‘THIS IS MY FACE’
AUDIO-VISUAL PRACTICE AS COLLABORATIVE SENSE MAKING
AMONG MEN LIVING WITH HIV IN CHILE

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# LIST OF CONTENTS

<table>
<thead>
<tr>
<th>LIST OF IMAGES</th>
<th>ABSTRACT</th>
<th>DECLARATION</th>
<th>COPYRIGHT STATEMENT</th>
<th>ACKNOWLEDGEMENTS</th>
<th>INTRODUCTION</th>
<th>CHAPTER 1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1. Initial considerations about HIV</td>
<td>1. Loss through a Fracture</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. The Scope of Stigma in Chile</td>
<td>2. Between uncertainty, Scarcity and Good-will</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Narratives and Sense-making</td>
<td>3. HIV as fracture in a post-dictatorship context</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Practice and Methods</td>
<td>4. Biographical disruption within the Health System</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5. Inner States and Emotional Responses</td>
<td>5. The price for Luis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6. The Ethical Framework of Practice</td>
<td>6. A certain Fracture, and a Chronic Disruption: Trying to make sense</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7. Structure of the Written Thesis</td>
<td>7. Sense Making beyond Disclosure</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. Their Uncertainty, Our Uncertainty: A new start ........................................ 56

CHAPTER 2 ............................................................................................................. 59
1. A PARticular type of Collaboration ............................................................... 61
2. Autobiography and Trauma ........................................................................... 63
3. Setting the First Encounter .......................................................................... 66
4. Tactics of Autobiography ............................................................................. 67
5. „I Was, I Am, I Will Be‟ .............................................................................. 73
6. The Elephant in the Room ............................................................................ 75
7. From Words to Images ................................................................................... 78

CHAPTER 3 ............................................................................................................. 89
1. Hermeneutic Reflexivity Through Mutual Questions ................................. 91
3. Face-to-Face Collaboration: Appropriation and Enstrangement. ............... 95
4. Dissambled Expressions and Memory as Practice .................................. 100
5. Photos as Statements ................................................................................... 105
6. Photos for the Past and Images for the Future ........................................ 112
7. Mise-en-Scène as evocation for Desired Worlds ....................................... 121

CHAPTER 4 ............................................................................................................. 126
1. Reflexivity in Filmmaking ............................................................................ 128
2. Reflexivity as a Form of Hermeneutic Enquiry ......................................... 132
3. Reflexive Elements of the Film Grammar ................................................ 134
   3.1 Mirroring Mises-en-Scène ..................................................................... 135
   3.2 Upsetting the Viewer’s Suspension of Disbelief ................................. 139
4. Reflexivity and Collaboration ..................................................................... 145
5. Limits to Collaboration ................................................................................ 148
6. Beyond an Anthropological Audience .......................................................... 151

SUMMARY AND CONCLUSION ............................................................................. 154

1. The Centrality of Hermeneutic Reflexivity for Sense-making ............ 160
2. Additional Social Elements of HIV Sense-making ............................ 163
3. Collaborative Mise-en-scène and Other Sense-making .................... 166
4. Concluding Words: Ways of Doing, Ways of Knowing .................. 168

REFERENCES .................................................................................................... 170

APPENDIX

Complete list of Collaborators´ life events ................................................. 184

WORD COUNT: 59,201
LIST OF IMAGES

Still image 1. From the thirteenth sequence of the film ‘This is my face’ ...... 136

Still image 2. From the thirteenth sequence of the film ‘This is my face’ ...... 137

Still image 3. From the thirteenth sequence of the film ‘This is my face’ ...... 137

Still image 4. From the thirteenth sequence of the film ‘This is my face’ ...... 139

Still image 5. From the sixth sequence of the film ‘This is my face’ ............... 141

Still image 6. From the seventh sequence of the film ‘This is my face’ .......... 141

Still image 7. From the fourteenth sequence of the film ‘This is my face’ ...... 142
ABSTRACT

The research project ‘This is my Face: Audio-visual practice as collaborative sense-making among men living with HIV in Chile’ is an interdisciplinary project that explores ‘collaborative mise-en-scène’ as a methodological tool to further understand the sense-making processes around the biographical disruption caused by HIV. It combines Anthropology and Arts methods as part of the PhD in Anthropology, Media and Performance, a practice-based program that fosters interdisciplinary approaches to the production of original knowledge, based on self-reflexive and critical research practices (The University of Manchester, 2018).

Relying on the specific competences of photography and film and the co-creation of an ethnographic context based in hermeneutic reflexivity, the collaborators on the project created and explored representations of critical life events, in order to make sense of the disruption HIV brought to their lives.

The collaborators were highly stigmatised individuals living with HIV, which hindered their possibilities for sharing narratives and for reflection, and as such, made it more difficult for them to come to terms with a diagnosis they described as a ‘fracture’ in their lives. This project analyses the creative process of ‘collaborative mise-en-scène’ as a way to provide further opportunities for reflexivity and sense making, a method that departs from their everyday face-to-face encounters as means of understanding what they are going through.

Representations of life events emerged from our practice, as well as evocations, which provided a means by which to understand their experiences with HIV, and opened up ways to re-signify their past experiences and projections of the future. Photography and film offered their specific expressive competences to the project, but also gave the possibility of making visible the collaborators’ experiences in order to promote a dialogue with others, moving beyond our creative encounters. Therefore, their evocations became ‘statements’ of what it means to live with HIV in Chile, and at the same time, by taking part in its creation, it provided access to the particularities of the sense-making process in which those images were embedded.

This collaborative creative process opened up ways to highlight the relevance for sense-making in face-to-face encounters, demonstrating that hermeneutic reflexivity as a practice-based form of mutual questioning can promote a critical engagement with life trajectories and with others beyond our practice.
DECLARATION

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For Andreas.

Dedicated to all of us who strive to make sense of an illness.

You don’t take a photo, you make it - Ansel Adams
INTRODUCTION

The research ‘This is my Face: Audio-visual practice as collaborative sense-making among men living with HIV in Chile’ is an interdisciplinary project that explores ‘collaborative mise-en-scène’ as a methodological tool to further understand the process of sense-making. It combines Anthropology and Arts Methods as part of the PhD in Anthropology, Media and Performance, a practice-based program that encourages interdisciplinary approaches to the production of original knowledge, based on self-reflexive and critical research practice (The University of Manchester, 2018).

This project looks at men’s experiences of HIV in Chile and how they create meaning about their ‘biographical disruption’ (Bury, 1982) within a context that limits their opportunities for sense making. This practice-based research is initially informed by Participatory Observation, but it has an interventionist character, by which additional means and contexts for sense making are proposed to participants. Relying on the specific competences of audio-visual media and the co-creation of a specific ethnographic context, four collaborators reflexively explored their relation to critical life events, expanding the possibilities of sense-making beyond words and everyday contexts.

From our practice emerged not only ‘representations’ of life events which re-signified past experiences, but also ‘evocations’ of potential worlds and desired futures, which provided a means by which to expand current understandings of people’s experiences with HIV. These evocations in the form of ‘statements’ (Radley, 2010) became visual objects that promoted a further understanding of what it means to live with HIV; but at the same time, by taking part in its creation, they provided access to the particularities of the process of sense making in which those images are embedded. The creation of these evocations opened up ways to further understand the social aspects of a sense-making process, demonstrating that a practice-based form of hermeneutic reflexivity can promote
dialogues about life experiences, and ideas about the future that would not otherwise emerge.

1. Initial considerations about HIV
HIV is a global problem with local characteristics. According to UNAIDS (2017), at the end of 2016 there were approximately 36.7 million people living with HIV/AIDS in the world, with five thousand new individuals starting to live with the virus every day (Ibid.). Despite this large number of people sharing a common diagnosis, their experiences of living with the virus differ significantly depending largely on the availability of antiretroviral therapy, the particular emotional and socio-economic context and what HIV means in their their local context. Paul Farmer (1992) suggests that in order to understand HIV, we need to consider the interconnection between people´s experiences at a global and local level simultaneously. By attempting to understand HIV from people´s experiences within their context, and within a myriad of specific opportunities and limitations, we can also further understand what HIV means at a global level.

Data has suggested that the introduction of quality HIV care can lead to a rapid reduction in stigma and increase in the uptake of testing (Castro and Farmer, 2005), and a growing number of HIV tests can lead to a reduction in the new cases of people infected (Wilson et al, 2009; Gray et al, 2013). However, the case of Chile demonstrated that the availability of quality treatment does not guarantee an epidemiological control, nor a reduction in stigma.

In 2001 HIV/AIDS became one of the few pathologies with guaranteed access to free therapy from the State (Wolff and Beltrán, 2004). However from 2010 to 2015, there was a rise of 44 per cent of new cases of people living with HIV (Instituto de Salud Pública, 2016). This means that nearly a third of the total population living with HIV in Chile (estimated to be 61 thousand) were diagnosed within a period of five years (ibid.).
In the last UNAIDS report on Global Monitoring for AIDS (2017), Chile presented the highest percentage of new cases of HIV between 2010 and 2016 in the Latin American region. The main affected group was people between 20 to 29 years (Instituto de Salud Pública, 2016), with a concentrated epidemic pattern in the population of men who have sex with men (García, 2011).

While in many parts of the world the HIV rates of new cases are more controlled or even reducing (UNAIDS, 2017), some specialists in the field have called the attention to the situation in Chile, which has been described as a ‘health emergency’ and ‘out of control’ from an epidemiological perspective (Beltrán on CNN, 2017). According to many local activists, the government has taken insufficient measures to prevent and control HIV, and the epidemic poses challenges to the government as well as to civil society (Tupper, 2017). Despite this emergent awareness about HIV from an epidemiological perspective, how people in Chile are affected by HIV in their everyday lives remains unexplored, except for studies focused on the relation between experiences of stigma from a more medical approach (Cabieses et al., 2010; Cianelli et al., 2011; Ferrer et al., 2009; Norr et al., 2006; Ferrer et al., 2005)

Although the presence of HIV and AIDS in Chile had been historically small—with an adult prevalence rate estimated at just 0.3 percent (Instituto de Salud Pública, 2016)—the lack of visibility of those affected together with poor information regarding the virus and its forms of transmission, reinforce a gap between those with, and those without the virus. In Chile, HIV activists believe sexual education policies are insufficient (Robles and Donoso, 2015), even though for many experts, an informed community is the central element for an effective response to HIV and AIDS (Carmona 2017).

People living with HIV prefer to keep their condition out of public knowledge, since they believe disclosure will produce stigmatization and isolation. In this context, HIV is secret and invisible, but—as this project will illustrate—it has a strong impact in terms of
dislocating relationships among lovers, friends and families; impacting them psychologically and emotionally. Green and Sobo (2000) suggest that understanding the social aspect and impact of HIV is a crucial step in reducing the human costs of the pandemic (p. 2). In this context, this project is an attempt to explore how men living with HIV create ways of making sense of the difficulties that HIV brings to their lives, and by carrying out a sense-making process through other means and contexts, a specific type of sense making might emerge.

2. The Scope of Stigma in Chile

HIV stands for Human Immunodeficiency Virus, which is the virus that can lead to an acquired immunodeficiency syndrome, or AIDS, if not treated. When it becomes a syndrome, the body becomes susceptible to different illnesses and symptoms, which are the so-called ‘opportunistic’ illnesses that can ultimately lead to death. This means that people do not die of AIDS, but because of the other illnesses that take advantage of their compromised immune system.

Although HIV is not a venereal disease, in Chile it is perceived as such, given that it is mostly transmitted through unprotected sex (Instituto de Salud Pública, 2016), carrying a ‘significant social component’ (Madru, 2003). HIV is considered by the Chilean health system as a ‘chronic illness’, and despite the fact that the State provides free antiretroviral therapy, authorities and policymakers have not sufficiently promoted a broader understanding of the illness by the general population (Beltrán, on CNN 2017). This lack of comprehension of HIV boosts the persistence of stigma, as it leaves space for people to create and popularise their own ideas about HIV and about those living with the virus.

Goffman (1963) describes stigma as ‘the situation of the individual who is disqualified

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1 It can also be transmitted through blood transfusions, sharing needles, and from mother to child during

2 In Chile, HIV is treated universally, which means that everybody regardless of their socio-economic conditions (meeting certain criteria in terms of progress of the syndrome) can get access to antiretroviral treatment. For more information, see: [http://www.supersalud.gob.cl/568/w3-propertyvalue-518.html](http://www.supersalud.gob.cl/568/w3-propertyvalue-518.html) [Accessed 14th August 2017].
from full social acceptance’ as a result of a ‘shortcoming’ or ‘handicap’, which could manifest as a physical deformity, a blemish of character or one’s ethnicity or religion (pp. 14). Stigma by illness implies that the person is associated with certain labels that have the purpose of degrading him/her as result of the medical condition, i.e. ‘dangerous’ in the case of people with mental illnesses, ‘abnormal’ if the person requires special treatment, or ‘polluted’ diseases that can be transmitted, to name just a few. Following Sontag’s (1989) analysis, people fear HIV because it is an illness that invokes some ideas of ‘danger’, as it might lead to death and it is not visible; ‘polluted’, as it can be transmitted; and ‘deviant’, as it is likely evidence of being promiscuous or engaging in homosexual practices. Also, stigma involves that the individual is blamed for contracting an illness, making them feel responsible for their health ‘when he or she is around normals’ (Madru, 2003, pp. 41). In this context, HIV becomes the patient’s fault as a consequence of his/her lack of safe habits and the engagement in ‘questionable activities’, which in Chile mostly refers to homosexual practices. In this way, the person living with the virus can be perceived as an attack upon safety, order and morals.

From the first cases at the beginning of the 1980s in the US, AIDS was called GRID, Gay Related Immunodeficiency Virus (Altman, 1982); and with the first case in Chile in 1984 (Robles and Donoso, 2015), HIV was associated with these global labels: ‘gay disease’, ‘sexual plague’, ‘homosexual cancer’ (Ibid.). Sontag’s (1978) analysis of illness as a ‘disorder’ can help us understand that HIV having such a moral component makes it not only an illness of the body as “every form of social deviation can be considered an illness” (57).

The emergence of HIV/AIDS in the local context was seen as a direct attack upon morals in the context of a country with a 76.7% Catholic population (National Census, 1991) and under the control of Pinochet’s military dictatorship. Accordingly, it became a ‘taboo’ theme of discussion (Sontag 1991), as homosexuality was still criminalised until 1999.
In the case of HIV in Chile, what is socially punished is not simply the illness itself, but the past acts that allowed the virus to enter the body, which are deemed as manifestations of social deviant practices (Sontag, 1990). The social deviation Sontag refers to is not just localised on the fact of being ill (as a result of my own behaviour), but also refers to a ‘deviant’ past wherein the activity that caused the disease took place.

However, considering the lack of sexual education in Chile until today and the current prominence of the Catholic Church, many ideas, images and beliefs about HIV remain undisturbed: e.g. that HIV is a death sentence (Sontag 1991) or that only gay men were susceptible to the virus (Robles and Donoso, 2015). Therefore, HIV is still often regarded as an illness that affects only homosexual men, transmitted only through anal sex between male partners. Considering that “Chile is a homophobic country in which homosexuality is not accepted” (Ferrer et al. 2005), the ones living with the virus are stigmatized not only for having the virus, but also because of the assumptions then made about their sexual orientation.

This context is where this project is situated, exploring how men who live with HIV in the capital (Santiago) make sense of their experiences in a place in which the idea that HIV/AIDS is transmitted only among homosexual men is dominant (Ferrer et al. 2005). In most of my encounters with men who did not self-define as MSM (Men who have Sex with Men), they expressed their perception of HIV as a ‘distant danger’, as they only had intercourse with people who are ‘clean’ because AIDS is for other types of people, meaning gay, bisexual and transsexual communities. Studies have proved otherwise, with an increasing number of new cases of heterosexual women who get HIV from their husbands (Cianelli et al., 2008). But here lies what has been described by Madru as perhaps ‘the most devastating effect’ of stigma on the HIV epidemic: the willingness and

---
3 ‘Peligro lejano’
4 ‘gente limpia’
5 ‘porque lo del SIDA es algo que le pasa a otro tipo de gente’
ease with which societies assign blame to a ‘minority’ or to those ‘seen as morally deficient’ (2003, pp. 48).

In the case of heterosexual men living with HIV, stigma operates in a different direction, as they are not being blamed for “sinful or deviant behaviour”, but for a careless attitude towards sex when being promiscuous. This difference between two ways of socially understanding the same syndrome reveals how an illness is turned into an opportunity to punish not only the ‘loss of health’, but also non-heteronormative sexualities.

Sontag suggests that the image of permanent contamination is the most terrifying part of the viral assault of HIV, considering that there is a period in which symptoms are not yet developed, and even if there are symptoms, these remain unseen for those who do not live with the virus. The ‘viral enemy would be forever within’ (Sontag, 1988, 106). However in the case of heterosexual men living with HIV that took part in this research, the fear of the virus that Sontag described was not bigger than the social gratification of being recognised as ‘successful and desired’ among women. This reflects how many of the local attitudes about HIV and stigma are informed by the ‘local moral world’ (Kleinman, 1992), which in the case of Chile manifests as: local models of hegemonic masculinity, local perspectives about risks and care, and homophobia as a widely accepted practice.

What remains as a pattern beyond the positionalities of those living with the virus is that after receiving their HIV diagnosis all the informants and participants of this research reported being affected by a ‘emotional and social strain of being HIV-positive’, especially when it comes to make decisions about how to manage disclosure.

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6 This has to be understood in a context in which the use of condoms is not always negotiable, nor even part of the negotiation. This occurs mostly because of two reasons: the action of asking for a condom implies a suspicious attitude towards the sexual partner, and its use is also perceived as decreasing sexual pleasure for men.
Goffman (1963) suggest that ‘information management’ becomes a critical element in controlling stigma, especially relevant in the case of HIV considering that it is not necessarily ‘visible’ or ‘noticeable’. Goffman (1963) established a difference between ‘discredited’, in reference to the one who has been already stigmatized, and ‘discreditable’, in the one that could be stigmatized, but prefers to keep the truth secret in order to avoid stigma. In this context, disclosing a diagnosis or not could mean the difference between being ‘discreditable’ and having a ‘stigmatized identity’, because stigma makes the epidemic an element of the person’s identity (Madru, 2003). Therefore, not disclosing, remaining silent and concealing its consequences becomes the main strategy by which to control the social consequences of HIV, as the very disclosure pushes people to wear a sign of the disease or more accurately to become a sign of the disease in their very personhood (Xiaopei and Rofel, 2010)

Therefore, the risk of stigma has a high relevance in terms of turning HIV into a secret, which in the context of Chile was enhanced by certain local factors: homophobia and machismo, the historical influence of the Catholic Church on the design of public policy, a post-dictatorship context, and the persistent absence of sexual education. Considering these factors, in addition to the presence of ‘information management’ (Goffman, 1963), Chile is still a context in which is difficult to socialise experiences of HIV.

3. Narratives and Sense-making
The general ‘silence’ around relevant HIV issues in Chile makes it difficult for people living with the virus to find spaces in which to socialise their experiences, which is a central element in understanding what they are going through. The impossibility of openly talking about it, as somebody with Diabetes or High Blood Pressure might do, is generalised and operates as a vicious circle that feeds itself: people living with HIV do not speak about it to prevent stigmatisation; stigmatisation grows as less people talk about it; as stigmatization
increases, people not living with the virus prefer to avoid any reference to the topic, and as nobody talks about it, the topic becomes more taboo.

The fact that HIV is not discussed openly has had an impact on the rising number of new cases (Beltrán on CNN, 2017) and also forces people already living with the virus to remain silent or conceal their diagnosis, leaving them with limited resources to confront death or negotiate a new life, an experience Irving has described as an ‘existential uncertainty’ (2017, pp. 2).

After the mind/body dualism, and with Merleau-Ponty’s understanding of embodiment, there has emerged an anthropological orientation towards an understanding that—regardless of its origin—illness affects the individual in mind and body at the same time, as the two are fused. Merleau-Ponty conceptualised the individual not as a mind with a body, but as a body including a mind, understanding that our perceptions, emotions, and interactions with others are articulated through our bodies. Through our bodies, we experience the world, or rather we become conscious of the world through it, while at the same time Merleau-Ponty suggests ‘psychological motives and bodily occasions may overlap’ (1962, pp. 99) because there is no independence between our psychic intentions and our physiological tendencies.

This becomes a central point in understanding that even though HIV is an illness that can be localized in the body, it affects the individual emotionally, psychologically and socially because it disrupts the way the person experiences and understands the world. However illness is not something that people suffer, but is a condition that can call for a ‘re-negotiation’ of their social identity (Gerhardt, 1989), as people facing illness strive to surpass their difficulties and re-shape relations with the self and with others in ways that are not universal.
Radley has suggested that there is ‘no universal response to suffering, in spite of the fact that people share beliefs about illness with others’ (1993, pp. 3). According to his analysis, this responds to the wide variation in the domains of everyday experience and the resources available for the expression of those experiences. Therefore, making sense of experiences of illness depends on what experiences will be considered, under which conditions (in terms of available resources), and the context in which those experiences are embedded. The possibility of sharing narratives of suffering becomes a central element in mediating disruption and creating continuity (Becker, 1997) as it becomes a way of searching for new meanings and creating new ways of confronting those aspects of life that have been disjointed. Following Becker (ibid.), the ongoing interpretation of experiences and in particular of those critical events that disrupt the continuity of life, enables people to make sense of their personal worlds.

Good (1993) stresses the importance of narratives in making sense of experiences, highlighting its intersubjective character, in which experiences are represented and recounted to others as having a meaningful and coherent order. Narratives in this context offer the opportunity to communicate more than mere reports of events, but also what that event means as something embedded in a life. However, as we will see in the case of men living with HIV in Chile, not every narrative is necessarily coherent, or even has an order that can be verbalised. It is in these intersubjective encounters that people find opportunities through language and other forms of expression to search, find and create meaning around life events that are difficult to process or apprehend.

