Interactive documentaries and health: combating HIV-related stigma and cultural trauma

Villanueva Baselga, Sergio (Universitat de Barcelona, sergio.villanueva@ub.edu)

Abstract

Interactive documentaries have been growing in number and importance on the international scene in numerous fields and markets. Interactive documentaries entered the field of health about a decade ago, and since then they have proven to be a worthwhile tool for exploring various health issues, such as living with HIV. More recently, experts and academics have started to explore interactive documentaries dealing with a newly emerging topic: stigma. Stigma can be defined as the establishment of a "mark" or characteristic identified as deviant and rejected by society. Stigma has negative consequences in every aspect of a person's life. When it comes to health, people with stigmatised conditions have the worst outcomes, a problem ultimately related to their own power and agency. There are many sources of stigma, but the structural sources are the least studied and have the biggest impact on health. The media and culture are two of these structural sources of stigmatization, and cultural trauma has been suggested as one of its mediators. This study seeks to examine interactive documentaries as a tool for raising awareness of the impact of HIV-related stigma and cultural trauma. To this end, it analyses two interactive documentaries, Vertical/Horizontal and The Graying of AIDS, focusing on the device, narrative, and textual elements used by these documentaries to deal with the impact of stigma in health, and elaborating on how these filmic pieces represent people living with stigma and whether that representation challenges or reinforces stigmatization.

Key words: HIV/AIDS, HIV-related stigma, interactive documentary, structural stigma, cultural trauma, media and health.

The study of identity is complex and numerous scholars have devoted considerable intellectual and scientific energy to understanding how we construct our identities and how they influence the formation of beliefs, attitudes, and behaviours. Identity impacts many spheres of our daily life, health being one of them. Many scholars have studied how identity determines individuals' health choices, values, and actions, under the assumption

that identity and health are inextricably entwined (e.g. Haslam et al., 2009). *Healthy* itself often becomes an identity, and messages about what it means to be a healthy person pervade health campaigns. It is therefore essential to take a comprehensive approach to identity to more fully understand its role in health (Hecht and Choi, 2012). Health communication is the study of how communication and health are related. In this sense, scholars in health communication study everything from how to build effective campaigns to how to understand the effect that culture and media consumption have on health identities.

Film is one of these media, and more and more frequently many filmmakers are working especially documentary films that address health issues and help to healing processes. There are film festivals devoted to mental health recoveries (Quinn et al, 2011), films addressing health at work (Mendes, dos Santos and Ichiwaka, 2017), and motivational films to quit smoking (Brown et al, 2016). Nevertheless, one important factor to make these films effective is that their production process is open to participation and interactivity. For that reason, a growing number of scholars are studying how participatory ways and practices of communication can be used as form of intervention in healing processes or to influence in modifying harming identifications (Parr, 2007; Lingard et al, 2015).

In recent years, many film producers have undertaken projects in which user-generated content, shared authorship, public commitment, and collective participation constitute the pivotal elements of the production process (Shaw and Robertson, 1997: 2-23). As Nico Carpentier (2011: 68) suggests, "participation in the media deals with participation in the production of media output (content-related participation) and in media organizational decision-making (structural participation). These forms of media participation allow citizens to be active in one of the many (micro-)spheres relevant to daily life, and to put into practice their right to communicate." Participation in filmmaking has taken many forms, and when it comes to documentary making, one of the most popular are interactive documentaries. These films, which are also referred to as digital documentaries or web documentaries, are characterised by "disseminated authorship and a surrender of control over the narrative discourse" (Guifreu Castells, 2013: 124-125; Chio, 2009). This research sets out to analyse interactive documentaries that are designed to address one specific health issue: HIV-related stigma.

Interactive documentaries: definition and characteristics

Defining what is understood by *documentary* is a complex and tangled discussion. But in order to establish an operative definition for interactive documentary, it is necessary first to reflect on the most important definitions of this film genre. Bill Nichols (2001), who bases his work on contemporary film theory drawing from the Derridean revolution, defines the documentary from three perspectives. The first perspective relates to the filmmaker: a documentary is defined as a film in which the director possesses very limited control over the story; he or she can control the filming and the camera, but not the performance. The second perspective relates to the text: documentaries are audio-visual texts that depict places and people connected by a thematic and historical logic and, therefore, are structured by external textual elements. Finally, the third perspective relates to the spectator: the documentary generates the expectation that the status of the text bears a direct relationship with the real world and that, consequently, there is a congruence between the image shown and the historical fact to which it refers; thus, the documentary generates a desire for knowledge and the spectator views it with little expectation of identifying with characters or plot twists (Villanueva Baselga, 2015).

