

Viral Voices

**Digital storytelling, women and HIV in *Podcast Positivos:*
Mujeres VIHvas project**

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ABSTRACT

Despite being considered as the "most social" infection, there is little data on HIV infection in women. Women have not been considered beyond their reproductive role as subjects with a sexuality that transcends the historical mandate of biological reproduction, maintaining a secondary role in the infection. At the same time, society seems to have forgotten that the infection is still present.

This thesis explores the voice of a group of positive women who, with their stories and through the digital narrative, will challenge the discourses that are established as hegemonic. In order to illustrate the potential of new tools as digital storytelling to disrupt and challenge the hegemonic *herstory* around women with HIV, the starting point for this thesis is *Podcast Positivos: Mujeres VIHvas* project.

Engaging with the theories of intersectionality, performativity and cyborg, it will be argued the use of language, voice and the role of listening. Phenomenological research and narrative discourse analysis will be applied as methodologies to, on the one hand, address the experience of HIV as an important dimension in women's lives and, on the other hand, use their stories as a way to understand the meaning of those experiences.

This thesis also discusses the creation of a cyber self, a *viralized voice* that is introduced into the already institutionalized podcast platform, to construct, deconstruct and challenge silences. Further, this thesis calls for an effort to listen, feel and write the stories of resistance of positive women and to put them into conversation within feminist academic debates.

KEY WORDS

HIV, AIDS, women, silence, voice, disclosure, hegemonic herstory, digital storytelling, performing narratives, intersectionality, cyborg, podcast.

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I GAVE OVER ONE FULL SECOND, IN MY HEAD AND MY HEART, TO ALL MY MOST EXTREME FEELINGS ...



Blue Pills: A Positive Love Story. Frederik Peeters (2015)

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1. INTRODUCTION.

A gendered picture of HIV today

Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious.

Sontag, 2015

What does it mean to discuss and reflect on HIV in the 21st century, more than three decades after the first medical descriptions of the infection?

The arrival of the AIDS epidemic meant a great change at the research level, not only in the microbiological, medical and health fields, but also in those spaces that involve human beings and their social behaviour. HIV is then an infection associated with fear, rejection, chronic illness, suffering, and death. It is undoubtedly a phenomenon that, due to its magnitude, involves different non-biomedical disciplines, such as anthropology, linguistics, and gender studies, which, based on discourse analysis among other qualitative research strategies, offer methodological alternatives to address social and health issues as cultural phenomena (Sevilla González et al., 2002).

Therefore, the constant search for new tools with which to address this phenomenon from a social perspective becomes a transversal axis; a hybrid between cultural, social, political practices, and activism, which proposes common actions through collective and collaborative methodologies. This performative nature is critical to understanding new practices around HIV and AIDS, as well as their *viral potential* as narratives seeking to break down the discourse that has been deeply entrenched in nearly four decades. Voice, as action, as sound and as performer of meaning becomes the focus of reflection. The discourse around the relationships between the self and the other is generated around voices (Martín Hernández, 2017).

And what does it mean to discuss and reflect on HIV and women?

Ya avanza el exterminio.

Eleva su oleaje. Lo abate, incontenible,

como un acto de amor.

Nadie escapa a la espada [...]

*Ten cuidado: hay en toda caricia
una amenaza. En toda lengua un dardo [...]
Y nadie sabe dónde, en qué labios estaban
sus semillas [...]
Rosseti, 1986¹*

As is widely known, in the first decades of the global crisis, HIV-positive women were made invisible by neglecting their voice, their struggles and stories, which contributed to a significant increase in HIV infections worldwide. This lack of visibility also led to the neglect of socio-cultural, economic, and psychological factors related to the construction of gender, thus increasing women's vulnerability to infection as they were excluded from access to information, prevention, early detection of the virus, and management and control of the disease (Fuster Ruiz et al., 2017; Mérida Jiménez, 2019).

Many activists have warned that women with HIV are often the most neglected population in HIV policies, guidelines, and strategies nowadays. Nevertheless, women now constitute a growing percentage of the population living with HIV. Around 18.8 million women worldwide are currently living with HIV, which is just over half of the total population of people aged 15 over-living with HIV. Transgender women, in particular, are 49 times more likely to be living with HIV than all adults in the reproductive age groups (Amin, 2015). This is one of the aspects that make the relation between women and HIV an increasingly relevant subject.

In addition to daily survival stress, women with HIV face other adverse life experiences related to the complex interaction of social identities that intersect with HIV, gender, race, and socio-economic status. These factors, along with other social determinants of health, have a strong influence on the health environment of women living with HIV. (Fumaz et al. 2019; Lennon-Dearing & Price, 2018.)

The discursive representation of HIV or AIDS in its different textual manifestations (such as chronicles, diaries, novels, and poetry) highlights the taboos, prejudices, and stigmas that are associated to both the disease and the carriers of the virus; a tradition

¹ One of the first Spanish literary texts on HIV - and AIDS - belongs to the poet Ana Rosseti (1986) and is dedicated to two of her friends who died of AIDS (Mérida Jiménez, 2019).

that is perpetuated since the moment that HIV makes its appearance. As stated by Lorde (1984), new tools are needed to dismantle and challenge these hegemonic ideas.

On this regard, it is the purpose of this project to listen to the voice of a group of *positive* women who, with their stories and through digital narrative, will challenge the discourses that even in the 21st century are established as hegemonic. This is the basis of *Podcast Positivos: Mujeres VIHvas*², a project developed by the State Coordinator of entities working with HIV and AIDS in Spain (CESIDA)³, which provides another dimension to a subject such as HIV by reflecting on the use of language, voice, and the role of listening.

Given the absence of women's voices and the archetypes perpetuated by those voices, the *Podcast Positivos: Mujeres VIHvas* project, and the use it makes of a digital platform as a speaker potentially allowing what I will describe as a *viral process*. Solving this crisis of representation - women and HIV - is important not only for all those who have been affected by the epidemic in one way or another, but also for the health of the HIV positive culture as a whole. To this end, it is essential to bring the existing representations of HIV to the fore, to rescue them from oblivion if possible, and to open spaces and platforms for their voice to be heard.

This research project is about stories and voices - stories and women's voices; stories and experiences embedded in the body - in an HIV-infected body. It is about recognising that the ways in which women narrate their experiences are not neutral, as they also embody a range of social attitudes and beliefs, so their stories can be seen as tools to give or subvert meaning (Méndez de la Brena, 2016).

This research is about understanding HIV as a viral process with cultural, social, and historical implications. It is about HIV as a material and discursive experience that shapes the specific circumstances of the bodies it occupies; bodies that are socially and discursively mediated. It is about questioning how gender discourses affect the ways in which HIV is experienced.

This research is also about storytelling, about telling HIV stories through women's voices. It is about how those stories affect our lives and what we do with these stories. It

² *Podcast Positivos: Mujeres VIHvas* literally means "Positive Podcast: Women Alive". *Positivos* refers to the serological status, HIV positive, whilst *VIHvas* refers to "alive", playing with the Spanish acronym for HIV in the construction of the Word (VIH). This play on words aims to equate *having HIV* with *being alive*. For this reason I decided to use the original name.

³ For more information, www.cesida.org

is about the stories that come to change those discourses and the ways in which women can challenge and disrupt them.

This research is about the materialization of the voice through a digital platform - *a viralized voice* -, a non-place as could be the radio waves from which to articulate words and rewrite and resist.

Finally, this work is also about resistance, the resistance of women with HIV. It is about becoming visible, about having a voice heard by telling a story in a different way. It is a work about the transformation, subversion, rupture, and destabilization of the hegemonic discourses. It is about creating narrative bridges, gaps, opportunities, new meanings to resignify HIV. But it is more than that: it is a work about stories of resistance, transgression, and survival of women with HIV.

In order to illustrate the potential of digital storytelling as a tool to transgress and change hegemonic stories about HIV through the voice of positive women, the starting point of this thesis is the *Podcasts Positivos: Mujeres VIHvas* project. This project was not only about the stories themselves, but also about the intersection of the production of the podcast episodes with its reception by the audience, which led to new understandings and new forms of interaction.

As AIDS spreads, so must the communication about fighting the virus. This project is an invitation to continue talking about HIV because, yesterday and today, SILENCE = DEATH⁴.

Aims and research questions

The history of AIDS will be full of silences, the silences of all the people who died among the fear and the stigma. The silence of the truncated lives of those bodies that did not understand how pleasure came at such a high price. Where did they articulate the words from? Were these the echoes of those silences that meant death? To speak about AIDS is to embody the shame of feeling oneself a survivor.

Carrascosa, 2019

⁴ SILENCE = DEATH is one of the best-known political icons in the fight against AIDS created by the Silence=Death Project collective, also used by ACT UP as a symbol of the fight against AIDS (Lebovici et al., 2019).

The AIDS crisis raised the decisive question of how the voice of the speaker - and the representation of the body - is constructed. Lebovici (2019) also questions the current representation of the self in relation to HIV or AIDS. Bodies are introduced into institutions in order to build and deconstruct norms, and to challenge the hegemonic discourse related to stigma. *The museum is always half empty. It is always half empty of us* (pp.32). Lebovici assumed it in first person, referring to all those identities and non-normative experiences that - in this case, the museum as an institution – had been ignored.⁵

Voice is also introduced into new institutions, such as the already institutionalized podcast platform, in order to construct, deconstruct, and challenge. The podcast platforms also seem *half empty* of identities and non-normative experiences, and the *Podcast Positivos: Mujeres VIHvas* project sought to fill that gap.

There is another crisis regarding representations. *How can we make visible a crisis that hits communities that are still invisible?* If there is a need for a greater presence of women in all fields, there is also a need for more works and interventions that reflect *from* women and *about* women around HIV.

The *exhibition space* is now a public place of information, education, action, and reaction - the podcast brings out this public space in which HIV-related issues can be discussed and thus, it creates a counter-public. The audience echoes the position of the podcast's protagonist by building a political self, by making the *self* of the infection/disease heard, and by deflecting and changing meanings through the women's experiences as HIV survivors (Lebovici et al., 2019).

In my role as an HIV activist and regular podcast listener, I was surprised to find a project that addressed HIV from the perspective of women in Spain. My daily life has been linked to HIV for some time now. However, and despite being aware of the factors that intersect with HIV - among which I include gender as one of the most important – it was only when I came across this project that I became aware of the significant lack of women's voices speaking about HIV. *Your silence will not protect you* (Lorde, 1977).

⁵ In the conference “All things queer, the impact of queer theory in contemporary art practices”, which took place at the University of Barcelona in 2019, Élisabet Lebovici referred to the intervention of Zoe Leonard at Documenta 9 in Kassel as an example capable of explaining how “*The museum is always half empty. It is always half empty of us*” (Lebovici et al., 2019, pp. 32).

Thus, I found this group of women as a confirmation of this, as well as the opportunity to make it part of my thesis project.

In doing so, I aim to gain a better understanding about the relationship between social discourses on HIV, AIDS, and gender. I also seek to shed light about the link that is created in the use of voice through a digital tool - the creation of a cyborg *self*, a viralized voice. This cyborg self has the potential of changing the hegemonic discourse that nowadays continues to fuel the pandemic through its narrative and performance.

In the present analysis of the *Podcast Positivos: Mujeres VIHvas* project I would like to address the following research questions:

- How can new tools as digital storytelling disrupt and challenge the hegemonic *herstory* around women with HIV?
- What is still silenced in the lives of women with HIV?
- How does the *listening community* interpret first-person stories about women living with HIV through digital storytelling?⁶.

In order to respond to these issues, the content of narrative pieces from the *Podcast Positivos: Mujeres VIHvas* project will be analysed. The project consists of a total of 8 podcasts: 7 of them one-way conversations led by 7 different women. The last podcast is a conversation between the 7 protagonists of the previous chapters.