Therefore, sense-making will be understood in this research as the ongoing process of searching, creating or appreciating the meaning of events, which is conducted in order to confront aspects of the disruptive consequences that HIV might bring. I suggest that this sense-making process emerges through intersubjective encounters in which individuals find themselves in a relation of trust and are open to expression, mutual investigation, questioning, interpreting and theorising.
Given the centrality of sense-making as a way of counteracting the dislocating consequences of illness, and considering its intersubjective character, the question emerges of what happens when people confront HIV in a context such as Chile, where their possibilities for expression about HIV experiences are limited? In other words, how do people find ways to make sense of their HIV experiences if opportunities for intersubjective investigation are constrained by the menace of stigma?

These are questions that this research will initially explore through Participant Observation, so as to ground the practice-based aspect of the project, in which lies its main focus and contribution. The practice-based aspect of this research has an ‘interventionist’ character, and does not respond to more conventional ‘arrival’ narratives of anthropology, but is informed by observation in the field in order to propose to collaborators a methodological devising more adjusted to the context in which this research takes place. However, it is important to note that many aspects of its methodological implementation was adapted during the practice as a product of negotiations with collaborators.

4. Practice and Methods

This project is concerned with exploring the sense making process beyond everyday means of expression, and the impact of expressions that might emerge when people do not only rely on words to make sense of their existential uncertainty. What sorts of ideas, images and ways of relating emerge when men use visual means to make sense of HIV, in an ethnographic context that promotes expressions, questions and mutual challenges, rather than silence, concealment and denial?

This practice-based research comprises a feature documentary film ‘This is my face’, two exhibitions (one in Santiago, Chile; and one in Manchester, UK), a Photo Book (which accompanies this text) and this written thesis.
The project explores ways of producing intimate and self-reflexive narratives using collaborative photography, which mediates their autobiographical investigation; and film, which mediated our relationship during the research process. Consequently, their autobiographical narratives have to be considered as embedded in a creative photographic and film process. In the same way, the written words contained in this thesis emerged by looking through the camera or listening through headphones, with the exception of what is presented in the first chapter, which corresponds to a Participant Observation, which grounded certain aspects of the practice.

As a practitioner, film is central to my way of knowing, and as such, film mediated the data gathered in this research process. However, it not only framed my gaze, but also opened up opportunities to engage with my collaborators in the mise-en-scène creation. While they were arranging and setting up the scene to take a photograph, I was creating my own mise-en-scène about their photographic process. Being engaged in the creation of a film provided a way of making sense of what I was perceiving, mirroring the collaborators’ process. Like the pieces of a puzzle that come together or not, we looked through the lens, sometimes not quite understanding how it would make sense, but within time and through our practice, the pieces started to come together.

Following MacDougall’s notion that ‘any image we make carries the imprint of our bodies’ (2006, pp. 3), the camera became an extension of our bodies, and our bodies affected how the camera and sound were used. As film is the way of knowing used in this project, what you will read here is also a product of that specific way of relating with the collaborators and with the world, which I am now attempting to translate into written words. In this project, images precede words, not the other way around.

In the film and in this written text, I suggest that sense making is an ongoing process, which is never fully completed, as there are always new life events, encounters, information and questions which continuously arising over a life span. The way in which
questions asked about images shape the way in which we find coherent answers to what we are experiencing, what I want to emphasise is that this text did not precede, nor is it more relevant than the images produced by this research. Images here are not evidence, nor only devices for framing reality, but are ways of knowing and a reflexive expression of how pieces of a puzzle came together for all of us.

The film follows collaborators carrying out an investigation about their sense-making process using autobiographical photography. The photographic aspect of this method differs from other methods such as auto-photo and photo elicitation in temporality, implementation and/or focus. While photo-elicitation is based on the ‘idea of inserting a photograph into a research interview’ (Harper, 2002), in this project there are no interviews in the conventional sense, but a mutual questioning about the coherence of our practice. Auto-photo relies on participants’ creation of self-portraits (Lombard, 2013) but this process is grounded in the collaborators’ creation of autobiographical photos, which are not necessarily self-portraits. And finally in contrast to other forms of image elicitation in which participants are encouraged to create photographs about their current circumstances (Radley, 2010; Irving, 2007; Pink, 2012), this project looks for images which have been consciously staged.

Autobiographic photography draws on the collaborators’ life events (from the past, present or future), giving them access to what it means to live with HIV, through their memory and imagination, as they are the ones in charge of create their own representations. Collaborators choose which life events to explore through images, imagining how they want to represent them and arranging a mise-en-scène from which their photograph will emerge. The participants used their creative work to represent challenges they had faced in their everyday contexts due to their illness, and engaged with the representations, and not directly with the memory of the event, through reflexive elements.
Autobiographic photography provides the opportunity of accessing visual materials created by the participants (highlighting the creative aspect of its internal construction), and by that, providing access to what it means to live with HIV. Sontag suggested that "photographs are as much an interpretation of the world as paintings and drawings are" (1978, p. 6) which implies that photographs are much more than simply evidence, but also paths to accessing understandings and interpretations of the world, and in this case of understanding how men living with HIV make sense of their experiences.

These creative ways of representing life events will provide space for the creation of images in which emotions and cognition are interconnected (Harper, 1988) in the process of sense making. By promoting a reflexive practice of autobiographical photographs, images will not only give access to life stories but will also reflect the meaning of their experiences: as pictures are more than representations but also mediators that give shape to ideas (Radley, 2010).

The film documents the autobiographical photographic process in order to create a research outcome that can be shared with others who are not necessarily part of an academic audience. But more importantly in methodological terms, by creating this film the participants and researcher (here, collaborators) are sharing the same activity, as we were both using cameras to create a mise-en-scène, in the same time frame and departing from shared elements.

The act of sharing the same activity (mise-en-scène creation) contributes to an engagement based in mutual questions about the creation of images so as to promote a continuous practice of attempting to reach across hermeneutic borders, from which understandings and negotiations about images creation emerge. This engagement is a fundamental aspect of the practice in order to stimulate reflexivity not about life events directly, but about its representations. In a different way to common research with a photographic component, in which reflexive expressions are promoted while looking at
images already produced, in this research the reflexive aspect is encouraged from the very process of producing the images.

By collaboratively representing experiences and promoting a reflexive approach to images, the researcher proposes to the participants a relation in which they can produce ‘shared understandings of their past experiences and current practices’ (Pink, 2006: 107) upon which informants can comment to then produce a further layer of knowledge (Lapenta, 2009). At the same time, sharing aspects of the image creation aspires to become part of the practice that, to a certain extent, disrupts power as questions and gazes will be mutually directed.

5. Inner States and Emotional Responses

The problems of accessing participants’ internal dialogues using images have been addressed by an anthropology which looks for methodologies that allow the researcher to get closer to the memory and imagination of their participants. This has usually implied challenging the distance produced by conventional interviews or participatory observation, trying to elicit first person accounts that provide a specific type of access to memory and imagination, emotion and cognition as part of the sense-making process.

Through a practice-based form of mutual hermeneutic enquiry about the visual creations, collaborative mise-en-scène provides some alternatives in the field by promoting a type of relation that attempts to disrupt power. This method promotes a type of intersubjective engagement with the images from a reflexive perpective, making sense of events through the creation of its representation and not simply by unpacking the emotional weight that some to these events might carry. The engagement with photographs and not only with life narratives allow collaborators to see their life events from a distance, seeing ‘familiar data in unfamiliar ways’ (Heisley and Levy, 1991, p. 257).
Despite the fact that these questions were directed toward the images and not the events itself, and the use of elements to create a distance from difficult memories, these images did refer to difficult memories and as such conveyed emotional responses. These responses are considered part of a sense-making process about events, chosen by collaborators in their condition of moral agents, and discussed with the researcher. Lennon (2006) suggests that we experience and construct the world through encounters with “objects and significant others”, from which our world gains its imaginary form. In the context of our research, imagination and memory will emerge as ‘psychical partners’ (Casey, 1976) to the image, but that image will also be shaped by our encounter. In this way, this research is looking for those spaces in which inter-subjectivity also permeates imagination, memory and its meaning.

Some life events were discarded for visual exploration due to the emotional impact they provoked every time collaborators referred to them. But at the same time, the explorations carried out had an impact on the way they related to those unexplored memories, as memories are not totally independent from one another. This project considers some ideas from visual ethnography and art therapy expressed by Pink and Hogan (2010) about the congruities between a feminist approach to art therapy and contemporary visual ethnography, in the sense that both are concerned with interior thoughts, make critical interventions and routes to knowing in practice. This is part of the potential of artwork, that ‘trascend[s] its frame’ since ‘acting through the imagination and into the world is what creates its power, effect, and meaning’ (Irving, 2009). Despite the fact that therapeutic outcomes are not what this research is looking for, there is a recognition that elements of this process could have followed that route, and were not curtailed or stopped, as they are considered part of the “self in process” (Hogan and Pink, 2010).
6. The Ethical Framework of Practice

In the context of this research, I am proposing a reflexive, dialogic and collaborative approach based on a Participatory Action Research (PAR) framework (Fals Borda, 1985), as a way of challenging certain ways of doing anthropology. The project seeks to go beyond more conventional anthropologic research by aspiring to upset the hierarchical researcher-subject relationship, following the idea that they are the ‘experts’ (Lombard, 2009), and the ones who know best the social and personal impact of the illness.

PAR has been described as a methodological approach to working with marginalized or oppressed communities with the aim of exploring forms of recognition and representation while seeking to promote changes in their environment (Johnson and Martinez, 2012, pp. 405) through the articulation of knowledge production and transformative action (Fals Borda and Rahman, 1991).

One of the main concepts behind PAR is the interdependent flux between action and research, pushing the boundaries of academia and popular knowledge by putting these to work in a horizontal relationship. In PAR, both forms of knowledge are relevant to identifying the particular struggles of communities and are key to conveying strategies to strengthen “the capacity of the individual to play the role of actor in his or her own life” (Miller and Rose, 2008, pp. 106). In this case by promoting a continuouos practice of expression, and the expansion of means and contexts for sense-making, new elements are added to the way in which they relate to some memories.

As has been recognized by Fals Borda and Rahman (1991) and Montero (1998), PAR also emphasizes the idea that knowledge produced should be meaningful and relevant to the people involved in the research. This will be conveyed in this practice-based research by opening up spaces for discussion and mutual questioning, and re-framing the way we approach image creation during the process.
7. Structure of the Written Thesis

This written thesis follows a choronological analysis of how the collaborative *mise-en-scène* was carried out: from the initial observations, which informed our practice, to the final stage of editing the film.

Chapter 1 is ethnographically informed through Participant Observation, in which difficulties of sense-making for those living with HIV in Chile are presented. By analysing the everyday restrictions faced by one of the HIV organisations operating in Santiago, I look at how people living in Chile create experiential and reflective knowledge through narratives as a ‘primary path for examining disruption and discontinuities’ (Becker, 1997), while constantly assessing the potential of ‘stigma’ (Goffman, 1963). I suggest that what they are going through can be understood through Bury’s concept of ‘Biographical Disruption’ (1982), but by unpacking this concept in consideration of the particularities of their socio-economic and historical context. This chapter highlights the economic, spatial and relational limitations faced by people with HIV in order to make sense of what they are going through, but also how they create strategies based on the intersubjectivity of their life experiences. This chapter takes into account data collected from my first visit to the organisation, and from the first few months of my fieldwork, pointing out the analysis that emerged from these encounters, which informed the methods of the practice.

In Chapter 2, the more interventional character of this practice-based research appears, introducing the idea that some of the elements of sense-making can be extended beyond their everyday settings, by creating a specific ethnographic context in which narratives can emerge. This chapter looks at the first workshop with collaborators organised to discuss ideas about autobiography, and looking at continuities and discontinuities through the ideas of Lejeune (1989), Augé (2016) and Smith and Watson (2010). This chapter also analyses how collaborators negotiate disclosure through ideas of everyday ethics (Lambek, 2010) and tactics (De Certau, 1984).
In Chapter 3, I present the framework used to implement collaborative *mises-en-scène*, as a process for the creation of reflexive autobiographical photos. I suggest that *mise-en-scène* (Bordwell and Thompson, 2001; Cook, 1980), a central concept in the cinematic language, can be borrowed and translated to other visual practices. This chapter also looks at the practice of ‘estrangement’ (Shklovsky, 1917) and Aristotelian plot structure as specific devices for storytelling and artistic creation were used to promote an engagement with *mise-en-scène* and not directly with life events. This chapter highlights the relevance of face-to-face encounters (Irving, 2014) in the promotion of reflexivity as part of intersubjective relations. Following Irving’s ideas, I suggest a specific practice-based form of hermeneutic reflexivity (in the Heideggerian sense) to promote a practice of ‘making’ photos, rather than ‘taking’ them (Ansel, quoted in Sontag 1978); but also as a way of displacing power. I suggest that what emerges from our practice were more than representations, but evocations in which imagination and memory emerged together as ‘psychic partners’ (Casey, 1976). This chapter works in dialogue with the Photo Book that accompanies this thesis, and accordingly I have included instructions for the reader to refer to specific photographs so as to analyse particular aspects of the images.

At the end of this chapter there is also an invitation for you to watch the film (‘This is my face’, available on Vimeo) on which the analysis of Chapter 4 is based. In this last chapter, I argue that reflexivity became a central element of our practice, and shaped the way the outcomes of this thesis were presented. I rely on Ruby’s (1977) analysis of reflexivity in film, and suggest this can be taken further (and not only as an *ex-post* practice carried out from the editing suite) so as to continue the reflexive process beyond ethnographic encounters, with the purpose of reaching a film audience. I analyse shots, clips and sequences from the film which attempted to upset the ‘suspension of disbelief’ so as to make the audience question not only the film, but also its methods and our intentions as collaborators. I suggest that our ethnographic encounter shaped the way the film was crafted (even when we had to adapt our methods), in particular with regard to the aspiration to create a film that could speak to a wider audience. I suggest that to create
ways of going beyond anthropological audiences becomes much more relevant when working with people who confront difficult scenarios to provide meaning to life events, which resonates with ideas of Public Anthropology.

In Conclusion, I summarise the specific findings of this research and propose potential adaptations of the methodology. In particular I focus on how reflexivity promoted the use of photos for sense-making in specific ways, as the only way in which these autobiographical images could have emerged. This analysis suggests that the outcomes of this research have been shaped in our encounter, as part of a specific way of creating relationships with collaborators, in which the sense-making process becomes relevant beyond their subjective experiences.
CHAPTER 1

‘AIDS is an awkward topic [...] It’s like talking about shit or semen. Who will talk about this out loud?’ - Juan Manuel, informant of this research.

This chapter draws on ethnographic material collected through Participant Observation to identify how men living with HIV create experiential and reflective knowledge to make sense of their illness and confront uncertainties after diagnosis, in particular those related to stigma.

Participants describe the impact of HIV in their lives as a ‘fracture’ (‘fractura’) due to the challenges this illness poses to socio-emotional wellbeing. They use the word ‘fracture’ as a metaphor for something that has been broken in the continuity of their lives; a moment in which life took a different turn, the result of trauma. I suggest that considering the way they describe the syndrome’s impact on their lives, it can be considered a ‘biographical disruption’ (Bury, 1982).

I argue that in the particular case of men living with HIV in Chile, Bury’s concept of biographical disruption has to be reframed considering the particularities of the local context, in which those living with the syndrome have guaranteed access to free antiretroviral therapy, but struggle to confront and contest the impact of stigma. Participants reported that, after they were told their results were positive, they understood the ‘fracture’ as ‘unescapable’. Recalling that moment, they expressed their concerns about prognosis and life expectancy, later overshadowed by overwhelming worries about how to re-negotiate relations with themselves and with others.

When confronting this type of disruptions in life, people tell stories in order to communicate and reflect upon their experiences, and therefore narratives become the

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7 ‘El VIH es un tema incómodo... Es como hablar de caca o semen en la calle. ¿Quién va a querer hablar de eso a todo dar?’
‘primary path for examining disruption and discontinuities’ (Becker, 1997) as they search for ways to come to terms with what they are going through. However, men living with HIV in Chile face this biographical disruption not having adequate spaces to share their experiences with others; and without comprehensive care from the State, which focuses only on the clinical and epidemiological aspect of HIV. Many claimed to be ‘left alone’ to confront the uncertainties of the virus and stigma (‘Who can I trust?’, ‘Will I be stigmatised?’) and look for opportunities to make sense of what they are going through by talking about their experiences with others, who are usually also living with HIV.

Becker has suggested that when a self has become something it never expected to be, by the emergence of a disruption, telling autobiographical stories can be a privileged means by which to re-establish a sense of continuity (Becker, 1997). In this way, people do more than tell others what has happened in a merely descriptive manner, but through narrating they can look back at their experiences and attempt to find meaning in the life events, and also try to ‘find redemption from the chaotic uncertainty of the future’ (2013, pp.19).

Jackson (2013), drawing on Hannah Arendt, highlights the importance of narratives not only being about telling stories, but about the sort of intersubjective common ground that can emerge when sharing experiential narratives with another. For Jackson, stories do not simply disclose ‘who we are’, but rather ‘what we have in common’, and in this way stories are looking for a potential common ground between ourselves and others. According to Jackson storytelling has the purpose of not only expressing ‘what we think we are’ but ‘what shared circumstances’ we are confronting and what that means to our fate (Jackson 2013, pp. 15-16) as means through which we can deal with suffering and uncertainty.

In this context, I argue that the possibility of engaging in intersubjective encounters and sharing stories about their experiences of living with HIV enables people to create knowledge based on shared experiences and reflections, generating strategies in the
constant face of the risk of stigmatisation. The possibility of finding an intersubjective common ground in which they can open up about experiences, learn from somebody else’s and create new knowledge through dialogue, becomes a way ‘to work through the situation they are in’ (Frank, 1998, p. 207).

However, when potential stigma hinders the possibility of their sharing narratives with others, this also undermines their chances of finding opportunities for understanding how to deal with the social aspects of their biographical fracture. In the context of Chile, HIV stigma also takes place within a myriad of cultural, socio-economic and historical circumstances, as will be explored further in this chapter.

1. Loss through a Fracture
A few months before starting my fieldwork, I spent time in Chile trying to create links with potential collaborators for this research, a task that proved much more difficult than I first imagined. I had already been in contact with 5 organisations and 3 had declined to take part in the project due to concerns about how disclosure could affect the well-being of participants. One of the groups I chose to contact is called ‘Organización por la vida de personas viviendo con VIH’ (Group for the life of people living with HIV), an organization of activists and people living with HIV working to improve the lives of those living with HIV in the borough of Puente Alto, Santiago.

The organization was not easy to find, since its scope of action was mainly local and they had a small and out-dated presence on internet. People who arrived here mostly knew about them through word of mouth, either through somebody who knew directly about the group or a health professional. An informant gave me their phone number, through which I arranged a meeting with their president, Luis.
The organisation’s office was 25 kilometres south from the centre of Santiago, where most of the participants I already knew decided to meet. Crossing the city on the overground Metro, the landscape became increasingly industrial: concrete was the norm here for most social housing, shopping malls, clinics and universities. We left behind any pretension to a ‘Chile lindo’⁸. Here, there were no historical buildings, no business people, no narrative of success at the human scale.

Though the office was located inside one of the concrete structures visible from the Metro, it was also hidden within the Sótero del Rio Health Complex, a health centre providing care for nearly a million and a half inhabitants of the boroughs La Florida, La Pintana and Puente Alto⁹. The entrance to the complex was chaotic, filled with street vendors offering everything from second-hand clothes to toiletries, as well as food, sweets and flowers... anything that could be necessary when visiting someone in the hospital. Street vendors also served as unofficial information points, telling the public about the hospital’s opening hours or where to find a particular section. There were no signs indicating how to get to the organization, so I asked the vendors where I could find it, but nobody knew.

I phoned Luis after trying to find the organisation’s office with no success, and he came to find me at the other side of the building. We walked to the other end of the complex and—just before the exit—was a modest wooden one-floor structure. It looked like an abandoned part of the hospital, and a handwritten sign glued to the door told us we had arrived at the organization.

I imagined how hard it would be for someone who was newly diagnosed to find the organisation, especially considering the disorientation that comes after being informed you have HIV, described by many participants on this research as a ‘fracture’ (‘fractura’),

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⁸ ‘Beautiful Chile’, a sentence used by locals when interacting with tourists to highlight the geography of the country and the generosity of the people. It is a sentence that can also be used ironically.
⁹ The hospital is located at Puente Alto, a borough with 15.40% of its population in a condition of poverty (Ministerio Desarrollo Social, 2011).
meaning ‘something that has broken’. How difficult must it be to walk around with a diagnosis that has changed one’s life, and with no signs as to where one could find help?

Despite the fact that HIV is an incurable condition but can be treated as a chronic illness, it continues to cause major disruptions to people’s relationship with others and their identity. Although the virus cannot be eradicated from the body following the infection, from the mid-1990s the introduction of highly active antiretroviral therapy (HAART) has dramatically prolonged the lives of many living with it. Currently, if an individual gets an early diagnosis and can access treatment soon after the infection, they can even enjoy a ‘nearly normal’ life expectancy (Watkins-Hayes, 2014, p. 432) producing new realities of prognosis, treatment and wellbeing. But, although this transition from regarding HIV as ‘death sentence’ to today’s characterisation of it as a ‘chronic illness’, people in Chile still struggle to come to terms with the stigma the diagnosis carries.

The fact that members of the ‘Group for the life of people living with HIV’ in Puente Alto described their diagnosis as a ‘fracture’ illustrates the impact of the event in their lives. The use of ‘fracture’ as a metaphor to describe that moment coincides with what Bury (1982) called ‘biographical disruption’, in the sense that in order to cope with uncertainty, people throw into relief all the available resources (material and cognitive) they have at hand. He described that in order to deal with pain and suffering—as the body develops new limitations in terms of its performance—the person with the disease needs to negotiate relations in order to cope with new everyday difficulties (Bury, 1982).