Based on the above, Nichols (2001) defines interactive documentaries as those that attempt to expose the perspective of the filmmaker. Thus, it is this type of film that most commonly includes interviews and in which the addition of the narrator's voice is not limited to post-production, as the filmmaker intervenes and can be heard on the scene of the events. This definition reflects a time when viewer participation through feedback mediated by technology was not yet a reality. When web-mediated interactivity began to intervene in the filmmaking process, interaction came to be understood as a trilateral relationship between filmmaker or author, viewer or spectator, and device (Almeida and Alvelos, 2010).

It is important to note that the cornerstone of an interactive documentary is not the use of web-based technologies, but the possibilities of interrelating and interconnecting the author and the viewers. In other words, not every documentary on a website is necessarily an interactive documentary. Aston and Gaudenzy (2012: 126) provide a technology-agnostic definition of interactive documentary as "any project with the intention to

document the real and that uses digital interactive platforms." In the same line, Galloway, Mcalpine and Harris (2007: 328) define interactive documentary as "any documentary that uses interactivity as a core part of its delivery mechanism" and identify four categories for facilitating interaction within the filmic context: passive-adaptive, active-adaptive, immersive, and expansive. In this sense, the notion of interactive documentary logically extends that of the documentary and should always refer not to the technology it uses, but to the platform that mediates it.

Aston and Gaudenzy (2012: 127) also point out that "interactivity is seen as a means through which the viewer is positioned within the artefact itself, demanding him, or her, to play an active role in the negotiation of the 'reality' being conveyed through the interactive documentary." In other words, interactive documentaries require their viewers to interact physically with the platform in order to generate, modify or alter the filmic narrative. These physical interactions may be broader or narrower depending on the degree of openness of the documentary. According to O'Flynn (2012), interactive documentaries have three levels of openness: (1) semi-closed, in which the viewer can search for content but not change it (jump between parts, but not change linearity); (2) semi-open, in which the user can participate but not change the content (can give feedback, change the order, jump between fragments, but not add); and (3) open, in which viewer and documentary dialogue adapt constantly (user can add content). In this sense, the level of openness of an interactive documentary is considered as an indicator of its participatory stance. In conclusion, in view of all the above, every interactive documentary's device should be analysed according to its platform, the physical actions it allows, and its level of openness. These three dimensions will be the ones surveyed when further analysing the interactive documentaries examined in this research.

Stigma and cultural trauma in health

As explained before, health has to do with identity. And identity is form by a myriad of dimension among which Gofman, in the early sixties, defined stigma (Gofman, 1963). There is growing evidence that stigma has harmful consequences on health that promote disparities between those who are stigmatized and those who are not. In this vein, a growing number of researchers are claiming that stigma should be considered a social determinant of health (SDH), a term defined by WHO (2008: 2) as "the conditions in which people are born, grow,

live, work and age that have an impact on individual health." In consequence, dealing with stigma and developing policies that lead to its reduction among stigmatized groups is urgently needed to meet the objectives set by supranational organizations like the WHO, or the United Nations Sustainable Development Goals (SDG), especially SDG 3, "Good health and wellbeing".

Major et al. (2018: 3) define stigma as "entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion, and discrimination." Stigma can manifest mainly in two forms: (i) internalized stigma, which refers to an individual's own adoption, consciously or unconsciously, of the negative societal beliefs and feelings associated with his or her stigmatized status (Lee, Kochman, and Sikkema, 2002; Simbayi et al., 2010; Turan et al., 2017); and (ii) enacted stigma, defined as negative biases in feelings toward and evaluations of stigmatized groups and unfair treatment of those groups by healthcare professionals or the general public (Kinsler et al., 2007; Lekas, Siegel and Leider, 2011). While consequences of both internalized and enacted stigma have been analysed in depth, their causes have not been as extensively studied, mainly because there is still a lack of critical and theoretical frameworks and, specially, because there are few reliable methods for such studies.

