance*, vol. 19, no. 1, Jan. 2014, pp. 23–38. *Web of Science*, doi:10.1080/13569783.2013.872427.
- Campbell, David. *The Visual Economy of HIV/AIDS*. May 2008, www.david-campbell.org/visual-hivaids/.
- Campbell, Tomás, et al. "An Evaluation of Performance-Arts Based HIV-Prevention Events in London with 13–16 Year Olds." *Perspectives in Public Health*, vol. 129, no. 5, 2009, pp. 216–220. *Google Scholar*, <http://rsh.sagepub.com.libaccess.lib.mcmaster.ca/content/129/5/216.short>.
- Chalmers, Jan. "Tapestry of Life." *The Lancet*, vol. 375, no. 9723, Apr. 2010, p. 1338. *CrossRef*, doi:10.1016/S0140-6736(10)60563-6.
- Chinyowa, Kennedy C. "Emerging Paradigms for Applied Drama and Theatre Practice in African Contexts." *Ride-the Journal of Applied Theatre and*

- Performance*, vol. 14, no. 3, 2009, pp. 329–46. *Web of Science*, doi:10.1080/13569780903072117.
- . “Helping Them to Help Themselves: Case Study of an Integrated Popular Theatre Approach in Africa.” *Research in Drama Education: The Journal of Applied Theatre and Performance*, vol. 12, no. 2, June 2007, pp. 133–47. *CrossRef*, doi:10.1080/13569780701320957.
- Cohen, Jon. “The New World of Global Health.” *Science*, vol. 311, no. 5758, Jan. 2006, pp. 162–67. www.sciencemag.org, doi:10.1126/science.311.5758.162.
- Cosgrove, Ben. “The Photo That Changed the Face of AIDS.” *Time*, Nov. 2014. [time.com](http://time.com/3503000/behind-the-picture-the-photo-that-changed-the-face-of-aids/), <http://time.com/3503000/behind-the-picture-the-photo-that-changed-the-face-of-aids/>.
- Elliott, Julian H., et al. “Living Systematic Reviews: An Emerging Opportunity to Narrow the Evidence-Practice Gap.” *PLoS Medicine*, vol. 11, no. 2, 2014, p. e1001603. *Google Scholar*, <http://dx.plos.org/10.1371/journal.pmed.1001603>.
- Epstein, Steven. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. University of California Press, 1996.
- Fabj, Valeria, and Matthew J. Sobnosky. “AIDS Activism and the Rejuvenation of the Public Sphere.” *Argumentation and Advocacy*, vol. 31, no. 4, Mar. 1995, pp. 163–84. *Taylor and Francis+NEJM*, doi:10.1080/00028533.1995.11951609.
- Geoghegan, Tom. “How a Red Ribbon Conquered the World.” *BBC News*, 2 June 2011, www.bbc.com/news/world-us-canada-13597312.
- Grünkemeier, Ellen. *Breaking the Silence: South African Representations of HIV/AIDS*. Boydell & Brewer Ltd, 2013.
- Hanna, Judith Lynne. “The Power of Dance: Health and Healing.” *The Journal of Alternative and Complementary Medicine*, vol. 1, no. 4, 1995, pp. 323–31. *Google Scholar*, <http://online.liebertpub.com/doi/abs/10.1089/acm.1995.1.323>.
- Haring, Keith. *Keith Haring Journals*. Penguin Classics Deluxe Edition. Penguin, 2010.
- Houghton, David Patrick. *US Foreign Policy and the Iran Hostage Crisis*. Cambridge University Press, 2001.

- Jeng, Eileen. "South African AIDS Art." *F Newsmagazine*, Oct. 2006, <http://fnewsmagazine.com/2006-oct/south-african-aids-art.php>.
- Johnson, Leigh F., et al. "Life Expectancies of South African Adults Starting Antiretroviral Treatment: Collaborative Analysis of Cohort Studies." *PLOS Medicine*, vol. 10, no. 4, Apr. 2013, p. e1001418. *PLoS Journals*, doi:10.1371/journal.pmed.1001418.
- Joint United Nations Programme on HIV/AIDS. "Global HIV & AIDS Statistics—2018 Fact Sheet." *Joint United Nations Programme on HIV/AIDS*, www.unaids.org/en/resources/fact-sheet. Accessed 3 June 2019.
- Kaimal, Girija, and Nancy Gerber. "Impressions over Time: Community Progressive Murals in an Outpatient HIV/AIDS Clinic." *Arts in Psychotherapy*, vol. 34, no. 2, 2007, pp. 151–62. *Web of Science*, doi:10.1016/j.aip.2007.01.002.
- "Keiskamma Altarpiece: Cape of Hope." *Telegraph*, 10 Oct. 2008. www.telegraph.co.uk, www.telegraph.co.uk/culture/4730703/Keiskamma-Altarpiece-cape-of-hope.html.
- Keith Haring Foundation. "Keith Haring Bio." *Keith Haring Foundation*, www.haring.com/!/about-haring/bio#. Accessed 19 July 2016.
- Mabala, R., and K.B. Allen. "Participatory Action Research on HIV/AIDS through a Popular Theatre Approach in Tanzania." *Evaluation and Program Planning*, vol. 25, no. 4, Nov. 2002, pp. 333–39.
- Melcher, Ralph. "Heaven and Hell." *Keith Haring Foundation*, www.haring.com/!/selected_writing/heaven-and-hell#.XO_oky0VTq0. Accessed 19 July 2017.
- Middelkoop, Keren, et al. "Design and Evaluation of a Drama-Based Intervention to Promote Voluntary Counseling and HIV Testing in a South African Community." *Sexually Transmitted Diseases*, vol. 33, no. 8, Aug. 2006, pp. 524–26. *Web of Science*, doi:10.1097/01.olq.0000219295.50291.1d.
- Miller, Tyrus. "AIDS and Artistic Politics." *Filozofski Vestnik*, vol. 29, no. 1, 2008, p. 131-144.
- Mitchell, Claudia. "In My Life: Youth Stories and Poems on HIV/AIDS: Towards a New Literacy in the Age of AIDS." *Changing English*, vol. 13, no. 3, Dec. 2006, pp. 355–68. *CrossRef*, doi:10.1080/13586840600971919.

