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The Harold Scott Story: Remembering and Documenting an Activist, Educator, Thirty-five-year HIV/AIDS Survivor (Video Essay)

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Abstract: *Harold Scott has survived more than thirty-five years living HIV+ and has dedicated his life to HIV/AIDS education and activism by telling his own story. A gay man who grew up in the rural southern US, Harold had no concept of homosexuality until his twenties and contracted HIV/AIDS from his first gay experience. Since the early 1990s, Harold's personal storytelling has impacted and instructed others about this ongoing epidemic in a heartfelt way made more profound by his simple delivery and sheer perseverance. Harold's remarkable longevity and resilience contrasts sharply with the early history of AIDS as a death sentence. The video essay and accompanying written narrative explore Harold's journey living with HIV/AIDS, finding healthcare and support groups in Tennessee, and his path to educating others about AIDS. His story is also a personal one. Dr Katherine Bertram, my mother, served as Harold's local doctor, the first physician to accept AIDS patients in the Upper Cumberland region of Middle Tennessee in the early 1990s. This project includes interviews plus photos and memorabilia to preserve his ongoing saga as a tool for education, activism and to prevent his story from falling into queer obsolescence.*

Figure 1: AIDS memorial quilt. Photo Harold Scott. Used with permission. With link to video essay.

The video essay is a memory-based narrative and archival intervention documenting an early and ongoing experience of the HIV (Human Immunodeficiency Virus)/AIDS (Acquired Immunodeficiency Syndrome) pandemic. The focus is on one individual, Harold Scott, a long-term HIV survivor, with the video as a piece of memory art to be considered alongside the saga of pandemics and their global impacts. The story is both a deeply personal and an intergenerational one as my physician parents and I have been involved with his journey for more than three decades. The project underscores the value of a "differentiated" vision, one that involves mobilising fragments of the past as a complement to scientific progress focusing on the identification and control of viruses (Schwartz and Baral; Ellenberg and Morris). The COVID-19 pandemic intensified the relevance of this project, revealing how viruses can profoundly reconfigure social relations, institutional practices, and cultural understanding.

In an age marked by global pandemics, climate crises, warfare, and the rapid growth of artificial intelligence (AI), human existence and health are under constant threat. The long-term impacts of the COVID-19 pandemic remain unclear. As with past pandemics, the dire effects, including global mass casualties, risk fading from collective memory due to institutional failures. While local, intergenerational or identity-based accounts may endure, their circulation and longevity may also be limited as time passes (Bikmen). As lived experience risks being overshadowed by sanitised and hegemonic discourses, a recognition of the vastness of memory—as a flexible and symbolic/representational object, such as the AIDS Memorial Quilt (Fig. 1)—foregrounds heterogeneity, individual and collective memories, and the ongoing impact of pandemics (Catlin 1468). The act of remembering thus allows us to engage meaningfully with contemporary crises, the concept of "usable pasts" across pandemics being especially pertinent (Catlin 1447). This position aligns with Certeau's concept of memory as "anti-museum": memory becomes functional and continuously enacted in the everyday and through a range of connections rather than being static or confined to a specific location (108). This proactive mobile stance is central to the project's approach. Accessing these "usable pasts" through "history, theory, literature and art" may help us to focus action during times of crisis by making sense of events, situating experiences within timelines, and imagining future possibilities (Catlin 1447).

While studies quantify demographic patterns between urban and rural spaces (Cohn), the wider scholarship overall remains focused on urban contexts.[1] This means that figures like Harold Scott can be considered emblematic of the often-overlooked face of HIV/AIDS in rural America. Documenting his story preserves the lived experience of one gay man living long term with HIV in the rural southern US, challenging long-standing stereotypes and representing resilience in the face of restricted agency.

Harold's experience of limited medical, community, and societal support in the initial years of his diagnosis illustrates how survival often depended on "making do"—the subtle, improvised, and largely unseen practices through which individuals and groups quietly resist the constraints of disciplinary systems (Certeau xiv–xv, 34–39), particularly during times of crises when resources can be scarce. Faced with an uncertain future when he learned of his HIV status, Harold adopted a constructive and iterative approach to navigating a socially and politically "cramped space" that effectively blocked him on multiple fronts. My ongoing work with him similarly embodies the logic of "making do", tactically deploying tools and opportunities available to me in resisting the disciplinary constraints of institutional and structural systems.

This experience has also intersected with my parents' roles as physicians, creating a form of interdependence in which clinical responsibility is inseparable from human care and compassion. The affective dynamic therein was key in shaping Harold's later activism, education and advocacy work, and long-term survival. I was ten years old in the autumn of 1982 when my mother (Dr Katherine "Kathy" Bertram) first encountered, in a medical school course, the virus that would lead to what would become known as AIDS. In the early years of the HIV/AIDS pandemic, as my mother explains, care was limited to "holding hands"—relationally essential and, in the absence of effective medical interventions, one of the few forms of care available. My childhood and adolescence were therefore shaped by the social and cultural dimensions of illness and scientific knowledge far beyond my years, at a time when HIV was framed as sexually transmitted and primarily affecting gay men.

Figure 2: Dr Katherine "Kathy" Bertram and Harold Scott. Photo Amy Bertram.

The COVID-19 pandemic brought into sharp relief persistent patterns of uncertainty, misinformation, fear, isolation, and uneven access to resources which exposed enduring demographic inequalities in both health outcomes and access to service provision, particularly for those already marginalised. While acknowledging the key differences between HIV/AIDS and COVID-19—in terms of the biological nature of the viruses, populations affected, and in individual and collective responses—there remain "profound political, affective, social and cultural connections" (Garcia-Iglesias, Nagington, and Aggleton 1). These shared dynamics draw on the transformative potential of viruses, making it clear how effective progress depends on fostering interconnectedness, collective care, and empowerment (Garcia-Iglesias, Nagington, and Aggleton 1).

