

# Surviving AIDS

## Cultural Trauma among middle-aged Gay Men in New York City

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Since the 1980s more than half a million people died of AIDS-related causes in the US. More Americans died than who were killed in all American wars of the 20<sup>th</sup> century combined. Only the death of actor Rock Hudson in 1985 caused straight America to confront AIDS. However, since 1981, when the first reports of a »gay cancer« emerged, HIV/AIDS attacked mostly marginalized communities.

1996 was a turning point in the fight against HIV/AIDS with medical advances improving the health of the infected. 1996 was also a turning point for the attention paid to the suffering HIV/AIDS created in society. These life saving drugs stopped the massive dying happening in the affected communities, and with them came a desire to forget the pain of the past. Nowadays knowledge about the extent of the epidemic, especially in people of younger generations, is not widespread.

Not only the dead are now forgotten, but so too are the survivors. Gay men, comprising more than 50 percent of all AIDS deaths in the US, can hardly ignore the catastrophe they lived through. Some of them have lost dozens, for some hundreds of people to AIDS.

Research on the experience of these men is rare. This article focuses on these survivors. It shows how this crisis perpetuates itself until today, influencing their lives, and argues that recently a new narrative is developing to process their experience - cultural trauma around »long-term survival« is constructed. The crisis is not over – it is simply transformed.

The article begins with a quick note regarding literature before taking a closer look on the research objective. This is followed by a contextualization of the research and a note on the methodology behind the project. The introduction of the concept of syndemics taps into the question where the community stands now by showing how survivors are affected by having high levels of depression and anxiety, drug addiction, etc., stating that traumatic experiences they have continue until today, creating syndemics. Following that it is argued that a new cultur-

al trauma narrative gets established through which an identity and community becomes established and experiences structured.

## Literature<sup>1</sup>

Research on the AIDS crisis and its effects on the people who lived through it is heavily dominated by studies in psychology, medicine and gerontology. People who are HIV-positive are the usual subjects of this research, focusing on the biopsychosocial aspects of living with HIV/AIDS. Reflecting the increasing average age of its subjects recent research questions more often also the intersection of HIV/AIDS and aging.<sup>2</sup>

Another branch of research asks how the AIDS crisis affects gay men in general, often written before or shortly after the introduction of the effective drug cocktail in 1996. Walt Odets' 1995 study for instance wonders how HIV-negative gay men experience(d) the crisis and how the gay community has been transformed. Other discussions revolved around posttraumatic stress disorder and/or »multiple loss syndrome« (see for instance Watney 2000: 216ff.). After some years of decreased interest Spencer Cox brought up the issue again in 2006 and 2007. Cox wanted to focus attention on the generation of middle-aged gay men who lived through the times before the drug cocktail, but did not receive the resonance he hoped for. Interest in this community increased nevertheless again and traces of this discussion can be found in other works (see for instance Gould 2009 and Schulmann 2012). Perry Halkitis' book »AIDS Generation« is the now most recent and most influential study on this generation<sup>3</sup> and its fate, sparking lots of discussions, media attention and events.

## Objective

This article concerns itself with the question of how a community of middle-aged gay men who lived through the first fifteen years of the AIDS crisis in New York City are now, as well as how they understand and process this experience. It shows how for the last years a narrative shift is happening, in which a new cultural trauma gets enacted based on already existing narratives.

This study focuses on self-identified gay men who lived in New York City in the 1980s and early/mid-1990s, the most heavily impacted subgroup of society, battling the disease while at the same time fighting off societal abuse.<sup>4</sup> As Sarah Schulmann says »Every gay person walking around who lived in New York or San Francisco in the 1980s and early 1990s is a survivor of devastation and carries with them the faces, and fading names, of the otherwise forgotten dead.« (Schulman 2012: 45).

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1 The literature and methodology section are abridged due to space constraints.

