Title:

Photographing AIDS. On Capturing a Disease in Pictures of People with AIDS.¹

Abstract:
The photography of people with AIDS has been subject to numerous critiques in the 1980s and has become a controversial way of visualizing the AIDS epidemic. While most of the scholarly work on AIDS photography is based in cultural studies and concerned with popular representations, the clinical value of photographs of PWA usually remains overlooked. This article addresses photographs as a ‘way of seeing’ AIDS that contributed crucially to the making of the disease entity AIDS within the history of medicine. Cultural studies methods will be applied to analyze clinical photography in the case of AIDS, thus contributing to the medical history of AIDS through the lens of photography. The article will reveal the conflation of disease morphology and patient identity as a characteristic feature of both clinical photography and a now historical nature of AIDS.

Keywords:
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In 1986 the *Journal of Audiovisual Media in Medicine* published an article by the clinical photographer A.R. Williams concerned with the risk that photographing people with AIDS (hereafter: PWA) poses to the photographer. He argued that although AIDS was still an inaccurately defined disease photographing PWA did not actually pose any threat to the photographer. On the contrary, he continued, because of the syndrome’s significant prevalence in young homosexual men, even the clinical photographer had to be careful with stigmatization, stereotyping and especially the weakened immune system of the patient in front of the camera: “The primary risk when photographing AIDS patients in the studio is not to the photographer but to the patient because of their heavily immunosuppressed status.”

The same year Williams published his article, HIV was officially acknowledged as the causal agent of the AIDS epidemic, the ‘acquired immunodeficiency syndrome,’ first recognized in 1981 and initially bound to some “aspects of a homosexual lifestyle.” Only a year later became AZT the first available treatment drug which had a very low efficacy and many severe side effects. The emerging epidemic challenged medical expertise as much as it confronted homosexual communities with the triple burden of high disease prevalence, reemerging stereotypes and false accusations. The 1980s were marked by exhausting and historically unequaled conflicts in which medicine, politics and a growing community of AIDS activists struggled to contain the deadly epidemic as well as its many meanings and stereotyped images, merging the disease with those most vulnerable to it. The medical photographer’s apprehension of the life-threatening aspects of photographing PWA was therefore deeply influenced by his concern about contributing to the existing “mass media panic,” in which PWA had been portrayed as isolated persons, marked by signs of the disease and lost to their unpreventable death. Williams’s rather technical arguments about hygienic precautions reflected the prevailing uncertainty of
medical professionals in dealing with the new disease and its patients. His argument also reveals the complex conditions of making photographic representations of AIDS. The problem Williams was confronted with when photographing PWA is a very common one in the history of medicine and was arguably never as pressing as it was in the case of AIDS: namely, whether and to what extent a disease can ever be captured in a photographic representation of the patient's body. Although visual representations of patients' bodies have been crucial throughout medical history to establish knowledge about various infectious diseases such as plague, smallpox and syphilis, it is striking that medical historians have mostly ignored these bodily framings in their histories of AIDS. This article will therefore engage with photographs similar to those made by Williams and his colleagues to understand how clinical photography contributed to the making of AIDS as an object of medical knowledge. The perspective of the following argument will rely both on the analysis of single photographs as well as on the conditions under which they acquire a clinical value. Hereby implied is a methodological approach based on iconology and iconography but adjusted to the specific circumstances provided by medical or scientific photographs. The “social biographies” of the photographic objects of the following exemplary case study will be specifically addressed in a series of AIDS atlases produced for a medical audience. The atlases have been published throughout the development of the epidemic and relied heavily on photography in its first decade. Furthermore, the photographs won’t be adequately understood in their historical significance, without comparing them to what some scholars call a visual culture of AIDS, usually to be identified in art, media coverage, public health campaigns and activism’s icons. Relating the analysis of clinical photographs to this particular context, the following argument will deliver a unique historical perspective on AIDS that needs to be attributed to the interdisciplinary potential of visual history.
Focusing on AIDS rather than HIV or the nowadays popular form of combining agent and disease in the acronym of HIV/AIDS, narrows the scope of the following argument down to a limited time and place. Predominantly formed in the USA, the clinical entity of AIDS was crafted to frame the unusual appearance of opportunistic infections on the bodies of otherwise healthy young men, which were often identified to be homosexual and later extended to drug users, hemophiliacs and Haitians (the infamous ‘4 H’).9 Clinical Photographs of people with AIDS have been predominantly taken in the first decade of AIDS; their following discussion is therefore embedded in a period, which is characterized by failing crisis management, dealing with and fighting off a variety of unusual opportunistic diseases and a prevailing sense of irritation and confusion. Photography, as will be shown below, serves in and outside the clinic as a visualization of the unusualness and uncertainty that was caused by the emergence of the a epidemic. The analysis of photography's unique faculty to demonstrate the many open questions on the nature of AIDS while delivering a visual representation of the disease in its bodily appearance remains often ignored. Discussion on photographs of PWA is instead often reduced to the identification and rejection of a vaguely defined clinical gaze that supposedly contaminated - or medicalized – the representation of AIDS.

The history of AIDS is accordingly expected to be found in three different and often competing historical narratives. Its scientific history is often told by scientists presenting an unfolding success story of modern biomedicine's ability to overcome the many obstacles of a newly emerged disease. The starting point of these triumphalist narratives is the identification of HIV and culminates in the introduction of antiretroviral therapies and the ongoing research efforts to develop a vaccine and cure.10 This narrative has been challenged from at least two perspectives. On the one hand, the social history of AIDS activism has pointed in numerous ways to the impurity of scientific
knowledge and established a new way of accessing medical history in which the achievements of patient-collectives, AIDS-service-organizations (ASO) and activist groups like ACT UP overcame national boundaries, substantially changed the trajectory of the epidemic, transformed the way clinical studies were designed and global health was conceptualized, to reveal how patients “served as collaborators and colleagues rather than constituents and subjects.”

Visual representations of AIDS have been predominantly addressed in cultural studies and art history. As indicated above, clinical representations were often mentioned but never thoroughly analyzed as such. AIDS art has been analyzed in its potential to reflect individual patient’s experiences and its ability to influence and transform the overall image of AIDS as a highly stigmatized disease. The many visual expressions related to AIDS activism have been identified as a key moment in the history of agit-prop activities that changed visual strategies of public health and the ways of publicly imagining AIDS.