In the process of delimiting the object of study, it is also necessary to ask: What is a research without the researcher's own interest? Despite the effort to objectify the social sciences by means of measurement techniques, it cannot be forgotten that the characteristic reflexivity of the researcher will make it her own object of study, in relation to the construction of the research design and the decisions that are taken as the investigation develops (Yarad, 2018). And here my interest in silenced stories - those of women and HIV - and the search for new creative tools - digital storytelling and radio podcasts - to dismantle hegemonic stories about HIV (Lorde, 1984).

Research that has been conducted specifically on digital storytelling and its role in reducing HIV-related stigma is limited, and focuses predominantly on how to reduce

⁶ *Does becoming visible mean being heard?* In the case of this thesis and due to the restrictions imposed by the COVID-19 pandemic in Spain, the *listening community* is limited to me as principal investigator and listener. However, in future research I would like to broaden the focus, and for that purpose, here I develop the methodology that I would like to apply to reach the *listening community*.

shame, and therefore stigma, for those involved in the project rather than on how the stories affected the audience attitudes. My focus is on how the digital storytelling created a critical space for participation and on how, in doing so, it enabled participants to learn to identify and address issues related to HIV and AIDS-related stigma, as well as to take charge of effecting change in their *listening community*.

Under what conditions can people living with HIV give public voice to their stories? This thesis will look at the processes by which people living with HIV make themselves heard and visible in the media. The study also attempts to analyse the reception of first-person stories: Who has access to these stories? What resources are needed to do the 'work' of listening? (Nengeh & Haig, 2012).

Previous research

[...] it remains a challenge for literary and cultural criticism to think about AIDS in terms of women.

Suquet, 2019

In this exercise aimed at creating and deconstructing stories within the HIV culture over the past decades, a number of AIDS-related exhibition, archival, and exhibition projects proliferated. Some developed by people from generations who lived through the crisis. Others, by those who were born around the official date of the virus' emergence and grew up with the epidemic already stifled thanks to the development of antiretrovirals which, while failing to cure the infection, leave the virus undetectable and reduce HIV-related morbidity and mortality - in the context of which antiretrovirals are accessible. AIDS has not disappeared, as it continues to spread stealthily (the World Health Organization's estimations should not be ignored: more than 36 million people worldwide are infected with HIV) and much of this research aims at making it visible again (Mérida Jiménez, 2019).

Despite this proliferation, "it remains a challenge for literary and cultural criticism to think about AIDS in terms of women," mentions Suquet (cited in Mérida Jiménez, 2019, p.111), highlighting the scarcity of female voices, and the archetypes that, even from hegemonic voices, have been perpetuated from the expulsion of women in the majority and dominant writing of the epidemic.

Empowering people living with HIV to improve their health and emotional well-being has become an important priority for the public health industry (Fumaz et al., 2019). Understanding what women consider as important aspects of their experience of living with HIV can provide valuable information that could improve the few policies and interventions aimed at improving their quality of life and increasing their visibility. As it concerns the Internet, it is increasingly being used as a medium for storytelling and visualizing both health and disease, making digital storytelling a valuable means to help address public health issues (Gray et al., 2015).

One strategy of participatory research identified as an effective and empowering tool for communicating the personal experiences of women living with HIV is the documentary photography method of photovoice. Projects that used this methodology in order to combine the voice and the photography of women living with HIV include those carried out by Robin Lennon-Dearing and Justin Price from the School of Social Work at the University of Memphis (Lennon-Dearing & Price, 2018) and the CESIDA's online project *ITINERANTAS*.⁷ The purpose of this research was to encourage women to share their stories about the reality of living with HIV through photographic documentation and critical dialogue with their peers about the challenges they face, how they overcome those challenges, and what hope they have for their future. This contributes to the visibility and empowerment of women living with HIV by improving knowledge and reflection on HIV, while also generating support networks among participating women.

A new generation of voices is ready to speak out, lead, and empower others in their HIV communities. Emerging technologies, social and gender inequalities, and the ever-present effects of stigma keep navigating this challenging paradigm. Hence, in the search for this new generation of voices speaking out on HIV, we can find a variety of interesting podcast projects, such as: *Storytelling in the waiting room*, a small-scale project in rural health clinics in South Africa's Limpopo Province (Zeelen, J. et al. 2010); *Inside HIV*⁸, a weekly podcast from Australia based on the experience of people living with HIV and the latest research aimed at creating a reference archive; *Positively Alive*⁹ from the UK, an NGO project under the same name aimed at normalizing HIV

⁷ Photovoice online project developed by CESIDA and *La Doctora Álvarez*, promoters of the project analysed in this thesis. More information at: <https://itinerantas.org/>

⁸ More information on its website: <https://viivhealthcare.com/en-au/community-partnerships/inside-hiv-the-podcast-for-positive-people/>

⁹ More information on: <https://www.stitcher.com/podcast/positively-alive>

and working on stigma; or *Platicando en Positivo*¹⁰, from the Mexican Institute of Radio, with the aim of informing and sensitizing the audience about what it means to live with HIV by sharing the life stories of people living with the virus.

Previous qualitative studies of women with HIV using journals, life histories, and structured interviews tend to focus their discussion on the area of biomedicine rather than on the social area, especially related to quality of life (Fumaz et al., 2019) or mental health (Orza et al., 2015). These works often focus on a specific variable of interest to researchers without reflecting on the issues that women themselves might have chosen to focus on, as they significantly affect their lives. In other words, they do not engage the voice of the protagonists (Brody et al., 2016).

Therefore, research on the processes and consequences of disclosure has rarely addressed or assessed the public telling of stories about HIV and the use of media by people living with HIV (Nengeh Mensah & Haig, 2012). In a similar manner, the analysis of these projects from the perspective of reflecting on the use of language, the place of listening, and the importance of affective narrative as an antidote to the stigmatization of people living with HIV remains overlooked, particularly in the Spanish context.

Before starting:

- ***Women and HIV: categorizations and vulnerabilities***

Silence is still a constant for those living with HIV, as new infections are constant and progressive. Of course, those who become infected are poorer, more marginalised, and in that group there are more and more women.

Dillon, 2004

Opening the door to the analysis of women's experiences can be a contested battle. It seems that the category of “women” carries the stigma of being essentialist in feminist discussions, to the point of becoming an invalid or even unconventional word. The main argument lies in the problems of situating “women” as a category of analysis without assuming “that all women, across classes and cultures, are somehow socially constituted

¹⁰ Podcasts can be played at: https://www.ivoox.com/podcast-platicando-positivo_sq_f1794789_1.html

as a homogeneous group" (Méndez de la Brena, 2016, pp. 29); that is, contributing to the false idea that all women experience the same problem simply because they are women.

In this thesis I will focus on, and refer to, the participants as women/women. Taking the risk of excluding the rest of the people related in one way or another to HIV honours the feminist political project which considers that the category of "woman" remains indispensable for feminist politics and knowledge production (Méndez de la Brena, 2016), in addition to being supported by the material from which this research is originated.

On the one hand, we find the scientific material used as a framework. Despite being considered as the "most social" infection, HIV infection is part of a clinical diagnosis. Both gender bias and gender blindness are the most frequent limitations presented in scientific research in general. There is little data on HIV infection in women. Their inclusion in clinical trials is still very limited and the focus so far has been on those directly associated with sexual and reproductive health: pregnancy and gynaecological conditions (Galindo Puerto, 2014). In Spain, with a few exceptions, there are few studies that address the phenomenon from a socio-cultural perspective, allowing thus biomedicine to be the privileged space for generating discourses on the disease (Mérida Jimenez, 2019).

On the other hand, we find the material analysed in the research. *Podcast Positivos: Mujeres VIHvas* is a project that has already been developed and completed. I am focusing on the categories that are marked on it and in which there is a marked binary distinction between sexes, with all the participants identifying themselves as women/women.

The history of AIDS has made it clear that the role that women have been given within it is under the prism of the transmission vector (children or sexual partner). Women have not been considered beyond their reproductive role as subjects with a sexuality that transcends the historical mandate of biological reproduction, maintaining a secondary role in the infection. As Judith Butler reflects on (cited in Martín Hernández, 2010, pp. 23) "the only sex qualified as such is the male, which is not exactly marked as male, but which struts to be the universal sex, quietly extending its dominance. To refer to a sex

that is not, is to refer to a sex that cannot be uniquely designated as sex but is excluded from identity from the outset".

Ironically, HIV today has certain very distinct characteristics: its face is increasingly feminine, younger, and poorer. From a biological standpoint, research evidence suggests a physiological vulnerability. In unprotected sex with vaginal penetration, the vaginal wall provides a larger surface area of mucosa exposed to sexual secretions, of which the semen has a higher concentration of virus, and thus the chances of becoming infected with HIV are higher (Fuster Ruiz, et al., 2017; Martín Hernández, 2010). Biological factors are responsible for women being 2-4 times more vulnerable to HIV infection than men (Galindo Puerto, 2014).

However, this physiological vulnerability is not the only one in a global problem related, above all, to the power of women in different societies. The context of gender inequality places women at greater risk of being infected and affected by HIV. Although physiology influences women's greater risk of HIV transmission, it is the inequality in their bodies and sexual lives, supported and reinforced by social and economic inequality, that makes them a vulnerable group to HIV, as well as being excluded from most clinical trials of antiretroviral treatment and other drugs, whose results are extrapolated from studies carried out mainly in men (Galindo Puerto, 2014).

Women have been made invisible in the major debates and research on the pandemic, so it is not enough to restore or re-establish their visibility. Integrating the concept of "woman" without analysing and critically reflecting on how "women's" identities and groups are constituted would, and in fact does, inevitably lead to another type of visual atrophy. At the same time, if women as a group are more vulnerable, vulnerability among women themselves is further fragmented by a combination of factors such as race, class, age, ethnicity, urban/rural location, sexual orientation, religion, and culture (Martín Hernández, 2010).

The challenges of women living with HIV are still present in the era of the *Undetectable equals Untransmittable*.

- ***Storytelling: the “power” of stories***

[...] the female narrative on AIDS focuses primarily on filling a gap - that of the female body with AIDS, identified as too problematic, an image to be fully represented in the

cultural space - and on managing the representation of themselves as women, insofar as this brings into play the administration of individual and collective memory, and the production of subjectivities.

Suquet, 2016

Given the wide range of types and uses of stories, I will here use the brief and generic definition proposed by Smith (cited in Colino Rodríguez, 2017). Stories are “something told by someone for someone”, which, by incorporating the relational element “for someone”, invites us to consider the social and cultural context in which stories are told. Conditions such as background, time, language, family, and culture influence the way a story is told and understood. In addition, the context and the positioning between the narrator and the audience contribute to the type of story and to the interpretation that it is made of it (Méndez de la Brena, 2016).

Storytelling commonly refers to the oral communicative act of transferring stories to a given audience, and it has been seen as an important communicative tool for understanding the complexity of human experience, being considered as one of the most ancient art forms (Palacios et al., 2015).

When stories are told from one person to another, they are *co-created* - the audience generates mental images and interprets the story as it is being told, or constructed, by the narrator (Palacios et al., 2015). Implicit in this approach is the assumption that stories matter, because they do things. Stories are more than a reflective experience; they are performative because stories produce what they name (Butler, 2011).

In this sense, stories can be used to disrupt the way in which the storytellers and the community of listeners think about HIV, to change the type of language used to refer to infected and affected people, and, in turn, to change the meaning of HIV-related stigma. This can consequently provide us with the opportunity to challenge wider social and cultural discourses, as it provides us with the ability to situate the experiences lived by the storytellers.

To this effect, it is particularly relevant to question what kind of stories are transmitted, what these stories are, how they shape women's lives, and why they are important. Within anthropology and history, storytelling has shown the importance of introducing

voices, stories, and perspectives from the margins, from those who are underrepresented (Colino Rodriguez, 2017). In the case of HIV history: the voices of women.