Pachankins et al. (2015) have systematically reviewed the most important advancements in the study of stigma and have shed light on questions yet to be answered. Among these, one of the most significant relates to the study of the sources of stigma, which are widely varied and to some extent difficult to characterize. Structural stigma, a term coined by Mark Hatzenbeuhler, is defined as "societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and well-being of the stigmatized to which they are ubiquitously exposed" (Hatzenbeuhler, 2016: 744). In this sense, structural stigma is intertwined with how culture and media relate to health identities and how they shape collective forms of identification in the face of adverse health conditions.

Based on this insight, Alexander (2004: 1) suggests that collective identities are constructed over cultural traumas, which are "horrendous events that leave indelible marks upon group consciousness, impacting memories forever and changing collective identities in fundamental and irrevocable ways." Cultural trauma is first and foremost an empirical, scientific concept,

suggesting new, meaningful causal relationships between previously unrelated events, structures, perceptions, and actions. But this concept also sheds light on an emerging domain of analysis. It is by constructing cultural traumas that social groups not only cognitively identify the existence and source of human suffering but also take on board some significant responsibility for it (Sztompka, 2000; Kansteiner, 2004). In this sense, it has been theorized that cultural trauma even becomes interwoven with health identities when a community evolves out of a health situation, such as the HIV community (Hudnall Stamm et al., 2004; Gailienė, 2019; Shea et al., 2019). It is clear that the rapid expansion of the HIV epidemic in the 80s and 90s was a crisis of such dimensions that it has become a cultural trauma that has laid the foundations of the HIV community's collective identity. Hence, HIV cultural trauma could be revealed through an analysis of the representations of the disease in contemporary cultural productions. At this point one might question how stigma and cultural trauma might be connected, and the answer can be found in the history of HIV epidemic.

HIV and stigma: from the epidemic to the U=U strategy

Since the start of the epidemic, approximately 1,000,000 people have been diagnosed with HIV in the European Region, according to the World Health Organization (WHO). While the growth rate has declined, almost 80,000 new infections were reported in Western and Central Europe in 2017, and the prevalence of HIV in Europe will continue to increase in the foreseeable future as people living with HIV (PLWH) can now expect to have a normal lifespan. In 2014, the Joint United Nations Programme on HIV and AIDS (UNAIDS) and its partners launched the ambitious 90-90-90 targets for 2020 as a commitment to improve access to antiretroviral therapy (ART) as a life-saving treatment, a transmission prevention measure, and a human right. The first of the three targets is the successful diagnosis of 90% of all HIV positive people. Target two involves delivering ART to 90% of those diagnosed; and finally, target three is viral suppression for 90% of those on treatment (Levi et al., 2016). In 2017, 79% of PLWH in the European Region knew their status, out of which 79% were accessing therapy, and 81% of these were virally suppressed. This means that only 47% of all PLWH are virally suppressed and, thus, cannot transmit the virus (see the U=U strategy discussed below).

The UNAIDS 90-90-90 targets have required innovative, multidisciplinary strategies to diagnose, treat and promote adherence to antiretroviral drug prescriptions. However, this

strategy is mainly directed towards biochemical solutions, and overlooks other important issues that PLWH face in their daily lives. As an example, PLWH have a 29% higher risk of reduced quality of life due to comorbid health conditions like cardiovascular disease, osteoporosis, and depression (Evans-Lacko et al., 2012) which can also affect their adherence to medication regimens (Markovitz et al., 2000; Gao et al., 2010). Many of these comorbidities are related to mental health and how PLWH interpret, deal with, and contextualize their life with HIV. In other words, how they manage their identity as PLWH and how they deal with HIV-related stigmas and cultural traumas. Based on this insight, researchers and activists have highlighted the necessity of adding a fourth '90' to the UNAIDS targets: improved quality of life, that is, reaching a 90% of PLWH with a high standard of quality of life that is free of HIV-related comorbidities.

Many PLWH have internalised the negative societal narratives surrounding HIV and fear that healthcare professionals (HCPs) treating these comorbidities will discriminate against them. Hence it is clear that negative narratives of HIV spread by the media constitute one the structural stigma that PLWH face in their everyday co-habitation with HIV. Furthermore, there is an urgent need to study how the media, and specifically cinema, has portrayed HIV to develop negative narratives surrounding the virus. In the last decade, most films that depict HIV still deal with the epidemics of the 1990s, portraying troubled characters who become emotionally detached from their friends and lovers to fight against the damaging consequences of HIV infection and ultimately die in a sad ending. In fact, more than 90% of the European films about HIV fall into the melodrama genre, more than 80% of their characters die during the story because of the HIV infection, and a similar percentage of characters get infected by their sexual partners or lovers.