This article aims to combine these histories in order to demonstrate the central importance of visual archives in the making of AIDS. Instruments from visual studies will be used not only to argue on the effects and after-lives of images originally dominated by scientific thinking but also to introduce methods from cultural studies into the field of medical history in order to understand how visual archives contribute to the medical making of AIDS. Thus, the following argument demonstrates the necessity of interdisciplinary frameworks in the recitation and making of the history of AIDS, bridging medical history with methodological instruments taken from cultural analysis and visual history.

To achieve these claims, the argument is developed mostly against the backdrop of recently developed perspectives on the interrelations of photography and science/medicine. Often influenced by Lorraine Daston and Peter Galison’s argument on
“mechanical objectivity,” photographic representations have achieved throughout the 19th century. But, as Jennifer Tucker and others have shown, medical photography is to be understood among those genres in which its evidentiary status never remained uncontested. At the end of the 19th century, medical societies, journals and professionals had heated discussions on the very benefit of clinical photography. But even today the history of clinical photography remains overshadowed by scholarship on popular representations of medicine, psychiatric photography and the ubiquitous research on studies of physiological movement. Given that the discourse of photography and science is often bound to the historical traces of establishing relationships between apparatuses of culture and visualized objects of nature, the unique condition of clinical photography will be grasped only if positioned between the poles of normal physiology and pathological morphology. This dichotomy is, as George Canguilhem has most famously shown, crucial to any historical understanding of diseases and their ontologies, and works throughout the following pages as a guideline in the analytical approach to clinical photography and its capacities of visualizing and making an emerging disease.

To raise the question of what counts as a medical photograph and how to define the distinctive features of the clinical photograph is deeply bound to the social, cultural and political conditions of their production, arrangement, printing, circulation and viewing. While this article is too limited in scope to engage with this discussion in depth, it shall put forward some preliminary pointers on how to further approach the history of clinical photography by looking at it through the lens of AIDS photography.
Photographs served well to demonstrate unusualness, irritating appearances and irregular symptoms; aspects that have been deemed characteristic of the early years of the epidemic. In regard to a broader visual culture of AIDS, which will be the subject of the first section, clinical photography has often been identified as a dominating visual regime, contaminating many of the often-criticized photographs of PWA to be found in media and art. By foregrounding a few clinical photographs, which will be analyzed in depth in the second section, the article will reject this assumption and will show that photography served in and outside of the clinic to visualize a disease in relation to the body of the patient. This rather trivial finding encloses an argument to be made on the early history of AIDS, in which photography’s contribution necessitated a way of seeing AIDS deeply bound to the social and usually sexualized body of those affected by it. By situating the clinical photograph in this context and by invoking the atlas as an archive used to establish a clinical picture through photography, the third and fourth sections will reveal the often problematic conflation of a patient’s identity and the disease’s morbidity as a characteristic feature of this period and thus will deliver a renewed perspective on the larger history of clinical photography.

**Photographing PWA**

Much has been written on the cultural and social implications of photographs of PWA and to many authors it seemed natural to place the medical or clinical photograph at the origin of the visual conventions spreading to art and journalism in the early years of the epidemic. The captured persons are often seen as de-sexualized, stigmatized and isolated, as being stripped of their individuality, history and dignity, and, most importantly, as being exposed to a pathologizing gaze.

In one of his numerous essays on AIDS, Douglas Crimp gives an account of concerns ACT UP raised in a protest against an exhibition at the New York Museum of Modern Art
The artist, Nicholas Nixon, had put a series of “Portraits of People” on display, some of which were of male patients with severe infections, including Kaposi’s sarcoma (herafter: KS) and emaciation as a result of the outbreak of AIDS. Nixon’s intentions can be interpreted as humanist and liberal, as his intention was to highlight the suffering of the neglected AIDS patient by giving AIDS a face in an effort to combat stereotypes and stigmatization. ACT UP nonetheless criticized the photographs and demanded their removal from the exhibition.

Crimp argues – and his argument broadly reflects ACT UP’s criticism of that time - that these pictures presented a phobic way of displaying a patient with AIDS as they removed the social and political context, isolated the patient and thus reiterated an all well to known image of AIDS-patients: “they are ravaged, disfigured, and debilitated by the syndrome; they are generally alone, desperate, but resigned to their ‘inevitable’ death.” Crimp’s critique points to the image of an individualized patient, governed by the disease and destined to die a cruel and lonesome death. With its protest, ACT UP pointed out that photographs like Nixon’s strip PWA of their social identity, their community and their lovers and friends, rendering them without context and promoting fear instead of solidarity. As Simon Watney argued, this photographic representation tended to “abstract the experience of people living with AIDS away from the determining context of the major institutions of health care provision and state. By being repeatedly individualized, AIDS is subtly and efficiently de-politicized.”

While all these problems came up around the public reception of such photographs, the question shall be raised, of how this relates to the topic of clinical photography? While public representations clearly have their own rationale in belonging to cultural economies of disease containment and public health endeavors in “imagining illness,” clinical photographs seem to serve a different purpose.
But a small comment in a catalog from another exhibition of portraits of PWA in 1988, which seemingly evaded the critics raised around Nixon’s photographs, might enlighten the determination of this excursus in an article originally concerned with clinical photography. The Grey Art Gallery director Thomas Sokolowski wrote in the catalogue’s preface: “The portraits in this exhibition have a different focus. They are, by definition, portraits of individuals with AIDS, not archetypes of some abstract notion of the syndrome.”

It is precisely in this double bind where the portrait of a patient becomes the illustration of an abstract notion of the disease. The phrase ‘giving AIDS a face’ thus works both ways: photographs visualize the individual suffering from AIDS, portraying individual experiences, and at the same time they transfer the abstract notion of a threat into a graspable and recognizable face.

It is in this distinction, where clinical photographs and artistic expressions share a common obstacle. While the artists in the above mentioned cases were primarily concerned with the depiction of individuals and individual suffering, their critics insisted on the failure of their endeavor: instead of individual persons in a social context, the photographs reduced the individuals to being the disease. In the case of clinical photography the state of affairs would be the converse: the photographs portray the disease; the patient’s body is rendered an interchangeable vessel.