- *New digital health technologies: the podcast era*

Technology has introduced storytelling into the digital age to give voice to the daily life stories as experienced by ordinary people, expressed in their own words and terms through a technological platform (Mnisi, 2015). Digital storytelling has flourished because of the increased access to technology for international audiences through the Internet.

This digital storytelling involves the overlapping of personal narration with emerging digital technologies for dissemination, combining the art of storytelling with a variety of multimedia techniques, such as images, audio, and video (Gray et al., 2015). Digital storytelling, used as a method of data generation in participatory research, has the potential to democratize research: participants control what they want to share, how they want to present it, and how they want to make their stories heard. As a form of political activism, it has the capacity to mediate the perceptions of others who challenge the dominant value systems that seek to exclude.

In this sense, new digital technologies are positioning themselves as innovative means to promote health, by making digital storytelling a valuable tool to address public health issues. The Internet is being increasingly used as a way to tell stories and visualise illnesses (Gray et al., 2015).

Human bodies interact with technologies in various ways, and the use of mobile devices is a transversal phenomenon in our everyday life. The techno-utopian visions of what biotechnologies can offer to the humans as identified in Haraway's writings in the 1980s, are clearly evident in contemporary representations of digital health technologies (Lupton, 2015).

Today, where the use of mobile media is central to the way in which information is communicated in both urban and rural areas, digital stories, as the digital data they are, can be easily transferred through popular social networks. This is key to the *renaissance* of the podcast, which is growing at a dizzying rate. Podcasts are everywhere and they are increasingly consumed by audiences because of its ease of use, immediacy, and relaxed format, and because of the ability to listen to the programmes on a delayed

basis. Last year, 46.2% of Spanish Internet users listened to online radio, and podcast consumption increased to 30.2% according to the Association for Media Research (AIMC)¹¹. However, in this third podcast era, now known as Big Podcasting, is there room for everyone? The digital gap refers to the unequal distribution in the access, use, and impact of ICT based on intersections such as social class, age, race, and gender (Yarad, 2018). Due to the economic factor, the use of new technologies is unequal throughout the world. Therefore, this new era of podcasting could reproduce such forms of exclusion, as consumption generates a kind of stratification between those who follow the established rhythms and those who are left out.

The ownership of this type of technical object does not imply the disappearance of social stratification, but rather a simulation of the homogenisation of these social classes through certain goods (in this case technological). Despite the fact that these digital devices are no longer distinctive goods, their forms of access and use are indeed distinctive: the fact that a subject possesses different technological items does not imply that this person's "technological capital" is high, as it is the use that this person makes of them and their exploitation that gives meaning to these practices (Yarad, 2018).

¹¹ The Association for Media Research (AIMC) is constituted by a large group of companies whose activity focuses on communication, both in its informative and commercial aspects, with the aim of finding out what media consumption is like in Spain. More information on their official website: <https://www.aimc.es/en/what-is-aimc/>

2. THEORETICAL APPROACHES

The idea of chronic disease that prevails in Western countries has not followed a similar path in its social representation. To this question, we must add the loss of that urgency experienced decades ago and all that it entails. The HIV epidemic is not an epidemic with similar characteristics globally, but rather a set of interrelated epidemics quite different in nature, with unequal causes and effects, that affects very different people. The multitude of ways of approaching the topic from different theories allows us to get closer to the polyhedral reality of HIV (Martín Hernández, 2017).

Intersectional voices

Class, age, 'race', nationality and dis/ability all impact profoundly on the social construction of AIDS, and on the ability of individuals to respond to the epidemic, to protect themselves from HIV infection or to get appropriate care if they become infected, on the policy agenda and, ultimately, on who dies and who survives.

Wilton, 1997

Intersectionality has acquired the status of an important cutting-edge theory in the international feminist debate (Bredström, 2008; Lykke, 2010). Kimberlé Crenshaw defined the concept in 1989 by making use of the metaphor of a traffic junction in order to illustrate how various axes of domination intersect and impact on each other (Crenshaw, 1989). Intersectionality is not a question of adding a form of oppression to the other, but a way to explore how different systems of oppression (gender, race, class, age) are mutually constructed (Collins, 1998).

Applying an intersectional theory to HIV research is not new. Feminist research has shown that gender is a crucial factor in understanding the phenomenon of HIV, no matter what aspect of the pandemic we try to analyse, thus contributing to the deconstruction of the dominant discourses on HIV. In *Intersectionality - A challenge for feminist HIV/AIDS research?* Bredström (2006) highlighted some ways in which feminist HIV research would benefit from an intersectional approach. This approach not only involves focusing primarily on the intersections between the different axes of subordination, but also on how they work to support each other.

This is also the main way in which intersectionality is used in this thesis: as a critical tool to expose how the discursive constructions embodied in the hegemonic *AIDStories* produce and reproduce the power and gender relations around HIV narratives. Distillation and deconstructive acts are key to this process.

During the analysis of the podcasts, some of the dimensions identified cut across the narratives around the experience of the disease (Gianni, 2008). The analysis of the narratives addressed the search for meaning within the experiences narrated in the episodes, by dividing extracts crossed by similar intersections into common categories that allowed new overlapping meanings to emerge. Gender constructions not only impose conditions of specific social vulnerability on each other, but also differential possibilities and limits in everyday life.

Although the concept of intersectionality has acquired status and has been widely accepted, it has also received some criticism, based on the generation of essentialist constructions of identity (Bredström, 2006).

Performing narratives

Performing narrative focuses on doing things with words and asking what difference(s) it makes to do it.

Langellier & Peterson, 2004

Richard Menary (2008) suggests that narratives are constituted by thoughts, feelings, and perceptions that are rooted in the human body, affecting the way a story is told. As a result, the story and the experience of the body find their way out through the narrative. In this sense, we can recognise women's bodies as the condition through which they experience the world, and storytelling as a tool for making stories that link the body, the story, and the experience with their journey with HIV. Narratives involve an active exploration of new ways of being in the world. As a new subject appears, it recovers and reconstructs its history. They are subjective stories, experiences expressed from the verbal and the physical scales (Gianni, 2008).

Storytelling is a form of narration that encompasses both the telling of a story-*performance* - and the impact of the story told - *performativity* (Butler, 2011). This way, storytelling is a performative act in which a story becomes an active force, an active doing.

Women's stories, such as those gathered in the *Podcast Positivos: Mujeres VIHvas* project, are part of specific social, cultural, and historical contexts. It is their stories that shape their narrative, their meaning, and their effects. Furthermore, as telling a story is not an act without a voice, the voice becomes the instrument with which the story is told (Méndez de la Brena, 2016).

If stories can transmit, reproduce, and legitimise hegemonic discourses, they can also expose, reveal, revise, and disturb them. In this sense, if women's stories do something in the world, they can also undo it (Butler, 2011). The performativity of these stories shows its potential for creativity and resilience, with the ability to subvert practices, norms, and conventions around HIV.

Thus, through an exploration of the theories of performance and performativity, I introduce storytelling as an act with the power to subvert hegemonic ideas about HIV. Hegemonic *AIDStories* are present in social institutions, influencing the way in which women with HIV describe and live their own lives. However, in the very act of telling the story, the same protagonists can subvert these hegemonic ideas about what it is like to be a woman with HIV and, therefore, create a counter-history.

I explore the meanings that the women in this project attribute to HIV, what they think of it and how they feel about it as represented in their stories. I focus on HIV as a bodily experience discursively embedded in their stories. I analyse extracts from the podcast episodes in order to reveal the dominant narratives in which the protagonists' stories are embedded and how they shape their experience of living with HIV.

Radio Cyborg

[W]e are all chimeras, theorized and fabricated hybrids of machine and organism; in short, we are cyborgs.

The cyborg is our ontology; it gives us our politics.

Haraway, 1989

The cybernetic notion of transgressed borders and filtered distinctions finds its immunological reference in the discourses on AIDS. Awareness of the presence of viruses has broken down the traditional demarcations of the body, blurring the

boundaries between inside and outside. The realities of HIV dissolve the limits of the discrete body, and the cyborg, still in need of connection, integrates it into its discursive network (Fraiberg, 1991).

Today we are moving from a written society to a cyber-oral society, from an organic society to a digital society. This can be seen in the planetary extension of the Internet, the generalisation of the use of mobile computer technologies, the use of artificial intelligence and algorithms in the analysis of big data, or the exchange of information at great speed. Teleworking and remote control devices are now in our hands 24/7.

Given this reality, it is easy for post-modern representation theories to predominate in approaches and practices that place "the body" within networks and systematised circuits. In this sense, we have Latour's (1992) concept of "shared agency" about the way in which technology and subjects are linked by its use and the relationships that are created around these devices. Under this perspective, therefore, elements are considered on the same level as a technological device such as a mobile phone, information, people or institutions, as they all participate in and condition social interaction. Thus, the technological device, for example, is an agent that in its interaction with the user allows him to construct new messages and different discourses. In this way, both condition each other and new options and paths emerge from their interaction and shared agency (Yarad, 2018; Lykke, 2008).

However, far from resisting this new paradigm of how we should feel (Paranoid? Horrified?) I follow Haraway's approach, which tries to focus on what to do, how to proceed and how to start thinking about pro-active strategies (Fraiberg, 1991).

In this way, by starting from Latour's concept of shared agency and continuing through the exploration of Haraway's cyborg theory, I introduce this thesis in the analysis of the relationship of women living with HIV by leading the *Podcast Positivos: Mujeres VIHvas* project with their voice to see how it materializes through the podcast. The foundation of cyborg gender, as suggested by Haraway, is to call for an encoding of communication and intelligence in order to subvert order or power. Cyborg technology blurs the barriers between humans and technology, the body and the electronic brain. It destroys the points of reference, the self, and rejoices in the imperfect and unfinished, in the illegitimate union of the human-machine, in the noise-voice of the podcast as a

proposal that tries to overcome the spatial and temporal dimension of the human species (Anta Félez et al., 2016).

Although new communication technologies and biotechnology lead to the cyborg, as a paradigm of the new codification of the human body, I take into account not only that these technologies do not affect equally all genders, groups, and ethnicities but also the social stratification that they entail through the already mentioned *digital gap*.

3. MATERIAL AND METHODOLOGICAL APPROACHES

Feminism is, in part, a project for the reconstruction of public life and public meanings; feminism is therefore a search for new stories, and so for a language which names a new vision of possibilities and limits

Haraway, 1991

Stories are the main source of the content of the experiences of the women participating in the project I am analysing during this thesis, *Podcast Positivos: Mujeres VIHvas*. Therefore, I tried to find a methodology that would allow me to address my research objectives. As my research questions focus on stories told through a radio podcast, on the ways in which the protagonists give meaning to these stories and challenge existing meaning, I needed to find a methodology that allows me to reflect on the experience of HIV, trying to make sense of it through storytelling.

On the one hand, I rely on feminist phenomenological research to address the experiences of women and HIV. Phenomenological research states that reality can only be understood through experience (Méndez de la Brena, 2016). In our case, this experience involves how the world is perceived from the body of an HIV-positive woman, the body of a woman living with HIV.

On the other hand, the analysis of the narrative discourse we found in the material used in the research, *Podcast Positivos: Mujeres VIHvas*, allows me to study the ways in which women have narrated these experiences. Narrative discourse is seen as more than just oral or written language, it is about how language is used in the reality of social contexts. Stories make our experiences present (Urrea et al., 2013). Phenomenological research and narrative discourse analysis are considered both the phenomenon and the method, since at the root of these two methodologies we find the belief that experiences and stories give meaning to people's lives and, as such, both (experiences and stories) are treated as data. Both methodologies offer me ways to make sense of the experiences of the project's protagonists and, at the same time, to position them within the powerful field of academic knowledge.