His analysis mirrors some of the experiences of men living with HIV in Chile, in particular when it comes to the uncertainty and the occurrence of existential questioning. Extending and applying Bury’s concept to the context of the participants in this research, I suggest that rather than focusing only on the physical consequences of illness, people living with HIV in Chile encounter most of their uncertainties in the occurrence of stigma after

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\(^{10} '\) hay algo que se quebró'
disclosing their HIV status. I argue that in Chile—where access to antiretroviral medication is guaranteed by the State—the major disruption caused by HIV is located not only in the body (especially after the fear of death has been done away with), but also in terms of how people living with the virus have to restructure relations with themselves and others in order to avoid being stigmatised.

*When they gave me the results, I went into shock, like really numb, speechless... I went out to look for a fast-coming bus, so I could throw myself under it and end it... When you are ill, you tell people—maybe not everyone—but at least your mum, your partner, your friends, but I couldn’t do that; something so basic. Nobody was going to take care of me, nobody would help me, so I had to disappear.*

Felipe’s description of his mixed emotions after receiving his HIV test results, is in accordance with many of the testimonies collected for this research: feeling lost, alone and hopeless; which later becomes intertwined with the fear and uncertainty about how to socially manage their diagnosis. Even though for some of participants, their HIV results did not come as much of a surprise, they reported that the moment at which their suspicions became a ‘inescapable truth’ or a ‘reality in front of my eyes’ had an enormous impact on them, regardless of their presentiment. Participants described this sense of confusion, doubt or despair after a HIV diagnosis, and it has also been frequently reported in many autobiographical pieces of work on HIV (Brodkey, 1998; Monette 1996; Joslin and Friedman, 1993).

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11 ‘Cuando me dieron los resultados, yo me fui a negro, asi de verdad como que no podía hablar... Salí de la consulta y me fui a la calle a esperar que llegara un bus que viniera muy rápido pa’ que me pasara por arriba y terminar con esta huevo... cuando estaba enfermo, le dices a la gente... bueno, no a todos, pero le dices a tu mamá, a tu pololo, a tus amigos, pero yo no podía hacer algo tan simple como eso. Me imaginaba que nadie me iba a cuidar, nadie me iba a ayudar, entonces tenía que desaparecer.’

12 ‘Un verdad de la que ya no podía escapar’

13 ‘Una realidad frente a mis ojos’
Irving (2017)—following Farmer’s (1992) ideas about localising understanding of HIV—suggests that even though at a global level there are commonalities ‘in thoughts, dilemmas, and emotional responses’ (p. 7), it is necessary to consider the particular circumstances and worldviews that impact how people experience what it means to live with HIV. In the case of men living with HIV in Chile, we need to look at this biographical disruption within the context of lack of awareness about HIV and scarcity of support in a post-dictatorship period, in which they mediate relations with themselves and others by negotiating elements of trust, silence and risk vigilance. They articulate a particular sets of strategies through which they manage narratives to protect themselves, using all they have to make sense of their disruption, reconfiguring and re-signifying experiences and relations.

In Bury’s conceptualisation of biographical disruption, questions such as ‘What will I do now?’ and ‘Why is this happening to me?’ are framed under the lens of increasing limitations within the body, experiences of physical pain and confrontation with the prospect of an early death. However, in the case of men living with HIV in Chile, concerns regarding the body were not the most demanding source of uncertainty, but rather the focus was often upon how relations would have to be re-negotiated, in a context of lack of material resources and emotional support. This has to be understood in a particular geographical and temporal context, and within a myriad of socio-historical elements that affect men living with HIV, while also considering their individual circumstances.

In the case of many men living with HIV in Chile, by not disclosing their status in order to reduce the risk of stigma—defined by Goffman as ‘the situation of the individual who is disqualified from full social acceptance’ (1963, p.9)—they also limit the opportunities of to talk about their experiences, further complicating and hindering their personal process of sense making. This process of understanding and re-signifying their experiences of living with HIV is affected by having (or not) appropriate cultural, material and emotional conditions to socialise experiences, as we will see in the following ethnographic data.
2. Between Uncertainty, Scarcity and Good-Will

Luis told me it was a ‘busy morning’ at the organisation, and when we arrived, I understood what he meant. The office was too small for its fifteen members all there engaged in different activities: while some took part in a volunteer meeting, others were having breakfast; and Mariana—the secretary—was answering phone calls. The same room was packed with a desk, a couple of sofas, a large dining table, fridge, cooker, and a cupboard with information leaflets and condoms. One toilet, which was out of order. In a corner, the radio announced the news while, at the same time, the TV was on.

Luis’ office was a tiny space located at the end of the room with a computer that didn’t work. He asked me to leave the door open so he could hear what was being discussed by the volunteers during our chat. Outside, people in the volunteer meeting were getting agitated and some of them started to shout in order to be heard. Luis rolled his eyes and shouted ‘Control yourselves! This is not the market’14. As soon as he raised his voice, everybody stopped speaking and as though he was the schoolteacher. Luis was in his early sixties, with a perfectly shaped moustache and haircut. That day he was wearing a thoughtfully ironed white shirt, conveying a sense of severity that he balanced with a friendly smile, although not particularly sweet when telling the volunteers to lower the tone of their conversation.

Luis was described as a ‘father figure’ by many of the volunteers. He helped them confront difficult situations after being diagnosed, such as being kicked out from their homes, dishonoured by the family, or facing mental health issues. Luis was respected by the others, not just because he was older, but also because he knew how to provide support when it was needed as he had been through similar situations. He had his own story in which he fought for survival. He was among the first group of people living with

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14 ‘Contrólense pues! Esto no es la feria!’
HIV at the Sótero del Río hospital, and as a result, he decided to create a platform of care for those living with the virus:

At that time, to get HIV was like gambling with a death sentence. We were told we were going to die soon, and that there was not enough medicine for everybody... We had our names written down on a paper like in a raffle to decide who would get treatment. There were just a few lucky ones would receive treatment. If you won that, you made it\textsuperscript{15}.

Luis referred to the fact at the beginning of the HIV outbreak during the late 80s and the beginning of the 90s, there was restricted access to therapy in Chile, and to organise and demonstrate was a matter of life or death. This is why Luis and others who had been diagnosed around the same time created a group to demand access to suitable medicines. The organisation ended up becoming a safe setting in which to socialise and talk about their experiences, which was particularly difficult during the political repression under Pinochet’s dictatorship, in which any type of social organisation was banned. They started to organise demonstrations to demand access to therapy, but there was a problem: they didn’t have a representative to speak in the name of the group. Luis said this was because nobody wanted to be associated with HIV:

\textit{Nobody wanted to be president of our group. We were all scared about being linked to AIDS, but then I thought that, since I have a professional career (as an engineer) and more economic resources, I would be more considered by others, including the authorities... This is how our country operates. You will only be heard when you have money or education}\textsuperscript{16}.

\textsuperscript{15} ‘En ese tiempo tener VIH era una sentencia de muerte y una lotería. Nos habían dicho que nos íbamos a morir pronto y que no había terapia para todos... Nuestros nombres estaban en en papel, así como cuando se hace una rifa. Y algunos suertudos recibían terapia, otros no. Así que si te la ganabas, podías pensar en vivir más.’

\textsuperscript{16} ‘Nadie quería ser presidente. Todos estábamos asustados y nadie quería mostrar la cara... Pero al final, pensé que como yo era profesional y tenía un algo más de plata que los otros, me tratarían más en serio... Así es Chilito. Sólo te van escuchar si tienes educación y plata.’
But that happened more than twenty years ago, and he was still in charge today. He said that he had tried to pass responsibility to other members, but nobody wanted to take it because it was ‘like having an unpaid full-time job’. The self-confident tone of his voice revealed he knew how to keep the organization running, yet at the same time, it was hard to imagine someone new would want to take on that responsibility. Mariana, his secretary, told me Luis was more than a president, ‘he is also the engine that keeps the place and the organization running’\textsuperscript{17} despite all their financial difficulties.

Historically, the group was in an unstable situation. They had their office because the hospital decided to lend some old and unused facilities to volunteer organizations. There was no contract or formal documentation, but only a verbal agreement, which meant they could use that space only on trust. The volunteers were conscious of this, so they took good care of the space and kept it open every day so the hospital would know the space was being used wisely, because, as Luis explained, ‘if it wasn´t for their goodwill we probably wouldn´t exist’\textsuperscript{18}.

The organization survived on the most basic means. They had almost made one million Chilean pesos (near £1000) in a year, and with that cash they could support some new arrivals, temporarily taking them out of dangerous situations such as poverty and violence, often caused by or worsened by their HIV status. To sustain this, a group of volunteers took charge of two public toilets at the hospital, where they sold toilet paper, soap and other toiletries to the general public. The money made was divided between volunteers in greater need and the organization. Sometimes they hosted raffles or other similar activities, and if an extra donation arrived, they used that money to celebrate Christmas or to buy a cake for a birthday. Despite this economic uncertainty, the volunteers agreed their time must primarily be focused upon their main goal: providing emotional support and advice to those who had just received an HIV diagnosis. Luis told

\textsuperscript{17} ‘Él es el motor de este lugar.’

\textsuperscript{18} ‘Si no fuera por su buena voluntad, nosotros no existiríamos.’
me that for some, after disclosing their status to families or partners, this was the only place they could go to feel safe:

3. HIV as a fracture in a post-dictatorship context

Participants understood the time of diagnosis as the starting point of a long-term fracture, in which a revelation about the body takes place through pointing to the presence of a virus that cannot be reversed and which they will have to live with for the rest of their lives. The moment in which they were informed of having HIV is when ‘everything changed’ and, in that context, it is vital they have access to support and are able to discuss their concerns about the potential social consequences of living with the virus. When they first receive their results, HIV is introduced as an addition to their lives that could confirm a suspicion or be a surprise. The irreversible character of the acknowledgment is what haunts them.

The realisation that – unless they are in the advanced stage of AIDS – HIV can be treated, and that antiretroviral therapy is guaranteed by the State, reduces the fear of death. But at the same time, uncertainty regarding how to deal with the social implications of HIV strikes: how will their relations change given that their bodies will forever host a virus associated with contamination, pollution and promiscuity? These are the initial questions within a long process of biographical disruption in which their self-image and relations with others will be affected and redefined.

With a HIV diagnosis, a clear prognosis and potential questions about the body can be answered by health professionals, but questions regarding how to re-negotiate relations and the cost potential stigmatisation – some of the main uncertainties in this particular biographical disruption – are often left unanswered.
Stigma, or its potential, becomes part of their everyday lives by shaping the way they think about themselves in relation to others, and how others relate to them. In this way, individuals living with HIV in Chile can suffer the consequence of stigma in more than two ways: by not being able to reveal their status, or by experiencing stigmatisation after disclosure. They either suffer the mental burden of keeping their status secret (which has a negative impact on their wellbeing) or they experience the constant danger of being stigmatised and/or abused (verbally or even physically), as I saw many times at the organisation in Puente Alto.

Goffmann (1963) describes the demeaning effect of stigma as ‘very extensive’, and in this particular context of potential violence or discrimination, people living with HIV have to constantly develop strategies to protect themselves and manage the risk of living with HIV. In the eyes of many in Chile, the individual living with HIV becomes a ‘sidoso’ – a derogatory term referring to someone who has AIDS – and by this assessment, the illness does not just become part of the body, but of the self. The individual living with HIV is disgraced and shamed, and ‘is assigned a less normal identity’ (Madru, 2003, p. 40); that of being ‘not quite human’ (Goffman, 1963, p. 15). This often results in what has been described as a ‘Stigma Theory’ (ibid.), an ideology which explains the inferiority of those stigmatised and legitimizes the abuse of some human rights for those living with HIV in Chile.

Schoepf (2001) has highlighted the fact that HIV stigma is based on the ‘creation of alterity’, which allows those in power to dehumanise those affected by the virus, by assigning them the status of ‘dangerous others [...] believed to be morally contagious and sexually polluting’ (pp. 340). This ‘creation of alterity’ as a form of othering has a direct impact in creating a disruption in social functioning (Skinner, 2004), which has been analysed since the beginning of ethnographic research on the pandemic, establishing the interfaces between structure and agency (Farmer, 1992; Parker, 2001) but also how people can create new, valued identities for themselves through collective struggles
Even though HIV is regarded as a pandemic affecting people all over the world, the way in which they are stigmatized (or not) varies across different contexts. This understanding led Farmer (1992) to coin the concept of ‘geography of blame’, which underpins the fact that HIV stigma has to be understood as ‘socially constructed’, and as such, working in different ways in different parts of the world.

Aggleton et al. (2003) suggested that in Chile, there have been numerous reports of people losing their jobs after being diagnosed; localizing machismo, homophobia, family honor and sexual silence among the key factors that contribute to discrimination. According to Cianelli (2011) there is a lack of qualitative research concerning HIV-related stigma in Latin America, but in particular in Chile, even though stigma is the main barrier to fighting HIV, as the fear of discrimination prevents people from accessing testing and treatment.

Aware of the potential stigmatization that those living with the virus could be subject to – including members of the organisation-, authorities at Sótero del Rio Health Complex created a special unit in which they could administer antiretroviral medication away from other patients. HIV is the only clinical condition in Chile to which these negotiations apply, and according to the hospital authorities, it encourages patients to continue receiving their antiretroviral medication.

However, it is possible to question who is really being protected, considering that according to Goffman (1963), people who are stigmatised are expected to learn new ways of being and to behave in ways that make ‘normals’ more comfortable, for example, by not disclosing their condition or by staying away after disclosure. Therefore, the question of who is being looked after remains valid.

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19 Those who does not live with the virus.
The occurrence of HIV stigma in Chile has to be understood within its post-dictatorship context. The first official HIV-related death took place in 1984 (Donoso and Robles, 2015) while the country was still under Pinochet’s dictatorship, which left almost forty thousand victims (Valech et al., 2004). During that period, many Chileans were fearful they might do or say something, even inadvertently, which would be deemed by authorities as challenging the military order, and therefore they would be punished, tortured, or even killed. In this context, remaining silent and avoiding trouble were good strategies for staying safe, and many practiced this on a daily basis for more than 17 years. Post-dictatorship, some of these strategies are still in place, affecting the way HIV is addressed or not by the authorities.

In this case, considering silence is deemed a potential risk-avoidant strategy, and with the constant threat of stigma, it is understandable that the conditions around what it means to live with HIV are not discussed, as is done with other health issues or chronic illnesses (e.g. diabetes or high blood pressure):

*AIDS is an awkward topic... you have to understand that nobody wants to talk about this. It’s like talking about shit or semen. Who will talk about this out loud? Nobody... People think that “This is a group of degenerates and they can do whatever they want, but surely they will get sick. And as long as they are away from me and my family, I don’t care”... I am not stupid and I keep my mouth shut. I don’t want people to look at me like an alien infecting everybody on the street*.  

Juan Manuel, one of the organisation’s members.

HIV is described by Juan Manuel as being linked to ‘degeneracy’ and having the same social value as ‘shit or semen’, which suggests the view that HIV is a detestable addition to

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20 ‘EL VIH es un tema incómodo... Tienes que entender que nadie quiere hablar de esto. Es como hablar de caca o semen en la calle. ¿Quién va a querer hablar de eso a todo dar? La gente piensa ’este es grupo de degenerados obvio que se van a enfermar. Que hagan la huevá que quieran pero lejos de mí y mi familia, me importa un carajo’... Yo no soy estúpido y me voy a quedar callado porque no me interesa que la gente me mire como si fuera un marciano que anda infectando a todo el mundo.’
somebody’s life that is subject to punishment. The punitive measures include an assemblage of humiliating and segregating social sanctions that those living with the virus are afraid of. In the context of being ostracized or marginalised, the task of ‘making sense’ becomes a much more difficult one, and in some cases, self-marginalisation can be a strategy to avoid being subjected to further stigmatisation.

Juan Manuel’s description provides an insight into how those who want to exert punishment upon those living with the virus have intertwined misconceptions about HIV with fear: First, of contagion, revealing an unawareness about how the virus is transmitted; and second, of being socially devalued, because of the reproachable morality with which HIV is associated. Stigmatisation follows a cycle which nourishes itself: Stigma is what prevents people from talking about HIV – regardless of whether they live with the virus or not - and this lack of socialisation fosters a proliferation of misleading ideas about the virus, which feeds stigma and ultimately reinforces it.

4. Biographical Disruption within the Health System

Participants considered HIV diagnoses as not taking place in ideal conditions, especially considering some would never access alternative methods of support outside of medical care. When first diagnosed, individuals received information from medical staff, who first inform them about their results and tell them how best to deal with HIV from a clinical and epidemiological perspective. In a following visit, the newly diagnosed person receives information about antiretroviral medication and how to access the free treatment currently guaranteed by the State.

Following official protocol — called ‘Manual de procedimientos para la detección y diagnóstico de la infección por VIH’\(^2\)\(^1\) (Ministerio de Salud, 2010) – HIV diagnosis is given

\(^{21}\) This handbook follows guidelines from OMS and ONUSIDA.
by a health professional who informs the ‘service user’ about the test results, providing additional guidance on how to prevent transmission and maintain a good state of health. They finally refer ‘users’ to a specific health centre for a clinical evaluation and further services, if needed. In this protocol, which provides the guidelines for HIV notification, there is no reference to providing emotional aid to the one being notified.

The procedure outlined by the Ministry of Health approaches HIV from an epidemiological perspective, describing every step, and the responsibilities of the service user within the health system, without reference to mental health or social care. Given that the Chilean health system provides care for the body living with the disease, but not for the overall wellbeing of the individual, the participants’ claim of being ‘left alone’ with the diagnosis clearly resonates. Providing support for the physical body but not for the person as a wider being, leaves the emotional side and an individual’s participation within society out of the care equation. Luis mentioned that this procedure at the time of diagnosis is prevalent across different hospitals and private clinics:

*They do not have the time, or any idea of what it means for someone’s life to get a HIV diagnosis... Many health workers are not prepared to guide you through the challenges that HIV would bring to your life.*

If we compare the above experiences with the guidelines in the protocol for health workers, we can see there is no wrongdoing, but at the same time, no indication of acting otherwise within a more comprehensive framework. Luis worked closely with users of the public health system, but testimonies provided anonymously by participants proved that the same types of practices were replicated across the private healthcare system. Luis

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22 Luis’ testimony is in accordance with all the forty interviews carried out for this research and the personal accounts included in the film: Oscar, who was told twenty years ago that he should prepare to die soon; or Diego, who two years ago was notified with pity, undermining his agency; or Claudio, who two years ago was informed about his status without receiving any emotional support; or Miguel Ángel whose medical doctor disclosed his status to his mother without consent.

23 ‘Ellos no tienen tiempo, ni idea de lo que significa para alguien que te digan que tienes VIH... Muchos de los que trabajan en salud no saben cómo ayudarte o guiarte para todo lo que se te viene.’
made explicit his disagreement with an approach that focused exclusively on the body, overlooking many crucial aspects of HIV. For him, ‘it is much more than an illness of the body, HIV is an illness of society’. HIV is able to destabilize, not just physically and emotionally, but also socially by modifying an individual’s position in society, as society projects its fears on those living with the virus: fears of contagion, pollution and immoral behaviour.

This becomes clearer when comparing the way some collaborators socially manage chronic illnesses. Miguel Angel says he doesn’t have a problem telling people he lives with diabetes, but he can’t be open in the same way when talking about HIV, due to its potential social repercussions. ‘HIV comes with a price’ says Miguel Angel, referring to a price paid outside the limits of the physical body. In Chile, the impact of HIV has been controlled from a clinical perspective (by accessing adequate and free antiretroviral medication), but the social impact of HIV in terms of stigma has not yet been addressed, in part due to the lack of guidance and support provided to those who are notified, who often find themselves confused about how to handle a diagnosis.

One of the group’s strategies to support recently diagnosed individuals was to create a network of health professionals who could inform them about the existence of the organization. However, Luis told me this was not enough: people can be told about the organization, but most will never get in touch, even if they need help. Medical confidentiality, in particular regarding HIV, prevents access to medical records, making it impossible for the organisation to reach recently diagnosed users of the medical system. In this context, emotional support from a group or a counsellor becomes a matter of luck and/or resources.

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24 ‘El VIH es más que una enfermedad del cuerpo, es una enfermedad de la sociedad.’
25 This destabilization can be observed in the film when all the collaborators narrate how HIV affected their relationships with themselves and others by pushing them to reframe their relationships.
26 ‘El VIH tiene un precio.’
27 Not epidemiological.
28 Private counselling can be accessed, but not everyone can pay for it.
5. The Price for Luis

At the time of his diagnosis, Luis was working as a construction engineer and was married to a woman with two children. He had what he described as ‘a good life’ but had started to become sick for no apparent reason more than usual. A HIV test he never imagined would come back positive defined his life from that moment on. He had cheated on his wife to whom he had been married for many years, and whom he still loved. At that moment, he said he felt the weight of Catholic guilt on his shoulders. The positive results would mean admitting to an affair and bringing an end to his marriage, perhaps to being rejected by his sons and the end of his professional career. ‘I had to tell the truth, or disappear… But I just couldn’t go away’, he said. One of his main concerns was that his wife might also be living with HIV because of him, and so he was prompted to tell her. She was tested a few days later and the results came back negative. This was a relief – ‘at least it was only me and maybe I could fix things’ – but later she would never touch him again.

The relationship with his sons also had to be reframed. The eldest went from not talking to him to later leaving the family home. After seven years, a time Luis named the ‘period of adjustment’, they began talking again, but with his second son ‘things are still difficult’. He never disclosed his status at the workplace and decided to retire early at the age of fifty.

Narrating his own life experience after diagnosis, Luis was using his own story to illustrate how HIV can become a ‘fracture’ in somebody’s life, telling me about the relations he lost and how much he suffered mentally. Luis referred to experiences which took place almost three decades ago, but his story revealed that even although some circumstances were now different, many others were still the same. Nearly thirty years ago medication was

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29 ‘Tenía que decir la verdad o desaparecer, pero yo no podía arrancarme’
30 ‘Al menos era sólo yo y quizás podía arreglar las cosas.’
31 ‘período de ajuste.’
very limited, where now the State guarantees access for everyone, but at the same time, stigma and the social impact of living with HIV in Chile remains high.