FIGURE 1

CAPTION: Photographs of patients with "typical lesions" of KS in an AIDS atlas from 1986.2

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2 This article was published in Charles F. Farthing et al., eds., *A Colour Atlas of AIDS (acquired Immunodeficiency Syndrome)*, 24, Copyright: Wolfe Medical Publications (ELSEVIER), 1986.
Photographing AIDS

The first two clinical photographs to be discussed in depth are to be found on the same page in the first AIDS atlas, published in 1986. Both are numbered (44 and 45) and accompanied by a short description and caption (Fig. 1). The first photograph shows the left side of the lower part of a face and parts of the neck. An arm erected and flexed fills the second photograph. While face and neck fill out most of the upper photograph and invoke the appearance of a detailed close-up, the second photograph suggests that the person was asked to keep the arm in a certain angle. It seems safe to assume that the fragmented body-parts shown in the pictures belong to male bodies and both bodies have unusual marks on the skin: five can be identified on the upper one, while the arm on the lower photograph seems to be almost covered in lesions. Both photographs deliver a rather technical atmosphere; the subject is brightly lit in front of a plain white background. Classic aesthetic norms from the genre of portrait photography seem not to have governed the positioning of the subjects or the overall composition of the photographs themselves.

On the surface of what both photograph’s show, they resemble the many photographs, artworks and film scenes visualizing KS while circulating in the public sphere in the 1980s. As pointed out above, the overall image usually put forward by the photographs is that of young men, often disfigured by another opportunistic infection, showing signs of emaciation, representing a suffering, isolated and ravaged person. Although resembling common photographs of KS, both pictures here need to be understood as a different genre.
The characteristic style applied in both photographs can be identified as ‘clinical:’ the absence of shadows, the white background and the harsh lightning allow for a maximum of visibility directed at the physicians gaze. The framing or cropping of the upper photographs circulates around the lesions, while the positioning of the arm in the lower one is used to make as much of the lesions as visible as possible. The fragmented appearance of body parts renders the persons involved as anonymous and exchangeable. It is here, where the description of the photographs becomes essential: with full disregard to the person's identity, name and story, it frames – or anchors - the photographs as representations of “typical lesions of Kaposi's sarcoma on patients with AIDS.” Additionally, the description is used to guide the reader’s gaze onto a “common appearance” of the linearity of KS lesions that is supposedly to be recognized in the photographs.

Clearly, both photographs contribute to a clinical picture of AIDS. They visualize a characteristic appearance of a KS lesion, one of the most common opportunistic infections on patients with AIDS. Thus, the intrinsic purpose of the photographs is the work of classification: it first guides the viewer's gaze onto the lesions on either the face or the erected arm, secondly it points out a consistent or characteristic feature of these lesions that allows for their identification as KS lesions to, thirdly, understand KS as being a symptom of the syndrome at hand, AIDS. Thus the resemblance between these clinical photographs and any popular picture of KS share the common task of establishing KS as an “index-marker” of AIDS. But it is in their commonality where the photographs can serve very different purposes, follow different interests and create different kinds of mindsets. Where clinical photography is often conducted to contribute to the abstract and artificial entity of disease specificity, popular representations invoke and are openly criticized for their vague conflation of disease, populations and identities. Polemically, one
might argue that clinical photography is about the abstract representation of the disease, while popular representations tend to focus on the people affected by and conflated with the disease in question.

FIGURE 2

CAPTION: Photographs showing Epidemic Kaposi’s Sarcoma in an AIDS atlas from 1989.3

This distinction remains over simplified and misses the crucial impact of photography in the medical history of AIDS, as the following example vividly shows. The page is taken from the second AIDS atlas series, published by the KS specialist Alfred E. Friedman-Kien in 1989 and contains six enumerated photographs with detailed descriptions of every single picture (Fig 2).34 The photographs are ordered in a serial way, showing the left side of a face, the left breast, an unidentifiable part of skin, two feet seen from below and another face captured from the left side. All six photographs resemble the qualities described for the plate above, as they guide the gaze to lesions on different and exchangeable bodies and body parts. Taken from the page’s title, all photographs are used to visualize “clinical manifestations of Kaposi’s Sarcoma” in an AIDS atlas.35 Yet, when it comes to the captions, the intrinsic content of the photographs changes drastically. Here, the descriptions are not only used to describe and define the visible features already shown in the photographs, but to guide the viewer’s gaze to additional information that remains invisible in the picture’s image.

3 This article was published in Alvin E. Friedman-Kien, ed., Color Atlas of AIDS, 25, Copyright: Saunders (Elsevier), 1989.
The editors use descriptions like “A 44 year old otherwise healthy, homosexual male,” “A 23 year old homosexual male,” or “A 39 year old homosexual male.” These descriptions of the sexual identity and age of the patient are accompanied by the usual repetition of what could already be recognized in the pictures as color and shape of the lesions. But the introduction of the patient’s identity into the overall endeavor of achieving a clinical picture of AIDS is significant to a visual history of AIDS. They clearly state a relevance of the sexual identity of the displayed patient for the enterprise of classifying Epidemic Kaposi’s Sarcoma. It is remarkable that here captions are not only used to point to a significant detail within the picture, but are used literally to add information that isn’t visible in the pictures at all. As these framings seem to resemble many of the stereotypical framings of photographs circulating in media at that time they also fit neatly into the narrative of a highly problematic re-medicalization of homosexuality in the course of the early years of the AIDS epidemic.

A number of questions can be attributed to these photographs: first, what is their specific capacity in the early years of the framing of AIDS? Why does it make any sense to photograph a disease and especially a disease that isn’t well established in the medical canon? Why do photographs appear in AIDS atlases and what can be learned of this particular placement of the photographs about this new and threatening epidemic that could not sufficiently be transmitted in written forms? Furthermore, it is impossible to understand clinical photography as an isolated practice, developed and used only by medical professionals. Clearly, the photographs as well as their captions reveal many relations to a general visual culture of AIDS that has been discussed elsewhere and was briefly summarized above. Here, the question remains, if clinical photographs could be understood as a point of origin for popular representations of people with AIDS, as it has been too often raised by scholars?
Photographing Disease

The act of photographing disease has been regularly discussed in the history of medicine. While some have focused on the history of psychiatry, some pointed to anatomical visualizations in early studies of movement and agility, others remain interested with the popularization of pictures of disease. Surprisingly few have contextualized medical photography within the realm of the clinical gaze and the construction of modern disease entities. But medical photography has been without a doubt an essential tool to replace the all too subjective media of illustrations in the second half of the 19th century and contributed quite substantially to the ways of seeing and understanding disease almost immediately after its invention. The new technology promised to eliminate the subjective eye of the individual pathologist and pledged to deliver exceptional cases to the eyes of many physicians. Thus, “photogenic drawings,” as William Henry Fox Talbot called his invention, were heralded at the end of the 19th century as both the successor to earlier “visual concepts of pathology” and a radical new “medium of seeing.”