Nevertheless, this is not the current situation of PLWH. In 2016, the Prevention Access Campaign, a health equity initiative with the goal to end the HIV/AIDS pandemic as well as HIV-related stigma, launched the Undetectable = Untransmittable (U = U) initiative. U = U signifies that individuals with HIV who receive ART and have achieved and maintained an undetectable viral load cannot sexually transmit the virus to others. This idea, based on strong scientific evidence, has broad implications for the treatment of HIV infection from a scientific and public health standpoint, and for the self-esteem of individuals by reducing the stigma associated with HIV (Rendina and Parsons, 2018;

Eisinger, Dieffenbach and Fauci, 2019). For this reason, over the years some filmmakers have tried to challenge the negative narratives promoted by mainstream cinema to frame HIV and offer more real and positive views of the lives of PLWH. And many of these filmmakers have chosen interactive documentaries as a means of multiplying the voices and experiences of PLWH. The two films examined here, *Vertical/Horizontal* and *The Graying of AIDS*, are two of these interactive documentaries.

Previous studies have assessed the effectiveness of participatory communication methods in multiple contexts and with multiple aims, e.g. to reduce risky behaviours (Berger and Rand, 2008), to promote health in children (Grabowski, 2013), or in the field of HIV, to empower PLWH in adverse social contexts (de Lange, Olivier and Wood, 2008). However, studies analysing tools such as interactive documentaries in health promotion are scarce. This study proposes a novel methodology for surveying whether interactive documentaries are effective audio-visual tools for tackling the structural stigma in communities affected by negative health identities.

Objectives and Methodology

In view of the above, the main objective of this study is to analyse how the device, narrative, and textual mechanisms of the interactive documentaries *Vertical/Horizontal* and *The Graying of AIDS* are articulated to unmask the stigmas associated with HIV and the cultural trauma associated with it. To do this, three secondary objectives are pursued: (1) to explore what operative aspects of interactive documentaries (platform, physical action, and degree of openness) are used to address disease stigmas and how they are articulated; (2) to interrogate these two interactive documentaries in terms of how they address and tackle the origins and dimensions (internalized and enacted) of health stigmas by connecting stories of individuals affected by or living with HIV; and (3) to analyse whether these interactive documentaries recreate the cultural traumas associated with HIV and the HIV epidemic in the 80s and 90s.

These two documentaries will be examined using a three-dimensional film analysis that pursues these three objectives. The first dimension will involve an analysis of the device with attention to the type of platform it uses and the nature of the user interface (UI), i.e., the physical actions that are required on the part of the spectator and the degree of

openness to participation it possesses. The second will be an analysis of how the stigma associated with HIV is represented, discussed, and articulated through the voices of both the social actors and the narrators. The third will be an examination of whether the documentaries, through their interaction mechanisms, will expose the cultural trauma associated with HIV and the origins of the pandemic. In conclusion, the two documentaries will be examined following a three-dimensional analysis: device, stigma and cultural trauma (see Table 2 later on).

Vertical/Horizontal: an app-documentary to update HIV information

Vertical/Horizontal is an interactive app-documentary produced in Barcelona (Spain) in which different participants offer testimonies from their own experience about HIV and the incidental conflicts associated with it. This project was the brainchild of Maria Jose Ferrer, a psychologist at the HIV Unit of Germans Trias i Pujol Hospital in Barcelona and the filmmaker Albert Kuhn of Factual Films. It brings together 35 PLWH of different ages, genders and sexual orientations who are presented in a talking-head format explaining different aspects of their experience living with HIV. The presentations are divided into 128 capsules, each one answering one specific question. There are 48 questions in all.

Vertical/Horizontal can only be viewed on smartphones after downloading the app, which opens with a screen that invites the user to start a new experience (Figure 1A). The authors of this documentary refer to the exploration of different questions related to daily life with HIV and its associated stigma as an experience. The home screen is worthy of analysis, as it presents watermark images, accompanied by a melodramatic melody, showing video excerpts of the beginning of the HIV epidemic in the 80s and 90s: young men in advanced states of AIDS, images of ACT UP demonstrations, footage of cells under a microscope, newspapers reporting thousands of deaths. Right from the outset, this opening transports the viewer to the worst moments of the epidemic, vividly depicting the cultural trauma associated with HIV, thereby positioning the viewer in relation to that traumatic past.