In the following section I examine how members of this group attempt to learn to live with the virus and overcome stigma, creating knowledge together (based on reflections on what they have lived) and adapting the experiences of others to their own circumstances.

6. A Certain Fracture, and a Chronic Disruption: Trying to Make Sense

If diagnosis is the starting point of this biographical disruption, it is followed by a process ‘of learning how to live with HIV’. Diagnosis brings up uncertainties that affect a wider scope of relations, ideas and circumstances that need to be reframed. These span from an understanding about the implications for the body when living with the virus in relation to particular bodies and everyday care (from the right use of antiretroviral medication to improved diets); to rethinking their identity and deciding whether or not to disclose their status to their families. This is a process in which body, mind and self are intertwined and re-shaped by their ability to narrate themselves in order ‘to articulate and resolve core, universal problems’ and as ‘a way to avoid or heal biographical discontinuities’ (Becker, 1997, p. 25)

I suggest that by narrating, individuals are able to better learn from their experiences, ultimately making sense of the illness for themselves and others. In other words, in order to overcome the uncertainty that comes with HIV, they intersubjectively create different ways of making sense of and understanding how to live with the virus, and how to confront stigma.

These understandings are based on their own experiences and personal reflections reshaped, ‘in ways that are socially acceptable and appropriate’ (Radley, 1993, p. 2). By
reshaping their narratives and therefore their actions in ways that are, following Becker (1997), ‘performative’, they also become ‘empowering’. Experiences are shared with others, leading to a collective enrichment, and they then come back to the individual who can adapt another’s experience to the particularities of her or his personal situation. However, in order for this process to be carried out – given that it involves socialisation – it needs to take place in a condition in which they would not feel the fear of being stigmatised. The organisation was a fundamental place³² for this purpose, being one of the few spaces in which members could talk about their experiences safely and be understood. This is why some of them described it as a ‘place of relief³³’.

In order to provide support to newcomers, the organization’s work was based on the volunteers’ own experiences, with peer-to-peer counselling at the heart of their approach. The office was a ‘safe space in which individuals could talk about HIV without fear of being stigmatised, as HIV here was not a revelation but a common element, and the office was often full of volunteers sharing their experiences. They could also talk without having to refer to HIV as a complicated issue, and they sometimes even joked about their situation, seeing it from a different perspective. Participants could be having a cup of tea while discussing the side effects of Ritonavir³⁴; they could share tips about marihuana oil for arthritis or talk about the latest TV show while also discussing and answering questions such as ‘Should I disclose?’; ‘How will my family or friends react?’; ‘When should I talk to them about it?’; ‘What if they don’t react well?’ or ‘What if I am insulted?’.

The threat of stigma was often described as ‘broad’, since it had a vast range of consequences, from a change in relations (such as a friend becoming more distant) to being insulted or physically abused. The continuous risk assessment in terms of stigma produced a constant state of vigilance, and the stress that came with it in some cases affected their mental health. In this context the opportunity to share with others who

³² Further on in this thesis, I attempt to separate ideas of place and space, in order to argue that safe spaces can be created even if the place is itself is not deemed safe.
³³ ‘lugar de liberación’ or ‘descanso.’
³⁴ One of the antiretrovirals used in Chile.
were going through or had been through similar situations helped to counteract the overwhelming sense of uncertainty and risk.

Outside of the organisation, the practice of a risk assessment of stigma or ‘information management’ (Goffman, 1963) involved constant decisions as to when, where, how and whom to open up to in order to avoid negative consequences. This strategy can be exhausting as it involves an analysis of many factors – many of them out of the individual’s control – and attempts to predict outcomes could become an endless mental exercise. This is why, while in settings in which their status had not been disclosed, participants preferred to remain silent and not reveal their diagnosis. Silence, risk vigilance, and not revealing they had any knowledge about HIV were among the strategies used to pass unnoticed with regards to their status, or to become less vulnerable to potential questions from others.

Participants conceived of disclosure as an act of trust, and even though they could have prepared for many potential scenarios, the outcome – measured by the reaction of the person they were talking to – always had elements out of their control. Disclosure was exceptional in the sense that silence and avoidance were the norm. Disclosure involved decision-making, and in making that decision, they prepared for many potential outcomes. At the organisation, I listened to many of them imagining what might happen if they disclosed to someone in particular. In these conversations, the same questions would appear: Why was it so important to disclose to that particular person?, How would you do it?, When and where?, What did you expect from disclosing? These discussions were relevant in preparing them for the potential results of that act of trust which had uncertain outcomes. According to them, this process of asking and answering questions was central to their discovery of the incongruences and continuities in their decisions, and also in their assessment of how best to deal with disclosure in relation to a particular person. This encounter between members of the organisation was pivotal in preparing
them for disclosure, allowing them to recognise the power of their own agency and giving them back a sense of control.

At the organisation, I never saw volunteers talking about HIV in the same carefree manner beyond the front door of the office, where some of them sometimes went to smoke. Every time we went out for a cigarette, volunteers would talk about something else, or would check that people passing weren’t close enough to hear what we were talking about. I realised that they were only able to talk about their experiences with HIV in a relaxed way inside the organisation’s office, as they believed they were only safe there. At the organisation, the physical division between the inside or outside of the office delineated spaces of safety for them, although the ‘safety’ of this space – marked by the materiality of the walls and the privacy it implied – could be modified. Whenever someone unknown entered the office, volunteers would lower their voices, stop their conversations or change topic, being cautious in their interactions until the new visitor was identified by revealing her or his connection with the organisation. Therefore their state of vigilance does not stop simply because they are inside the office. Their sense of safety cannot be establish a priori by dichotomies such as inside/outside, or known/unknown, but have to be understood as fluid and subjective, something which will be developed further in the next chapter.

7. Sense-Making Beyond Disclosure
I have suggested that people living with HIV in Chile contest the uncertainties of their biographical disruption by sharing narratives of their experiences in an intersubjective reflexive process, also creating knowledge that can be shared and adapted. Radley (1993) described this feeling of confusion as the ‘uncertainty’ felt by individuals when trying to answer the question ‘What is going on here?’ As stated by Kleinman et al. (1997), ‘relationships and interactions take part, sometimes a central part, in the experience of
suffering’ (p. 2), and when it comes to living with HIV, the scope of suffering goes beyond the question of disclosure. The relevance of contesting uncertainty in relation to chronic illnesses has largely been recognised from a clinical perspective (Davis 1960; Wiener 1975, Jenkins et al. 2005), but Radley (1993) proposed that there is ‘no universal response to suffering’ (p.3) and adds that linguistic expression may provide some answers.

Those living with HIV at the organisation bring their experiences and worries to share in order to find solutions, ease their suffering, and learn from each other. By sharing with their peers, they are free to talk about anything relating to the illness without feeling the constraint of holding back experiences usually being deemed risky: here, suffering does not have to be withheld because – as Morris (1997) has suggested – it falls within their moral community. The interaction is taking place in a safe setting and with others going through similar situations, which increases the likelihood of being understood and learning from the experiences and reflections of others. Suffering can be difficult for other people to understand, especially when they themselves do not live with HIV, or if their life trajectories are not connected to similar experiences. Given the complicated reality of HIV, words might not be able to accurately reflect what they are trying to narrate (Becker, 1997), because as Morris describes, an inaccessible dimension of suffering happens in a realm beyond language (1997, p. 27). This aspect of suffering takes place when it is shared, because, even though language is used to try to communicate suffering, it will never be experienced by the other, only imagined, ‘in which case one would say that language is hooked rather inadequately to the world of pain’ (Das, 1996, p. 71).

Despite the fact that those experiencing life disruptions will never be able to make others ‘experience’ their pain, the mere act of engaging in an intersubjective encounter of trust bring opportunities for sense-making, expanding the way particular experiences are signified. In these encounters, in which ‘intersubjective borders emerge between persons’ (Irving, 2017, p. 112, there are moments of recognition and differentiation (e.g. ‘I
understand you’, ‘I feel you’, ‘I had a similar experience...’). In this engagement, every individual brings their own life trajectories and intersectionality, opening up possibilities for other potential understandings of experiences and self-creation. Experiences can make sense to the one who narrating and his/her interlocutor, while their subjectivities remain ‘fluid, contingent and open to transformations’ (Kleinman and Fitz-Henry, 2007, p. 55).

When in dialogue with others, people can narrate their experiences and, through telling their stories, push themselves to articulate ideas and reflect upon their own lives, engaging as ‘moral agents’ in the way their stories are told (Irving, 2007). In the particular context of the organisation, people support each other to deal with their emotions and life projects while also providing practical aid, such as a place to stay, food, clothing, if things become more complicated.

Weekly meetings at the organisation bore a similarity to psychotherapy groups, but without the support of a mental health professional. They did everything by relying on what they had: a basic training and their personal experiences. They create a circle, identify the main challenges of the week and discuss them. Someone brings to the group an experience or a problem, such as: ‘Should I disclose?’, ‘What if I lose my partner?’, ‘Am I dying?’, ‘How do you cope with mood changes?’.

Some members of the group tried to provide emotional support to those in difficult situations, while others would pose further questions in order to encourage a deeper understanding. For example, someone shared the personal consequences of disclosing to family members, and everybody listened carefully. To support that person, some would share their own experiences, identifying commonalities and differences, while a few would ask further questions such as ‘What were you expecting to get from them?’, ‘What if you teach your family about what HIV really means?’, ‘What will you do about it?. From these conversations would emerge new ways of understanding individual experiences, but also what other members of the group were going through. From these intersubjective
encounters emerged new strategies and ways to approach particular challenges of a time post-diagnosis.

However, these conversations were not always straightforward, and for some of the volunteers (especially the new ones) it was difficult to articulate questions or identify a particular problem, as they seemed overwhelmed by their personal situation. In those cases other volunteers were even more supportive, and tried to help that individual put their ideas in order so they could be understood by others. Radley (2009) highlights the centrality of narratives (verbal or otherwise) when it comes to making sense of disruptions, while at the same time Irving (2017) recognises that ‘it is problematic to assume that people can vocalize – let alone understand or fully access – their internal states, especially during periods of illness, uncertainty, and emotional intensity’ (p. 112)

These conversations had a mirror effect: those who were trying to help by listening and/or advising somebody else were also helping themselves by reflecting on their own situation. When the group discussed a problem, each of them adapted what had been shared to their particular circumstances, finding new approaches in order to confront their own issues. In this way, knowledge was shared and created collectively and horizontally, based on the similarities and differences of their experiences, which had a strong impact upon reducing their level of confusion. Available cultural, emotional and material resources in terms of individual knowledge were put to the service of this collective search for sense-making.

Certainly, the way each life event was experienced was unique, however as Toren has argued, the social aspect of self-creating has to be recognized as central, as it ‘is embedded in close and continuing relations with conspecifics. In other words, I can become myself only in relations with other humans who are also becoming who they are’ (Toren, 2009, p.136). In this sense, even though their experiences are unrepeatable and – as discussed earlier – inaccessible to others, it is only in encounters with others that their
their narratives will be enriched and re-shaped, ultimately impacting their identity and sense-making process.

8. Their Uncertainty, Our Uncertainty: A New Start

Luis said it was necessary for us to talk about considering potential significant consequences for those deciding to take part in the project. His advice was that the decision to go public in front of a camera, and working on an autobiographical project, had to be taken after sensible consideration for themselves and also for their families. These considerations seemed more of a reminder than a warning, as a way to make me think that HIV was perceived by others across society in a very different manner.

These considerations also seemed reasonable, especially considering that I had received refusals from other organisations, which argued that the project’s level of exposure could put their members at risk. Luckily, Luis was happy to take part in the project in the name of the organisation. He said that hopefully, with his participation, others would feel safer and consider getting involved. I returned to the UK to sort out final permissions, and when that was ready, I called Luis at the office. His secretary answered the phone:

- Hey Mariana, how are you doing? I said.
- As good as I can be in times like this... We are all devastated with Luis’ death.
- (silence)
- Yes, he died two weeks ago.

And then she stopped talking. Probably holding back her tears back on the other end of the line. I felt confused and unable to say anything more than ‘I’m sorry’ to comfort her.

- I think we will close this place. The office has been closed since his death... You are lucky, because today I came to gather my stuff and there’s not a single soul around... Nobody knows what will happen with our group, with this place, with us.

35 ‘Estamos todos mal con la muerte de Luis.’
36 ‘Él murió hace dos semanas.’
I couldn’t even begin to comprehend what this would mean for the project, but most importantly what the closure of the organisation – as the ‘place of relief’ - would mean for its members. In all my visits there was a sense of ‘home’, but always combined with a fragility: the fact that they didn’t have a place in their name; that they were only operating because the authorities had the goodwill to lend them that space, or their financial scarcity. Although the volunteers had learned how to deal with uncertainty on so many levels, either by using preventive measures or by getting used to navigating challenges, maybe Luis’ death was an insurmountable disruption for the organisation.

I asked myself if they would be able to reconfigure the organisation given that so many of its aspects had relied on the same person for such a long time? There were many similarities between what was going on with the organisation and what volunteers had experienced with their own personal disruptions: shock, confusion, loss, sorrow, fear of being left alone. Although most wanted to keep the organisation running, they had never been confronted with the responsibility of actually doing it.

I was told that after a period of discussion and ‘chaos’, which included people shouting and crying, they decided to elect a new president: Oscar, who would become one of the main collaborators of this research. Oscar was one of Luis’s long-term supporters, and for years he had been working from the shadows for the organization, which gave him a good understanding of how to manage it. However, he was scared of taking on this responsibility, especially because Luis had left such a strong impression that he felt he might not be able to live up to.

In my visits to the organization, I began to notice a new spirit in the group and a new way of doing things. New people were joining, more activities were available – including

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37 ‘Quizás cerremos. Hemos tenido la oficina cerrada desde lo de Luis... Hoy día vine a buscar algunas de mis cosas, así que tienes suerte, porque si no, no encuentras ni un alma aquí... Nadie sabe qué va a pasar con nosotros, ni con la oficina.’
acupuncture, yoga and cooking lessons – and more funds were being raised. In order to reach potential new members, every Thursday a group of volunteers took coffee and biscuits to the part of the hospital where people were awaiting their HIV test results.

But not everything was perfect. It became increasingly difficult for some of the old volunteers to get used to the new style. A small number never came back, perhaps because it was too difficult to cope with Luis’s death or because they didn’t like the new path the organization was taking. Despite being a difficult time for them emotionally, the volunteers managed to organise again, and offered the group what they could. And as with every challenge they had confronted before – and facing it – they sat together in a circle and made sense of it on their own terms.
CHAPTER 2

‘We have to show that we are not monsters, nor victims... We have to show our lives with all the possible truth, so people can believe us’ - Jaime Lorca, collaborator of this research.

Some individuals living with the virus consider HIV organisations as spaces in which to create experiential and reflective knowledge in order to confront their biographical disruption, and they rely on those spaces to get support from their peers and to make sense of what they are going through. Given that they find themselves in a context in which first person accounts about HIV are ‘taboo’ or socially discouraged, spaces to open up about their life experiences are limited, and mostly subject to the existence or not of an organisation.

I argue that a specific type of context can be created through negotiation, in which narratives can emerge, even outside familiar places for discussing HIV experiences. This chapter looks at ethnographic evidence from the first workshop (designed to discuss methods) in relation to how collaborators negotiate space and conceptualisations of autobiography, as the preliminary and necessary step to create a particular ethnographic context through which specific types of experience and expression can emerge. I suggest this ethnographic context only appears as a product of our encounter, shaped by intersubjectivities and mutual challenges, resulting in a context in which not only narratives emerged, but also negotiations about the research.

In other words, this is not an account based on material collected by an ethnographer ‘arriving’ in the field, but refers to a co-created ethnographic context with collaborators during practice in the field. Ethnographic material emerges from encounters articulated through practice, and it is this practice that facilitates new experiences, while negotiating a space that promotes autobiographical narratives. For Casey ‘a place is something for
which we continually have to discover or invent new forms of understanding, new concepts in the literal sense of ways of “grasping together”’ (1996, p.26). It is this action of ‘grasping together’, as a continuous re-adjustment, that creates a specific ethnographic context that facilitate narratives and mutual questions. Therefore, the ethnographic material emerges from this co-created context and would not exist otherwise.

Many of the collaborators’ responses to the project deal with memories of suffering and trauma, both difficult to access when not in the appropriate condition. I argue that the impact of using unorthodox and more experimental combined methodologies can be significant when attempting to create that ethnographic context, in which participants can not only play an active part by opening up about their life histories, but can also feel responsible for the results of the research. As has been addressed by Irving (2007), accessing inner worlds has been a recurrent problem for anthropologists, and given its ‘centrality to all social life’, this poses the question of ‘how to access memory and the imaginary when there is no independent access to consciousness’ (2007, p. 185). He argues ‘we need to create new forms of collaborative research and representation with regard to understanding experiences of illness’ (Ibid.) and that one response to the challenge of accessing memory and the imaginary can be found beyond the limitations of what he characterises as ‘orthodox approaches’.

Accordingly, I propose a methodological approach that connects autobiographical photo and film creation within a collaborative frame, which I name Collaborative autobiographical mises-en-scène. I suggest this methodology offers tangible opportunities to access experiences and reflect on them outside of everyday spaces, while at the same time allowing them to narrate themselves and as such contest public discourse about HIV. This ensures collaborators are their own theorists and the makers of their own representations.
Given that experiential and reflective knowledge is produced in inter-subjective encounters, I analyse how, from these encounters, there emerge particular ways of defining and understanding crucial concepts at the heart of this research. This research is shaped by a collaborative framework in which participants are considered ‘co-researchers’—as has been defined by Fals Borda (1985)—in which the main concepts informing the project are in constant negotiation. In this way, I examine how questions such as ‘What does autobiography mean to them?’ or ‘How is disclosure negotiated in a different setting?’ are shaped through interactions and not imposed by the researcher. I suggest that these negotiations are a necessary step towards creating an appropriate ethnographic context through which to look at critical events and for the development of a methodological appropriation, promoting reflexivity and the emergence of a sense of authorship, as will be explored further in the following chapters.

From a methodological perspective, this ethnographic context has to be conceptualised as a continuous process of negotiation—welcoming the uncertainties and fluidity that comes with it—because in those challenges it becomes possible to refine methods for future ethnographic encounters.

1. A PARticular Type of Collaboration

O’Neill and Stenning (2014) have stressed the need to create a close collaboration with participants when using biographical methods: ‘clearly engaging with [them] and being within a creative process is central to undertaking qualitative and biographical research’ (p.3). This suggests that when creating biographical work with people, researchers have to attempt to unsettle the conventional distance with participants, and aspire to replace it for a subject-to-subject relationship.

In this context, this research was conducted in ‘collaboration’ with participants who, recognising their different positionalities, create a more horizontal relationship with the
researcher towards the development of a specific project. This collaborative approach is informed by Participatory Action Research (PAR), which ‘aims to articulate knowledge production and transformative action’ (Johnson and Martinez Guzman, 2012, p. 405) as it understands that action and knowledge-research do not have to be separate from one another, but can exist in interdependence.

Participatory Action Research (PAR) is an interdisciplinary approach that seeks to work ‘with’ people and not ‘on’ or ‘about’, paying attention to the process of knowledge creation as a product of intersubjective encounters with the researcher taking a non-hierarchical position. In this way, participants ‘acquire an active and creative role, participate in defining problems and generating transformations strategies, and provide local and experiential knowledge about the issues being addressed’ (Johnson and Martinez Guzman, 2012, p. 406). This demands a level of ‘Inclusion’ in which participants are considered experts and involved in democratic processes of decision-making. Therefore the researcher has to leave behind her/his position of outsider and become involved as another participant (Greenwood and Lewin, 2017) and from there promote a non-hierarchical project, in which all are ‘co-researchers’ or ‘collaborators’. PAR is not a method per se, but an ethical approach through which to work with groups and communities often described ‘marginalized […] as a means to explore forms of recognition and representation while seeking to promote changes in concrete and local conditions’ (Johnson and Martinez Guzman, 2012. pp. 406-407).

PAR does not have one foundational text but rather a wide variety of sources: from Paulo Freire’s ‘Pedagogy of the oppressed’ (1970) to Orlando Fals Borda’s ‘The challenge of Social Change’ (1985); it has especially inspired many academic projects in Latin America and Asia. PAR has expanded to disciplines across the social sciences (i.e. Johnson and Martinez Guzman, 2012; Miller and Rose, 2008, Montero, 1998) and resonates strongly with the idea of ‘impact’ within academic results, seeking outcomes that are often print based, performance based or art/exhibition based.
PAR has generated some critique for being an uncertain framework, given that it does not establish rigid limits to engagement, nor specific boundaries. Rather than seeing this as a source for methodological uncertainty, I conceive of it as a space for opportunity. By understanding that people are their own ‘theorists’, we can promote a type of ethnographic engagement in which participants can actively shape the research and take responsibility for its outcomes. As such, in this research collaborators are involved in defining strategies and shaping research concepts based on their own experiential knowledge, as you will see in the text and the film. This strategic approach to our encounters in the field aspires to disrupt power by engaging in a relation in which questions are not uni-directional but mutually asked.

2. Autobiography and Trauma
A line of anthropology has been concerned with autobiographical accounts, but often in relation to ethnographers (such as O’Kely and Callaway, 1992); auto-ethnography (Behar, 1996, 2007; Tillman-Healy, 1996; Bochner and Ellis, 2002; Delamont, 2009); or in relation to written texts (Augé, 2016). Expanding on these studies, this project is concerned with how in inter-subjective encounters with other collaborators (i.e. peers, family, ethnographer, friends), the individuals create their autobiographical representations. In other words, this project explores how in an ethnographic context that fosters reflection, an autobiographical representation emerges, and from there results in possibilities for re-signifying life events, using narrative and visual means.