2 See Heckmann, Halkitis (2014) for an overview on HIV and aging.

3 He focuses on HIV-positive men as well, though.

4 Other males who are had sex with males during that time most likely made often similar experiences.

## Advent of AIDS

Together with San Francisco, New York City became unquestioningly the center of American gay life in the second part of the 20th century, nicknamed »The Gay Metropolis« (Kaiser 2007).

Before the 1970s gay people were threatened and invisible, existing mostly in the periphery. Nevertheless a desire to matter emerged. Although not the first gay protests, became the Stonewall Riots in 1969 a seminal moment for the emergence of a gay movement (Duberman 1994). With Stonewall as important point of reference, a strategy of »gay identity« emerged, based on a logic of identity politics that equated the potential for social change with individual authenticity. Inclusion instead of liberation, identity politics instead of revolution (Gould 2009: 51f.; Ghaziani 2008: 25ff.; Bronski 2011: 211ff.).

Previous decentralized gay life shifted to big cities. Gay »ghettos« emerged. They offered infrastructure, a self-affirming culture and the development of community organizations and businesses (Ghaziani 2008: 29ff.; Levine 1979). Gays became visible in parts of New York City and nationwide. In this time of progress comes the arrival of HIV/AIDS, first reported on in 1981. An outbreak of this mysterious disease starts, and the toll of infected and dead rises fast. Randy Shilts (1987) chronicled the early history of AIDS, showing how ignorant the mainstream media were towards the mysterious disease until it started to affect also non-marginalized communities, primarily white and heterosexual, more strongly.

Adding to the invisibility by the media is the widespread negligence of the disease by the government. The rise of Ronald Reagan and the Religious Right created a hostile cultural and political climate, in which the government neglects funding and support. A moral hysteria around AIDS develops (see Halkitis 2014: 3.f.; Ghaziani 2008: 72ff; Gould 2009: 49ff.). Major Ed Koch in New York City responded weakly to the crisis as well, making him a target for AIDS activists and survivors.

This negligence led to the death of more than 600,000 people in the US alone. Stigma, panic, isolation and ignorance related to HIV/AIDS brought the gay movement to a halt (see Halkitis 2014: 3). The gay community was torn between the ideas of gay liberation, the gay movement and the dominant homophobic discourse (Gould 2009). An adequate response to the crisis seemed complicated due to previous negative experiences and a general distrust of politics and society as well as a lack of scientific knowledge. After some years of more community-centered and quiet activism a more confrontational AIDS activism develops in the end-1980s.

1996 changes everything. The number of deaths and hospitalizations was reduced drastically by the arrival of HAART (highly active antiretroviral therapy). In the following years the gay community becomes transformed, normalization ensues. Increased visibility in media and society as well as embourgeoisement and mainstreaming set in, gay culture gets hetero-sexualized. Recent history is gradually rewritten, forgotten and/or silenced. Re-stigmatization of HIV/AIDS happens, while at the same time the numbers of infected people still rise.

## Methodology

Two main approaches for data collection were used.

14 narrative interviews between one to four hours were conducted with 13 different men. After the exploratory input of the first four interviewees were the other ten interviews structured by an in advance prepared questionnaire arranged around question clusters.<sup>5</sup> During the interview it was intervened as minimal as possible to guarantee openness and flexibility. It is important to keep in mind that the experiences of these men are a »continuous experience«, similar<sup>6</sup> to what Grada Kilomba describes in her study on the phenomenon racism: These experiences are »not a momentary or punctual act, but rather a continuous experience throughout one's biography, an experience that involves a historical memory of [...] oppression« (Kilomba 2013: 46). A policy of minimal interferences enables the interviewees to construct their own subjective realities and create their own biographical narratives. It also provides opportunities for the provision of additional associations and experiences beyond the prepared structure (see Kilomba 2013: 46f.)