Before exploring the chosen methodologies, I would like to situate the feminist project that I will analyse, which is nourished by the use of storytelling and the digital platform, and from where data is obtained: the project *Podcast Positivos: Mujeres VIHvas*, along

with an interview with the coordinator and promoter of the project, *La Doctora Álvarez*.¹²

A group of women living with HIV in Spain and a team of radio artists from *La Doctora Álvarez's* team collaborated in the digital storytelling project *Podcast Positivos: Mujeres VIHvas*. The aim of the project was to create a space and speaker for stories of women and their way of living with HIV with the intention of challenging what it means to be a positive woman. First-person stories about living with HIV are portraits or narratives based on personal experience of being HIV positive (Gray et al., 2015; Nengeh Mensah & Haig, 2012).

This work also seeks to respond to a feminist political and academic commitment. It does not intend to deliver universal, univocal or fixed results. Women's experience should not be seen as a category prior to the social facts, discourses, and practices through which it is articulated. The “women's experience” does not pre-exist as a prior source, ready to be appropriate in one description or another. Experience can also be re-constructed, remembered, re-articulated (Haraway, 1991).

Podcast Positivos: Mujeres VIHvas Project

What is being positive? It is to be optimistic, cheerful. It is looking with eyes of illusion at each of the challenges we have to face in life. For the 7 women who have participated in this project of podcasting creation, the word "positive" also describes their serological state.

This is how the State Coordinator for HIV and AIDS in Spain (CESIDA) announced on its website the project whose content and discourse I intend to analyse in the development of my thesis. The project was developed during 2019 in collaboration with *La Doctora Álvarez*, coordinator of the project, and funded by the Spanish Ministry of Health, Consumption and Social Welfare through the public call for personal income tax 2018.

¹² *La Doctora Álvarez* is a science communication agency specialized in the field of health and science communication consultancy, founded by Débora Álvarez, BA in Sociology, PhD in Surgery, Medical and Social Sciences, and MA in Radio Communication. For more information: <https://ladoctoraalvarez.com/>

Once the project was approved, CESIDA launched a call for proposals to social organisations in Spain that work with HIV, in search of positive women participants from all over Spain to design and elaborate a podcast programme that would be coordinated by *La Doctora Álvarez* and later published in the free and universally accessible podcast platform iVooX¹³.

The first phase of the fieldwork took place during the first semester of 2019 in a common geographical point: Madrid (capital of Spain). During this phase the 7 participants were invited to a rural cottage where they had access to Internet in a computer laboratory, and where they could work together, during a weekend, without interruption, coordinated by *La Doctora Álvarez*. Although there were 12 places available for participants, *there is little demand in general, I think because women with HIV are generally afraid to share HIV-related spaces (extract from the interview with La Doctora Álvarez, 2020).*

During several sessions, training was given on the principles of radio language, the functions of the sound technician, as well as on how to write a script and do interviews. This was done in an interactive way, so participants could also get to know each other, as they came from different geographical points in Spain, and build networks, which was another objective of the project.

Participants were asked to choose an HIV-related topic on which to base their episode. They were also trained in different creative techniques to be included in their podcast or accompanying music, so that they could begin writing their script. They had complete freedom to identify themselves, promoting thus the privacy that voice over radio allows. Each episode was intended to be different, as they were a reflection of what the protagonist was trying to narrate. The only part that had to be similar was the closing. Each episode ends with a statement called '*I am this*', a life story where the protagonists tell how they perceive themselves and discuss the role that HIV plays in the construction of their identity.

Thus, each episode is divided into parts with different protagonists: a first-person narrator, a narrator who addresses the listener, then an external narrator who intervenes,

¹³ The open link is https://www.ivoox.com/mujeres-positivas-mujeresvihvas-musas-violencia-audios-mp3_rf_41945960_1.html. At the beginning I had the idea of transcribing the podcasts, but since it would be a transcription and translation exercise (the podcasts are narrated in Spanish) I would consider carrying it out in a future more in-depth research, as a project to be developed in the long term.

etc. In this way, the story is composed of fragments told from different perspectives. Likewise, chapters do not respect a chronological order, as they constantly alternate present, past, and future.

The second phase of the project took place during a second weekend of retirement in the second semester of 2019. During the time between the first and the second phase, participants had to work on the contents they wanted to include in their episode with the techniques they had learned in order to edit the episode and to proceed with its broadcast. In this last retreat, in addition to the individual creation of the seven episodes, a collective episode was produced as a closure in which all the participants were involved in a kind of debate moderated by *La Doctora Álvarez* and broadcast live on a community radio station in Madrid called Radio Vallekas¹⁴

In total, the *Podcast Positivos: Mujeres VIHvas* project consisted of 7 individual episodes of approximately 20-30 minutes, alongside a live broadcast collaborative episode of approximately 50 minutes.

- *Episode 1 - Muses and violence.* Featured by Luna - fictitious name. Young migrant woman - the youngest in the group - recently diagnosed. The topic she chooses to address is violence and HIV in women.

The rest of the women in the following episodes share the profile of a woman in her 50s and 60s, who was diagnosed at the beginning of the pandemic in Spain (1990s).

- *Episode 2 – AGAVIHda.* In this podcast, Cándida Álvarez from the AGAVIH association talks about sexually transmitted infections (STIs). Cándida is one of Spain's best-known female HIV activists.
- *Episode 3 - Carmenza, there was silence and you were hurt.* Carmenza narrates how having been sexually abused as a child impacted her life and how silence shaped her path. At 27 she was diagnosed with HIV and at 33, she was diagnosed with bipolar disorder. She has recently made herself visible after a lifetime of living with HIV.
- *Episode 4 - Empower yourself with Gretta.* In this podcast, Gretta shares her thoughts on when she was diagnosed with HIV and how she coped with it. She identifies herself as not visible.

¹⁴ Radio Vallekas is a community radio in one of Madrid's neighborhoods (Vallecas). More information: <http://www.radiovallekas.org/>

- *Episode 5 - Undetectable = Untransmittable.* Andrea Petrocheli discusses what U=U (Undetectable=Untransmittable) means - how having an undetectable HIV viral load makes a person unable to transmit the virus. Diagnosed in the 1990s when she was 20 years old - she is now 40 years old.
- *Episode 6 - My first radio churumbel* (Churumbel, a word from the Romany slang meaning son, child). In this podcast, Sonia 'La Faraona' explains how the HIV epidemic began and how the first affected people experienced it and the stigma that remains. Sonia also shares how HIV impacted on her life, with the help of her 15-year-old daughter, Graciela. She has been living with HIV for 31 years.
- *Episode 7 - Look at me with different eyes.* Arancha speaks about health workers' stigma towards people living with HIV. She was diagnosed at the age of 20, and this year marks her 30th year living with HIV. In her process of disclosure.
- *Episode 8 - Live program Mujeres VIHvas.* In this programme, which was broadcast live in June 2019 from *Radio Vallekas*, the women who participated in the *Podcast Positivos: Mujeres VIHvas* project describe the experience of having participated in this initiative.

The project *Podcast Positivos: Mujeres VIHvas* uses a set of resources, such as: the voluntary anonymity of the protagonists and guests, the free indirect discourse, the fragmentation of narrative time -highlighting the density of affections created and staged-, the marked prevalence of positive female figures, and the representation in the final chapter of the "family", created during the development of the project as a place for the practice of an ethic of care (Meruane, 2012).

People living with HIV may share several motivations for media testimony, such as educating the public, challenging stigma, expressing themselves creatively, and re-articulating categories of knowledge and power relations (Nengeh Mensah & Haig, 2012). First-person accounts can also provide important opportunities for personal development, education, and access to support and services, and the expression of solidarity in relation to shared concerns.

○ *Interview with La Doctora Álvarez*

From the most classical schools such as Merton and Kendall (1946) it is argued that the semi-directed or open-ended (semi-structured) type of interview provides, unlike other techniques, depth, specificity, and breadth of response. These *face-to-face* meetings between researcher and interviewee become flexible and dynamic conversations in which the informant provides the researcher with first-hand insight, opinion, and reflections on a given topic as a series of questions are asked.

In this thesis I wanted to approach the origin of the project through an open dialogue with the coordinator of the project *Podcast Positivos: Mujeres VIHvas, La Doctora Álvarez*. The interview with *La Doctora Álvarez* allowed me to place my research as well as the origin and motivations that led to the creation of this project; a kind of framework to place myself as a researcher before entering into an in-depth analysis of the content of the podcast episodes.

From the beginning of the interview, which was conducted via telephone, the intention was that it should remain open so that the interviewee would be the one to guide it. However, we cannot leave aside the symbolic phenomenon represented by an open interview in which the subjective sense of language is combined to create discourses, thus allowing the researcher to interpret her own (Yarad, 2018).

The starting point of this project was based on the previous research *Women with HIV, sexuality and desire for procreation: a qualitative approach*¹⁵, with the aim of exploring the desire for motherhood and the sexual life of women living with HIV in Spain and deepening the impact of HIV diagnosis on both areas:

A few years ago I did qualitative research with women with HIV through interviews and most of them were living in a huge loneliness, very much afraid that people would find out, self-stigma, loneliness [...] I had the feeling that in the associative and community world related to HIV there were many interventions with men who have sex with men and that women were quite forgotten. [...] The idea was to make women living with HIV visible but in a way that women who are less empowered would also have that possibility. These women really want to talk. (Extract from the interview with La Doctora Álvarez, 2020)

¹⁵ Presented at the V National Gesida Congress, held from 19 to 22 November 2013 in Sitges, Spain. For more information, <http://gesida-seimc.org/>

La Doctora Álvarez, BA in Sociology, PhD in Surgery, Medical and Social Sciences, and MA in Radio Communication thought that the latter would be a valuable tool for people who perhaps do not want to be identified but who really need to talk, being a way of becoming visible but not necessarily:

My experience in radio made me think that it was going to be a good tool and in fact I think it has worked very well with them. It has served them well; they have created a space that otherwise they would not have had. Even though the project doesn't go very far, they do perceive that you are giving them a voice and that they have the capacity to make that message go very far (Extract from the interview with La Doctora Álvarez, 2020).

The idea of using the podcast as a tool was to make the protagonists tell their story in the way they wanted to tell it - respecting their way of presenting themselves to the world. On the other hand, designing the project through face-to-face meetings allowed women who lived further away from the most central urban centres to create networks and spaces for self-reflection and empowerment.

However, *La Doctora Álvarez* was also aware of the limitations of the project:

This is a grain of sand. Stigma cuts across anyone living with HIV, and the coronavirus is making this clear. It's all just a small contribution. In the area of HIV, especially for women with HIV, everything is still to be done (Extract from the interview with La Doctora Álvarez, 2020).

- ***Placing my voice among their voices***

*To understand the meaning being shared, one must listen carefully to what is said and
unsaid.*

Palacios et al., 2015

When you start a thesis, the first question that arises is what you want to transmit, and why is this topic important for others (Eco, 2001). In this sense, Eco refers to the discovery of something new or to the reinterpretation of an existing phenomenon, told from another point of view because it has not been previously explored.

When I decided to start working on HIV I did so thinking of the many contradictions that my own academic and professional experience generated. I was challenged by an issue that, when questioned beyond the biomedical field, produced surprise. For few people around me, there seemed to be *something* when asking about HIV. It is an issue

that continues to create otherness. As if the society we live in is a neutral space. As if the society we live in is HIV-free. That is the reason why this research is also an exercise of alienation from my own society and my own context, which forces me to recognise that the society in which we live, like any other society in which an anthropologist - as it is my case - can carry out her field work, has specific ways of organising the world mediated entirely by the social scale (Geertz, 1987).

What attracted me most were the narratives around HIV and how they had become stuck in the past. Medical advances around the infection are making great progress while the social imaginary is stuck in 1983. One part of the society is openly targeted while another is masked or silenced: women with HIV, who were also associated with specific hegemonic ideas that did not help disclosure.