So far, the most renowned autobiographical texts about HIV have explored what it means to live with the virus during its outbreak in the 1980s and the start of the 90s (Monette, 1998; Moore, 1996; Brodkey, 1997; Conigrave, 1995), but the politics and social repercussions of what it means to live with HIV has changed in the following decades.
While in the final decades of the twentieth century, HIV was still conceived of as a death sentence—demonstrated in the autobiographical pieces mentioned before—today, pharmacological advances offer a new potential life expectancy, which changes the experience of living with HIV. However in the last two decades, there has not been the vast production of autobiographies that could update the understanding of how men experience living with HIV in a context that can offer a better prognosis.

Although autobiography has been referred to as a genre of written texts, in this research the written text will only be a point of departure for other formats of expression, narrative and inquiry, namely photography and film. Written text allows for the possibility of printing the creative work and making it public, which are also ways in which film and photography can be articulated. Despite the fact that these formats have different methods of creation, and have different languages, in the context of this process they foster each other, and are not exclusive but complementary. In this way, this investigation departs from written text, and then relies on visual means, where other types of autobiographical expressions are also possible.

This approach allows for an exploration of the ways in which men living with HIV create their autobiographies and locate critical events, which refer to traumas, but also allows the identification of hopes and dreams in relation to possible futures. Trauma (traûma) from the Ancient Greek refers to “wound,” in relation to ‘the self-altering, even self-shattering experience of violence, injury, and harm’ (Gilmore, 2001, p. 6), and at the centre of the difficulty of its expression lies the verbalisation of its impact, and engaging the other in personal experiences of suffering. As with suffering, trauma highlights the insufficiency of language, its ‘unrepresentable’ character, as described by Gilmore: ‘that trauma is beyond language in some crucial way, that language fails in the face of trauma, and that trauma mocks language and confronts it with insufficiency’ (2001, p. 6). Traumatic events are experienced and remembered in different ways by different people,

and the same event which is traumatic for one may not be regarded as traumatic by another; with this in mind, this project does not only look at unpacking events but at re-signifying them during the process of creating its visual representation. This process of re-signifying does not end once the photograph has been taken, but rather extends beyond the parameters of this research, as part of the individual’s ongoing process of sense-making.

I organised a one-day workshop with the collaborators in order to discuss methods and central concepts for our research, and also to familiarise them with the use of cameras. Although photography is part of their everyday life as an spontaneous practice, related to memory and documentation (especially with the use of mobile phone cameras), they were not accustomed to creating pictures as part of a project, in which they would then be used to recall and re-signify memories. This shift, from photo-creation as a documentation of memories, to photographs as a means by which to access a memory, was central to our practice and would shift their approach from the everyday ‘taking’ photos, to a reflexive ‘making’ photos, a distinction proposed by the photographer Ansel Adams (quoted in Sontag, 1978).

In the following sections, I analyse how collaborators negotiated creative, political and aesthetic aspects of the project, which then became the basis of their visual representations. This section looks only at the workshop, which was informed by preceding participant observation, and is understood as a crucial preliminary stage for autobiographical photographic *mises-en-scène* creation, as it is the first time they think about autographical events and their visual representations.
3. Setting the First Encounter

Despite the difficulties in finding collaborators to take part in this project (I met and interviewed more than forty potential participants), six individuals finally committed to taking part: Claudio (18), Diego (26), Oscar (48), Herman (39), Jaime (65) and Miguel Angel (46). They were invited to a one-day workshop at Acción Gay’s headquarters to discuss the general framework of the project and to work on a few autobiographical exercises. Up until that point, they were not part of the same organisation but represented their local groups, and had different types of relationship: while three of them worked within the same group of activists; Diego and Claudio started a romance a couple of months before the research began.

I conducted participant observation with each of them over several months, which helped to develop our mutual knowledge and to build a relationship based on trust. I met their families and friends, and they also met mine, and they were able to open up as our relationship changed overtime. This was an important aspect of the project, in not attempting to replicate hierarchies of researcher-subject, but rather to see each other as collaborators and be explicit about the fact that in our investigation gazes would be directed both ways, and not only from the researcher.

The first day was an opportunity to discuss the basic methods we would use, and to find ways of using them in accordance with their particular and collective aims. This would be a challenge, especially given their diversity: some had lived with the virus for more than twenty years, while others only received their diagnosis a few months ago; their ages ranged from 18 to 65; and they were from heterogeneous educational backgrounds (from unfinished secondary schooling to completed university degrees). I conceived this initial workshop as the first collective adjustment to the project, because later in the research we would not necessarily be working as a group but more individually.
The workshop was the first day of filming and, as with every first day of filming, my collaborators had to get used to the cinematic gaze and its pace, for example, so as not to be constantly monitoring the camera’s location, or in understanding that we would need time to set up equipment. There is debate among visual anthropologists regarding when the camera should be introduced to fieldwork: either from the very beginning of the research, so people are used to it from the start, or only later in fieldwork after relationships of trust have been built. Certainly both approaches have aesthetic, ethical and political implications, but I believe this decision should not be predetermined, but adjusted for each project; and particularly with this project, if its intention was to be collaborative, this decision must also be made alongside my collaborators. I only started filming once collaborators had time to think about it and evaluate the potential implications of their exposure. I emphasised when we would start filming, and gave them a few indications about how it would work (e.g. asking them not to look directly into the camera, or trying to avoid overlapping in conversation), and stated very clearly that we could stop at any moment if they felt they needed a break.

4. Tactics of Autobiography

It was necessary to discuss with collaborators what kind of autobiographical explorations would be carried out, since as the French anthropologist Marc Augé suggested ‘there are many kinds of autobiographies’ (2016, p. 24), referring to how the concept of autobiography has been used in a comprehensive and interchangeable way to refer to memoirs, journals or testimonies. The exploration of a self life writing—relying on the literal mean from the Greek of ‘self’ (auto), ‘life’ (bios) and ‘writing’ (graphe)—is vast and personal.

Therefore, a discussion about it in relation to the project would be the starting point of the workshop. They sat in a circle and began talking about what autobiography meant for them, bringing examples of readings, films and images they linked with the concept. No
definition was imposed, but rather a shared idea of autobiography was created for them to work on, creating a conceptual common ground, but also an ethical one.

Claudio defined it as ‘telling my story’, while Miguel Angel indicated that it is a narrative in which the narrator is also the protagonist; therefore autobiography was starting to be delineated as the specific practice of narrating their own story using a first person account. In this sense, the one who creates the story—in the sense of choosing the narrative elements for the piece of work—is the same person who tells the story—the voice that narrates the events—as well as its protagonist. Diego stressed that an autobiography should not be told as a linear or chronological narrative, as he explained past experiences and future expectations meet in a present; bringing up opportunities for exploring elements from the domain of dreams and desires.

These ideas resonate with how Smith and Watson (2010) defined autobiography as the act of narration in which the teller becomes the observing subject and the object of investigation, remembrance, and contemplation. This definition shares a reflective and reflexive element with the one discussed by collaborators, exploring memories in the form of remembrance, and contemplating other aspects of the protagonists’ internal worlds.

Herman also suggested that an autobiography is a story in which the narrator examines her/his life diversions, bifurcations and fractures, as those are the moments in which the protagonist's life changes direction. Oscar complemented this, suggesting that those diversions can be challenging but are also opportunities for learning and become stronger; and that by knowing those events you can understand why somebody behaves in a particular way. Therefore autobiography as discussed by them was becoming a way of knowing about someone’s life, not only in terms of facts, but how life stories had shaped the protagonist’s understanding of the world. This can be linked to Lejeune’s (1989) idea that an autobiography is a retrospective narrative that someone makes of his own existence, putting the principal accent upon the story of that personality. Lejeune explains
that by understanding life events as part of an individual experience of the world, the reader can understand the nuances of the protagonist’s subjective world, as Oscar and Herman suggested.

Through their intersubjective encounter, the collaborators were defining the concept of autobiography that would be used in this project, which resonated with literary conceptualisations. They conveyed the elements of a ‘first person account’ and ‘narrating our own lives’, as part of an investigation of life events in terms of continuities/discontinuities explaining the protagonist’s understanding of the world.

Becker (1997) has suggested that ‘narrative is the primary path for examining disruption and continuity’ (p. 25) as they reflect people’s experience in the way they see it and how they want other people to see it. This dialogue to conceptualise autobiography among collaborators was an opportunity for them to shape the frame in which they would tell their stories and narrate their experiences. By engaging in this dialogical intersubjective encounter, collaborators were not only expressing their points of view, but also re-shaping their ideas about the project, and therefore this dialogue was central to together shaping the way in which they would approach the practice of autobiographical work, and subsequently how these would be perceived by others.

In this context, Jaime brought up some doubts about what was being discussed. He argued that this intersection of protagonist-narrators could make it difficult to keep a certain ‘objective attitude\textsuperscript{40}, meaning that this might result in them creating one-sided versions of their events. By relying on their subjectivities, only certain aspects of their lives would be presented—or only what they wanted to expose— influencing how they would be perceived by a potential audience. Jaime said: ‘I prefer the unauthorized biographies, because they tell you the truth, not only what somebody wants to show you’\textsuperscript{41}.

\textsuperscript{40} ‘actitud objetiva’

\textsuperscript{41} ‘A mí me gustan más las biografías no autorizadas, porque te dicen la verdad, no sólo lo que te quieren mostrar’
However, not everybody agreed: most of the collaborators had said they wanted to take part in the project because it was a way to ‘show their truth’ and to subsequently come to terms with their experiences, rather than to necessarily provide a ‘version closer to reality’\textsuperscript{42}. The collaborators were not reclaiming fiction as the space in which their accounts would circulate, but rather focusing on using their experiences to revisit memories and share their dreams. Through this conversation, collaborators were trying to establish a common ethical—and aesthetic—ground upon which they could build their autobiographical projects: for some this meant placing the personal as a priority, while for others, the political had to be put first.

Here a question can be raised: Why were these collaborators who had never met each other—no less having a sense of a group or collective—trying to find a common ethical framework for this project? It would be much easier to work from their individual ethical standpoints and avoid engaging with each other in such complicated conversations. I argue that in this project they saw an opportunity, and their actions were therefore informed by particular ‘tactics’ (De Certeau, 1984) that could have not only aesthetic, but also political, implications. As we will look at later, Jaime was proposing something rooted in an aspiration to be deemed trustworthy, which, according to him, would validate his narrative in social life, and thereby reclaiming something that people living with HIV felt had been denied them: to represent themselves in order to contest stigma.

In his book ‘The Practice of Everyday Life’ (1984), De Certeau identifies that practices are not accidental or aimless, but rather connected to each other by an intrinsic logic, which are sometimes used as ways to contest power. He distinguished two main concepts in this regard: ‘strategies’ and ‘tactics’. For him, strategies are the calculus of force-relationships to circumscribe a place establishing its borders, in order to generate relations with selected others. These strategies were generated by institutions and those in power, seeking ways to establish borders as a form of control or hegemony: ‘political, economic

\textsuperscript{42} ‘versión cercana a la realidad’
and scientific rationality has been constructed on this strategic model’ (De Certeau, 1984, p. 17). On the other hand, ‘tactics’ are of the purview of those he called the ‘weak’ (meaning not-in-power). Tactics do not have borders because they are not located within institutions or spatial limitations, but it ‘insinuates itself into the other’s place, fragmentarily, without taking it over in its entirety, without being able to keep it at a distance’ (De Certeau, 1984, p. xix). In this case, collaborators discussing ideas about autobiography can be understood as a way to create common ‘tactics’ to contest dominant representations of HIV in the local context.

Given that strategies are victories of space over time, tactics also depend on time but within a fragmentary approach, by always being on the watch for events that can be turned into ‘opportunities’ (De Certeau, 1984, p. xix). In this sense, the project was seen by Jaime an ‘opportunity’ to legitimise HIV experiences within the social space, proposing particular tactics in terms of how to counteract misrepresentations of HIV in Chile, and by that, affecting the way in which people living with HIV would be seen by others. During the workshop he explained:

‘We have to show that we are not monsters, nor victims… We have to show our lives with all the possible truth, so people can believe us.’

Gilmore (2001) states that criticism of autobiography is often political in this way, as it offers the possibility of promoting the writer in ways that can be beneficial. However, this is not in terms of disputing whether the events described actually took place, but whether they happened in the ways they are represented. This is only presented as a ‘possibility’ by Gilmore, which is in accordance with the stories analysed by my collaborators, which are not stories of success—in a capitalist and heteronormative fashion—but rather contestations in which they expose their suffering as a way to contest stigma, challenging the audience more than trying to find allies.

43 ‘Nosotros tenemos que mostrar que no somos monstruos, ni víctimas… y para que la gente que nos crea tenemos que mostrar nuestra vida con toda la verdad posible’
According to Jaime, events have to be told from a certain distance in order to be trustworthy, and through that trust—which does not leave opportunities to be discredited—reclaim spaces for new discourses about HIV. In other words, in order to destabilise hegemonic and popular representations of HIV already available within social spaces, they should provide narratives that could be trusted and believed, not potentially vilified. This reveals a tactical approach in which to be believed is something to aim for; and, in this context, a more ‘subjective’ approach would increase the possibilities of being discredited. Diego confronted Jaime’s ideas with an argument about the impossibility of hiding a subjectivity behind a narrative, and thus proposed a different approach, in which the ‘subjective’ is acknowledged as formative of experience and narration:

‘Even if you decide not to tell something, this would come out within the story anyway... What you don’t say also says something about you, because it’s what really challenges you... Silences can be even more powerful than what we say’

The dialogue in the workshop helped us understand that each collaborator had particular tactical approaches to their autobiographical accounts: there was an agreement that the photos they created should contest pre-existing images circulating in the social space, but the question was how to approach this problem. In particular, in the case of those living with HIV in Chile, HIV political actions are perceived as necessary and urgent, as a continuous activity for people like Jaime, who had been involved in them for more than twenty years. In this way, Jaime’s political affiliation was informing his performance in the space of the workshop, trying to turn an ‘event’ into an ‘opportunity’. All the collaborators had the same objective, only different tactics. This demonstrates that space was negotiated in terms of tactics ranging from the personal to the political, from the

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44 ‘Incluso si hay algo que no dices, eso siempre va a estar presente dentro de lo que estás contando y en algún momento sale a se evidencia...Lo que yo calla también tiene algo de mí, porque es lo que te pone en jaque... Los silencios pueden ser incluso más fuertes que lo que decimos’
individual to the collective, re-shaping the ethnographic context and the outcomes of the project.

5. ‘I Was, I Am, I Will Be’

During the workshop, we conducted different exercises in relation to autobiography and photography in order to link the roles of protagonists and narrators. In one of these exercises, collaborators were invited to write three stories about themselves using the sentences ‘I was’, ‘I am’ and ‘I will be’. This first exercise was aimed at drawing attention to the sense of continuity/discontinuity within their narratives, before creating the lists of events they would work on using photography.45

During this exercise, I observed different registers of response, ranging from the descriptive (i.e. Oscar: ‘I was a candy seller on the bus // I am a hairdresser // I will be the owner of a business’) to others with more evocative approaches (as in the case of Diego: ‘I am their exile // I will be the end of their circuit’). Diego’s exercise revealed an emotional landscape expressed through a more poetic sensitivity (‘I was the one who went out barefoot’), but also silence and a dichotomy of presence/absence (‘I was the one who waited behind the door // I will be the one who appears like a ghost’) and these were two aspects he would go on to explore in his photos. At the same time, Diego placed himself in relation to others, most notably in relation to a family and parents (‘I was the boy of mum and dad’), and their presence or absence will be interrogated during the mise-en-scène process. This element is also shared in Claudio’s exercise, in which we can find references to the family structure and his position as a young man transitioning to adulthood (‘I was another baby for my grandmother // I am the spoiled child who will

45 Due to space, the full version of exercises is only included in the annexe.
46 ‘Yo era un vendedor de dulces en la micro//Yo soy peluquero//Yo seré un hombre de negocios’
47 ‘Yo fui el niño de papá y mamá//Yo soy su exilio//Yo seré el final de su circuito’
48 ‘Yo soy el que salió descalzo’
49 ‘Yo fui el que esperaba detrás de la puerta//Yo seré el que aparezca como un fantasma’
50 ‘Yo fui el niño de papá y mama’
never stop being a boy\textsuperscript{51}). Miguel Angel crafted part of his exercise by thinking about a positive future, but within a more metaphoric framework: ‘I will be open wings flying over the world // I will be the freedom embedded within me\textsuperscript{52}). In these lines, a brighter future resists the past, conveying images of pain, loneliness and forced silence (‘I am the cosmos’ solitude // I was a mouth sealed with tape // I was an innocent soul pecked by hungry birds\textsuperscript{53}).

Through this exercise, collaborators were starting to locate themselves in this intersection of protagonist-narrator, and even though it would not be used directly for the final creative outcomes of the project, it is interesting to contrast this material with the final photos, especially in relation to narrative continuities and disruptions.

In this exercise, collaborators did not mention HIV, although it was possible to see some elements that might be associated with HIV disruption: ‘I was the one who waited behind the door’ or ‘I was a mouth sealed with tape’, which could be related to the idea of silence, or someone who is trying to ‘pass’ as an individual who is not living with HIV. Although this connection is uncertain and could refer to other types of silence, given that HIV is not written, what we are left with is its silence; not necessarily a denial, but silence as an act of not acknowledging HIV in the chronology of their lives. This evidences that even in a context among people living with the virus, ‘information management’ (Goffman, 1963) is carried out and shapes the way they engage with others. Additionally, people who live with HIV do not want to be primarily defined in relation to the virus, therefore this silence is a way to avoid tying the chronology of their lives with HIV. In this way, they differentiate who they ‘are’—a sense of self—with what is happening or has happened on their lives—their lived experience—even though these two permeate each

\textsuperscript{51} ‘Yo fui otra guagua para mi abuela // Yo soy el niño regalón que parece que nunca va a dejar de serlo’

\textsuperscript{52} ‘Yo seré unas alas abiertas volando sobre el mundo // Yo seré la libertad que está dentro de mí’

\textsuperscript{53} ‘Yo soy la soledad del cosmos // Yo soy un boca sellada // Yo era un alma inocente picoteada por pájaros hambrientos’
other in the sense that HIV is constitutive of their life trajectories and their lives constitute how they experience HIV.

6. The Elephant in the Room

Everybody in that room knew that they were all responding to the same invitation: to discuss the impact of HIV in their lives, and yet nobody mentioned the acronym HIV. They had already taken part in a few basic autobiographical exercises, engaging in discussion for nearly three hours. When collaborators engage in inter-subjective encounters, a constant risk assessment has to take place, questioning the impact that actions will have on others and the shared space, and in this case, what is at risk if disclosing even to people who share the same diagnosis.

At that point I was beginning to ask myself why I had previously been able to talk with them so openly about HIV, and yet now they seemed to restrain themselves: Was this happening because they didn’t want to present themselves in relation to HIV? Was it the presence of the camera that was causing this? Or perhaps the invitation to talk freely and in an environment of trust had not been effective? The collaborators were sitting in a circle talking directly to one another, and the filming took place behind them. Their circle was never broken to get a better shot, and only a couple of times when the dialogue became very lively they were asked to repeat a sentence for the camera. An omnidirectional microphone was used that day, placed between the collaborators and the ceiling, without interfering with the dialogue or the visual space between them.

It was possible to observe a certain anxiety in their bodies and their voices: their interventions seemed more tense and from time to time they looked sideways to check where the camera was being placed, so as to guess at who was being filmed. Being in a space in which, while being filmed, there was an awareness of the exposition involved, it is
understandable that before talking about HIV they had to appropriate the space on their own terms. At one point, Herman—who is an actor—started to speak directly to the camera, making jokes like “Are we broadcasting live?” or “I won’t reveal my age, I’ll let the camera guess”\(^{54}\). Herman’s intervention made all the collaborators laugh, loosening them up and changing the way they related to each other and the space. It is difficult to know to what extent that tension was produced by the presence of the camera and/or by the situation of getting to know each other. Eventually—as can be observed in the documentary film—this tension with the camera dissipated, and the collaborators appropriated the film and the spaces we were in as a discursive platform\(^{55}\).

Lambek defines the idea of ‘Ordinary Ethics’ (2010) first as ‘intrinsic to speech and action’ (p.1) and secondly as ‘relatively tacit, grounded in agreement rather than in rule, in practice rather than knowledge or belief, and happening without calling undue attention to itself’ (p.2). In this way ordinary ethics are not linked to law or regulation, but rather conveyed in everyday actions that are understood as ethical by others. Due to his training as an actor, Herman was the only one who had previous experience with cameras, and thus felt compelled to disrupt the way it was affecting the interactions of the other collaborators. Thereby he was redirecting attention onto themselves and dismissing the strain of being filmed, confronting the tension created by the camera not only for him, but for the group. After this, the camera was referred to a couple of times, but after Herman’s jokes the group seemed to feel more in control, even asking to cut or repeat a shot again. Herman had modified their general ethics through his actions, without having to explain them or their purpose. Furthermore, he challenged the convention of not looking directly into the camera, taking a risk that resulted in a release of tension for the group.

\(^{54}\) ‘Ya estamos en vivo’, ‘Yo no voy a decir cuántos años tengo, que la cámara adivine’

\(^{55}\) I will come back to the collaborators’ negotiation with the camera in the next chapter, analysing the transition from the film equipment being disruptive to eventually becoming a platform for addressing an imagined public. For now, I would like to focus in how the camera affected our effort to convey the sense of a safe space.
This vignette reveals how the collaborators were articulating their interactions through negotiations and risk management, which ultimately impacted on the ethnographic context. Ethics, argues Lambek, is ‘not only about executing acts, establishing criteria, and practising judgement, but also about confronting their limits, and ours’ (2010, p. 39). In this way, their specific acts were informed by an on-going judgement about what was taking place around them, and how they could re-shape it through practice.