Sampling when working with communities of sexual minorities and HIV/AIDS is not easy (see Kalton 1993; Meyer, Northridge 2007 and Meyer, Wilson 2009). The initial interviews were acquired through social contacts and referrals. For the second round of interviews were requests for interviews and a project description posted in three Facebook groups of AIDS activist and gay networks in New York. Further interviewees were recruited through meetings of a NYC-based AIDS activist organization. »Snowballing«, in which interview partners nominate further potential interviewees, was also used.

The interviewees were mostly white, one Chinese-American and three Black men in their mid-forties up to mid-sixties. All were college-educated. Although never asked, they revealed the majority of interviewees their sero-status.

The interviews were recorded. Five interviews were transcribed completely, the remaining ones only partially. They were openly coded, compared, and re-coded.

Additional participant observation was employed. As Rachel Sherman points out: not everything of interest is »necessarily conscious in the minds of the participants« (Sherman 2007: 272). Many of these men are only slowly understanding themselves as a community sharing a common experience. Identifying members of this community is hard and events catering exactly to their situation were only starting to happen (then often branded as »AIDS Generation« or »AIDS Survivors«). Events which would have a high likelihood that »survivors« will be present were attended, e.g. movie screenings and discussions related to the subject. One interviewee allowed me to »shadow« him, thereby giving me the opportunity to experience an HIV-positive long-term survivor interacting with bureaucracy and medical staff.

Furthermore did I start to spend regularly time with one of my interviewees, providing access into the everyday life of a survivor as well as to a person who would help me to mitigate my own position as stranger. He also functioned as a gatekeeper to places and events not accessible

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<sup>5</sup> The clusters were identity and community, the impact of HIV/AIDS, knowledge about recent discussions on the »AIDS Generation«, memories, aging, legacy and the relation to the younger generation(s) as well as trauma.

<sup>6</sup> Although not equal.

otherwise. In addition one highly active Facebook group of alumni of an AIDS activist organization was helpful in understanding ongoing discussions and exchange of experiences.

Similar to what Halkitis (2014: 15) describes were my own positioning and specific experiences repeatedly of importance. Talking about the experience of HIV/AIDS and the loss and suffering interviewees encountered over the years can be very emotional. Being not known to most of them it was important to build trust to encourage them to open up and tell their story. To help with this trust-building I sometimes »revealed« my own positioning as a non-straight person, breaking the usual hetero-normative assumption of straightness. Sometimes I was explicitly asked by interviewees.<sup>7</sup> People seemed more willing to open up after recognizing me as a fellow non-straight person. The age difference as well as my foreignness became also important, allowing many of them to open up. Talking with other survivors instead can be difficult. As interviewee Matthew describes: it would be like »looking into a mirror«, potentially causing pain by requiring a certain acknowledgement of their own experience when seeing a »mirror image«.

## Syndemics

The majority of the more than 100,000 HIV-positive New Yorkers who died have been gay men. Almost no gay man is untouched by it, either directly by losing friends and lovers, or indirectly as (involuntary) participants of a radical change in their community as well as suffering from the nationwide hysteria and conservative backlash (see Halkitis 2014: 141).

An unprecedented crisis had to be faced. Either gay men became infected and had to deal with the expectation to maybe being dead soon, or they had to live with a fear of infection while surviving inside a hostile society and experiencing the death of their community as they knew it. The journalist Andrew Holleran describes this experience very vividly: »Living in New York [...] felt like attending a dinner party at which some of the guests were being taken outside and shot, while the rest of us were expected to continue eating and making small talk.« (Holleran 2008: 5).

Having a »normal« life seemed impossible for many gay men of this generation, in particular in cities with bigger gay populations. All interviewees remarked on how HIV/AIDS affected their lives, although with varying degrees. For most of them the experience is profound. »Charles«, himself HIV negative, put it very simple: »it«, meaning the AIDS experience, is just who he is.