On the other hand, there was also a concern about the use of the material from the *Podcast Positivos: Mujeres VIHvas* project as data to be analysed in the development of my thesis. *Were these stories reliable and important enough to be the basis of a thesis?* This invited me to rethink what is ethically expected from women's stories in academia. These stories are not intended as a truth that fits the standard of objectivity. They come from the truths of women's experiences and perhaps this can be the beginning to encourage new ways of approaching women's experience as a real positioning in academia.

Treating the stories or narratives as data to be analysed also implies a process of reflexivity that affects the researcher herself. In the end, meaning is always meaning to someone.

Methodological approaches

Stories are a way of understanding lived experiences and offer a powerful transformation in their telling.

Connelly & Clandinin, 1990

I needed a methodological approach that, on the one hand, could address the experience of HIV as an important dimension in women's lives, and, on the other, could use their stories as a way to understand the meanings of those experiences. The following section focuses on phenomenological research and analysis of narrative discourse. These two

methodologies complete each other. Both focus on the details of experience, but, while phenomenological research explores experiences as they are lived, narrative discourse analysis focuses on how and why a particular story is told.

- *Phenomenological research*

Phenomenologically-oriented research allows the focus on the body (the body living with HIV) as a coherent framework for understanding the meaning of experience. This means that it assumes that reality can only be apprehended through experience, so that the way in which every aspect of the world is perceived is through the body that represents the primary source of experience (Merleau Ponty, cited in Lozano, 2010). This body is, however, a socialised body, whose understanding implies the incorporation of the structures of the world in which it acts.

In this sense, phenomenological research, unlike other methodological approaches, is primarily interested in how an individual reflects on his experience - how the individual thinks and feels - in an attempt to describe the lived experience of individuals in relation to a particular phenomenon, in our case HIV (Gray et al., 2015).

By focusing on the lived body, phenomenological research allows me to be aware of how experience is lived in different ways by different bodies. Phenomenological research provides a framework for exploring the meaning of the experience of HIV as expressed by the voice of an HIV positive woman. Phenomenology involves the researcher in listening, observing, and empathically understanding another person as well as their thoughts.

However, the limitation I found in phenomenological research is that it focuses more on the specific ways in which experience is lived rather than on how it is told. As such, I needed a complementary methodological approach to help me unpack and connect experience with the language as voice.

- *Narrative discourse analysis*

As every act of discourse and action, narrative discourse is a cognitive process built through stories we have and/or experience. A narrative as discourse is the integration of sentences that produces a global meaning (Urrea et al., 2013). Narrative is not a neutral medium or a simple use of language: its form, presentation, and organisation also refer to the image of the self that the narrator expects to transmit to others (Gianni, 2008).

Narratives are stories told in a series of events, chronologically and logically related, and caused or experienced by the authors. Its analysis seeks to understand their structure and functions, by examining frameworks, asking questions about discursive representation and how narrative works in a new context, in this case in the context of producing and listening to a podcast that addresses HIV through a woman's voice.

To analyse a discourse is to deconstruct it, to dismantle its elaboration from the subject, to divide it into its components, separating them temporally and methodologically until the existing relationship between the objects and the discursive operations is understood. It is to identify semantic axes, metaphors, forbidden words, acts of speech - implicit ones-, and presuppositions, etc.; to then construct and reconstruct cultural and social practices. It is necessary and fundamental to be able to understand the existing meanings and countermeasures in the discourse of the subject affected by HIV (Sevilla González, et al. 2002).

This deconstruction allows to find common analytical grounds and categories that do not intend to reduce the voice among women's stories in the podcasts, but to recognise their specificities while finding certain common patterns.

Researchers' interest in narrative studies is no longer focused exclusively on what people say or narrate, but also on how they speak in front of an audience, in front of another. In this sense, narratives are delimited by situational factors and by the interaction between the narrator, the interlocutor, and the narrative context, which affects the ways in which the story is presented (Gianni, 2008).

Podcast listening and data collection method

Sometimes people hear so lightly what others say so intensely, and sometimes people hear so intensely what others say so lightly.

Plummer, 1995

By looking at the stories of women with HIV, this research is putting stories of invisibility on the map. Using storytelling implies seeing how their voices open up opportunities for connecting with other women with HIV.

As it is an Open Access material and due to time constraints, the most relevant narrative extracts obtained from listening to the podcast episodes were transcribed and became

the basis of the analysis. By applying a phenomenological approach, the stories were carefully listened to in the search for meanings within the experiences, without yet attributing meaning or connotations, separating similar extracts into common categories when overlapping themes or clusters of meanings start to emerge.

The discussion that follows these narrative extracts describes a wide range of literature, through which the stories acquire their own structures of meaning and propose perspectives on the experiences that the protagonists have in living with HIV.

Finally, it is important to note that in the transcription of these narrative extracts I was confronted with the challenge of language, since the episodes of *Podcast Positivos: Mujeres VIHvas* project were published in Spanish. As a researcher, I needed to position myself between two languages and to make strategic translation decisions while being aware that, when translating, the researcher becomes an active participant in the very act of translating.

4. ANALYSIS

Shame may prevent the story being told, pride may lead to it being shouted.

Plummer, 1995

Taking into account these theoretical approaches and methodologies, the following chapter presents the narrative extracts I gathered in the process of listening to storytelling through a digital medium. The process of storytelling has helped reveal stories of inequality, margins, and silences but also flows of resistance and subversion.

HIV ambiguously placed as a "partial secret"

Once told, secrets are no longer secrets. Even naming them as possibilities implies putting them on display as objects of knowledge. HIV is ambiguously situated as a partial secret, in a continuing and precarious tension between public knowledge and acceptance of HIV, the constitution of HIV as a condition of citizenship with full human rights (Squire, 2015).

- **Silence:** *"You had to live it in silence because it was, it is an illness that you were pointed out"*

Silence is all we dread.

There's Ransom in a Voice—

But Silence is Infinity.

Himself have not a face.

Emily Dickinson

"What is the first silence, Carmen, that you remember throughout your life, that first silence that marks you?" Episode 3.

Related to the evolution and history of the pandemic, an issue associated with the experience of living with HIV emerges: the management of the secret of the infection. The handling of the secret is at the centre of everyday experience, becoming one of the nuclei of the organisation of everyday life. Its management is a process that begins

when the diagnosis is known, and it is permanently in transit. The ways in which the secret of the infection is managed are associated with the ways in which stigma is managed, which, in the case of women, takes on different meanings, among them, the feeling of "shame" in communicating this condition to others (Gianni, 2008).

"Health" is the convention by which some bodies are read as normal (natural) and others, as pathological. Health and its opposite "disease" are indicators of the level of functional or metabolic efficiency of a body, and, by extension, of its productive capacity and right of representation.¹⁶

"Is HIV another of your silences? It is another silence too, very important and painful because I was also diagnosed with HIV at the age of 27. And then, you see, a 27 year old woman at that time, also knowing that you were HIV positive, you thought that you were dying, but you didn't know if in two days out of three, out of four, you wouldn't know how you were going to die, if the agony was going to be very long, and the truth is that you were very afraid and very lonely because it is a disease that we are trying to normalise today, but the truth is that you also had to live it in silence because it was, it is an illness that you were pointed out". Episode 3.

Seropositivity is kept secret and is not shared except under limited privacy conditions. The experience (real or imagined) of feeling discriminated against and rejected by others is a recurring theme in their stories (Gianni, 2008).

"Over the years I never said it at work or to any of my colleagues, and then already in 2003, when my daughter was born, the total silence outside my environment and my friends, and also we live in a village and I did not want her to be harmed". Episode 3.

"For example, I work in a hotel where there are thousands of workers of all ages, of all nationalities, and if I were to say openly that I have HIV, their reaction would be very unpleasant. If I did that test, if I did that test, I would look very lonely". Episode 6.

"I haven't made myself visible, they don't know it in my work for example. But this is a process I want to get through". Episode 4.

"It has slowed me down when it comes to establishing an affective relationship. That moment when you sit there, "I have to tell you, look I am this..." is disgusting to me". Episode 5.

Disclosure of HIV status is often not easy and can have both beneficial and negative implications. With worrying frequency, people living with HIV are denied employment

¹⁶ Project 'Anarchivo sida'. It proposes to activate a process of identification, collection, and analysis of the aesthetic practices, representations, collective experiences, and performative tactics that have determined the policies of HIV/AIDS. More information: http://www.anarchivosida.org/index_es.php

and insurance, barred from entering other countries, rejected by their partners, provided with inadequate access to reproductive health services, denied the possibility of adoption, and in some cases violently attacked (Nengeh Mensah & Haig, 2012).

A fragmented approach to reality, i.e. dividing it up into areas, can lead us to simplify the concept of women. We can fall into the initial error of creating a rigid category of women and claim that only one type of woman in each field will suffer certain discrimination. Therefore, it is important to bring up again what was said before: the meaning of woman is not discovered through the elucidation of specific characteristics, but through a complex network of aspects. This shows that, within each area, many women (and very different women) can potentially be discriminated. In each area, situations of discrimination overlap.

If we focus on one of the most frequently mentioned areas in the selected extracts, the field of work, we find out that the rights that every person with HIV and AIDS has, particularly women, are violated. Therefore, they should benefit from reinforced and specific legal protection.

The International Labour Organization (ILO) in its 2016 *Recommendation on HIV and AIDS and the World of Work*¹⁷ states that, "actual or presumed HIV status should not be a reason for termination of employment". The same text also mentions that HIV status should not be a reason for discrimination that would prevent a worker from being hired, remaining in employment or achieving equal opportunity. And yet there are sectors in Spain, such as public transport, the State Security Forces, and the Armed Forces, that block access to people living with HIV.

"My silence, my secret, huh, well the secret hurts and I think it is good that little by little we are giving light to it, making all our fears visible, our doubts, and our difficulties because the secret eats you up inside and that silence that you speak about is very painful at times - very corrosive - and you feel a sort of distance from other people, you have the feeling that you are always hiding something from them, as a feeling of guilt for not being honest [...]". Episode 3.

Seropositivity, as it allows "silencing" the infection as it does not present visible signs, can be understood more than as a component of identity, as a real temporary resource

¹⁷ International Labour Organization (ILO), International Organization for Migration (IOM) and UNAIDS (2008). Policy Brief: HIV and International Migration from labour. Available at: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/dataimport/pub/manual/2008/jc1589_policy_brief_labour_long_en.pdf

that allows living as normally as possible (Meruane, 2012). However, this asymptatology is considered as ephemeral if it is not subjected to treatment and medicalization. In the absence of treatment, the experience of medication brings them closer to that experience of death. The experience of the illness is legitimised. Taking medication permanently reminds them that they are sick and that they are living with the virus twenty-four hours a day.

“Is it still one of the silences of your life? Yes, I think so”. Episode 3.

In these terms, storytelling - and by extension small stories - are seen as a counter-narrative movement that highlights silenced and marginalised voices (Méndez de la Brena, 2016).

The telling of these stories offers a mode of communication that makes visible the moments of imposition within the prevailing narratives, so it can benefit HIV positive people by revisiting the debilitating discourses currently available when talking about "the disease that has no name" (Fink, 2010).

- **Disclosure: “To break those silences is to be able to say it personally”**

El silencio nunca es tan grande como cuando algo se rompe.

Pilar Adón, 2018

“Why do you decide to break that silence at a given time? I was about to burst inside. I couldn't take it anymore, because my life was always about things, about rebelliousness since I was a child, about going against the tide, about always fighting, about not feeling fulfilled, about not finding myself, about being lost, about being in a deep and very pitiful submerged loneliness. And so, I decided, come on, I'm still at it, integrating my experience into my life to take it as normally as I can”. Episode 3.

Managing disclosure at the interpersonal level is a daily challenge for most people living with HIV/AIDS. Even the term “dis-closure” carries a certain weight that is useful to clarify: derived from the Latin *claudere* ('to close'), disclosure therefore means 'to unclosed'. Thus, the connotations of shame and threat associated with this word can recapture the ways in which, since the beginning of the pandemic, HIV positive people have been placed in a framework of guilt and innocence (Nengeh Mensah & Haig, 2012).