In this sense—and without mentioning HIV in direct relation to them for a few hours—to recognise living with HIV became an important moment that would change the ethics of the encounter. Miguel Angel was the first to address it at a personal level: ‘I have been living with HIV for 17 years... and this is the first time I admit in front of other people that I am a carrier.’ As in the case of Herman addressing the camera, Miguel Angel also took a risk with that declaration, and a more personal one. It was difficult to imagine that Miguel Angel—an activist at Acción Gay, who regularly talks about HIV prevention at a gay night club—had never publicly recognised his diagnosis. Every Friday he attends ‘Fausto’, a gay nightclub, to promote safe sex and raise awareness about HIV, giving away condoms while wearing a T-Shirt promoting safe sex. Usually, people who are activists in Chile already live with HIV, because many of these occasions are used as an opportunity for the public to unpack issues related to the virus, or maybe just to ask for advice, as a kind of informal counselling. On the other hand, a potential stigmatization might prevent those not living with the virus to take a more visible position when it comes to prevention campaigns.

Miguel Angel would clarify later that his work as an activist differed from his own personal life. He distinguished that to give information about HIV as a topic was one thing—and by that operation he separates his body from the virus—but acknowledging that he lives with it is another. In this way, ‘spaces of ambiguity’ could become ‘safe spaces’ for people living with HIV.

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56 ‘Yo he estado viviendo con VIH durante 17 años...Y ésta es la primera vez que digo así abiertamente que soy portador’
Therefore, to talk about HIV and to disclose are two different actions: while the first involves referring to the virus from a detached perspective—even using biomedical language—the latter involves exposing the bond of one’s own life with the virus, which cannot be reversed. And in that sense, when it comes to reaching a more personal involvement, this leads to implications of exposure and therefore potential threats, or even a fear of stigmatising experiences. However, after Miguel Angel decided to open up and confront his diagnosis in front of the group, all the collaborators started to speak openly about it, and share stories, with HIV as a topic to which they could refer in first person with the intimacy one can have with another whom they’ve known for a long time.

7. From Words to Images

The final section of the workshop was pivotal in bringing together the discussion held during the day and setting out the path for the representations they would create and explore during the following months. Accordingly, collaborators were asked to create a tentative list of events they wanted to work on over the coming months, and imagine the pictures they wanted to create as a representation of that event. We called this exercise ‘My story’. Given the challenges this exercise would pose for them (emotional and creative in particular), it would be unlikely that we would get polished photographic ideas, but this was something we would develop overtime in additional face-to-face encounters.

The critical life events they chose were linked to trauma or painful disruptions, resonating with their description of living with HIV as a ‘fracture’. I would like to emphasise that they were asked to create a list of experiences in relation to HIV that they considered critical (in terms of bringing about a disruption or bifurcation in their life plans), without conveying any positive or negative implications. However, what emerged were mostly experiences that linked HIV with trauma in relation to a past, as well as hopes for a different future. When referring to trauma in this research, I am not trying to convey a category linked to
the pathological, but rather the experience of an event that one is not prepared to face, therefore unsettling a way of being in the world. As Caruth (1995) explains, trauma ‘is the confrontation with an event that, in its unexpectedness or horror, cannot be placed within the schemes of prior knowledge—that cannot as George Bataille says, become a matter of “intelligence”—and thus continually returns, in its exactness, at a later time’ (p. 153). In this way, trauma cannot be defined by the external characteristics of an event, but rather by how that experience is assimilated while occurring, and also in its persistence in memory. Therefore trauma cannot be defined by external parameters of atrocity, but as how that event is experienced, and becomes an inapprehensible part of that individual’s memory. As Caruth explains, it ‘may or may not be catastrophic, and may not traumatise everyone equally’ (1995, p. 4); the difference is in the structure of its experience, which is constitutive of and constituted by subjectivity.

Given that ‘My story’ required to access some memories that evoked suffering and/or were difficult to access57, some of the collaborators decided to stay in the same room while others found a different space in the building. There was silence. No more laughing, no jokes, no conversation, as something had radically changed, and a slower pace and a general disposition allowing for introspection replaced lively conversation. The setting was the same, but the space had completely changed. Space is constitutive of this ethnographic context but does not precede individuals, rather being socially constructed or produced by relations (Lefebvre, 1974; Massey, 2005). Massey, following Lefebvre, proposed that space as a product of relations is a ‘never closed system’, conceptualising it as ‘open, multiple and relational, unfinished and always becoming’ (2005, p. 59), shaping the way that people relate to each other and to space itself. Up until this moment, collaborators had engaged with each other to discuss concepts that informed our research, which demanded a high level of inter-subjective contact, in order to make ideas explicit and refine agreements. But when facing a specific task that demanded a different level of interaction so as to allow a more inward conversation, space was also modified,

57 We asked them to write this list in confidence as we would not share these memories in front of other collaborators as part of the exercise. However, I have their permission to include them in this thesis.
and that change facilitated an internal exploration. The social construction of space is made more evident when interactions take a different route and space is transformed, and by this reshaping interactions are also modified. As Massey has explained, space is ‘a product of interrelations’ and these relations are ‘embedded practices’ (2005, p. 10). A change in space as a product of interactions also implies a change in the ethnographic context in which a moment of investigation, remembrance, and contemplation is proposed, paraphrasing Smith and Watson’s definition of autobiography.

In this way, space does not appear as such until relations between identities/entities has taken place, because as Massey (2005) identifies, the relations “between” them ‘and the spatiality which is part of them are all constitutive’ (p. 10) of space. The space of the workshop is now different for the collaborators, who have the task of writing “My Story” on a piece of paper58, which demanded a different type of engagement with others and themselves, affecting the spatiality of our ethnographic encounter. The following is part of the list of events they created for autobiographical investigation:

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58 The original texts in Spanish can be found in the Annexe
Claudio

- October 2014. I think my ex is hiding something from me, I see him taking some pills he’d shown me.
- Facebook message in which Diego tells me his HIV test came back positive.\textsuperscript{59}
- The day I asked for permission to do some “paperwork” but instead I went to Redoss alone. I drew a map to get there. But I couldn’t get tested.\textsuperscript{60}
- June. I went to Redoss with Diego and I got tested. It took a long time. In an autumnal garden, I was asked to be his boyfriend, and when Luis came back he showed me the two lines that indicated the result was positive.\textsuperscript{61}
- The day I got tested, it came back negative. Outside Redoss I cried because I felt it was unfair what Diego was going through. I got called again because my test was ambiguous. I had to wait another month to finally get to know.\textsuperscript{62}
- Many blood tests, among them a PPD (tuberculosis), three days after I had to go to the hospital to learn the results, it came back positive, I had tuberculosis, they gave me a face mask and I felt terrible, alone, sick. In that moment I realised that this was much more serious.\textsuperscript{63}

\textsuperscript{59} Mensaje de Facebook que me manda Diego contándome que el examen del VIH le salió positivo
\textsuperscript{60} Un día en que pedí permiso para un “trámite” fui a Redoss solo desde Ñuñoa a Conchalí, me hice un mapa pero no pude tomarme el examen.
\textsuperscript{61} Junio, acompañé a Diego a Redoss y me vuelven a tomar el examen rápido. El Lucho se demoró caleta. Me pidieron pololeo en un patio muy otoñal y cuando Lucho llega me muestra las dos rayitas que señalan positivo.
\textsuperscript{62} El día en que me tomaron el examen, salió negativo. Afuera de Redoss me puse a llorar porque encontraba injusto todo lo que le pasaba a Diego, me vuelven a llamar y mi examen estaba indeterminado, debía esperar un mes para saber.
\textsuperscript{63} Muchas tomas de sangre, entre ellas un PPD (tuberculosis), 3 días después tuve que ir solo al hospital a la lectura de este examen, salió positivo, aparte tenía tuberculosis, me ponen una mascarilla y me sentí horrible, solo, enfermo, y en ese momento me di cuenta que esto ya es más grave.
Miguel Ángel

- The day I received my HIV notification. Pablo, my partner at the time was there with me. I didn’t have time to cry or get depressed, because he cheered me up all the time. Photo: 2 young men, hugging each other. One supports the other. It could be a close-up shot of their faces together.64

- My situation of being HIV+ and diabetic. I am fed up with diabetes; to be diabetic is the worse thing, unlike being HIV+. Photo: My bed, bedside table, on the carpet some medication, syringes, insulin doses (I am sitting on the edge of the bed).65

- I remember when I tried to commit suicide. I was at the hospital, on a stretcher. The doctor questioned me about all my illnesses. He went out and told my mum about my HIV. Photo: My mum sat on the sofa. I am lying down, with my head resting on her legs. I am reading out a book about HIV.66

- My current work on HIV prevention at the night club. Photo: Talking with somebody, giving away leaflets and condoms at the club.67

- Currently one of the HIV medications make my eyes look yellow. That makes me sad because I feel people look at me with suspicion, and everybody asks me about it. Photo: Me, on a swimming pool or at the beach, with crystalline water, completely naked).68

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64 El día en que me notificaron como VIH+. Pablo, mi pareja de aquel momento, me acompañó. No tuve tiempo para llorar ni bajonearme, porque él en todo momento me tiró para arriba. Foto: 2 hombres jóvenes abrazándose. Uno apoya al otro. (Puede ser un primer plano detalle de sus caras juntas).
65 Mi situación siendo VIH+ y diabético. La diabetes me tiene harto; ser diabético es lo peor, no así ser VIH+. Foto: Mi cama, el velador, sobre la alfombra medicamentos, jeringas, frascos de insulina (estoy sentado en la orilla de la cama).
66 Recuerdo cuando intenté suicidarme. Estaba en la posta, en una camilla. El doctor me interrogó sobre mis enfermedades. Él salió y le contó a mi mama sobre mi VIH. Foto: Mi mamá sentada en el sofá. Yo acostado con mi cabeza sobre las piernas de mi mama. Yo leyendo en voz alta un libro sobre el VIH.
67 Mi actual trabajo de prevención del VIH en la discoteca. Foto: Yo conversando con alguien, entregando folletos y condones en la disco.
68 Actualmente uno de los medicamentos para el VIH provoca que mis ojos se vean amarillos. Eso me produce pena, porque siento que la gente me mira raro y todos me preguntan. Foto: Yo en una piscina o en la playa, con aguas cristalinas, totalmente desnudo.
Oscar

• It was so difficult to fight my own family’s stigma. Especially when I was going to the toilet, and after that my mum cleaned everything with bleach.\textsuperscript{69}

• Being unable to kiss my daughter because of the fear of passing HIV to her. 20 years ago there was so little information, so when I could do it for the first time, I was so happy.\textsuperscript{70}

• Working at Sótero del Rio hospital in peer-to-peer counselling, giving support to people who are newly diagnosed, and showing them—through my own experience—that you can carry on with your life.\textsuperscript{71}

• It was not easy to take my medication every day, in particular to get used to the timetable.\textsuperscript{72}

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\textsuperscript{69} Lo difícil que fue vencer el estigma que se creó en mi propia familia. Sobre todo cuando iba al baño y mi madre iba detrás limpiando todo y desinfectando con cloro.

\textsuperscript{70} No poder besar a mi hija por miedo a contagiársela por la falta de información que existía 20 años atrás y lo feliz que me sentí cuando lo pude hacer.

\textsuperscript{71} Trabajando en el Hospital Sotero del Río en consejería entre pares conteniendo a personas recién diagnosticados y enseñando con mi propia vivencia que se puede seguir viviendo.

\textsuperscript{72} Habituarme a tomar mis remedios en forma constante. Horarios ya que fue lo que más me costó.
Diego

• The days in which I suspect I got infected. Partying by myself in the city centre, pathetic.
  Photo: Drinking beer in a park.\textsuperscript{73}

• The walks around Toesca to understand the situation.
  Photo: The footbridge at Vial.\textsuperscript{74}

• The coldness of the room in which I received my test results.
  Photo: The empty room.\textsuperscript{75}

• The day I told my mother, during breakfast.
  Photo: The tea and bread she left on the table.\textsuperscript{76}

• The call I made after receiving the results.
  Photo: A public telephone.\textsuperscript{77}

\textsuperscript{73} Los días en que presumo me infecté. Carreteando solo en el centro, patético. 
  Foto: Tomando cerveza en un parque.
\textsuperscript{74} Las caminatas alrededor de Toesca para comprender la situación.
  Foto: La pasarela de Vial.
\textsuperscript{75} El frío que había en la sala donde me dieron el resultado.
  Foto: La sala vacía.
\textsuperscript{76} El día que le conté a mi madre durante el desayuno.
  Foto: La taza de té y el pan que dejó sobre la mesa.
\textsuperscript{77} La llamada que hice al salir con mis resultados.
  Foto: Un teléfono público.
The collaborators\textsuperscript{78} shared events which made explicit part of the disruption HIV brought to their lives, referring to suffering, trauma, fear and resilience, and as such, revealing interesting aspects about how their relation with HIV changed overtime.

In the case of Diego and Claudio—who had been living with the virus for only a few months—their accounts revealed their internal struggle with fear and efforts to give a new meaning to their life with HIV. This is an element repeatedly observed in people recently diagnosed during the period of participant observation. The quest for them was one for meaning as in ‘Why me? What will I do now?’, that resonate with a young biographical disruption and the sense of confusion that comes with it. Given that this sense of being lost led to a more urgent quest for sense making—as will be observed in the photos—it reveals the need for appropriate spaces for sense making, and peer support in particular, in the times that follow a diagnosis.

The events chosen by Claudio, for example, are more descriptive than metaphorical or analytical, and they tell of a difficult sequence of events in his life: his disruption started with a suspicion that his ex-boyfriend was hiding something from him; later that suspicion would become a certainty. In his account, we can also read about the early consequences of HIV in terms of feeling frustrated and lost (“I got called again because my test was ambiguous. I had to wait another month to finally get to know”), which are elements also visible in Diego’s account: “The walks around Toesca to understand the situation...”. Their accounts refer to the need to make sense of what is going on with their lives, a first awareness about the consequences HIV will pose, and an unsettling process of coming to terms with what is going on.

\textsuperscript{78}So far we have read a few examples of this exercise, but only from four collaborators, as two of them (Jaime and Herman) decided to abandon the process in the following months. In the case of Herman this happened after he took a second job, and his time to invest in other activities became very limited. Jaime decided to leave after his mother’s health deteriorated and he became her carer. Even though I have their permission to use all the material produced during this workshop and, while conducting participant observation, I considered their processes as unfinished until now. To analyse their incomplete individual creative accounts would be unfair, as their stories would be interpreted from fragmented material, with too many gaps to fill, thus encouraging opportunities for misrepresentation.
In the case of Oscar and Miguel Angel, we can observe that their relation to HIV had been established over a longer period of time, which enabled them to give meaning to a life with HIV beyond their own existence and to confront fear from a different position, working with and for others as a way of delving into sense making. This can especially be seen in Oscar’s account: “Working at Sótero del Rio hospital in peer-to-peer counselling, giving support to people who are newly diagnosed, and showing them—through my own experience—that you can carry on with your life.”

By creating the ethnographic context in which collaborators could explore how they see themselves and articulate a first list of life events in relation to HIV, it is possible to observe that they do not define themselves in relation to the virus (as seen in the first exercise) but that at the same time, HIV impacted upon their life trajectories, provoking a readjustment of identities and relations with others. In these exercises, even though just the start in the context of this project, a long journey in the quest for sense making can be seen in which a past is connected with a present and a future: uncertainty and shame, feeling lost (even to the point of suicide), trying to understand for themselves and for others, working with others in the same situation, and so on.

Memory appears in this context, in this particular space that has been collectively created, in the form of the individual recalling of events embedded in a life trajectory. The ethnographic context has been central to conveying the emergence of memory, and even though these are fragmented, and some perhaps not well articulated (please refer to the original versions in Spanish in the annexe), what they convey is a sense of what it means to live with HIV in Chile, and how this has impacted how they experience the world.

Even though in the originals in Spanish the language appears clumsy or disorganised in some cases—unstructured sentences, lack of punctuation, unfinished sentences, notes on the side—this reveals not only that recalling was not an easy process but also gives a sense of how memory works under the improbable rules of order—that for some might
appear chaotic—not following linear patterns, and not necessarily facilitating access even to the one who had the experience.

The use of written text helped in this context as it allow them to conduct a more intimate process of memory recall, in which words emerged first in an internal dialogue with the self, and was later written in text. In this way, words are not uncontrolled but rather thought in a process in which the collaborators have time to assess what they’ll write and the implications of that writing. By working individually and using written words, they have a greater sense of control over what is expressed while at the same time promoting a more intimate contact with those memories.

In the weeks after the workshop, I met with the collaborators individually in order to discuss ideas and polish a final list of photos. In order to promote a sense of authorship over the images, conversations about what they wanted to achieve with each photo were central to these encounters. They would be the creators of their photos and in that respect they would have to be involved in every decision, even though some were worried they did not have any experience beyond their mobile phones. In our conversations, they understood I would help with the technical aspects of lighting or production, but that they would be the ones in charge of imagining the photographs, and deciding which elements they wanted to include, such as characters, props, location, time, colours, shot type and angle of the camera. It became clear to them that they were the directors of their own autobiographical photos, in the same way that a film or theatre director has to decide each element appearing on screen or onstage. By making these decisions, the collaborators were starting to create their autobiographical mises-en-scéne, a concept I will analyse in depth in the following chapter⁷⁹.

⁷⁹ Our aim was to put together an exhibition in which each collaborator had the same ailments, therefore we agreed not have more than five events/photos from each collaborator.
This chapter has examined how space and the concept of autobiography has been negotiated in this particular encounter, allowing the collaborators to establish certain frameworks that will inform the following practice of photo-creation. By promoting an ethical setting in which they are in charge of the conceptual negotiation of the project, this particular ethnographic context facilitates access to critical life events. As mentioned earlier, this process will continue to develop further as they become involved in representing themselves, transitioning from “protagonists-narrators” of their own story to “protagonists-narrators-directors” of their own autobiographies.

Later, when discussing how we could work on the visual representations of events—and not the events directly—the collaborators approached their events not only as difficult memories, but from a creative perspective in which they somehow reclaimed a certain control. In our conversations and with them as directors, we discussed technical aspects of ‘how to stage’ these photos, and by this they created a distance from the events themselves, making them strange so as to make creative and aesthetical decisions about them. This emerged in an ethnographic context in which collaborators could take a more active position in order to represent their life stories; and from there a process of re-signification could be promoted, as will be examined in the next chapter.
CHAPTER 3

‘These photos are traces of my life, which are here for other people to see’ - Claudio Letelier, collaborator of this research

So far I have suggested that from our first collective encounter, in the workshop that preceded the photographic representations of their life events, the collaborators engaged in negotiations to shape the investigation ahead. These conversations and mutual challenges were the beginning of their appropriation of the research methods and promoted a specific way of thinking about their own visual autobiographies.

In this chapter, I will analyse the collaborative photographic mise-en-scène production. I argue that the process of creating reflexive autobiographical photos in a collaborative context facilitated the creation not only of representations of a past, but evocations of a complex system of inter-relations with others, and explorations of potential worlds. In other words, the practice of a collaborative mise-en-scène provided a means by which to re-signify life experiences in unexpected ways: not only as considerations about the collaborators themselves, but also in their relation to others; and not only in relation to a past, but also in relation to futures.

In order to understand this, we need to examine mise-en-scène creation as a process in which collaboration and reflexivity are central in establishing the intersubjective grounds in which to ask mutual questions about the process of image creation. Through this, collaborators integrated elements and made decisions that nuanced the photographs, which are more than just ways of creating representations, but are also specific ways of knowing, and practices of taking part in the world (Crang, 1997; Hogan and Pink, 2013).

This process started with an exploration of photographic mise-en-scène creation as a method to represent narratives from their memories and imagination, which could then be used to start conversations with others, thereby conveying reflections beyond individual sense making in relation to HIV. From this process emerged evocations not only
of how they experienced past events, but—given the centrality of their reflexivity in the process—memory and imagination worked together to identify how those events could have worked out and what it might have led to in the future. These were evocations of desired worlds, which had not yet been revealed. In this way, their photographs are versions of a multiplicity of worlds they imagined from the positions of power they adopted by being in charge of creating their own representations. Furthermore, their evocations were not only directed to themselves as a way of re-signifying their experiences, but were also directed to others in the form of ‘statements’ from which they could begin a dialogue with people they might not even know.

This chapter is in conversation with the Photo Book that accompanies this text, in which all the photographs displayed in exhibitions in Santiago, Chile and Manchester, UK are presented (please also see the exhibition catalogue that comes as part of the thesis folder, which deals with additional material and press coverage). The Photo Book is presented as a separate object, so as to replicate—to a certain extent—the experience of the audience when attending the exhibitions. Throughout the chapter, I will refer to specific photos and ask you to look at them, but before that, please open the Photo Book and study the collaborators’ own visual evocations, paying attention to which life events they chose, and the elements they decided to include. These are the images that emerged from the practice of collaborative mise-en-scène as a form of hermeneutic reflexivity, a concept I will develop in the following section.
1. Hermeneutic Reflexivity Through Mutual Questions

Davies (1999) suggests there is not just a single way of understanding or practicing reflexivity in Anthropology, as reflexivity within the discipline has taken a variety of forms, with all of them affecting the research process. With the rejection of metanarratives brought to the discipline by postmodernism, Davies (1999) suggested more ‘radical’ takes on the concept arrived and displaced the ‘benign introspection’ of the fieldworker who kept a diary (Woolgar, 1988). This shift made possible the emergence of new forms of reflexivity, including auto-ethnography in which reflexivity is used as a way to ‘analyse personal experience in order to understand cultural experience’ (Ellis et al, 2010).

In Visual Anthropology, reflexive photographic methods usually seek to elicit engagement from participants after images have been produced (by the participants, the ethnographer or others). The meaning of these images resides in the way participants interpret what they are seeing and what they express in their dialogue with the researcher (Stanczak, 2011). For example, in photo-elicitation, images are used within interviews (Collier & Collier, 1986; Harper 1988, 2002) with the researcher asking questions about the images to prompt an interpretation from the participant. The participant engages visually with an image and from there describes, recalls and reflects upon her/his understanding of the world, which relies on the understanding that ‘photographic images are inherently reflexive’ (MacDougall 2006, p. 3).