The arrival of new medication in 1996 was a breakthrough. It helped people who were infected and had access to health care to prolong their lives, sometimes even rescuing them from the deathbed. Also the rest of the community was relieved to have at least potential medication at hand. It did not stop the suffering nonetheless. Roughly fifteen years of having your community and networks devastated cannot be cured with a simple pill. One also has to keep in mind that most people, besides the general hostile climate, often lost many people they knew, again and again, over a longer period of time. The process of grieving was difficult, »multiple-loss syndrome« occurred, where the »constant interruption of the grieving process by the additional

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<sup>7</sup> It has been widely discussed in the past how positioning matters, in particular when researching sexual minorities (e.g. Bolton 1995; Walby 2010).

loss prolonged the mourning process and prevented completion of the tasks of mourning« (Cox 2006: 4).

Charles is a strong example of this recurrence of death. He lost between 200 to 250 people to AIDS in the last thirty years. Some people also keep notes: One interviewee interrupted me once to simply say »I got 236«. And these numbers are not fixed: people are still dying, evoking lots of emotion. Charles exemplifies that when talking about the loss of an old college friend some years ago:

»And I just remember being so hurt that he is dead [...] and me thinking that in my life the people who mattered to me, [...] the people who been instrumental and important to me are all dying and gone[...] and, you know, that thing which happened in my twenties was continuing to happen [...] and it's kinda fucked up [...] you know [...] you shouldn't be 40 years old and already have a life history of dead people in your life.«.

Spencer Cox, who researched gay men in mid-life (roughly forty to sixty now) defines several afflictions these men seem to suffer from disproportionately. Cox mentions:

1. Depression and anxiety
2. drug and alcohol addiction
3. sexual risk-taking
4. partner violence (and broken relationships/inability to have a lasting relationship)
5. the inability to positively imagine or plan for the long-term future.

Often these afflictions can be direct (e.g. depression) or indirect (e.g. drug use to counter the depression) results of their AIDS experience. Often they are also not independent from each other, but overlap and reinforce each other in a phenomenon called »syndemics« (see Cox 2006: 20; Cox 2007: 28), a term championed by medical anthropologist Merrill Singer (Singer 1996)

These afflictions came up repeatedly in interviews. Matthew, talked a lot about how they interrelated, overlapped and reinforced each other in the people and community he knew. From depression and anxiety disorders to drug abuse (alcohol and others, especially crystal meth) as well as unsafer sex<sup>8</sup>. He linked the latter to his generation's special relationship to sex. Many became fully adult in times when the sex between two men was often linked mentally with the fear of becoming infected with HIV and death. According to him they now, in an »epidemy of counterphobic reaction«, try to overcome their difficult relationship to sex by engaging in practices they most feared – unsafer sex. He also talked about the apparent problem of his generation to make relationships last as well as simply not having achieved what they wanted to before their lives got disrupted by HIV/AIDS. With his descriptions, echoed by the other interviewees, he lays out the image of a community in the grip of syndemics and painfully aware of it.

One might also want to add social isolation as an affliction. Health issues like depression and the problem of nurturing relationships can lead to a life away from public, which is enhanced by the loss of old networks. Even more so when considering how gay men still have to face adversity by society (which is still often anti-gay) and even inside of the often youth-obsessed gay community (see Halkitis 2014: 174ff.). There are also economic restraints enhancing the chance of feeling socially isolated. Socializing costs money, which is often scarce in their generation. Even more so in a country in which access to health care is expensive and often not even attainable.

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<sup>8</sup> Some interviewees also do rarely or never use condoms.

The synergetic interplay of the afflictions can create something of a vicious circle for the individual as well as for their community. Nonetheless it is important to keep in mind how they also work as defensive mechanisms and can partially also provide resources to people. Halkitis mentions the importance of drugs and sex here: Although they are »not traditionally viewed as an effective or active coping strategy, for the men of the AIDS Generation, these outlets provided a form of escape, a release, a decompression, from the ongoing onslaught of the AIDS epidemic. It is too simplistic to judge these behaviours as deviant or destructive unless you have walked in the shoes of these men« (Halkitis 2014: 136).