In a recent study that looked at the disclosure experiences of some women living with HIV, researchers found that participants described consistently the management of the secrecy of the HIV status as a heavy burden on day-to-day basis. Obstacles to disclosure included fear of rejection, fear of being judged, and fear of making loved ones worry (Guionnet et al., 2014).

“Carmen, what does it mean to you to break those silences? Well, breaking those silences is talking about it, being able to say it in the first person.

And when do you break the silences, when you speak out, when you raise your voice and express what is wrong with you, what does it do to you, what is it good for? Well, it helps me to know myself and to feel myself, so I can feel myself as a woman, as a person”. Episode 3.

“Well, I'm also breaking one of your silences, which is living with HIV. What happens with that silence? That makes you part of creating a social cage, a social prison, because you come to the conclusion that every time you undress your soul a little you put yourself at risk and get hurt [...] You undress your soul and you are afraid to find a distance, a rejection, and a pain in between”. Episode 3.

It is recognized that disclosure of HIV status is an important, potentially difficult and complex process. However, evidence shows that HIV disclosure may also be associated with improved health outcomes and positive behaviours, such as improved adherence to antiretroviral medication. Telling one's story in public leads to greater well-being and reduces stress. The paradox of publicly disclosing a person's HIV status is that the risk incurred from experiencing stigma also allows for a psychological release from the burdens of secrecy and shame (Nengeh Mensah & Haig, 2012).

Much of the individual experience depends on the struggle for rhetorical appropriation of the disease: how to possess it, assimilated in discussion and stereotype (Sontag, 2015). Despite the advantages - felt and recognised - that the act of disclosure can imply, it does not have to be a total: it can be only disclosed to closer environments, in certain moments of life, or just before some situations that facilitate the process.

“I am not visible, I maintain a discretion on a personal level, not to justify myself, but simply because it is something very intimate and those around me know it. If someone else found out about it, sincerely it is something I don't care about, but it is something I don't share with people so easily”. Episode 5.

“I have experienced it [stigma] myself and I couldn't become visible until a few months ago because I live in a very small village with my daughter and I don't want this to be used to hurt her. I've only ever dared in my most intimate environment and family, never in my work, with my bosses”. Episode 6.

“And you're still keeping it in silence? No, no, I talk about it more, I talk about it more [...] and I usually talk about it with friends. Now it's time, and since I'm already retired, I don't have any problem in that sense”. Episode 3.

Throughout her writings, Butler continually reinforces this emphasis on community building as essential to maintain physical and emotional well-being (Fink, 2010). This enables a shift towards re-imagining the illness as a catalyst for community building and responsibility, identifying the historical and linguistic constructs that inform our experiences of illness. The disease brings out an identity that might have remained hidden, a certain identity (Sontag, 2015) which in turn served to create a community spirit.

“Well, in addition to breaking my silence, my loneliness is getting smaller because I have colleagues who are also going to share their experiences with us, with HIV”. Episode 3.

“I think that a very good solution against stigma would be to educate people, talk about it, make it public, always in an atmosphere of respect”. Episode 6.

Participants felt that, to them, revelation was a starting point, and that digital storytelling allowed them to talk about the challenge of revelation. Not all participants were visible; despite the anonymity of the radio, most of them did not want to reveal their real name for fear of being identified. In a country the size of Spain, these remain very real concerns for many women living with HIV.

“My name is Cándida, I am a woman, and I was diagnosed HIV positive and HCV coinfection in 2005. The impact of the diagnosis and starting my process of facing my new reality, facing my diagnosis, my fear, my anger, rage, the anguish of not seeing my son grow up [...] I decided to work in response to HIV in AGAVIH (entity that works with HIV in northern Spain, Galicia)”. Episode 2.

“My name, as it has been said, is Arancha, and this year I will be 50 years proud of having resisted and of having come this far, and of having seen my children grow up because this in a day that is very far away was a real chimera. My diagnosis came when I was just 20 years old, so this year I will also celebrate 30 years of living with HIV”. Episode 7.

“My name is Andrea Petrocelli and I have been diagnosed with HIV since 20 May 1990. For years I thought that I would die soon, that I had no future, that I would get sick and die soon [...] Little by little I lost my fear, the medication was advancing and people stopped dying from AIDS and I relaxed and thought I was a survivor. What do I want to do with my life now that I am not going to die?” Episode 5.

However, they did agree that it was a moment to perform on the radio, to move from being silent and hidden to telling that they are positive and thus, changing history. They saw digital storytelling as a social space where they felt safe to discuss the often-unspeakable issue of HIV in their community.

This effort to get rid of this disease, which arouses so much guilt and shame, and of these meanings and metaphors, is particularly liberating, even consoling. However, metaphors are not driven away by simply sticking to them: they must be exposed, criticized, punished, worn out (Sontag, 2015, pp.205).

Intersecting voices

During the analysis of the project I came to know (and recognize) the voices of the protagonists, the voice they give to their lives with HIV. All I know about this project are their voices, the noise. To investigate how these voices are crossed by intersections allows us to reach the constructed categories, the symbolic burdens placed on the body, the main stigmas surrounding HIV, and the use of narrative as a therapeutic strategy (Valencia, 2019).

In this way, we can find out how external voices have affected the protagonists of the episodes, through stigma and violence, but we can also find out how internal voices, self-stigma and fear, make them powerful in learning to live with it and to accept their infection.

○ *Voices from the outside >> Stigma and violence*

What stuck me was that the people directly affected never had a say. Somebody else always spoke for them: specialist who spuck on their behalf, trade-unionist, and so on.

Many people, especially women, never spoke for themselves.

Carole Roussopoulos, 1981. Reina Sofía Museum, Madrid (Spain) 2020

Stigma: “Who knows what you’ve done”

“The stigma is that I have felt it from the first hour, from the first moment. And I’m still with it [...] And it’s not that you’re self-stigmatising, which maybe you are too, but when you’ve been stigmatised for so many years and in so many contexts, then...”. Episode 6.

HIV- and AIDS-related stigma is a complex and multidimensional psychological and sociological phenomenon that evolves over time and takes new forms as infection levels and awareness of the virus increase, and as the availability of antiretrovirals improves (Mnisi, 2015).

As cultural theorists such as Paula Treichler and Susan Sontag have previously explored, HIV/AIDS is linked to a variety of metaphors that shape our understanding of the pandemic, encouraging social disapproval and stigmatisation of those who test positive for HIV. Metaphors of the disease foster unprecedented fears in people living with HIV, influencing physical and social experiences of suffering (Fink, 2010).

“It also happens that with this pathology when you say, well, that you have HIV, there is a certain tendency to judge us to say, ‘Well, you get the flu because there is a low temperature and you don’t warm up, but HIV, who knows what you have done’. So, well, it makes you a little afraid”. Episode 3

While all people living with HIV may be stigmatized, stigma and discrimination are some of the main obstacles faced by women living with HIV. "The stigma associated with HIV and AIDS is such that almost all HIV-positive women keep their HIV status a secret, fearing negative reactions and discrimination against themselves and their families", as stated by Brunning, the voice of Positive Women (Gray et al., 2015).

“Being a woman is always an exponent in the face of any adversity or problem that life gives you, or any setback. Being a woman almost always multiplies it, for being a woman, a lot. A woman who is HIV positive is quite different from a man who is HIV positive, you can see the emotional burden that a woman carries throughout her life”. Episode 6.

HIV has been identified as being overloaded with moral and cultural significance in Western countries: the stigma associated with HIV, as a woman, is linked to “*deviant behaviours*”, such as promiscuity and illicit drug use (Gray et al., 2015). This develops

logics of exclusion and differentiation that cut across all discourses, narratives, and metaphors about the epidemic (Sontag, 2015).

“Stigma began with the spread of the virus in the 1980s and spread in the same way because, at first, those most affected were drug addicts, gays, and prostitutes. It was said that this was a punishment from God due to the lifestyle of these groups, and it came as a perfect fit to marginalize us even more”. Episode 6.

“Another group (are) the haemophiliacs, but they were hardly mentioned, and only they were considered victims, the rest of us we had asked for it and deserved it”. Episode 6.

The narratives of illness determine how we speak about life and suffering, how we speak when we live and suffer, and ultimately, how we live and suffer. These stories often present people living with HIV as threats to those who are, or appear to be, 'healthy', using metaphors of otherness and infection to represent the disease. One such metaphor can be found in the figure of the vampire, as in Octavia Butler's latest novel, *Fledgling* (2005). To metaphorically turn the person living with HIV into an outsider vampire is to blame those with HIV for their own medical condition (Fink, 2010).

“How do you see the evolution of this issue? Evolution? Well, if we don't make revolutionary social changes, HIV will continue to be a stigmatized affect, including stereotypes, and if contact is made with it, that person will be probably discriminated, because socially they have not evolved in the face of the prejudice that exists”. Episode 7.

Stigma can come in all forms and from the least expected place, as in the case of the healthcare system, which in turn creates relationships of domination and stigma for those who are considered *patients*. Considering a disease as a punishment is the oldest idea that people have about the cause of a disease, and it is an idea that opposes all the care that a sick person deserves, that care worthy of the noble name of medicine (Sontag, 2015).

“Do your patients bring to you a situation in which they perceive some distinction in their treatment? Yes, especially in some specialties, for example dentists, because there are some dentists who leave certain interventions until the end of their consultations and some who even refuse to treat some HIV-positive people”. Episode 7.

“We call on health workers to implement universal measures without distinguishing other patients and those living with HIV”. Episode 7

For Grimberg (cited in Valencia, 2019), "experience is a variable process, situated in a web of intersubjective relations, constructed and reconstructed historically and socially in a diversity of dimensions (e.g. cognitive, normative-valuable, and emotional)". In other words, the same illness can be experienced in different ways, which are often determined by the person's environment and the support community.

"Come to treat yourselves and above all to re-educate yourselves on the subject: we have fears, guilt and pressures, but if we re-educate ourselves and maintain healthy attitudes this is experienced as any chronic disease". Episode 5.

It is here that categories such as stigma, discrimination, rejection, and social exclusion make sense, since from them it is possible to construct multiple interpretations and assessments of the phenomenon. Stigma is not a static attitude, but a constantly changing social process, which seeks to legitimize its own dominant status in existing structures of social inequality. It is here that semantic approaches to the concept can give meaning to the word and lead to discourses capable of legitimizing and destroying this type of argument (Valencia, 2019).

Violence: *"It seems that if I'm a woman I cannot be wrong"*

"Men are still born into privilege and we women have to earn our rights. This approach is already unequal and violent, because male violence is already impregnated in all our areas". Episode 1.

Gender norms related to sexuality confer different expectations on women and men. To women, a central issue is freedom from violence, which is a crude expression of the power, control, and entitlement of some bodies over others (Amin, 2015). This norm places certain bodies in social positions more directly exposed to disease, pain or violence, and conditions their access to care. Power is manifested here in one of its most insidious forms (Platero & López Rodríguez, 2019).

The excessive rigour with which society examines a *woman who cannot be wrong* is accentuated in women with HIV. Violence, *the voice coming from outside* that a woman experiences because of her diagnosis. A body that embodies an infection, which is expected to be the object of compassion and care, is the target of violence.

“Violence is perpetrated against women just because they are women, this is the main issue we are going to focus on in this chapter. It can be physical, sexual, from strangers, from friends, family members even [...] As sexual assaults within marriage. Because they realised the hell we were living in, or because someone stood in front of them, or whoever it is that we have to thank, is now considered a crime and this makes me very happy as I think it does many of you”. Episode 1.