Once an experience is initiated, a video is shown with no title or context and then the first screen presents four questions; for each question, one to four participants provide answers (Figure 1B). Once a question and a testimony are chosen and the corresponding video is viewed, the user jumps to a new screen with four new questions and their corresponding testimonials. On each screen, the four questions are not related to the previous screen, and each time that a new experience is initiated, the questions are randomized. In this sense, there is no logical order or pathway that the viewer can choose to follow. In addition to the previous characteristics, it is worth noting that the 128 capsules are not accessible by any other means than through the app, even though each experience (that is, each sequence of answers) is saved in an archive that can be reviewed later, although it is not possible to search through the videos stored there. In consequence, in terms of the level of openness, users can neither search for content nor provide feedback, but they can generate their own narrative pathways. It can therefore be considered a semi-open interactive documentary.





Figure 1. *Vertical/Horizontal*, the interactive app-documentary fighting against HIV-related stigma. Picture A shows the webpage where it can be downloaded and the home screen. Caption B shows one of the character screens, the question he/she is answering, and the possible paths to follow.

In terms of content, *Vertical/Horizontal* stories have local settings, mostly in the city of Barcelona, but with a minority of stories portrayed in Madrid, and the characters speak in Catalan and Spanish. They openly reveal their fears, secrets, and histories of living with HIV, or how they dealt with knowing someone else who is living with the condition. The questions compiled in the app-documentary can be divided into three groups that are shown in table 1: (i) general knowledge about HIV; (ii) life with HIV; and (iii) HIV and stigma. In this sense, stigma is a specific topic of more than 30% of the questions, but it is not present on every screen. In addition, stigma is treated as a broad concept and framed only in relation to how people speak about HIV. In this sense, stigma is only understood as internalized stigma, while enacted stigma is not addressed. Moreover, the origins and sources of stigma are not exposed or examined.

Table 1. Classification of the questions in Vertical/Horizontal

Type of question	Examples
General knowledge about HIV	What is HIV?
	Are there more infections nowadays?
	Is there any risk in lesbian sex?
	Who are "longtime survivors"?
	Does taking drugs increase risk of infection?

	Should I take more precautions if I have sex with someone who is HIV+?					
Life with HIV	What does "serodiscordant couple" mean?					
	How does life change when I have HIV?					
	Will I have to take medication all my life?					
	What are my sexual relationships like living with					
	HIV?					
	How can I reduce the risk of transmitting HIV?					
HIV and stigma	Is there still social stigma nowadays?					
	When will the stigma disappear?					
	Should we speak politically correctly?					
	Why don't some people reveal they have HIV?					
	What differences between now and the past are					
	there in the social perception of HIV?					

The Graying of AIDS: stories from an aging epidemic

The Graying of AIDS is a participatory interactive documentary project and educational campaign that combines portrait photography with oral and video histories and health education materials to promote awareness, increase dialogue, and work for improvements in treatment of older adults at risk of or living with the virus. The project is co-directed by the video journalist Katja Heinemann and the health educator Naomi Schegloff. It first started as a stand-alone short documentary called *The Graying of AIDS: Women on Aging with HIV*, describing how three older women living with AIDS in different parts of the United States navigate the physical and emotional highs and lows as they challenge collective assumptions about what it means to live, and to age, with HIV. Nevertheless, the project soon evolved into an interactive documentary that allowed the authors to expand the initial portrait to a broader range of men and women whose stories were not organized linearly but intertextually connected.

The website where the documentary is accessible hosts stories that are 3-5 minutes long in a direct and impactful style. As all the testimonial participants are older than 65, most of the stories are memories of the worst years of the AIDS epidemic and are sad memories

of those turbulent decades. A 77-year-old Chicago man reflects on the beginning of the AIDS epidemic in the early 1980s: "It was terrible. We were pariah at that time. You don't want to dare tell anybody because they think terrible of you. They're accusatory: 'You're a dirty person. You've done something wrong.' No, this is just another illness in life. It's not damnation." A 73-year-old woman who was infected by a male friend and diagnosed with HIV at age 58 relates how little some things have changed: "You can have cancer; you can have multiple sclerosis; you can have bird flu, and that's acceptable. But HIV is not acceptable in any way" (Scheidt, 2014).