Not everybody can develop coping mechanisms and resilience however. Some members of this generation also succumb and take their lives. Suicide has been a recurrent theme. One example of this is the death of Spencer Cox, who was quoted before. Spencer died in the end of 2012. His death reverberated through the community and led to discussions on the current situation of men his age. Charles for instance told me how Spencer's death »was really disturbing«. He explained how he knows of several people of his generation who decided to take their lives. Suicide seems to be a powerful option for parts of this generation, posing a danger for not just the individual itself, but also the community in general. Seeing it as an »exit option« taken by others might reduce resistance against it for some people, who end up considering taking their own lives as well. It becomes almost infectious. Which again just reinforces the problem – the suicides of middle-aged gay men weaken their social networks, increasing vulnerabilities for surviving members of this network.

## Cultural Trauma

For many of these gay men this experience has been influential in their lives, and for some of the older ones it might even have been the death of the gay world as they have known it. The experience constitutes a major phenomenon going beyond the individual. Losing one's best friend in a car accident might be individually traumatic – but rarely constitutes a collective suffering as a wider community. The massive scale of the AIDS epidemic instead concerns more than its individual members. It constitutes a trauma, in which a collective constructs culturally a »symbolic-cum-emotional representation« of its experience (Alexander 2012: 2).

According to Jeffrey Alexander »occurs [cultural trauma] when members of a collectivity feel they have been subjected to a horrendous event that leaves indelible marks upon their group consciousness, marking their memories forever and changing their future identity in fundamental and irrevocable ways« (Alexander 2004: 1). Even though individual experiences of suffering and pain fuel this trauma, is it not defined on a individual level. »[I]t is the threat to collective rather than individual identity that defines the suffering at stake« (Alexander 2012: 2). The suffering collective does not exist just by itself. As Alexander says: »[It] must be imagined into being« (Alexander 2012: 2).

An event is not inherently traumatic. It becomes traumatic. The construction of a cultural trauma can be understood as a process in which a group starts to attribute this event as traumat-

ic. »Trauma is not the result of a group experiencing pain. It is the result of this acute discomfort entering into the core of the collectivity's sense of its own identity.« (Alexander 2004: 10).

The construction of this trauma constitutes a process of ongoing meaning-making. The intent behind it is simple: Making sense of this experience, and with that a community and its members try to move along with this experience collectively. A »we« must be constructed or developed from an existing »we«. Here »we« constitutes the gay community, which in the process of trauma construction stays the gay community – although transformed by the trauma.

With this it shares certain similarities to grieving on an individual level when grieving is understood as a process in which meaning gets (re)created to cope with an experienced loss. Through the process of grieving and the related meaning-making, the individual positions itself in a new world transformed through the loss (Odets 1995: 82ff.). In the construction of cultural trauma the collective also positions itself through collective meaning-making in a world which has been altered.

## Long-Term Survival

This study now argues that a visible shift in the narration of the lives of middle-aged gay men is happening. Building up on existing narratives like war and survival a new cultural trauma is increasingly developed. Recent cultural production (documentaries, articles, books, etc.) and the »(re-)discovery« of the unique experience of this generation produces this new narrative. Through this narration this social group »not only cognitively identif[ies] the existence and source of [their] human suffering but »take on board« some significant responsibility for it« (Alexander 2004: 1).

This trauma narration gets constructed in an interplay between academics, artists, writers/journalists, and activists, following a recent increase of interest in HIV/AIDS and its effects on this generation of gay men. Some of these men also start to let their voice heard and confront their experience more publically.