Because of the diagnosis, violence is accentuated; it becomes stronger, by taking other forms and being legitimated through other discourses. Invisibility is also another form of violence: women are invisible in HIV-specific public policies, what must be added to the other discriminations that women face in their daily lives, some of which are reinforced or increased when they come across the diagnosis. For example, the structural violence that women suffer places them in a situation of vulnerability or greater risk of transmission when this violence implies a loss of control over their sexuality, or over the sexual practices they engage in, and the conditions in which they do so.

Worldwide, 30% of women have experienced in their lifetime physical and/or sexual violence by an intimate partner. Data show that intimate partner violence against women is associated with an increased risk of sexually transmitted infections (STIs) or HIV (Amin, 2015).

"The violence I saw, that anger towards me.... It seems that if I am a woman I cannot be wrong". Episode 6.

"Apart from HIV, I have also been a woman who has been abused and she [my daughter] has unfortunately experienced some episodes when she was a child". Episode 6.

"Today I come to give voice to my silence, it has destroyed me enough [...]. I was sexually abused in my family, in my childhood, from my first memory until I was nine years old. He was my paternal grandfather and he did it with the support of his wife, my grandmother. Anyway, it was crazy. That's when my silence and all the consequences began". Episode 3.

There seems to be an overlooked angle in the research on the prevalence of violence among women living with HIV. Increasingly, the ways in which gender inequalities shape women's risk of acquiring HIV are being mapped out, particularly with regard to the intersections between intimate partner violence and HIV. But, we must not only think of violence in a micro framework, but also in a macro framework, as whole

system that perpetuates violence against women: social violence, institutional violence, violence in research, invisible violence (Fuster Ruiz et al., 2017).

“It's not something I can tell you that appears in statistics, because it doesn't. Even statistics don't show how women are infected, even in that there is institutional violence: the invisibility of women in demographic studies”. Episode 1.

“Gender-based violence is the invisibility of women in HIV infection. The infection is predominantly male, more than 80% of people living with HIV are men. That 20% is invisible. That invisibility, the system itself, is generating violence against women living with HIV because resources are not even designed. For example research on treatment and all that is now starting to include women, but until now research was only done with men”. Episode 1.

The disease is precisely an effect of their vulnerability which, in the different contexts in which they live, exposes them to rejection, exploitation, violence, and contagion, but at the same time, it functions as a stimulus in the search for freedom and sincere and profound human relationships. The strength and resistance of the protagonists of the *Podcast Positivos: Mujeres VIHvas* project accompanied their vulnerability in their transit across the borders of nations, gender, pain, and disease, through their voice (Meruane, 2012).

○ ***Voices from the inside >> Fear and power***

Is this what discrimination is about? Not having the opportunity to reach out to you?

Not being able to forget that you are afraid to come inside me?

Dillon, 2004

To be afraid: “I am the one who wants to be visible, but is afraid”

“I'm that woman who has been very afraid, who has fought to overcome herself, who decided to be happy, who the next day is anxious, who won't shut up, who wants to be visible, but is afraid. That, that's me”. Episode 5.

This fear is also found in the relationship of the body with HIV and sexuality, which at the same time implies understanding that body from life and affections. This vision claims the sick, the representation of a body that beyond its condition of being HIV positive or sick is capable of enjoying and looking for pleasure, as a synonym for life. Likewise, the identification of contagion through certain sexual practices calls for the

generation of images that put an end to their social demonization (Martín Hernández, 2017).

“Almost always, I believe that, when you show this part, the resulting 99% of the time is super positive, but you feel that fear again, that anxiety, fear of rejection. But here we are to overcome these things”. Episode 3.

“Suddenly you have this responsibility to others. You think about sexual practices that you are not going to do because you are afraid that the other person will be harmed, that you always think it is good if they protect themselves... but you are left with the idea of not doing it freely”. Episode 5.

At a time when antiretroviral therapies have significantly extended and improved the quality of life of people living with HIV, it is necessary to reclaim the image of the sick body, linked to an imaginary shaped during the early years of the epidemic, in which the body with HIV was synonymous with an organism with reduced vital functions. We need to start talking openly about how HIV-positive people incorporate their HIV status into the development of their daily routines, including sex (Martín Hernández, 2017).

“The certainty that you will not transmit the disease if you do things right, if you follow the proper controls and take the medication, can eliminate the fear and the internalized stigma that makes a person self-limiting when they have HIV”. Episode 5.

To not be afraid: *“I like so many things in life, especially living it”*

“I'm a fighter, a mum, with a great desire to live, very positive, I consider myself a survivor. I like so many things in life, especially living it”. Episode 7.

With respect to the reconfiguration of subjectivity, in women's stories the disease operates as an "other" that poses a break with "the woman" that one was before the diagnosis, an image that is deconstructed through "being HIV positive" as a dimension of identity (Gianni, 2008).

This learning provides resources to cope with the situation and to develop strategies for it; it refers to a process of empowerment and experimentation. This power and self-construction goes hand in hand with learning to live with the virus, which means that for some women living with HIV has shed light on different aspects of life.

“Well, I hope that after this great work that our great friend Débora [La Doctora Álvarez] is helping us to make, all the women who are here will now take up the cudgels and change this. I believe that if we do our bit, little by little we will achieve it”. Episode 6.

Learning about the disease and its treatment is not only about acquiring knowledge (common or scientific) but also about creating a subjective resource for women when they rediscover themselves as subjects in an active situation, that is, when they face adversity. The process of normalisation enables them to regain control of the situation, placing HIV and treatment within an order, a routine, and a normative framework that regulates it.

The process of normalization involves two movements that are not necessarily articulated: one aims at adapting to the medical norm and prescriptions, at the inclusion of the medical model of care in daily life; and the other calls for the deployment of resistance strategies aimed at protection and activism in response to the situation of vulnerability they are going through, because of both their status as people living with HIV and as women (Gianni, 2008).

“I want to share with you why I chose this song from the group Led Zeppelin called “Stairway to heaven”. Besides being one of my favourite songs, it also talks about an empowered woman who turns everything she touches into gold”. Episode 2.

Embodying the virus

The virus attaches itself to and interferes with our system, trying to take over it, causing a change in its hegemonic functioning. How does the virus change my identity? The virus not only affects the body, but it also affects and transforms my subjectivity: how I will behave in society and how society will behave towards me.

However, these women accept that situation, they accept that they embody the virus and that they will live with it, but they also challenge it through their voice and this podcast project. In this way, they are *hacking the virus*: they find a path to narrate or act in a way that they were not ready for. They were not ready to live with HIV, but now they are hacking this situation and trying to subvert what the virus has caused in their world and their subjectivity. And they do it through their voice.

The virus is somehow giving voice to something that was previously silenced in the subjectivity of these women, freedom to assume things that were not given before. They are the voice of the collective of women with HIV in Spain, pioneers in talking about HIV openly on the Spanish public radio. They were confident that they could use their digital stories as a tool to stimulate discussion on HIV- and AIDS-related stigma, and that their podcasts could be considered an important method of communication (Mnisi, 2015).

○ **I am a virus: “It is stuck to me”**

ATTENTION I have been elected to inform you that throughout your process of collecting and executing files, you have accdientally (sic) ¶HÜçKΣ► [PHUCKED] yourself over: again, that's PHUCKED yourself over. No, it cannot be; YES, it CAN be, a √itûs [virus] has infected your system. Now what do you have to say about that? HAAAAHAHAHA. Have ¶HÜÑ [PHUN] with this one and remember, there is NO cure for AIDS¹⁸

“It was, it is a disease that they pointed out to you, that they put you as, I don't know, as that it seems to be spilling over, that you are dropping it”. Episode 3.

HIV permeated everything, because of the way it appeared, because of the connotations that derived from its modes of transmission, because of the populations that were most affected, and because of its invisible and asymptomatic nature in the early stages of infection. Disinformation, rumour, criminalization, and stigma were fundamental in the configuration of a myth that would devastate an entire generation and that would change the ways of relating affectively, of having sex with known and unknown people, of practising and visiting some spaces.

“The Human Immunodeficiency Virus is a virus because it is something strange that enters our body, but we can live a perfectly normal life”. Episode 1.

As in Octavia Butler's vampire metaphor, the understanding of HIV is based on the same premise that the presence of a foreign body in our blood system can radically alter our physical essence and behaviour (Fink, 2010). We tend to shape everything we perceive, and HIV or seropositivity is no exception. In this rational need to organise the disorder, the subject comes to conceive the virus through the act of thinking, and

¹⁸ There is a computer virus called AIDS. When it attacks, it displays this message. Available at: [https://en.wikipedia.org/wiki/AIDS_\(computer_virus\)](https://en.wikipedia.org/wiki/AIDS_(computer_virus))

through euphemisms and metaphors tries to mitigate the contagion and the disease (Sevilla González, M et al., 2002).

“Now that I'm starting to have new relationships I'm becoming afraid that someone will transmit an infection to me. I've been suffering all my life for not spreading it”. Episode 5.

Dillon feels it in the flesh how the distance that separates her from the virus fades away. "Does it hurt to confuse me with the virus, because I no longer know when it is because of me and when because I have AIDS?" (Dillon, 2004: 69). The inclusion of the medical model of care in daily life responds to the perception of the fragility of one's own body and health, as well as to the control of the risk that these women perceive they represent for others. Care is at the heart of changes in daily routines (Gianni, 2008).

“Right now I cannot disassociate HIV from my identity. It's stuck to me”. Episode 4.

HIV has long been a disease with a significantly greater burden of stigma, and a much greater capacity to damage an identity (Sontag, 2015).

- **My voice is hacking a virus: “I am a person who, despite the prejudices or stigmas of society, is determined to be a voice”**

The question is - insisted Alice - if you can make words say different things.

Lewis Carrol, 1865

“It is not contagious. It would be better to say it is not transmitted, we have to change the language little by little, but it is also difficult for me to say “to infect” or “to transmit” instead of “contagious”. Episode 5.

In disease, words seem to possess a mystical quality. We can only grasp what is beyond their superficial meaning. It's not just a new language what we need, more primitive, more sensual, more obscene, but also a new hierarchy of passions (Woolf, 1930). Language is a virus.

Narratives are one of the primary instruments for the creation and communication of meaning. In other words, thinking of narrative as a device for mobilizing the experience of HIV can, in turn, mobilize new meaning around the disease in ways that reduce stigma and strengthen the citizenship of people living with HIV (Valencia, 2019).

This highlights the centrality of narration in social experience based on the ways in which narratives produce knowledge and meaning, establish connections between

events, and provide perspectives on how to understand the world (reasoning) and how to speak about the world (representation) (Nengeh Mensah & Haig, 2012).

“We well know that talking about these topics makes people aware of them”. Episode 4.

“This is tremendously important because it serves to reduce stigma, and to reassure other people living with HIV and the people living in their environment”. Episode 5.

The intimate journey that means living with viruses can open up to other directions, other voices, and other scenarios. AIDS will remain a new language that will generate new ways of reading bodies and creating subjectivities, and new forms of social control and paradigms. AIDS will remain as the grammar that serves to adapt abjection to its time (Carrascosa, 2019).

“I was and I am transformed every day [...] As people, we are free, we are not a condition, we are not what one opinion can say about one. We are what there is”. Episode 1.

In the *Podcast Positivos: Mujeres VIHvas* project a queer temporality is activated that blurs the limits between times and spaces, so those struggles of the past are revived to take shape, ours, in the present (and the future, since it is a storytelling that will remain on the web).

“I am a person who, despite the prejudices or stigmas of society, is determined to be a voice that brings something meaningful to society”. Episode 4.

“I want to be like a virus inside an institution. In other words, all the ideological apparatuses are replicating themselves because that is how culture works. If I function as a virus, an impostor, an infiltrated element, I will be able to replicate myself with these institutions” (Lebovici et al., 2019, pp. 55).

What is not seen, not heard, not understood? It was all about standing and listening. The answer is as old as time: telling stories. Allowing people living with HIV to tell their own stories. Now, three decades into the epidemic.