The scholarly contributions touching on this topic frequently hesitate to analyze clinical photographs in depth: Fox and Lawrence have delivered a convincing study of the representation of medical practice in the late 19th century, but explicitly avoided interrogating the genealogy of photographs of diseases beyond a brief sketch of its origins. Golden and Rosenberg similarly delivered a comprehensive study of the photographic representation of health, but explicitly stated that the photographed disease would be in need of another specific research design. Maehle demonstrated only very briefly the shifting nature of thinking and seeing disease through photography. He argued that the visual pattern at hand favored a somatic understanding of disease, reducing the
complexity of illness to a localized affection visible to the lens of the camera. Sheehan on the other hand delivered recently a study on the use of medical metaphors in professional studio photography, convincingly revealing the deep ties between medical authority and the practice of taking photographs, but evading once again the question of how the photographic depiction of disease leads to the professionalization of medical photography as such. Furthermore, some authors published extensively on photographic representations of diseases in the public sphere to contest its capacity of containing e.g. infectious diseases. If one wants to look further back, a couple of descriptive accounts of medical photography can be found, mostly written in the spirit of representing medicines rich heritage and its deep ties to the emergence of a professional account of photography in the 19th century. While the historical gravity of clinical photography becomes evident throughout these contributions, the lack of a detailed study of its origins, of the controversies surrounding its path to success and its development into a standardized practice in the beginning of the 20th century remain a research desiderate until today.

Many of the existing descriptions resonate with the idea of a clinicians muted gaze as accounted for by Foucault and others, thus placing photography in the realm of the idea of the pathological specimen being enabled to speak for itself. But throughout the 19th century, a pathological appearance was often not understood to be a repeating, similar and identical entity, but rather an endless “aleatory series” of appearances bound together by the clinician’s eye in order to become a symptom. Influenced by Virchow’s understanding of pathology as endless variety, and dominated by the visual traditions of Hunter and Cruveilhier and Gray, the type of visual pathological representation, to be captured by photographs has therefore to be understood as characteristic: “It is no accident that pathological atlases were among the first to use characteristic images, for
neither the typus of the ‘pure phenomenon’ nor the ideal, with its venerable associations with health and normality, could properly encompass the diseased organ.”

So, while mechanical drawings promised to improve the muted gaze of the clinician, bearing any theory or preconceptions when approaching pathological appearances, its results often seemed too silent and too arbitrary to many clinicians to deliver anything meaningful for the practice of diagnostics and treatment. Additionally, mistrust was raised by the fact that the history of professional photographs of diseases can’t be disconnected from the representation of monstrous and spectacular cases, to be found in numerous exhibitions, albums and atlases at the end of 19th century. Some professionals like Edward Lesser and Moritz Kaposi explicitly rejected photography at the end of the 19th century on these grounds and remained committed to the common methods of illustration and wax moulages in their dermatological atlases.

Preliminary and regarding the argument to be made on photographs of PWA it suffices to argue that clinical photography relied on a specific way of seeing diseases. This new visualization of diseases wasn’t so much contested in its capacity do deliver an objective account of an illness, but in its very condition of delivering a typical picture of a disease’s appearance relying on just a singular case. As such the emerging visual genre was drawn into essential epistemological shifts in medicine itself, where the position of individual cases was either to be a characteristic example of similar cases or an especially spectacular and even monstrous case, that has lost all relation to normal physiology and often also to any typical account of pathological morphology. It is precisely in these conflicts where the specific historic trajectory of clinical photography differs from the broad field of scientific photography, which was dominated by the problematization of delivering objective accounts in the 19th century endeavor of establishing a “wordless” science.
To ask, how and to what end photograph y could historically establish itself in the practice of delivering characteristic images of diseases exceeds the frame of the argument in this paper. As a preliminary hypothesis it could be argued that clinical photography had to rely on the visualization of a disease in individual cases, thus established a way of seeing disease that remained as much bound to the representation of very unusual and new sightings as to the promising ability of mass reproduction of extremely characteristic cases. And it is in this current where the overshadowing discourse on photography in science delivers nonetheless an important backdrop for an analytical perspective onto the epistemological position of clinical photography. Comparable to how scientific images achieve their evidentiary status only through a series of conventions, material conditions, paths of distribution and discourses unfolded upon the circulating photographs, clinical photographs have to be made characteristic images through a set of conditions external to the aesthetic features of the individual photograph. Even further, I would argue, the clinical photograph is especially prone to overarching techniques of a contextualizing anchoring due to its reliance on the unstable entity of the single case. Much alike any single photograph, the case delivers only exemplary appearances, constantly in need to be transformed into symptomatic signs of a disease or syndrome.

The theorist of visual studies, W.J.T. Mitchell, has pointed out that to acknowledge this epistemic quality of photography inevitably means to double the subject, as the focus lays both on the photographs and on the way they are used to establish a fact or – in the case of diseases - a diagnostic relation. Therefore the photographs I discuss here belong to a bigger picture “that shows us what pictures are, how they function, where they are located.” As these “metapictures” are often compared to “pictures-within-pictures,” clinical photographs never lose their attachment to the clinical picture of the disease at
stake. But while the latter is never sufficiently to be found in photographs, the photograph will be always read and understood as a key feature of the clinical entity.

One way to approach this double bind is to pay very close attention to the material conditions in which photographs become a visual argument. As Edwards has demonstrated, the “material forms in which photographs are arranged, how they are printed and viewed, as albums, lantern slides, or mounted prints, is integral to their phenomenological engagement, structuring visual knowledge as well as those related human actions in modes of viewing.” By following the entangled layers of singular and grouped photographs in their surroundings, by focusing on the way the photographs are made usable and readable for their intended purposes, one moves beyond the assumption of a single photograph being a passive image which is made readable through various practices and framings and reveals their “social biographies.”