These characters, men and women of diverse origins and sexual orientations, express themselves in a talking-head format, talking openly about their experiences and fears after a long life with HIV. In consequence, *The Graying of AIDS* positions the viewer constantly in the context of the AIDS cultural trauma, making overt and constant references to images and imaginaries of the epidemic. The documentary has a global perspective about aging with HIV and speaks openly about internalized sigma; however, very few of the testimonials tackle enacted stigma, and those that do mention it do not refer to how such stigma is perceived or fought. However, it is worth mentioning that *The Graying of AIDS* website offers numerous toolkits to inform members of the Lesbian, Gay, Bisexual, Transgender (LGBT) and HIV communities about their rights in different contexts.

With respect to the device, *The Graying of AIDS* is explicitly identified as an ongoing work in progress, as the authors will continue to collect new testimonials that will be uploaded to the website. The various stories are placed in a mosaic of pictures showing the protagonist's face in a black background and a brief description. Each video has to be viewed separately and there is no linear connection between them. In a certain way, it could be argued that instead of an interactive documentary, *The Graying of AIDS* is a database of individual stories. Viewers can filter the videos according to age, gender, and place of origin (see figure 2), and feedback can be provided via the website and on social networks. Based on this data, the interactive experience seems limited and the degree of openness might be considered semi-closed.



I stop seeing the doctor because the doctor says, "You need to be on medication."

I rather, you know, feed my children.

Ella, age "nearly 50" / Selangor, Malaysia

>

Figure 2. Caption of *The Graying of AIDS* website and browser.

Conclusion

As stated above, the main objective of this research was to analyse how the device, narrative, and textual mechanisms of the interactive documentaries *Vertical/Horizontal* and *The Graying of AIDS* are articulated to unmask the stigmas associated with HIV and the cultural trauma associated with it. In order to carry out this research, a three-dimensional analysis has been conducted, exploring: (i) how the device is conceived (the platform, the actions required, and the level of openness), (ii) how HIV-related stigma is portrayed; and (iii) how cultural trauma is dealt with. The results of this analysis are summarized in table 2.

Table 2. Classification of the interactive documentaries examined by a three-dimensional analysis of device, stigma, and cultural trauma

Documentary	Device			Stigma	Cultural Trauma		
	Platform	Action	Openness				
Vertical/	App	Experiences	Semi-open	Local (Spanish), a lot of	The opening is a		
Horizontal		(pathways)		content devoted to	mosaic of images		
				information about	of the epidemic		
				internalized stigma and			
				how to deal with it but			
				does not tackle enacted			
				stigma or its structural			
				sources.			
The Graying	Website	Browse	Semi-	Women and men over 50,	Overt and		
of AIDS		testimonials	closed	global in nature.	constant		
		(database)		Internalized stigma is	references to the		

		explained, but none refer				80s	and	90s
		to enacted forms of			epidemic			
		stig	ma.					

Both documentaries reflect HIV cultural trauma with overt references to the epidemic. In this sense, they have lost an opportunity to move beyond an evocative narrative that impacts negatively on PLWH identity construction. The way the documentaries deal with stigma is similar: if discussed, only internalized stigma is addressed while the question of enacted forms of stigma and how they are produced is neglected. This is of particular relevance for *Vertical/Horizontal* given that it was created, according to both directors, to tackle and reduce stigma affecting newly diagnosed people. Finally, in regard to how the devices articulate interactivity, it was found that neither one is completely open, representing a missed opportunity to create openly interactive experiences. In this sense, neither initiative had exploited the real potential for interactive documentaries to offer interconnected, multi-level narratives, the submission of stories by viewers, or usergenerated timelines.

This study has proposed a novel methodology for surveying whether interactive documentaries are effective audio-visual tools for tackling the structural stigma in communities affected by negative health identities. It must be acknowledged, however, that more work needs to be done to expand this analysis to other interactive documentaries dealing with HIV, like HEALTHSMNET (already studied by Dobson and Ha, 2007), or to other health conditions highly affected by social stigma, such as mental health disorders. Nevertheless, the results obtained can be taken into account to explore and innovate in the ways participation and openness can be articulated when reflecting on stigma and cultural trauma in interactive documentaries, and can constitute a call to action for future filmmakers working in the field.