- Moore, Sarah E. H. *Ribbon Culture: Charity, Compassion and Public Awareness*. Springer, 2008.
- Nambiar, Devaki, et al. "Knowledge, Stigma, and Behavioral Outcomes Among Antiretroviral Therapy Patients Exposed to Nalamdana's Radio and Theater Program in Tamil Nadu, India." *AIDS Education and Prevention*, vol. 23, no. 4, Aug. 2011, pp. 351–66.
- Nance, Kevin. "The Spirit and the Strength: A Profile of Toni Morrison." *Poets & Writers*, Nov. 2008.
- Noland, Carey M., et al. "An Exploration of the Impact of Celebrity on the HIV/AIDS Pandemic." *Journal of Health & Mass Communication*, vol. 1, no. 3/4, 2009, pp. 194–210. *Google Scholar*, <http://dro.deakin.edu.au/view/DU:30050337>.
- Petty, Mary Stuart. "Divine Interventions: Art in the AIDS Epidemic." *ProQuest*, Jan. 2000, pp. 1–144, <https://repository.upenn.edu/dissertations/AAI9989637>.
- Phillips, Kate. "White House Marks World AIDS Day." *The Caucus*, 30 Nov. 2009, <https://thecaucus.blogs.nytimes.com/2009/11/30/white-house-marks-world-aids-day/>.
- Pietrzyk, Susan. "Artistic Activities and Cultural Activism as Responses to HIV/AIDS in Harare, Zimbabwe." *AJAR: African Journal of AIDS Research*, vol. 8, no. 4, Dec. 2009, pp. 481–90. *Web of Science*, doi:10.2989/AJAR.2009.8.4.12.1049.
- Rabinowitz, Lindsey. "Addressing HIV/AIDS in South African Classrooms." *PLOS Biology*, vol. 10, no. 9, Sept. 2012, p. e1001390. *PLoS Journals*, doi:10.1371/journal.pbio.1001390.
- Ress, Hanni Eran. *Changing the Lens of Stigma: An Exploration of Disclosure in Self-Portraits by South Africans Living with HIV in the Through Positive Eyes Arts Initiative*. University of Cape Town, 2012. *Google Scholar*, <https://open.uct.ac.za/handle/11427/3574>.
- Samji, Hasina, et al. "Closing the Gap: Increases in Life Expectancy among Treated HIV-Positive Individuals in the United States and Canada." *PLOS ONE*, vol. 8, no. 12, Dec. 2013, p. e81355. *PLoS Journals*, doi:10.1371/journal.pone.0081355.

- Schmahmann, Brenda. "A Framework for Recuperation." *African Arts*, vol. 43, no. 3, 2010, pp. 34–51. *ProQuest*, <https://search.proquest.com/docview/747773051/abstract/AB072D2F0BDC44DEPQ/1>.
- Schrader, Valerie Lynn. "'No Day But Today:' Life Perspectives of HIV-Positive Individuals in the Musical *Rent*." Vol. 36, 2009, pp. 23–36.
- Shapiro, J., and L. Hunt. "All the World's a Stage: The Use of Theatrical Performance in Medical Education." *Medical Education*, vol. 37, no. 10, Oct. 2003, pp. 922–27. *Web of Science*, doi:10.1046/j.1365-2923.2003.01634.x.
- Thukral, and Tagra. *Thukral and Tagra's Work*. www.thukralandtagra.com/new/work/. Accessed 30 May 2019.
- UNAIDS. *Global Report*. Joint United Nations Programme on HIV/AIDS, 2013.
- . *World AIDS Day Report*. Joint United Nations Programme on HIV/AIDS, 2012.
- Visual AIDS. "About Us." *Visual AIDS*, <https://visualaids.org/about-us>. Accessed 30 May 2017.
- . "The Red Ribbon Project." *Visual AIDS*, <https://visualaids.org/projects/the-red-ribbon-project>. Accessed 30 May 2019.
- Ward, Laurien. "Drama: An Effective Way to Educate about AIDS." *Social Casework*, vol. 69, no. 6, June 1988, pp. 393–96. *SAGE Journals*, doi:10.1177/104438948806900612.
- Xiaopeng, Jiang, and Edmund Settle. *Arts and Media AIDS Advocacy Initiative: Addressing Stigma and Discrimination in China through Public Private Partnerships*. UNDP China, Dec. 2010.

IMAGE NOTES

Figure 1: Generic search string.

Figure 2: Keith Haring, *Untitled*, sumi ink on paper, 76 x 57 cm, 1988. © Keith Haring Foundation

Figure 3: Keith Haring, *Silence = Death*, silkscreen on paper, 99 x 99 cm, 1989. © Keith Haring Foundation

Figure 4: Artists of Keiskamma Art Project, *The Keiskamma Altarpiece* (open), Humburg, Eastern Cape, South Africa, 2005. Mixed media, 4.15 × 6.8 m © Keiskamma Art Project. Image courtesy of The Keiskamma Trust.