The AIDS atlas

All editions and series contain numerous photographs of patients with AIDS. Furthermore they visualize AIDS through maps of its epidemiology, through electron micrographs of HIV, through histological indications and countless diagrams of virus transmission, T-cell suppression, immune reactions and so forth. In sum, each atlas provided and continues to provide an archive of a variety of aspects deemed to be relevant for diagnostics, the physician's practice and the teaching of medical students.

When Farthing published the first atlas on AIDS, the epidemic was only five years old, its etiology was still the subject of dispute, no promising treatment was in sight and only complex blood-testing methods available. Photographs of characteristic infections like KS functioned at that time as a diagnostic tool by making the KS lesion a key visual marker of the epidemic. As most physicians where unfamiliar with AIDS and as the epidemic's dimension was threatening to many, the atlas is to be understood as a clinical teaching instrument, delivering characteristic pictures of the appearance of those opportunistic infections that point to the conclusion of an AIDS outbreak. As a tool for comparison at the clinical bedside and as a visual handbook for educational purposes, the atlas allowed a structured view onto a new and still messy clinical entity bound to an unidentified etiological agent and apparently highly prevalent in certain subpopulations, as e.g. homosexual men.

In both the first and the second editions, photographs of KS lesions remain the largest series. In pictures like the one shown in Figure 1, photographic close-ups of the lesions are used to display the symptoms of KS in a broad variety, usually leaving the patient anonymous and unrecognizable.

The chapter on clinical manifestations contains few pages on other apparent diseases associated with AIDS, such as herpes and lymphoma, and is accompanied by small chapters on epidemiology, immunology and clinical practice. It is notable, that the chapter
on virology in the first edition uses the name “HTLV-III/LAV” to designate the virus responsible for the outbreak of AIDS. While the virus-hypothesis itself seemed uncontested, its name and identity remained to be clarified.66

When Friedman-Kien edited his atlas in 1989, his outstanding work on KS transformed into a “Color Atlas of AIDS.”67 The atlas even opens with a portrait of Moritz Kaposi himself, before the bulk of photographs in this monograph is used to categorize and establish “AIDS associated Kaposi's Sarcoma” as a distinguishable disease. Almost all chapters in this atlas remain concerned with KS. Throughout the atlas the editor distinguishes between a classic and an endemic version of KS, placing the classic variation in certain regions in Eastern Europe and the endemic variation essentially in some parts of the African continent. The third and here crucial categorization is an epidemic form of KS that the editor associated strongly with homosexual male patients with AIDS, not mentioning any geographic prevalence in this case.68

The whole atlas is introduced with the remarkable sentence: “It is a rare patient with AIDS who does not present with or develop a cutaneous manifestation of the disease.” As these signs could sometimes be confused with benign signs or signs of completely different diseases, the atlas draws the necessary distinctions to recognize those infections that point to AIDS. And KS, the introduction states, occurs in “about one third of patients with AIDS” and is therefore seen as essential, indeed as an “index-marker.”69

The rare chapters not tied to the task of visualizing KS in AIDS patients are used to distinguish KS lesions from “clinical simulators” and engage with the microscopic diagnosis of Epidemic Kaposi's Sarcoma,70 while only the last chapter deals with other cutaneous signs of AIDS and with infections in patients with the HI-Virus.71

Consequently the rest of the atlas is filled with series of photographs of KS lesions. As in the example in Figure 2, the pictures do not differ from Farthing’s atlas, but cover a
broader spectrum and every single picture has a detailed description of what shall be recognized and what can be said about the sexual identity of the patients displayed.

The series of photographs of lesions on mostly young men are accompanied by a detailed description of how to understand the appearance of KS-lesions in the case of AIDS. The author points to the fact that 95 percent of AIDS-related KS cases were diagnosed among homosexual or bisexual patients, but argues that this prevalence a) declines over time and that b) its occurrence might be related to a reporting artifact, as the diagnoses of AIDS were often made without registering the apparent KS.72

Not discussed in detail in this article, this clinical picture completely changed in the second edition of the atlas in 1996. Against the background of working antiretroviral therapies and with the steady decline of full blown AIDS within the USA, the focus of the atlas shifted away from KS and onto the many cutaneous signs of an HIV infection.73 The atlas now presents “superb clinical photographs of the many mucocutaneous manifestations of the various HIV-related diseases”74 and contains chapters on oral, ophthalmologic and pediatric aspects of HIV infections as well as a chapter concerned with the clinical appearance of AIDS and HIV in Africa.

The rapid transformation of the epidemic is acknowledged in the foreword and is well reflected in the placement of the chapter on KS. While it contains an identical collection of photographs and presents the same classification system as the first edition, it became just one of many chapters related to cutaneous manifestations of AIDS and HIV, while the focus shifted strongly towards the virus and the clinical symptoms of a positive sero-status. In other words: By 1996 KS had lost its former position as an index-marker and clinical photography ceased to be the essential way of seeing AIDS.

The series of AIDS atlases published by Springer Medicine, edited by Donna Mildvan, sometimes co-edited by Gerald L. Mandell, verified this transformation. While the first
edition remains part of the larger project of an Atlas of Infectious Diseases, the overall structure of the atlas remains the same throughout the following independent editions. Although the clinical picture of AIDS has radically changed since antiretrovirals have been made available, the atlas remained engaged with “visual clues,” as its purpose still lies explicitly in diagnostics.  

Nonetheless, clinical photographs are hard to find in this huge volume of virtually every significant fact about AIDS and HIV. Aside from the foreword and a brief introduction, every textual section of this atlas series works as a comment on some kind of visualized information. But most of this information is presented as diagrams, maps and arrays, while just a few photographs of patients and electron micrographs of viruses are to be found. It is notable that the chapter on clinical manifestations is edited by Friedman-Kien and most of the clinical photographs remain the same as in his own atlases. But with its high level of diversification, the atlas of AIDS by Donna Mildvan creates a clinical picture of AIDS that is not at all bound to the realm of cutaneous manifestations and their interpretation. Visualizations of the virus, both in the form of diagrams and electron micrographs, seem to dominate the long chapters on virology, immunology and epidemiology. They reflect the shifting focus onto antiretroviral therapies as the most promising way to understand and contain the epidemic at that time.