References

Alexander, JC (2004) Toward a Theory of Cultural Trauma. In: Alexander, JC,
Eyerman, R, Giesen, B, Smelser, NJ and Sztompka, P (Eds) Cultural Trauma and
Collective Identity. Berkeley and London: University of California Press.
Almeida A., Alvelos H. (2010) An Interactive Documentary Manifesto. In: Aylett R., Lim
M.Y., Louchart S., Petta P., Riedl M. (eds) Interactive Storytelling. ICIDS 2010. Lecture

- Notes in Computer Science, vol 6432. Springer, Berlin, Heidelberg
- Aston, Judit & Gaudenzi, Sandra (2012) Interactive documentary: setting the field, *Studies in Documentary Film*, 6:2, 125-139
- Berger, J., & Rand, L. (2008). Shifting signals to help health: Using identity signaling to reduce risky health behaviors. *Journal of Consumer Research*, 35(3), 509-518.
- Brown, J., Michie, S., Walmsley, M., & West, R. (2016). An online documentary film to motivate quit attempts among smokers in the general population (4Weeks2Freedom): a randomized controlled trial. Nicotine & Tobacco Research, 18(5), 1093-1100.
- Carpentier, Nico (2011). *Media and participation. A site of ideological-democratic struggle.* Bristol: Intellect.
- Chio, Insook (2009). Interactive Documentary: A Production Model for Nonfiction Multimedia Narratives. *Intelligent Technologies for Interactive Entertainment*, 9, 44-55.
- de Lange, Naydene; Olivier, Tilla & Wood, Tilla (2008) Participatory video documentary: just for whom?, *Education as Change*, 12:2, 109-122
- Dobson, MW, Ha, D (2007) Exploring interactive stories in an HIV/AIDS learning game: HEALTHSIMNET. *Simulation Gaming*, 39(1):39-63
- Eisinger RW, Dieffenbach CW, Fauci AS. HIV (2019) Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable. *JAMA*: 321(5):451–452
- Evans-Lacko, S., Brohan, E., Mojtabai, R., & Thornicroft, G. (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine*, 42, 1741–1752
- Gailienė, D. (2019). When culture fails: coping with cultural trauma. Journal of Analytical Psychology, 64(4), 530-547.
- Galloway, D., Mcalpine, K. B., and Harris, P. (2007) 'From Michael Moore to JFKReloaded: Towards a Working Model of Interactive Documentary'. *Journal of Media Practice*, 8 (3): 325-393
- Gao, X, Nau DP, Rosenbluth, A, Scott, V, Woodward, C (2010) The relationship of disease severity, health beliefs and medication adherence among HIV patients. *AIDS Care*, 12(4): 289-398.
- Grabowski, D. (2013), "Identity, knowledge and participation: health theatre for children", *Health Education*, Vol. 113 No. 1, pp. 64-79
- Gofman, E (1963) Stigma: Notes on the Management of Spoiled Identity. New York: Simon and Schuter.
- Guifreu Castells, Arnau (2013). El documental interactivo. Evolución, caracterización y perspectivas de desarrollo. Barcelona: UOC Press.
- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social identity, health and wellbeing: An emerging agenda for applied psychology. *Applied Psychology: An International Review*, 58, 1–23.
- Hatzenbuehler, M. L. (2016). Structural stigma: Research evidence and implications for psychological science. *American Psychologist*, 71(8), 742–751
- Hecht, M. L., & Choi, H. (2012). The communication theory of identity as a framework for health message design. *Health communication message design: Theory and practice*, 137-152
- Hudnall Stamm, B, Stamm, Henry, Hudnall, Amy & Higson-Smith, Craig (2004) Considering A Theory Of Cultural Trauma And Loss, *Journal of Loss and Trauma*, 9:1, 89-11
- Kansteiner, W (2004) Genealogy of a category mistake: a critical intellectual history of the cultural trauma metaphor. *Rethinking History: The Journal of Theory and Practice*, 8(2): 193-221
- Kinsler, JJ, Wong, MD, Sayles, JN, Davis, C, Cunningham, WE (2007) The Effect of