Using cultural artifacts like the documentaries *How To Survive a Plague* and *United in Anger* as historical backdrop, a story about »long-term survival« is being told. Long-term survival draws on already existing narratives like the work of Michael Callen and his book *Surviving AIDS* (1991) about long-term survival among people living with AIDS. The trauma also draws heavily on a war narrative, which has been prevalent for a long time. Marita Sturken already talks about the war narrative in the mid-1990s, explaining how AIDS is often compared to the Vietnam War while AIDS activism is compared to Anti-Vietnam activism (see Sturken 1997: 15). It never went out of fashion as recently Kergan Edwards-Stout illustrates, writing about the times »in which I often felt as though I were engaged in a secret war« and comparing his sexual awakening in the AIDS crisis with a »series of battles, describing AIDS activism as »quiet war« (Edwards-Stout 2013).

It also provides a sense of agency: being a soldier. Signorile evokes the image of a young soldier laying in mud when he writes: »All of us who were in the trenches of the AIDS war« (Signorile 2013). Other articles even use it for headlines: *The Death of Activist Spencer Cox: Wound AIDS Warriors Suffering, Dying on Their Own* illustrates (Voelcker 2013). The interviews also pro-

vide us with similar narratives. Charles explains his good relationship to his dad, a war veteran, with having somewhat similar experiences. He also uses the image of soldiers going into battle for describing what the fear felt like one had back then again and again.

Over time these soldiers transformed: They become also veterans, survivors, wounded warriors. There is a feeling of not being taken care of, though, of being silenced and unsupported. This marks a difference to soldiers in »real« wars, which receive partially support and recognition from government and public in the US. However, for neither »AIDS soldiers« nor »real soldiers« re-integration into society is easy. Especially for the AIDS ones, considering the lack of any kind of support. An additional problem for the »AIDS veterans« is the fact that their war is not over. People still die, the crisis continues. Interviewee Matthew alludes to that: »You know the peculiar thing for gay men is that... not only have all your friends died but there is still the possibility that you might [still] as well...«

Even though the exact terminologies »AIDS Generation« or »Long-Term Survivor« are not used by all men of this generation, all interviewees knew these terms. Some were also increasingly active using the opportunities the surge of these terms and discussions allow them. Employing the terms gives them partially an identity they can link their experiences to, but also provides them with opportunities to discuss and move forward to cope with their experiences as well as get help and advice for everyday life situations. Several long-term survivor groups got created in a short time; Kenny tells me of four groups he knows which got founded just in a couple of months. With that the narrative also becomes spread wider, in turn creating new groups, discussions, etc. Arts take part in this conversation with productions like the dance piece »The Missing Generation« by Sean Dorsey Dance. At the same time community is created with events using the same rhetoric and references. In an example »the unique challenges and struggles we share« are mentioned and a »free community forum« is held »to discuss the needs of the generation of AIDS Survivors« (Medius Working Group 2013).

In the construction of this cultural trauma a diversity of experiences get connected through the construction of a shared history of experiencing systemic forms of oppression around HIV/AIDS in the 1980s and early 1990s, maybe even up to now. In that it defies a definition of trauma as something private and »resists the melodramatic structure of an easily identifiable origin of trauma« (Cvetkovich 2008: 33). This diffusing of the causes of trauma into a broader context opens up the need for more structural changes instead of just »fixing« individuals (see Cvetkovich 2008: 33).

A collective is stabilized through all these singular acts and artifacts, common knowledge is shared, an unique collective with its specific experiences and needs constructed. At the same time they identify the existence and the source of their suffering as their AIDS experience and assume a certain responsibility by addressing the needs of their generation.

## Conclusion

This article explored the context of the arrival of HIV/AIDS in the gay community. Focusing on the generation of now middle-aged gay men it argues that it had a striking impact on them, visible through the syndemics these men face in the present. Existing narrations (e.g. war-

related) become transformed and a new narrative centered around Long-Term Survival emerges. A new cultural trauma gets constructed, one through which identity and community get created, experiences restructured, and a legacy developed.

A community of survivors develops in which they can talk and engage each other and confront their feelings and memories. The intense recent debates and increasing attention this generation creates, its willingness to come together and organize, and the outpouring of emotions and urge to tell me about their experiences seems a good indicator how there seems to be the time ripe for them to face the ambiguities of remembrance.

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