We have always had a story to tell and a story to listen to. And maybe, just maybe, this would help bring about change, the kind of change that happens from new understandings and insights.

With these voices from women living with HIV, the possibility of healing some of the damage done to them as individuals and to society at large is beginning to emerge. For

the storytellers, that healing could come through remembrance, through shaping and validating experiences, aspirations, beliefs, and knowledge. For the listener to the stories, that healing could mean making amends for fragmented ideas, filling gaps in knowledge, building bridges To narrow the gap between people. For the society, it would mean the possibility of making new and clear decisions based on the lessons learned from the stories told.

“Do you think this experience has made you stronger? If I already had experience with resilience on other issues and in relation to HIV diagnosis, I feel that I am now a stronger person and that this experience has empowered me”. Episode 4.

“The sick are the deserters, the dissidents” (Woolf, 1930, pp. 26)

5. CONCLUSIONS

I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood.

Audre Lorde

The Transformation of Silence into Language & Action, MLA Conference, 1977

Silence has many forms and many ways of manifesting itself. There is the silence after receiving bad news, the silence of shame, or silence as a verb. The silence that happens when someone speaks, but we still don't hear it. In this thesis we have spoken of voices that cannot be heard. In fact, more than speaking about them, these voices have spoken to us. They have spoken of another silence: the one that surrounds HIV. In order to understand the meaning that is shared, one needs to first listen carefully to what is said and what is not said.

The stories explored in this study through the *Podcast Positivos: Mujeres VIHvas* project speak about the multifaceted experiences of a group of positive women who decided to share their stories in a radio podcast and thus, to provide both insight and context to their HIV-related life experiences.

Talking about HIV and AIDS today, 37 years after the first cases were detected, places us in a privileged position to reflect on the possibilities of the podcast as a tool to address a social problem. What is presented here is a journey through life stories with two main themes. First, HIV as the vertebral element of the discourses and, second, the voice as a symbolic space in which all these views converge (Martín Hernández, 2017).

Women and HIV: a double invisibility

HIV infection affects women at all stages of life: childhood, adolescence, reproductive age, menopause, and old age. Being a woman with HIV presents specific challenges. At each of these stages different challenges arise that can be addressed in a variety of ways, which will impact on their quality of life and on their acceptance of the infection. Acceptance of the diagnosis is a complex process that sometimes can lead to its denial.

Throughout life HIV can influence many aspects: from work, family, and friends, to the possibility of pregnancy. Disclosure of HIV is also a complex process, as it can be associated with situations of rejection. The reasoning behind non-disclosure is often to protect others from suffering and fear of discrimination. The time to start treatment can also trigger many fears of side effects. All these challenges can be taken up and accepted over time, allowing women with HIV to grow as individuals, or not, with what this can mean for their quality of life.

Inequality in women's access to health care, counselling, and information means that they are less likely than men to receive early and accurate prognosis and treatment of HIV infection. There is an urgent need to further study gender differences and to identify the existing bio-psycho-social inequalities that affect the quality of life of women with HIV, as well as specific programmes for women living with HIV. More holistic social science research agendas are needed to provide women-centred services to women living with HIV and to promote their sexual and reproductive health and well-being, based on social justice and human rights (Amin, 2015).

Women and HIV: digital storytelling as a tool

In this thesis, I propose the use of digital storytelling as a method for generating stories about HIV- and AIDS-related stigma - experienced, witnessed, or heard of – that can enable the community to take action on such stigma. I also argue that a community's stories can be used within the community itself to bring about change.

Digital storytelling is an effective method for communicating important information, as it does not rely on a single method to tell a story, but it offers multiple ways of learning: the spoken word and the radio stage work independently and collectively to transmit messages to audiences. By understanding someone else's experience, the audience can be able to relate it to their own narrative, and there lies the power of the storyteller to change or subvert hegemonic stories.

Storytelling can be used as a means of encouraging, motivating, and reorienting the lives of the protagonists. It also provides an opportunity to share emotional experiences that can be therapeutic for both the storyteller and the listener, and to experience

beneficial outcomes from connection, such as identification, catharsis, acceptance, and empowerment (Robillard et al., 2017).

The stories could be used to disrupt the way in which the participants and the community itself think about HIV and AIDS in particular, to change the type of language used to refer to those infected and affected, and thus, in turn, to change the meaning of HIV- and AIDS-related stigma.

As a replacement, this could lead to build new and non-judgmental stories about affected and infected people, and thus, to take action to eradicate stigmatizing practices.

Podcast Positivos: Mujeres VIHvas project

This thesis addresses the effectiveness of digital storytelling as a form of communication design when dealing with the stigma and discrimination associated with being HIV-positive.

In the examination of the stories shared in the *Podcast Positivos: Mujeres VIHvas* project, a number of topics appeared that are likely to ring true to other HIV positive women. Their stories focus on their experiences living with HIV, and this probably reflects the importance of these stories in their lives. The stories also reflected a deep and strong interest in challenging HIV stigma and educating others, the audience. These women saw the opportunity to tell their stories as a mechanism to do so: to help prevent HIV and to empower other women living with HIV. They saw their own life experiences as learning experiences. Many of the shared stories can serve, when shared with other women living with HIV, to evoke a sense of identification with the women who were sharing them.

Self-realization, as a topic, appeared frequently in these women's stories. The several references to fighting stigma and facing the future with optimism point out their desire to find a meaning in their lives that transcends HIV. Despite these brave expressions, others reflected on loneliness, resignation, and fatalism. While many women expressed their empowerment, it was also clear that this state was not static. Even in these brief stories, some women seemed to waver in their personal confidence and HIV-related empowerment.

Often, the women protagonists commented that they had never shared their story with another person, nor had they realised how therapeutic it was to disclose what had been stored inside them for some time. Some of them expressed surprise when becoming aware of their experience in a way that they had never before understood, to the point of saying it out loud to an audience, which, although invisible in the case of radio, was going to listen to them.

They recognized the importance of communication through digital technologies as a way to actively participate and effectively address, for example, people's unnecessary fears about HIV. In this way, they could promote acceptance of people affected and infected by HIV. This, in turn, could help address the prevalence of stigmatization. The debate that the participants had on how they could take action to communicate the knowledge produced in their digital stories demonstrates a strong sense of the possibilities of today's technology and media.

These digital stories came out of their real lives and proved the possibilities of sharing stories in digital spaces as a tool to encourage dialogue and reflection in their community, their society, with a view to taking action against stigmatization. Perhaps the participants, by exploiting their newly acquired agency, will begin to replace these stories, over time, with new ones, in a new language, with new meaning and new thinking.

Limitations of the research

○ Who is speaking?

This study was based on a project that had already been published, where we assisted as spectators and listeners. Therefore, it was not possible to interfere in the creation of the group of women willing to share their stories. As such, these stories should not be considered as representative of all Spanish women living with HIV.

On the other hand, the *Podcast Positivos: Mujeres VIHvas* project adjusts and adapts itself to the context of Spanish society (even if by language it could reach every Spanish-speaking person). There is thus a lack of theoretical work that takes into account the variability of narrative structures in different cultures, as well as of ethnographic work that explores oral storytelling in different socio-cultural contexts of

use. This could help us understand how the success or failure of stories before a certain group of listeners depends closely on social and cultural factors, such as the shared knowledge between narrator and audience, the relevance of the story to a certain audience, and place and time (Colino Rodríguez, 2017).

Despite these limitations, these stories demonstrate women's interest in contributing to prevention and support for other HIV-positive women. Their stories suggest that they have a desire to be heard and to have their stories told, which allowed them to identify themselves as an important part of the *AIDStory*.

- *Who is listening?*

As noted above, a key component of storytelling is its malleability and fluidity, as it can be shaped and reconfigured by a range of factors: e.g. the audience, the timing, and the concern of the storyteller and of the researcher.

While it is known that narratives share this fluid character, not everyone who analyses storytelling recognises its role in the construction of the story, and it is possible that much is lost or misinterpreted during analysis (Palacios et al., 2015).

Thus, the stories do not draw *their power* from the void, but from a certain socio-cultural context, and here lies in part their anthropological interest. The same story can work for one audience or at one time while it fails at another. Its ability to achieve a particular purpose depends on what the story tells, who tells it, how it is told, where it is told, when it is told, for whom it is told, with whom it is told, and against whom it is told, among other symbolic and social variables (Colino Rodríguez, 2017).

And here I assumed the role of the person who listened and interpreted them, from my personal interest and within my own context. My imprint as a researcher is thus inevitably present.

Further research: a future pilot project

As 'testimonies cannot be understood in isolation from listening, reading, consumption' (Plummer, cited in Nengeh Mensah & Haig, 2012), I would have liked to focus part of this research on the people who receive the testimonies. During the analysis of the stories that appear in the *Podcast Positivos: Mujeres VIHvas* project, I had in mind a

number of questions about how these stories are received, going beyond how they are received by a person with a role or desire for research. *Who is listening and how are they listening?*

However, I was aware of my possibilities and limitations. Fieldwork research is seen as a confrontation with reality, that is to say, as the materialisation of the whole research process where the researcher has to adapt the design to his/her possibilities (time, resources, mobilisation, etc.). Due to the limitations, in this case, time constraints and a vital moment crossed by a global pandemic while researching on another, this focus group research is presented as a pilot project with the idea of being further explored in the near future.

Focus groups are often used in communication studies as an effective way of assessing which messages have been heard by participants and of examining the audience's understanding of the considered issues. The group is encouraged to talk to each other, to ask questions, exchange anecdotes, and comment on each other's experiences and views. The role and impact of audiences, listeners - the people who receive these stories - has emerged as a key issue (Gray et al., 2015; Nengeh Mensah & Haig, 2012). Analysing the community interpretations of the stories and having a closer look at how testimonies are received, can provide new tools for critically understanding how people living with HIV can be better heard when they talk about their lives.

Therefore, in this future research we would be facing the creation of a discussion group that would not listen to all the podcasts present in the project *Podcast Positivos: Mujeres VIHvas*. Instead, they would have access to some of the extracts that have been selected for analysis, in addition to the discussion included in the last chapter, *Episode 8 - Live Programme Mujeres VIHvas*, an episode broadcast live as a closing of the project in which all members participated in a kind of debate moderated by *La Doctora Álvarez*.

Focus groups can enable us to examine how speakers and listeners interact with these stories in predominantly alternative ways, sometimes resistant, that shape the meaning and social implications of media testimonies and the visibility they give to people living with HIV.

Consumers of first-person narratives can be attentive and sensitive, and they can identify themselves. Alternatively, they may be indifferent or deaf. They may consume

first-person narratives in relative isolation or they may do so through a community, real or imagined, of class, race, gender, experience, or taste (Nengeh Mensah & Haig, 2012). Consumers interpret the stories that are told and they make sense of them. Studying how this audience does the work of listening is crucial to understanding the nature and implications of any culture of storytelling.

...

An individual's life, and its role in the community, is best understood through a story. We pay more attention and become more aware of our own lives through the process of turning them into storytelling forms. Reclaiming our story is part of our birthright. Explaining our story allows us to be heard, known, and recognised by others. The oral telling of a life and the recollection of one's own life history has a healing effect on the individual and on society as a whole.

As a society, we still have to collect many stories from those who have been traditionally less listened to, such as women, in our case: women with HIV. Women's voices need spaces to be heard, analysed, and theorized as an essential part of humanity.

I hope the reader can understand that HIV is just an excuse to write about embodied stories, an excuse to talk about the powerful potential of their stories to destabilize normative discourses. This thesis is aimed at an audience that, like me, is more concerned with writing about women's experiences as they are felt, lived, embodied, and told, than with abstract conceptualizations. This thesis implies an effort to listen to, feel, and write women's stories of resistance and place them in conversation within the feminist academic debates. Last but not least, this thesis responds to a personal effort to place the stories of these *women and survivors* within the academic landscape.

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