- Perceived Stigma from a Health Care Provider on Access to Care Among a Low-Income HIV-Positive Population. *AIDS Patient Care and STDs*, 21(8)
- Lee, R.S., Kochman, A. & Sikkema, K.J. (2002) Internalized Stigma Among People Living with HIV-AIDS. *AIDS Behaviour* 6, 309–319
- Lekas, H.-M., Siegel, K., & Leider, J. (2011). Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering. *Qualitative Health Research*, 21(9), 1205–1219.
- Lingard, H, Pink, P, Harley, J & Edirisinghe, R (2015) Looking and learning: using participatory video to improve health and safety in the construction industry, *Construction Management and Economics*, 33:9, 740-751,
- Major, Brenda, Dovidio, John, Link, Bruce, Calabrese, Sarah (2018) *Stigma and its implications for health: Introduction and Overview*. In: Major, B, Dovidio, J and Link, B (Eds) *The Oxford Handbook of Stigma, Discrimination, and Health*. New York: Oxford University Press.
- Markovitz, JC, Spielman, LA, Scarvalone, PA, Perry, SW (2000) Psychotherapy Adherence of Therapists Treating HIV-Positive Patients With Depressive Symptoms. *Journal of Psychotherapy Practice and Research*, 9(2): 75-80
- Mendes, L., Dos Santos, H. B., & Ichikawa, E. Y. (2017). Health and safety at work: analysis from the Brazilian documentary film Flesh and Bone. *Safety and health at work*, 8(4), 347-355.
- Nichols, B (2001). *Introduction to Documentary*. Bloomington: Indiana University Press.
- O'Flynn, Siobhan (2012) Documentary's metamorphic form: Webdoc, interactive, transmedia, participatory and beyond, *Studies in Documentary Film*, 6:2, 141-157
- Pachankis, J. E., Hatzenbuehler, M. L., Hickson, F., Weatherburn, P., Berg, R. C., Marcus, U., & Schmidt, A. J. (2015). Hidden from health: structural stigma, sexual orientation concealment, and HIV across 38 countries in the European MSM Internet Survey. *AIDS*, 29(10), 1239–1246
- Quinn, N., Shulman, A., Knifton, L., & Byrne, P. (2011). The impact of a national mental health arts and film festival on stigma and recovery. *Acta Psychiatrica Scandinavica*, 123(1), 71-81.
- Parr, H. (2007). Collaborative film-making as process, method and text in mental health research. *Cultural Geographies*, 14(1), 114-138.
- Rendina, H. J. and Parsons, J. T. (2018) Factors associated with perceived accuracy of the Undetectable = Untransmittable slogan among men who have sex with men: Implications for messaging scale-up and implementation. *Journal of International AIDS Society*, 21(1):e25055
- Scheidt, Rick (2014) Linking Up: The Graying of Aids, *The Gerontologist*, 54(1): 136–137 Shaw, Jackie and Robertson, Clive (1997). *Participatory Video: A Practical Approach to Using Video Creatively in Group Development Work*. London: Routledge
- Shea, H., Mosley-Howard, G. S., Baldwin, D., Ironstrack, G., Rousmaniere, K., & Schroer, J. E. (2019). Cultural revitalization as a restorative process to combat racial and cultural trauma and promote living well. *Cultural Diversity and Ethnic Minority Psychology*, 25(4), 553–565
- Simbayi, L, Kalichman, S, Strebel, A, Cloete, A, Henda, N, Mqeketo, A (2010) Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science and Medicine*, 64(9): 1823-1831
- Szomptka, P (2000) Cultural Trauma. The Other Face of Social Change. *European Journal of Social Theory*, 3(4): 449-466
- Turan, B, Budhwani, H, Pariya L. Fazeli, Wesley R. Browning, James L. Raper, Michael J. Mugavero, and Janet M. Turan (2017) How Does Stigma Affect People Living with

- HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. *AIDS Behaviour* 21, 283–291
- Villanueva Baselga, S (2015) Collaborative Practices in the Contemporary Documentary: A Proposed Analysis and Revision of the Participatory Mode in Documentary Theory. *L'Atalante. Revista de estudios cinematográficos*, 20.
- Whetten, K, Reif, S, Whetten, R, Murphy-McMillan, LK (2008) Trauma, Mental Health, Distrust, and Stigma Among HIV-Positive Persons: Implications for Effective Care. *Psychosomatic Medicine*, 70(5): 531-538
- WHO Commission on Social Determinants of Health (2008). Closing the gap in a generation. Health equity through action on the social determinants of health. Geneva: WHO, 2008. Available at http://www.who.int/social_determinants/en/