Daston and Galison have pointed out that atlases not only collect and distribute the best and most convincing pictures, “they set the standards of a science in word, image, and deed – how to describe, how to depict, how to see.” The atlas not only delivers a visible catalogue but structures the way of seeing by framing, captioning and contextualizing the pictures it contains. This is achieved fundamentally through the social nature of atlas production, which makes the resulting atlas an exemplary form of collective empirical research. The existence of a published atlas thus implicitly states, so argue Daston and
Galison, that the importance, extent and complexity of the phenomenon at hand exceeds the capacity of a single mind and intellect.  

AIDS atlases thus can be understood as visual dictionaries of AIDS, providing not only an opinion or a perspective, but delivering a powerful standard in recognizing an epidemic, that has led to a vast amount of confusion and crisis. The examples discussed above are rendered in the atlases in order to become manuals, of how to interpret and understand pictures of lesions as symptomatic signs for KS. They establish the symptomatic relation of KS as a sign of AIDS and thus deliver information that cannot be communicated without the picture, as seeing and recognizing similar signs is “the alpha and the omega of the genre.”

But the atlas can also approached as being an archive, which contains a set of photographs that once were used to deliver a comprehensive, but nowadays outdated clinical picture of AIDS. Edwards understands the photograph as being a linking object, in which the past and present are brought into a specific relationship. On the one hand this is achieved by the photograph in being a representation of the ways of seeing and understanding AIDS in the early 1980s, while on the other hand the idea is invoked, that AIDS has actually looked as it is captured in the timelessness of the single photograph. And indeed, following the social biography of the photographs through different atlas editions, it becomes clear that transformation is not happening on the surface of the pictures, but in the way they are understood, captioned, positioned and used. Furthermore, some photographs remain the same, but yield different visual representation of AIDS, when used in different atlases and times.

All AIDS atlases share the common object of putting the clinical picture of AIDS on display. However, it is the position of clinical photographs that changes drastically over time, thus allowing for a different view onto the history of AIDS. While photography has been a key
media in presenting the strongest visual argument about the nature of the epidemic in the first editions of AIDS atlases, they lose their significance as this very nature changed. The concluding question therefore is what kind of disease does the clinical picture of AIDS entail when represented by clinical photographs? And secondly, what can be learned about the epistemic qualities of photography against the background of the history of the AIDS epidemic?

**AIDS photography**

The relationship between medicine, its highly specified instruments and its particular way of seeing disease – often referred to but seldom explained as a medical gaze – and popular representations of disease is an old one; not only in the history of medicine. And as many scholars have argued, the history of AIDS has had an impact on this relationship itself, shifting the identities of doctors and patients, as well as raising mistrust in biomedicine’s ability to successfully overcome a crisis of health. As argued at the beginning of this paper, different ‘stock narratives’ of AIDS history have found different ways of emphasizing and interpreting this relationship and its crisis. One fairly popular and lasting narrative identifies a clinical gaze or a pathologizing view as being the origin for many popular and artistic photographic practices that have been discussed and criticized for rendering the identity, the biography and the particular individuality of depicted patients to being representations or abstract notions of a disease.

Within the final part of this article I will argue, that this narrative of a kind of visual medicalization is in need of fundamental revision. Not only to overcome a historically questionable notion of the dichotomy between the popular sphere and a supposedly isolated clinical community, but to demonstrate that popular and clinical photographic
representations share a common problem, which is found here in the visualization of the disease itself and there in the portrait of those affected by it. Translated to the terminology used by Canguilhem and Foucault, both visual practices share the problem of separating the body of patient and the disease. Clinical photography is therefore not to be seen as an origin of a broader visual practice but rather as a complementary aspect of a shared visual endeavor.

In his study on medical discourses of AIDS, Alex Preda grasps the early formation of scientific knowledge around the new epidemic. He frames his analysis of metaphors, narratives, and classifications in the first years as “making up the rules of seeing” and argues that the challenge of AIDS was not so much the recognition of an entirely new disease, but the shifting habitat of well-known and well-classified diseases. As mentioned before, KS as well as PCP were described and classified long before the outbreak of AIDS.

Preda’s analysis of rhetorical structures quickly reveals the unusualness in the appearance of well-known diseases and infections in completely non-characteristic social categories as crucial condition for the articulation of the new syndrome. In the case of KS before AIDS, the rare skin cancer was regularly assigned to old men from various geographic regions. In the early 1980s KS resurfaced in very “unusual, ‘rare’ and ‘uncommon’” ways, where the rhetoric of the unusualness served to distinguish a KS belonging to the past from a new KS, that needs new classification as it seemingly belonged to a new kind of disease. Preda argues that the new rules of seeing KS in its new habitat were delivered by crafting homosexual men as the predominant risk group. And while this prevalence reflects the initial entanglement of AIDS with homosexual lifestyle, it prevailed in the classification of KS until the end of the 1980s.
What is crucial for Preda’s argument is the rhetorical establishment of homosexual men as a fundamental condition to allow physicians to see KS as a symptom of a new syndrome. Thus, the new framing of KS was bound to the social categories of the patients in which it appeared, to establish KS as the index-marker for what was only later to be known as AIDS. The background of the subpopulation was necessary to make the new disease visible in the foreground; it served as a framing to enable KS to be an index-marker for AIDS.

This rhetorical figure can be translated to the visual argument clinical photographs of KS-lesions entail, while it reveals at the same time its characteristic conflation of disease visualization and bodily representations. This is nothing new and not exclusively bound to the emergence of AIDS, as e.g. Gilman has shown for the historic case of syphilis. But the case of AIDS serves as an excellent example to understand the epistemic value of photography in medicine.

Accordingly, the first atlas collected photographs of opportunistic infections that appear in an unusual milieu. The well-known KS was shown in an unusual context, its vast appearance on bodies of young otherwise healthy men was drastically presented by long series of photographs. Every visible sign was accompanied by a detailed description in the caption of the pictures or in the surrounding textual fragments. The authors described the lesions at length and here and there one could find clues on the sexual identity of the patients in the pictures and last, but not least, all the patients and cases depicted in these atlases appear as white and male.

But on the other hand the authors tried carefully to keep the patients anonymous and the captions did not distinguish between cases and persons, but remained focused on the appearance of clinical signs (as shown in Figure 1). The countless photographs were made readable as characteristic pictures of KS-Lesions on patients with AIDS, the
physician were to recognize the significant signs without being distracted by contextual information, faces or questions of identity. Every single picture worked as a representation of the clinical picture of AIDS by putting the KS-lesion as an index-marker to the fore.