This use of methodological reflexivity relies heavily on looking at an image already produced, rather than on fostering its emergence during the process of its production. This interest in the negotiations that take place during the production of images is what this chapter explores, and I suggest that the inclusion of reflexivity as a constant element throughout the creation of images can be a valid methodological practice. In this context, use of the words ‘reflexive’ or ‘reflexivity’ does not refer to an inherent characteristic of images which can be revealed after they have been created, but rather to the practice of reflexivity as an on-going process of negotiation during the process of image creation, by which aesthetic decisions are probed as to whether they are coherent with the expressive
purpose of the image or not. The practice of reflexivity as a form hermeneutic enquiry about images makes possible the emergence of ethnographic data that would not emerge by using a different methodological approach. This call to attention to the different aspects of image creation—from the use of particular elements over others—becomes even more relevant when working with people who ‘take’ photos, rather than those who ‘make’ them.

In this context, collaborative *mise-en-scène* creation seeks to elicit reflexivity not by analysing an image produced in the past, but rather throughout the process of image creation and in the form of mutual questions, so as to engage in a hermeneutic circle in which reflexivity is promoted. In this way researcher and participant (here, collaborators) are both engaged in the construction of an image (object), with their positionalities and worldviews meeting in a common area where image creation takes place. As happens in a hermeneutic circle, collaborators are engaged in a dialogue discussing perspectives so as to increase our understanding of the world, in this case in relation to the *mise-en-scène* creation. Therefore our mutual questioning serves to highlight their decisions and whether they resonated with what they were wanting to express, in terms of creating an image that emerged from their autobiographical accounts. Here, the focus is on the process of creation and what emerges from our dialogical and reflexive interaction, as opposed to only being driven by the final object (the photograph).

Hermeneutic reflexivity is elicited through mutual questioning and it is in this terrain of back-and-forth where a ‘clearing’, or ‘lighting’ in the Heideggerian sense, can take place. Heidegger’s phenomenological perspective focused on the ‘situatedness’ of human beings in the world: a world of shared background practices and familiarity (Plager, 1994) but in which we also have individual interpretations. Heidegger’s concept of clearing changed throughout his career, but in his later work he opened up to a form of clearing that was more local and focal, and which could therefore be specific to individuals and groups, such as families or friends (Plager, 1994). This suggests that we are dialogical beings, engaging and disengaging from others in a hermeneutic relation to self-interpretation: ‘this activity
involves an understanding of what being means, and it is this understanding that opens a clearing’ (Dreyfus 1984, pp. 73).

Through the production of a hermeneutic reflexivity, the object is constantly changed as perspectives are challenged and modified while in this face-to-face dialogue. It is in this territory where the collaborative *mise-en-scène* takes place, as a method to create an ethnographic context in which people reflect upon the creation of images that refer back to their lives. The purpose of this hermeneutic circle in not necessarily to elicit answers, but to open up a dialogue and discussion, a territory in which further questions can be asked, constantly re-shaping the relation between collaborators and with the object. This is a practice-based form of hermeneutic enquiry, not in the sense of a Biblical scholar, but through dialogue in an ongoing dialectic.

This type of engagement departs from Irving’s idea that ‘epistemological and empathetic borders, rather than simply being fixed impediments to understanding other people’s embodied experiences of the world, can also open processes of critical reflection, moral questioning, and intersubjective transformation’ (2017, pp. 98). Irving follows Throop (2015) in suggesting that people have the capacity to shift perspectives and attitudes towards themselves and others. From here, Irving applies this to fieldwork, by reconsidering Sartre (1943) and indicating that the very act of attempting to reach across the ‘hermeneutic divide’ opens up the possibility for ‘small movements in perception, personhood, and understanding in which someone comes to the realization that life can be seen, felt, and known from another perspective’ (Irving 2017, pp. 98).

While engaged in collaborative *mise-en-scène* creation, the act of posing mutual questions becomes part of the ethics of our face-to-face encounters, and emerge from our ‘epistemological and empathetic borders’ in which we are looking at the same object (photo), or more precisely at the process from which images will emerge. Our
positionalities result in different ways of seeing the process ahead, and through dialogue we attempt to find ways to illustrate what it means to live with HIV in Chile.

2. *Mise-en-scène* in a Photographic Research Context

Central to the development of these photographs is the concept of *mise-en-scène*, which is one of the most important terms in cinematic vocabulary, and refers in general terms to how different elements interact within a frame in order to tell a story. It can be translated as ‘placing on the stage’ and as such is widely used in theatre and filmmaking, with origins that can be traced back to nineteenth-century theatre (Thompson and Bordwell, 2001). In their text ‘Film Art: An Introduction’, Thompson and Bordwell defined *mise-en-scène* as ‘putting into the scene, [including] those aspects of film that overlap with the art of the theatre: setting, lighting, costume, and the behavior of the figures’ (2001, p. 112). In other words, *mise-en-scène* refers to the inclusion/exclusion and control of some of the elements that are made visible to the audience. David Cook in ‘A History of Narrative Film’ refers to *mise-en-scène* as ‘putting in the scene’, namely ‘the action, lighting, decor, and other elements within the shot itself’ (1980, pp. 968), but emphasised that *mise-en-scène* is circumscribed to what is IN the scene ‘as opposed to the effect created by cutting’, or *montage*. Therefore, *mise-en-scène* is what is visible as part of a cinematic ‘*diegesis*’, the world that the characters experience and encounter; and not of the editing, including visual effects or post-production.

Within its definition, *mise-en-scène* highlights a sense of authorship revealed in the expression of the director’s vision and control of elements made visible to the audience, an aspect I wanted to extend to the visual practice of our research. By using this concept as a way of emphasising the importance of authorship when arranging the components of
the frame, collaborators were not only invited to ´stage´ a photo, but also to assess the internal coherence of their arrangement in relation to what they wanted to express.\footnote{In the field, we used the translation of \textit{mise-en-scène} to the Spanish (´puesta en escena´) which is widely used in common language, not only for film and theatre, but for any form of representation to which the concept of ´setting´ can be applied.}

Thompson and Bordwell acknowledge the power behind this construction: ´In controlling the \textit{mise-en-scène}, the director stages the event for the camera´ (2001, p. 112), and by extension offers a determined perspective for the viewers. Even though we were working with film but also with photography, we used the term as a way to emphasise the control collaborators would have over their photos, and the fact that these—although autobiographical—did not have to be ´evidence´ but could be also opportunities to create, opening possibilities for imagination.

In this section, I will first analyse an encounter with \textit{mise-en-scène} and visual methods as part of a longer process, so as to emphasise that its implementation in the field was not exempt of challenges. However, those ´challenges´ opened up avenues of mutual learning and negotiations within the practice, by which they appropriated the visual in different ways, creating possibilities within the autobiographical photo that were not foreseen but appeared as central to our practice. As a consequence of this practice—and as part of a continuous dialogue—emerged epistemological opportunities based on successes and failures, agreement and dissent, from which an appropriation of methods was possible.

\section*{3. Face-to-Face Collaboration: Appropriation and Estrangement}

On page 9 of the Photo Book, you can see Miguel Ángel’s visual creation of his relationship with the memory of his deceased partner. Miguel Ángel managed to convey a sense of intimacy, and project it towards an audience (by looking back at the camera), as a form of visual statement to how his partner ´is still alive in my heart´ (Photo Book, page 8). As I will
analyse in the next section, this photo emerges by promoting a sense of authorship and by making strange objects and places, which were two of the central elements when working on these *mise-en-scène*.

Please have a look at the photograph and its companion text (pages 8 and 9 in the Photo Book), and then return to this thesis.
Miguel Ángel wanted to create his first two *mise-en-scène* at home, because he felt ‘more comfortable and safe’ there, as opposed to in public parks, where the rest of his photos would take place. I waited for him near the Metro, and on our way to his house we discussed our plan for the day ahead, as an informal type of ‘production meeting’. Miguel Ángel decided to start with a *mise-en-scène* about his relationship with his partner, Pablo, who had died more than 10 years ago. Starting with this photo—and not the second about his relationship to Diabetes—would give us some time until his next insulin injection.

We went into the living room, where a couple of his cousins were watching TV. He introduced me to them by saying “She is the someone from the documentary”\(^{81}\) and we went through. Our cameras were not visible as we carried them in backpacks, so unless Miguel Ángel had told his cousins, it was impossible for them to identify the purpose of our visit. I realised he didn’t introduce us as the ones who were coming to assist with the photos, but the most predominant aspect was the documentary, which suggested he would be filmed (as a subject) and would not be one of the producers of the visual work. He did not identify himself as such, yet.

Miguel Ángel was slightly anxious about this first *mise-en-scène*, as he wasn’t certain about how the process would work in practice. We had conversations about how it would operate, but it was difficult for him to visualize it beforehand and from my work in other participatory projects, I knew that conversations and explanations about methods were only the starting point, and only through practice would it become clear what had been put into words.

His *mise-en-scène* idea was simple, but not entirely developed. For someone who does not often ‘make’ photos—conceiving of it as product of reflexivity as oppose to ‘taking’ them, a spontaneous register of a situation—the act of imagining full images before shooting wasn’t easy. He had a clear idea about the event that inspired this photo (the day of his HIV diagnosis) and he also knew that he wanted to show old photos of his partner to the camera. So I began asking him questions to visualise what he wanted to convey, starting

\(^{81}\) ‘*Ella es la del documental*’
from elements such as ‘Where does it take place?’, ‘Which of Pablo’s pictures do you want to use?’, ‘Can we see it?’, ‘Will you appear in the photo?’, ‘Will you be sitting or standing?’, ‘What props do you want to use?’, and so on. These questions might seem simple but had great implications not only in the mise-en-scène at hand, but in the whole process of working with the collaborators as directors of their own representations, challenging them to take control of their creation.

Usually, the first mise-en-scène creation was the longest and the most challenging one for collaborators, as we were trying to work together through mutual questioning to understand how we would put methods into practice. However, these questions had the purpose of facilitating the expression of what they were imagining, and making decisions about what they would make visible and leave out, and how that resonated with what they wanted to portray. In other words, by asking questions we were attempting to foster some aesthetic consistency to put at the service of their photographic objectives, correlating what they wanted with how to convey that idea. These questions were focused on the technical and aesthetic, and not about the autobiographical event that inspired the photo.

These questions did not only facilitate the expression of visual aspects, but also served another purpose: the one of ‘estra
gement’, as a means through which to disrupt familiarity with space and objects. Almost all the photographic mise-en-scène created for this project were staged in places which the collaborators knew well, and this familiarity could have made them overlook many aesthetic elements that could end up accidentally being part of the photo. Heidegger suggested that we are so culturally and socially embedded in familiarity with our practices that we forget that our being exists within this familiarity (Heidegger 1927; Plager, 1994; Dreyfus, 1991); therefore, in order to produce these images, the collaborators have to ‘make strange’ familiar elements, and engage with them from a different perspective: the one of directors. This process involves not only a recalling of a memory, but also a deconstruction of its meaning from an aesthetic point of view, in order to make decisions about how elements would be included or not as part of the mise-en-scène. In this way collaborators are not engaging directly with the event (from
the position of only being the individual affected by it), but with its representation and from a different position of power.

‘Estrangement’ as a device for perception comes from ‘making strange’ as defamiliarisation, a term coined by the Russian Formalist Viktor Shklovsky, who was preoccupied with the sense of automatization of perception, by which—according to him—we no longer really see what is around us. In his text ‘Art, as Device’ first published in 1917 he proposed art has different ways of de-automatizing perception, allowing us to invert the familiar with strangeness and through this make us see again: ‘The goal of art is to create the sensation of seeing, and not merely recognizing things; the device of art is the ‘estrangement’ of things’ (Shklovsky 2015, p. 162). In this sense, asking questions of the collaborators would counteract that familiarity, produced by repeated experiences with the same places and objects, that according to Shklovsky led to recognition, by which ‘a thing is in front of us, we know this, but we do not see it’ (2015, p. 163). This automatized perception could impede collaborators’ reflections on how to choose and organise components of their mise-en-scène.

Therefore, asking questions became a way of counteracting and disturbing these forms of familiarity with objects and spaces, and invites them to consciously consider the elements which would be included in the photos. Through this, the collaborators could transform familiar objects into props, familiar spaces into settings, and themselves into characters; from this a reflexive mise-en-scène could emerge.

To see things not as elements of the everyday, but as ‘signifiers’ in the context of a staged visual representation, is part of the director’s duty. With the collaborators acting as directors for the first time, that consideration of objects and places did not always appear by itself; and in that context questions resulted in being a useful device for making decisions based on semantic considerations.
As stated by Thompson and Bordwell (2001), components of the *mise-en-scène* are not in isolation, but combined with all other visible elements, creating a specific ‘system’. The director’s role is an articulation of that system by controlling components and its interrelations. Therefore by making conscious decisions about the elements they would include and its organisation within the *mise-en-scène*, collaborators created a ‘system’ within the frame that could be consistent with their vision as ‘directors’. Elements involuntary included in a photo can dislocate the ethos of the visual narrative, and play against the story being conveyed.

In this context, Miguel Ángel explained that wanted to evoke a sense of intimacy with his photo, and he would do that by setting it up in his bedroom and with his cat. His bedroom was not only a room, but for the purposes of the photo, a place for the evocation of his partner’s memory. He wanted to be at the centre of the frame looking at the camera, while sat on the bed holding one of Pablo’s pictures.

4. Disassembled Expressions and Memory as Practice

I also asked the collaborators to create a simple structure of actions following the Aristotelian principle of beginning, middle and end: ‘How will you start to prepare this *mise-en-scène*?’, ‘What will happen?’ and ‘How it will end?’. This would result in a chronology of actions: choosing and organising the necessary elements for the photo, then making it and finally dismantling the setting they had created as a form of closure. In this way, Miguel Ángel and all the collaborators made decisions about the *mise-en-scène* arrangement not only in terms of its components, but also about the process in which is embedded. In this way, they moved between larger and smaller units of meaning, from which decisions about the photo would speak not only to that particular process, but to the autobiographical project.
Miguel Ángel said he would start by collecting a box full of memory-objects from the corner of his room, taking it to the bed, and then making the photo. To end, he would return the box with the photographs to the same corner. This chronology was coherent with how he conceived of his memories with Pablo as something that, even though it still hurt, he could unpack. In this way, taking the wooden box out from that hidden corner of his room and opening it up was a physical action that resonated with the internal movement of unpacking memories; which were later to be placed back in the corner of his room.

These chronologies were an integral part of all the *mise-en-scène* and marked for the collaborators when we would start and finish filming. Defining a beginning, middle and end for the photographic *mise-en-scène* also became the internal structure of the film sequence. By putting in place the necessary elements for the *mise-en-scène*, a narration about the event would emerge while they were immersed in the creation of the ‘system’ they’d envisioned.

Miguel Ángel said he was ready, and we started to film. He moves to the corner of his room, picks up the box full of old photographs with Pablo and takes it to the bed, where he sits. He opens the box and slowly takes out a bunch of old photos: these are the last images he has of his partner. He chooses one, and looks at it; his eyes moving all over the picture. He does not talk. Then, he takes another photo and handles it with the same lack of urgency. And then another, and another.

Even if what he is investigating appears as unstructured thoughts, undefined emotions, or disassembled expressions, this has to be understood as part of the process of attempting to socialise them. Memory is unstable and sometimes difficult to express, especially when related to suffering or pain, and therefore when it emerges with the purpose of communicating, it does not necessarily appear as a linear narrative. This is especially the case with traumatic memories such as the death of a partner, which is not often narrated and thus the difficulty of dealing with that experience becomes visible, particularly when trying to put that experience into words.
Caruth (1995) has indicated that recalling a traumatic event is not the same as recalling a simple memory as it is largely difficult to control, and therefore accessing and making a ‘narrative memory’ of it requires a putting into language of something that defies simple comprehension: ‘the truth of an event, and the truth of its incomprehensibility’ (p.153).

Memories emerge from experience, but that ‘original experience’ has to be put into words in order to be expressed. Therefore, the subject—in this case Miguel Ángel—has to find a vehicle for its expression, which, in the case of trauma, is a most difficult task.

After being absorbed in Pablo’s old photographs for some minutes, he was able to speak again. It was not easy for him, but he started to share some words and memories that emerged with every picture. While he was remembering, there was a different relationship with the objects, with the space, and between us. This was not just a bedroom anymore; in that moment it was a space for memory. Silence and slow movements facilitate a looking inwards, as opposed to the previous mutual questioning about how we would create the **mise-en-scène**. Not only with Miguel Ángel’s photo but with all the collaborators there begun a chronology of actions that led to the **mise-en-scène**, and then came silence, a different speed of action, a different relation with objects and space that was out of the everyday. When in the process of photo-creation, collaborators were involved in multiple levels of dialogue, with themselves, with us, with their memories and with the **mise-en-scène** creation. Therefore the pace of our dialogue was shaped by these tensions from which at times words emerged:

This is the house where we lived... here is where we used to go for walks... this is Pablo playing with our cats...

He was with us some of his memories with us, and we were listening to his stories while filming. We were all immersed in that process of memory-recalling that would lead us to create an image of that memory investigation. O’Neill and Hubbard (2010) and Pink et al. (2011) have explained that taking part in the same activity as a form of shared embodiment, shapes the relational process and can open up a discursive space that is also a reflexive space, and ´in this space for dialogue and reflection, embodied knowledge,
experience and memories can be shared’ (O’Neill, 2014, p. 78). Empathetic dialogue takes places by everyone being immersed from different perspectives in the process of creating an ethnographic sharing of those memories, which is also the context to create images that depart from those memories.

- So tell me how you would like to take the photo? – I asked
- I would like to be sitting on the bed, and take it from out there [pointing out at the balcony]. I will stay here, holding Pablo’s photo.

Then Miguel Ángel passed me the photographic camera, with the idea that I would take the photo and decide for him, so I gave it back, saying he was the director of the photo and had to make those decisions.

The fact of collaborators passing me the camera with the intention that I could shoot the photos was a repeated occurrence with all the first photos. Even though I’d explained that they would create and shoot the photos, this attempt to ‘pass the photographic camera’ happened with all of them, revealing that they were following particular ideas of what it meant to be part of a research project as participants in terms of being observed and not actively creating the outcomes. This suggested that despite the fact we called each other collaborators and asked questions back and forth, the aspiration of working collaboratively in a less hierarchical relation required the constant practice of tactics to displace power, such as by returning the camera to them, or by asking questions to make them feel more at ease with making decisions about the photos. By acknowledging our relation as collaborators could be problematized in terms of power, we articulated strategies through dialogue to displace that power, and the fact that they later took increasing control over the images we produced was a sign that our efforts were productive to a certain degree. However, the difference in our positionalities was also seen as a positive element, as a source of new perspectives that challenged us to be more explicit about our hermeneutic borders and talk about each other’s perception and understandings.
Once Miguel Ángel had taken back the camera, he went to the balcony, looked through the lens to decide on the shot, angle, and focus, so I just had to press the button once he was back in the frame. He made the last arrangements, such as closing the drawers of his closet and calling his cat, making sure his idea was represented in the *mise-en-scène* he was creating.

Miguel Ángel was not only creating the ‘setting’ for his photo, but was arranging a ‘system’ (Thompson and Bordwell, 2001) that reached beyond the interpretation of the real; a ‘system’ as ‘trace’ (Sontag, 1978) to his memories with Pablo and how he experienced the world after he died. His photo was not only about a past, nor just about the present, but a conversation of different moments across that life continuity. This process of creation provided the means by which to examine the disruption of having lost his partner, re-signifying and updating the meaning of that event: ‘he is still alive in my heart’.

The emergence of the unfamiliar as a form of ‘estrangement’ (Shklovsky, 1917) provided a particular emotional detachment by which Miguel Ángel was able to make aesthetic decisions and create a *mise-en-scène* which made sense as a coherent photographic artefact. This *mise-en-scène* creation as an on-going process promoted a space in which he could embody this ‘directorial’ role, by which he was in aesthetic and emotional control so as to promote memory recall. ‘Familiar’ and ‘unfamiliar’ perceptions and relations with objects, space and others were intertwined in the creation of this *mise-en-scène*. That interaction between these two aspects promoted a more conscious approach to those relations with objects and space, but also an inward looking dialogue, a thoughtful conversation that facilitated the emergence of memory and reflection.

As in the case of Miguel Ángel, the *mise-en-scène* presented many challenges for the collaborators, especially during the first session in which many questions were answered through dialogue and practice. i.e. what creating a *mise-en-scène* meant in reality and what it involved; what the internal structure for each *mise-en-scène* would be, what elements I would include to represent that memory, would I be able to make a good
photo, among many others. We engaged in continuous dialogue and mutual learning about how to introduce visual methods to facilitate the reflexive aspect of the process, providing the framework for upcoming *mise-en-scène* creations. As the collaborators became less concerned about how a *mise-en-scène* creation worked, they started to extend the possibilities of the process beyond memory representation in more explicit ways.

If we think about memory as a ‘practice’ in terms of departing from experiences but shaped by subjectivity (which is not organised in linear ways); or as Antze and Lambeck (1996) have proposed not as only the ‘as the act of gazing and the objects it generates’, we are emphasising the fact that ‘memory’ and ‘memories’ depart from events but are also re-shaped by the subject who experienced the event and by the context in which she/he is unpacking those narratives. Therefore, what can be reached are versions of how an event was experienced within a specific context from which particular reflections about present and past can emerge, not only as a representation, but rather as evocations, as I will develop further in the following sections.

5. Photos as Statements

In this section I will examine how Oscar’s photo with his daughter and its corresponding text (pages 22 and 23 of the Photo Book) had the purpose of challenge misconceptions about HIV, as a form of photographic ‘statement’. During the process of the *mise-en-scène* creation, the collaborators became increasingly aware of the opportunities their photos could offer in terms of speaking to an audience. The way in which this particular *mise-en-scène* was shaped and informed by this consideration about a future observer will be addressed in the following section.

Please open the Photo Book on pages 22 and 23 and look at the image and its description, paying attention to how Oscar and his daughter look at the camera as if looking into the
eyes of the viewer, and how the camera portrays them from a low angle. And then return to this text.