In this context, Harold's voice, body, and memory function as materials of resistance in drawing our attention to pressing and often ignored issues in contemporary HIV care: the rising prevalence of HIV amongst older populations, increased comorbidities in those living with long-term HIV infection, heightened experience of isolation and loneliness in the older patient with HIV, and delayed diagnosis and restricted access to care in rural settings (Quinn et al.). These intersecting concerns underscore the continuing structural and systemic failures shaping health outcomes in social and geographical terms. Harold's resilience and longevity stand in stark contrast to the experiences of most patients during the early years of the AIDS pandemic when a diagnosis of HIV was widely understood as a death sentence. The life expectancy for people living with HIV has increased significantly with advances in antiretroviral therapy—initially through the introduction of azidothymidine (AZT) and later with developments in combination therapies incorporating a range of antiretroviral inhibitors (Trickey et al., "Survival"; Trickey et al., "Life Expectancy").

The video emphasises this catalytic element through its engagement with Bill Nichols's "participatory" and "reflexive" modes of documentary—the former highlighting the political and ethical stance of the filmmaker in shaping reality through direct engagement with the subject/participant (190), the latter highlighting the engagement of the filmmaker with the viewer and the construction of the image represented (194–5). As with the pre-Stonewall narratives that Nichols discusses, Harold's reflection on more than thirty-five years of living with HIV, alongside his work as an activist/educator, exemplifies what Nichols calls "films of testimony" (194). Such accounts have a "highly compelling quality" because they extend beyond a simple recounting of the past, situating personal experience within a broader political and ethical frame (Nichols 194). Harold's testimony as re-presented in the video is an intentional act of remembering and memorialisation which honours those who died from AIDS while challenging the marginalisation of those who continue to manage HIV.

The video essay is formally structured as a bricolage, assembling a range of materials from Harold's past and present to document his ongoing journey living with HIV. This format is inspired by Chris Marker's short masterpiece, *La Jetée* (1962), which is a striking exploration of memory composed entirely as a *photo-roman* (photo-novel). In *La Jetée*, memory is neither fixed nor linear, but dynamic, fragile, and ultimately the mechanism for humanity's continuation. Space and time in Marker's film, as in pandemics, are nonchronological: the past is not simply behind us but is an active force shaping how we consider both the present and the future. The linear, and sequential, are disrupted by a series of "instants" that coexist and operate simultaneously in the present (Kawin 16). The video, in its layering (including my authorial voiceover), is an active challenge to the obfuscation, false narratives, and systemic failures in public health strategies of both the HIV and COVID-19 pandemics.

The temporal dimension is emphasised through the inclusion of archival audio from a conversation in 2019 between my mother and Harold for the *StoryCorps Archive*—an online repository of oral stories in the US that aims to connect people through shared experience and to foster collective understanding and compassion. In May 2025, I also contributed to this type of oral archive in a series of guided discussions with Harold and my parents. The visual and aural materials assembled in the video reflect active participation in an intergenerational dialogue and the cultivation of relational memory, an ongoing and interactive process that develops across time and through different contexts and textual forms.

The video also integrates documentary technique and testimony with pedagogical practice as part of my academic role. These converging elements operate as a "rhizome": nonhierarchical, nonlinear, and composed of lateral connections that generate new possibilities through their interaction (Deleuze and Guattari 22–23). The rhizomatic structure is made explicit through the inclusion of students from my course as part of the film crew, their on-screen presence pointing to the constructed nature of representation and situating the narrative across interconnected bodies and spaces.

Harold's role as guest speaker in my *Sexuality and Gender in Cinema* course at Belmont University brings his testimony into direct contact with teaching and learning activities. His open and honest dialogue with students, particularly for those who identify as queer, allows the affective power of his story to complement canonical queer cinema, such as the documentary film *Silverlake Life: The View from Here* (Tom Joslin and Peter Friedman, 1993). While these course texts are essential in supporting an understanding of the historical impact of AIDS on the gay community in the 1980s, Harold's presence adds immediacy and encourages real-time reflection on how epidemics and pandemics are lived, represented, and remembered.

Long-term survival is dependent not only on biomedical advances but also compassionate and humane healthcare. Harold's sustained relationships with his healthcare team reflect the importance of care grounded in trust and dignity. The acknowledgment in 2024 of long-standing institutional complicity by the *New England Journal of Medicine* in perpetuating harmful stereotypes about sexual and gender minorities marked a significant moment of professional reflection and accountability (Halem, Manion, and Streed 385). This position contrasts sharply with the resurgence of anti-LGBTQ+ hostility and a fear-based political rhetoric that seeks to scapegoat (im)migrants, people of colour, women, and transgender people (Snyder).

Yet, Harold, I, and the many who refuse to be silent and invisible resist these censorial constraints. As the director of this project, remembering with and through Harold, I assert the value of lived experience, community care, and resistance. Counter to a nostalgic position, memory emerges not as retreat but as both a force for survival and a catalyst for transformation. In returning to "usable pasts"—through archival material, personal reflection, and established filmic and documentary techniques—this project demonstrates how memory can guide action in moments of crisis, making experience intelligible, situating responses within temporal frameworks, and opening pathways to future possibilities.

Note

[1] See the National Rural Health Association (NHRA) website for extensive information on the history of AIDS in rural America. Notably, in 1997, the NRHA convened the Southeastern Conference on Rural HIV/AIDS, "Issues in Prevention and Treatment", held in Atlanta, Georgia (www.ruralhealth.us). See also Susan E. Cohn's "AIDS in Rural America", which highlights the urgent need for education among adolescents and adults in rural areas regarding HIV prevention, testing, and management (239).

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