It is this current between putting what is new and unusual onto display and at the same time classifying what is seen on the pictures that characterizes the history of clinical photography. In the case of AIDS, the appearance of known disease entities in the new and unusual setting of mostly young male homosexuals was one of the most crucial characteristic features of the syndrome in the early 1980s. My argument here is therefore that photographs were deployed in atlases precisely because they allowed the relation between what was assumed to be a homosexual male body and the signs of KS to be visualized, and thus made AIDS visible without drawing an immediate conclusion about the nature of this relation. The photographs invoked the long standing tradition of a clinical photography, where unusual, spectacular and unknown phenomena were captured to be interrogated, understood, classified and normalized. But it was also through clinical photography, where the intrinsic relation of AIDS and male homosexuality was made an integral part of the disease entity because photographs put them on display in such a way as to render them indistinguishable.

This became the *modus operandi* in the atlas by Friedman-Kien, the KS-specialist, which was published in 1989. To establish the different classifications of KS he proposes, he focused exclusively on the identity of the population KS is found in. The classic KS appears in an “elderly Ashkenazi Jewish male” population, or on the body of an “75 year old Italian male” patient. The endemic KS belongs to the African continent and is exclusively apparent on Black bodies, while the epidemic AIDS associated variant belongs to the habitat of the homosexual male body.
Here the conflation of the identity of the patient and the symptoms of a disease that signals the outbreak of AIDS has become crucial for the way of seeing AIDS as an immunodeficiency syndrome that seems to affect mostly homosexual men. While the connection of disease morphology and patient identity was rather loose in Farthing’s first atlas, it became a standard feature in Friedman-Kien’s dermatological atlas at the end of the 1980s. The male homosexual patient and the significant prevalence of KS even within those populations affected by AIDS became part of what is characteristic about the epidemic AIDS-associated KS and, as I have shown here, the clinical photograph served best in establishing this relation: both in 1986 when the connection was rather loosely made and in 1989 when the sexual identity became an explicit aspect of the classification of an AIDS-associated KS.

All this changed in the mid-1990’s. The second edition of Friedman-Kien’s atlas – now co-edited by Jay Cockerell – shifted the focus from clinical manifestations of AIDS to signs that signify the infection with HIV: “Although AIDS-KS may be the classic AIDS-related malignancy, the spectrum of HIV-related cancers and their clinical mucocutaneous presentations continues to evolve.” 88 The same photographs that served to classify the AIDS-related malignancy between morphology on the skin and the identity of its milieu, now visualize the trace of a cause that is also not to be seen on the picture. The etiological argument is now pointing to the virus as the causal agent and dismisses the sexual identity of the patients as irrelevant. The etiological depth is now what is of interest: it is found beneath the skin and exists in a qualitative difference from the body altogether. The virus is not only the cause of the symptoms to be seen on the photographs; it became the nature of the disease, thus transforming the photographs’ visual argument into one that gives evidence for the agility - or virility – of the virus.
Clinical photographs disappear accordingly from the center of AIDS atlases. In Mildvan’s series, the photographs are found in the chapter on cutaneous manifestations – edited by Friedman-Kien89 - now without any clue about the sexual identity of the patients. They became photographs without any diagnostic functionality, their visualized contents belong to a well-established clinical entity, which nature and structure is now better displayed in epidemiological maps, electron micrographs and complex diagrams that construct the viral identity of HIV, thus reflecting the shifting focus onto antibody tests, antiretroviral treatment and the newly classified entity “HIV-disease”, which led to new ways of seeing and knowing AIDS.90

Thus, it is argued here that the analysis of photographs of PWA allows a way of accessing the complex procedures of visualizing disease that cannot be reduced either to the medical sphere or to a public representation. As has been shown, male homosexuality has as much become a frame to visualize AIDS in medicine as the visualization of AIDS has become a way of seeing male homosexuality in the early years of the epidemic. Photography, or rather its clinical application, isn’t to blame for this way of seeing, but should be understood as a vehicle of raising questions directed to the relation of a disease to those it appears in. This faculty of photography of bringing a relation onto display that yields further inquiry and requires a perpetual anchoring cross cuts the often-antagonistic narratives of cultural and medical history of the epidemic and thus allows access to a different history of AIDS.

Conclusion

In the early years of the emerging AIDS epidemic photographs of PWA allowed physicians to have a closer look onto the new disease. The unusual appearance of KS on so many bodies of young otherwise healthy men was striking and disturbing to the existing
systems of classifying this rare skin cancer. As I showed, photographs were essential in
crafting a new medical understanding of KS in relation to AIDS.

But photographs were also essential to a public understanding of the new emerging
epidemic and were used throughout arts, journalism and activism to reveal what AIDS
looks like, to ‘give AIDS a face’ in order to raise an ethical visibility for those affected. As
discussed above, these photographs were often criticized for an overly clinical way of
putting the PWA on display. This enclosed an idea of a public representation of PWA as
being contaminated by a clinical way of seeing, where persons portrayed are constantly
over layered with the abstract notion of a disease.

This notion of AIDS photography is outdated and the article delivered a first step in the
re-evaluation of this crucial element of AIDS history. Instead of following the presumption
that photography outside the clinic is to be understood as an altogether different genre as
clinical photography itself, I traced the commonalities of photographs of PWA as they
cross cut these perpetuated narratives of different knowledge spaces. Rejecting the
underlying assumption of a clinical way of seeing which supposedly spread through
photographs into a broader public, thus tainting political, ethical and moralistic
endeavors of photographers in arts, journalism and activism, the above argument showed
that photographs of PWA in fact share faculties regardless of their intended functionality.

As I have demonstrated, photographs of PWA rested in the atlas as well as in art galleries
and newspapers on the conflation of a patient’s body and the disease. If these
photographs are therefore understood to be a visualization of an embodied disease they
still maintain a crucial uncertainty about the nature of the relation between the affected
person’s body and the notion of the disease. It is in the analysis of the social biographies
of these photographs where conclusions are drawn, where framings become established
and single pictures are made into larger narratives and images. But as the photographs
themselves remain invested with what is unusual and what remains uncertain, it is their analysis which allows the cultural, social and medical history of AIDS to become one entangled history; epitomized in the photographed portrait of the patient with AIDS. In has therefore be shown, that the specific epistemic virtue of photography for medical purposes lies in its ability to visualize a disease through the visualization of its carrier, to show the uniqueness of KS lesions through their appearance on bodies belonging to a subpopulation at risk of the emerging syndrome. This virtue can easily be understood as a vice, as the commentary and the captions throughout the discussed atlases has shown that it is impossible to draw a clear line where and when on photographs a disease is depicted and where a person is shown.

Photographs of PWA clearly visualize disease deeply entangled in the life of the patient. And as much as photography was essential to make up medical knowledge, this entanglement played a crucial rule in the making of AIDS in the public sphere. Therefore, popular representations of PWA and the photographic visualization of AIDS within atlases of the 1980s share the same obstacle: the modus of visualizing AIDS relies here and there on the assumption that AIDS as disease was to be approached, analyzed and understood within a certain lifestyle of a certain subpopulation. Photography allowed raising this question, to powerfully invoke the unusualness of a serious of diseases to appear in young otherwise health homosexual men, but photography also allowed to keep this an uncertain relation. It can be concluded, that to capture AIDS in photographs of PWA therefore remains a task to be carried out in the captioning, framing, arranging and positioning of photographs. But the photograph of a PWA is nevertheless already involved in carving out the way in which this capturing of AIDS is approached, as it lays out the way of seeing AIDS as a series of unusual embodied opportunistic infections. The conflation of disease and identity as a characteristic feature of both the early years of the
epidemic and of clinical photography throughout history has been the reason for public objections but it can now also be understood as the very condition of the recognizability of AIDS.

In conclusion, the photographic capturing of AIDS until the end of the 1980s served to build up a way of seeing AIDS, which was deeply bound to the problem of an unknown, unusual and threatening disease. While photography on the one hand worked well to capture this unusualness, it also bound the unusual aspects to the population, AIDS was initially linked to: young, homosexual males.

What happened over time, and why photography ceased to be the visualization tool of choice, can be explained with regard to Canguilhem’s work: photography, it can be argued, is always bound to a visualization that captures a disease in situ, thus favoring a disease conceptualization that remains in mere quantitative distinction from health and life itself. The disease seems to be just an excessive variance or a causal outcome of a lifestyle that gets pathologized by becoming a predisposition of the disease, symbolized through the bodies of the patient on photographs capturing a disease.

When photographs of PWA shifted to the sidelines of the atlas to provide an actualized and valid clinical picture, another conceptualization has become powerful, delivering its own icons and visualizations to open a new chapter in the social biographies of the remaining photographs. Instead of the quantitative model a rather ontological concept of AIDS was delivered with the predominant focus on HIV as the causal agent that shifted AIDS from being an aspect of a lifestyle to a global epidemic to becoming a normalized disease.

Photographs of PWA are characteristic of images from the first decade of the AIDS epidemic. They reflect uncertainties in medical, artistic and journalistic approaches to the social configuration of this deadly syndrome and can stand as symbols for the poor
understanding of AIDS’ etiology in the 1980s. Three decades later, these photographs color the archive of a different AIDS, a disease which bears only a passing resemblance to how it is seen today. Revisiting these visual archives is critical to deepening historical understandings of AIDS that cut across tired narratives of social, cultural and medical AIDS history. Of urgent importance for the story of AIDS, analyzing clinical photography also has the power to focus attention in new and revealing ways with respect to other diseases. To turn the lens onto the history of clinical photography through the exemplary case of AIDS should encourage new perspectives and new methodologies for appreciating untold visual histories of clinical photography.


4 Williams, “Acquired Immune Deficiency Syndrome” (n.1), 8.

Edwards application of a social biography of photographs allows to interrogate the history of a photograph as a genuine social and living object, bound to numerous practices of archiving, sorting, framing, printing and captioning but also confined to incite social practices, when e.g. a disease is visualized. Elizabeth Edwards, *Raw Histories: Photographs, Anthropology and Museums* (London: Bloomsbury Academic, 2001), 13.

AIDS atlases have been published since 1986 in three different series by Wolfe Publishing in London, Saunders in Philadelphia, USA and Springer Current Medicine in New York, USA. The editors are well known physicians who devoted most of their career to the treatment of PWA and clinical research on HIV and AIDS. The atlases contain photographs of dermatological signs, epidemiological maps and visualizations of the virus as they aim to deliver a total picture of AIDS. The atlases way of visualizing the epidemic and the ongoing process of transforming and actualizing the epidemic’s image makes for a visual history of the medical knowledge of AIDS, which has been the topic of my recently finished PhD on the *Clinical Picture of AIDS*, Humboldt University Berlin, 2013.


20 Daston and Galison, *Objectivity* (n. 5).

21 Tucker, *Nature Exposed* (n. 5)


27 Crimp, “Portraits of People with AIDS” (n. 25), 88.

28 Ibid., 86.

29 Watney, “Photography and AIDS” (n. 17), 187.


33 Ibid., 24.


35 Ibid.
36 Ibid.


40 Fox and Lawrence, *Photographing Medicine*, (n. 22), 24.


42 Fox and Lawrence, *Photographing Medicine*, (n. 22), 26.

43 Golden and Rosenberg, *Pictures of Health*, (n. 39), xxv.


45 Sheehan, *Doctored*, (n. 5.).


49 Ibid., 119.


52 Daston and Galison, *Objectivity*, (n. 5), 82.


56 As demonstrated by Tucker, *Nature Exposed*, (no.5); Wilder, *Photography and Science*, (no. 5); Edwards, *Raw Histories*, (n. 6).

Edwards, *Raw Histories*, (n. 6), 16.


Epstein gives a detailed account of the history of the naming of HIV, which was the final and unifying name for many different concepts and names, given in 1986 by the subcommittee for retroviruses of the International Committee on Taxonomy of Viruses at the WHO. See Epstein, *Impure Science*, (n. 11), 79 ff.


Ibid., xv.

Ibid.

Ibid., 71,83.

Ibid., 93, 125.

Ibid., 36.

This relates very closely to what Roland Barthes has famously called the that-has-been effect of photography, demonstrating that photographs always remain attached to the visualization of an event that is already in the past when represented through the photograph. Roland Barthes, *Camera Lucida: Reflections on Photography* (Farrar, Straus and Giroux, 1981).

81 Alex Preda, *AIDS, Rhetoric, and Medical Knowledge* (Cambridg, UK: Cambridge University Press, 2005).

82 Ibid., 46.

83 Ibid., 56.


87 Ibid., 15.