Before creating the photo, Oscar said his family did not allow him to get too close to Dorca, his daughter, during the first four years of her life. His family wanted to avoid any type of HIV risk for the girl, and with the information they had at the time, they decided to separate them to prevent any type of contact. He left his parents’ house, but his daughter stayed there and he was allowed to see her as a visitor, reducing all his expressions of love to only being able to hold his baby at weekends. He was not allowed to feed his daughter, change her nappies, or fulfil basic parental duties.

These restrictions became too painful for Oscar, and even though he learnt that his daughter would not get HIV just from being close to him, it was difficult for him to convince his family of this. He tried to fight back, and one way was by creating an awareness about HIV transmission within his own family in order to challenge their beliefs; and as he said “the best counselling I have done is the one I did with my family”.

After four years of accepting his family’s judgement, he decided to challenge the restrictions and kiss his daughter before her first day at nursery, and they took a photo of that moment, instead of the official picture of her first day at school. That day Dorca was another student like everyone else, but her photo was different, as she doesn’t stand still to show the camera her new uniform (as the other new students do), but rises up and kisses her father; while Oscar bends so as to get close to his daughter. That photo was a confirmation of their kiss in the eyes of his family, and had many consequences for Oscar. Despite this, he felt the photo was not ‘something sad’ but rather evidence of a different kind: of the moment in which he directly challenged his family’s misconceptions about

82 Twenty years ago, it was popular in Chile that for the first day of school, a photographer would make individual pictures of the students wearing her/his new uniform. In these photos, the new pupil would be photographed standing straight with her/his new backpack looking at the camera; and that image would be printed and framed with the inscription ‘My first day at school’. Then these photos were printed and sold to the parents and/or legal guardians as a souvenir, to remember the moment when the children started their education.
HIV. Now Dorca is 25 years old, and Oscar wanted to make a photo to create new ‘evidence’ about how wrong perceptions about HIV could have damaged his relationship with his daughter.

For the *mise-en-scène* ahead, they didn’t want to replicate the old picture, but rather create a new photo in which past and present could meet, conveying a sense of continuity of that relation that was almost broken. We discussed his idea of using the old picture as an aesthetic reference and also as a prop: according to Oscar the use of the old picture was a way to replicate certain aspects while at the same time subverting others, such as the hierarchies between him and his daughter. Collaborators engaged with the creation of visual material in different ways for each photo, as each *mise-en-scène* conveyed personal experiences with which they related in ways that could not be predicted. In this context, no assumptions could be made and asking questions about what they wanted to convey with the *mise-en-scène* became a way of getting them to further explain their intentions, starting from the simple inclusion of props, places, and characters. The act of putting into words their ideas (which sometimes proved to not be an easy task) allowed them to organise their thoughts and identify incongruences or opportunities for their *mise-en-scène*. This was reinforced as part of our dialogue in which the film crew offered ideas and possibilities to put forward their intentions as directors.

Given that they were creating their *mise-en-scène* knowing that these photos would become public, the assessment of the potential repercussions of the images became increasingly relevant. To the question of ‘How will I represent these memories?’, collaborators added extra questions: ‘What do I want to say to others through this photo?’, ‘What do I want to reveal to the audience?’, ‘Who will the audience of my photo be?’

Speaking about the *mise-en-scène* and the purpose of the photo, making decisions and assessing the implications of including and excluding elements was at the heart of the
mutual learning process. These conversations tried to bring about the most accurate visual representation of what had been imagined, prioritising its reflexive implications over aesthetic or artistic elements. As collaborators we were all engaged in the process with the purpose of bringing forward an image that matched what the author had in mind, and much of that was clarified through trial and error, by looking through the camera or being in front of it, and by asking questions.

Oscar wanted both of them sat on a bench, with Dorca at a higher level as she is now an adult. She would be holding him from behind as a way of reversing the hierarchies of adult-child as documented in the old photo, in which Oscar is the one who bends to get closer to her. Finally, they would hold the old photograph together, connecting past and present. By this rearrangement of their positions and use of the old photo as a significant object, they wished to convey a new narrative in which his daughter is now an adult and they can express their feelings without the risk of familial consequences.

As in the case of Oscar, what can be seen in the structure of the collaborators’ *mise-en-scène* are not only representations, but evocations of life events involving both memory and imagination, as they are not only recalling a past, but also projecting towards the future. This configures a particular type of evocative projection of their lives, in which they do not access difficult experiences or traumas as a form of emotional confrontation, but rather through the position of being in charge of composing their *mise-en-scène*.

Through this, the collaborators were not looking at their difficult memories directly or reviving the trauma by grasping the source of pain, but rather they were focused on arranging a *mise-en-scène* in which they could evoke feelings, but which had greater expressive and imaginative possibilities, from which they could refer to an imagined audience. For example, for his photo Oscar wanted a slightly low angle shot, in which they would be looking down to the lens. After instructing me about how to shoot the photo, he sat with his daughter on the bench, and told her they should look straight to the camera,
because the lens represented the audience’s gaze. This type of shot was not a random choice, but rather a conscious decision as he was aware of the implications of hierarchy within low and high angles. He said ‘I want them to look up to us’\textsuperscript{83}, which indicated that he was making these decisions with the awareness that this photo would be seen by others. By saying ‘them’, the presence of a viewer was implied, in front of whom he wanted to make a statement about his relationship with his daughter, which was not limited anymore by the restrictions of others.

Each collaborator was asked to reflect upon their choices as directors and how their decisions related to the present. In this context, Oscar stressed that through his mise-en-scène he was creating evidence about their relationship, but was also shaping how their relationship should be perceived by others: ‘we are just daughter and father, like any other family... but people think that you can’t be a good father if you live with HIV’\textsuperscript{84}. The memory of their separation persisted even after twenty years, and by creating this photo Oscar was attempting to respond to those who believe that being a father is incompatible with a HIV+ status, as a way of conversing with the past.

Harper suggests that: ‘Photographs appear to capture the impossible: a person gone; an event past. That extraordinary sense of seeming to retrieve something that has disappeared’ (2002, p. 23), which establishes how photos can allow for a dialogue with other tenses within a life trajectory. By creating this photo and its subsequent material presentation, Oscar created a conversation with a past that persisted in his memory as a critical event, re-signified it and attempted to shape relations beyond our encounter.

With that photo, Oscar was attempting to publicly recover a sense of normality in their relationship, something he felt had been disrupted early on in their relationship. By creating autobiographical photos with an audience in mind, the collaborators were

\textsuperscript{83} ‘Yo quiero que nos miren hacia arriba’

\textsuperscript{84} ‘Nosotros somos papá e hija, como cualquier otra familia... Pero todavía la gente piensa que no puedes ser un buen papá y vivir con VIH’
creating opportunities for dialogue with an observer, which for Oscar was a way to re-signify his life experience. Through the image he created, he was demanding the opening of dialogues and the right to be seen in a different way, as just ‘normal’.

If we look at the photographs in this way, the collaborators were not only directing the internal organisation of the photograph via its *mise-en-scène*, but were also shaping the gaze of the audience, re-shaping relations beyond the context in which that photo was taken. As Sontag stated: ‘Photographs furnish evidence […] In one version of its utility, the camera record incriminates’ (1979, p. 3). Therefore, a photograph achieves a status that is difficult to discredit. With this photo, Oscar made something visible not only to himself, but also to others, so as to start a dialogue from a different position to the one he had when the school photograph was taken.

What this photo-creation conveys exceeds the context of its creation, but as Sontag (1979) has indicated, cameras can capture ‘our very sense of situation’, offering the possibility of informing viewers about much more than just the image, giving them the sense of an existence before and after. Seeing the photographs created and reflecting on the process of creation is to understand—even partially—what it means to live with HIV in Chile, as it involved ‘breaches in[to] the lives of the people concerned’ (Radley, 2010, p. 270). In this way, the viewer exposed to these photographs does not only have partial access to memories of critical life events, but also to the context in which those events took place, apprehending beliefs and understandings that enrich the ways of seeing the picture. In other words, photos provide access that exceeds the representation of a memory, in the sense that they do not only inform about an event, but also about the social context in which the picture is embedded.

This does not only refer to the general social aspects relevant to understanding the narrative of the photo; but to the specific context in which that photo was created. More specifically, the collaborators’ images provide evidence that the decisions behind the
photograph are not random, given that most of its components are carefully decided during its production. This refers not only to technical and aesthetic decisions about how to represent, but also to how they wish to be perceived by an audience and the continuities/discontinuities relevant to this. As Radley has pointed out, a photograph can be a ‘statement of a social condition’ (2010, p. 269), and given that we had agreed to open an exhibition at the end of the process, the fact that these would be ‘communicated’ to an audience was increasingly taken into account in the making of these photos. The conception of photographs as ‘statement’ shaped the way collaborators produced their *mise-en-scène*, as it implied a future communication—even if with an unknown audience—which was at same time an opportunity to speak and illustrate aspects that had been silenced or made invisible.

When Oscar’s photo was finally displayed on the wall at the exhibition, and the audience could only access what had been made visible to them through that low angle shot, in which they had to look up to the father and daughter who were looking down at them, a symbolic re-balancing of power was produced for him, conveying a new element for his personal sense-making process.

Finally, by being involved in the process of creating that photo, Dorca and Oscar remembered the context of the original photo and talked about it, and by that they had a new experience: one in which they looked back twenty years ago, and created a new picture of their relationship. Thus, the experience of creating the image together became a new memory for them, which will remain as an experience documented in the photograph. This new memory does not compare the old one in its intensity or persistence, but the process in which this memory was created served as an instance in which to reflect on the painful situation they had gone through.

This was made possible by the fact that the collaborators had taken control of their narratives, deciding which events they wanted to work on and how, under the premise
that they were open to explore and reflect upon these events. The challenging potential of these *mise-en-scène* is produced by reversing the positions they were in when the original events took place: now they are no longer simply receivers of the actions of others, but active agents and creators of a new discourse, which became public.

For each *mise-en-scène* the potential receiver(s) of the visual message varied, but the lens of the camera always represented a viewer who would look at the images, and as a consequence, a viewer they wanted to address: the lens could have stood for family and friends, for the ones who stigmatised them, perhaps others living with HIV, or members of the general public, and so on. The potential receivers of the message were defined by the collaborators on each photograph, and although they did not necessarily identify them verbally, the collaborators created their *mise-en-scène* with a particular viewer in mind, who had to be addressed, informed, or responded to. In this way, the *mise-en-scène*—from the moment the collaborators became conscious about this discursive potential—became a platform for reacting, contesting, and responding through visual discourse. The *mise-en-scène* creation promoted an approach to memories from a different position of power, in which they directly referred to others, and voiced what was previously unvoiced.

6. Photos from the Past and Images for the Future

When discussing ideas for the *mise-en-scène* with the collaborators—first during the workshop and later in separate encounters—we referred to the photos as autobiographical, and as inspired by critical life events. However, this did not mean those events necessarily had to refer to a past: they could also be events from the present or even from the future. For the younger collaborators (Diego and Claudio, who were also the ones who had been diagnosed most recently) the possibility of creating photos about a future wasn’t difficult and they eventually created some photographs which explicitly referred to a tense separate from that of the past. However, this proved more difficult for Oscar and Miguel Ángel, who projected their *mise-en-scène* into a future, as a type of
continuation of their present experiences. In the act of thinking, narrating and creating autobiographically, imagination (usually conceived of as the source of materials about a future) and memory (events referring to a past) emerge as ‘psychical partners’ (Casey, 1976) making the borders difficult to identify. The interaction between the two has an impact on the creative action of representing themselves, and by analysing the process of creating mise-en-scène, it is possible to analyse how they act together as intertwined partners in this creative ethnographic encounter. Considering Casey’s ideas, I will examine how memory and imagination are intertwined in the making of an autobiographical mise-en-scène, looking at the specific aspects of two photographic creations: one by Claudio and another by Diego.

In Claudio’s final photo (page 34 and 35 of the Photo Book), imagination emerged as an important element within the creative and performative aspects of the mise-en-scène creation. As I will analyse in the following section, the specific practice of this photo-making offered opportunities to explore memory and imagination, but also ways of counteracting the possibility of forgetting and creating new memories.

Please look at the photographs and text on pages 34 and 35 of the Photo Book before returning to the text.
It was the last day of *mise-en-scène* creation with Claudio. We had already completed three visual reflexive photographs recalling events from his life, and he was familiar with the use of the camera and the methods we were using.

Unlike the other collaborators, all critical events that gave rise to Claudio’s visual investigations had only occurred in the last few months of his life. Therefore his photographs revealed some confusion and pain in terms of the emotions he was conveying through the photos, as he was referring to a past that was not distant but had occurred in the last few months of his life. For his last *mise-en-scène* he wanted ‘to make a photo about my future’, and chose the Museum of Memory and Human Rights\(^85\), where an exhibition of Pedro Lemebel was currently showing, as the location in which to place the picture. Lemebel was a Chilean visual artist, writer and performer whose work critiques HIV stigma, homophobia and authoritarianism from a queer perspective and whose work became a hallmark of LGBTQI and HIV/AIDS activism in Chile during the 80’s and 90’s.

Claudio wanted to take the photographic camera into the museum, responding to the artist’s influence on him by having similar photographic gear as the artist used for his own visual work. From another perspective, he was ‘mirroring’ Lemebel’s art, by presenting himself in front of the artist’s photographic work with a camera, and creating a new visual object.

As with all the collaborators, Claudio was in charge of deciding when and how the *mise-en-scène* would start, which also started the filming. This one in particular would begin with his entrance into the museum, carrying the camera and “Loco Afán”\(^86\), one of Lemebel’s most famous books. Calmly, Claudio walked down the stairs of the museum, and just before entering the exhibition, he saw Lemebel’s Manifesto (1986), printed on the wall. He stops to read from it: ‘I don’t need a disguise // Here is my face // I speak for

\(^{85}\) *Museo de la Memoria y los Derechos Humanos*
\(^{86}\) ‘Crazy Desire’
my difference // I defend what I am

as if repeating a mantra. This being Claudio’s fourth photo, he understood and had appropriated the process and is able to fully direct it. He knows how his mise-en-scène starts and ends; there is no rush, no time pressure.

In the exhibition room, Lemebel’s voice inundates the place with his words, amplified through speakers and running in a continuous loop. On the walls, black-and-white self-portraits and posters of his work hang from pillars, and at the end of the room some the artist’s performances are screened. Claudio walks into the exhibition, staring at every photograph, every document, and every text. He doesn’t talk, but it looks as though he is having a conversation with each object. He no longer looks sideways to make sure we are following his actions with the film camera, and he simply becomes himself with Lemebel’s images and sounds, reflecting on how HIV was experienced thirty years ago. Claudio sets a different pace to the one used outside these walls, for himself and for us, the film crew, formed by myself and another person. With every step, he opens up the space for we who were filming: we were not seeing pieces of art, but the relation Claudio was making with the exhibition. Despite the time gap, there was still a lot in common, as Lemebel also talks about silence, stigma and uncertainty. He was establishing relations with the objects, and we were establishing a relation with the space shaped by his encounter and our encounter with him. There was a performative aspect to this dialogue, but Claudio was not performing primarily for others or the film crew, but for himself.

He stood in front of a self-portrait of Lemebel and said: ‘Here... This will be the photo about my future.

He said there were many reasons behind choosing this photograph, starting from how much he admires Lemebel as a student of Art, and how, in the future, he would also like to become an artist who brings the political to the forefront by using his own life experiences. He pointed at Lemebel’s portrait and said: ‘This is what I want to do

87 [(...] No necesito disfraz //Aquí está mi cara //Hablo por mi diferencia //Defiendo lo que soy [...] 88 ‘Aquí está foto será sobre mi futuro’
with my work, and by taking this photo, I will not forget where I have to direct my work. Claudio created a *mise-en-scène* that spoke to himself and served as a reminder for his future. He created a photograph not about an event that had happened in the past, but that relates to his present as an art student, and his future as an artist, pointing toward a desire for things to come.

According to Casey, imagination and memory are immediate derivatives of "sense" or sensation, and ever since ‘Aristotle conjoined them under the common yoke of "experience," philosophers and psychologists have attempted to keep them together in a conjugal state’ (1976, p.2). One could argue that Claudio’s photo emerges as something closer to imagination than to memory, although both elements are present, as imagination cannot emerge independent of a subjectivity, which is shaped by the memories of past experiences. His *mise-en-scène* does not belong to the realm of fiction, but to imagination, as a projected continuity of his present, which is intertwined with memory.

Casey was able to establish at least five differences between the two. From the perspective of memory it can be explained as follows: memory is ‘rooted in perception’ and it ‘links to a past’; these two characteristics come together in its ‘retentionality’, or ‘the capacity to retain a former experience in mind’ (1976, p.5). A memory is characterised first by its familiarity, as we can only remember something with which we are already acquainted, and while this is indispensable for memory, it is not so for imagination.

Finally, memory is characterised by its ‘belief’, in the sense that we believe something happened as we remember it, or as Casey explained: ‘I take this object or event to be something that once actually appeared or occurred in my presence. I accept or take it as possessing the quality of having been part of my past experience’ (1976, p. 8). Following Casey’s idea of memory, it is possible to argue that memory can act as evidence for the

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89 ‘Ésto es justamente lo que quiero hacer con mi arte, entonces si tomo esta foto no me voy a olvidar para dónde tengo que ir'
self: I believe it, because I remember, and I remember because I experienced it; which is what took place in Claudio’s photo-creation.

Casey referred to ‘retentionality’ as ‘the capacity to retain a former experience in mind’ (1976, p.5), as a characteristic of memory and not of imagination. In this case, Claudio is creating a route which moves through imagination—not based on a previous experience but a staged event (the mise-en-scène production)—and transforms it into a memory, which can be retained. The act of retaining that memory serves as the last aspect described by Casey, ‘belief’, as the consideration that a particular event actually happened. Through that photo Claudio is projecting one of the futures he desires, and therefore the photo itself becomes a memory not only of the event of creating the photos, but a reminder of where he is trying to direct his life-project. This photo about a future refers to a time which is not within the present yet, to a time in which he wants to arrive. In this way, mise-en-scène also serve the purpose of engaging with other potential tenses, which derive from their current desires and dreams. He had imagined and created a memory for a future which is guiding his present.

Consequently, the mise-en-scène became a more complex exercise, and went from being understood as a reflexive photograph referring to memories, to the creation of a representation in which performance and imagination are intertwined. This demonstrates that both memory and imagination were part of the process of creating photographs for this project, as they were intertwined with the psyche of collaborators. As Langford states in her study of memory and photography: ‘Memory and imagination are closely connected, the differences between them [are] not very clear’ (2007, p. 16), the two emerged entangled and inseparable in the way the photographs were produced. In the moments succeeding the production of the picture, it became a photograph about a past, transitioning from a photograph deeply rooted in his imagination, to one about an event he experienced, a memory.\(^{90}\)

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\(^{90}\) We need to distinguish between the photograph as evidence, or a trigger of memory.
On her study of memory and absence, Keenan (1998) proposed that old photographs can function as ‘sites of memory’ or as ‘testaments to forgetting’ as they can be incorporated into the present. Keenan (1998) indicated that ‘memory is a phenomenon that occurs in the present’ (p. 61), because it is from the present that we refer to a past, and by that operation, past experiences are put to our disposal, ‘whether or not we are conscious of its agency; whether or not we remember how we learned what we have retained’ (Langford 2007, p. 100). Claudio’s creation of a photograph for the future is one way of solidifying imagination and memory into a physical format, a form to resist the possibility of forgetting, what Casey (1976) described as ‘the primary other of memory’ (p. xi). Photographs being ‘by nature an instrument of record or retention’ (Langford, 2007, p.100) that refers to the past context in which it was produced, a photo can contest the failures of memory.

Memory is characterised by its instability, is ‘partial’ and ‘schematic’, and therefore subject to our mnemonic limitations, as has been suggested by Crapanzano (2004). According to him, people contest this deficiency through metaphorizing and carrying memories in external devices that have the capacity to store memories in more persistent ways than our elusive minds. In the case of Claudio’s photo at the museum, the image that emerges from this mise-en-scène is, on the one hand, an evocation of a future, and on the other an effort to overcome mnemonic limitations, the operation that Crapanzano distinguished as ‘the memory’s conquest of forgetting’ (2004, p.158). In this way, the photo Claudio created can be projected into a future, as that future will eventually become a present; and by rediscovering it, memories about the mise-en-scène will emerge. In this way, as we have seen with the other collaborators, a new memory is created in the act of the mise-en-scène production, one that can open possibilities for new forms of reflections with other memories in particular, and with memory as a whole.

Memory implies personal acquaintance with what it’s remembered, in this case what will emerge is his experience—although fragmented—in the context of the production of that
photograph, in which the performative aspects of his *mise-en-scène* were a vehicle to make imagination tangible and even material. In other words, his performance was part of the means by which imagination was manifested. Imagination becomes visible by the creative and performative aspects of this *mise-en-scène*, and by that operation more tangible and communicable, in a way that words or images alone would not have satisfied.

Claudio is not only creating an expression of the imagination that emerges from his mind, but also engaging with the possibilities that the real world offered to him. Drawing on Sartre’s idea that all of our engagements with the world have the potential to activate the imaginary process (1989), Fumanti (2015) has suggested that because the imaginary process relies on intentionality, ‘the world is constituted not from the outside into the consciousness, but rather we constitute the world based on our intentions towards it’ (2015, p. 131). In this way, imagination offers the possibility of re-signifying the world and by that can become a space of creative resistance.

For example, in Claudio’s photo, he is re-signifying the museum as a space, from which a future can be imagined, but he is also evoking a future in which art and work meet. By this Claudio is re-signifying his present and past experiences (in particular those related to HIV, to which he refers as ‘this journey’), by imagining a future in which these, up until now ‘painful experiences’, will become material for his work.

The use of imagination as a space for resistance can be found in all the photographs produced by the collaborators, despite the fact that each image presents us with a reliance on elements from imagination. A particularly interesting example can be found on pages 38 and 39 in the Photo Book, where you can see an image of a regular family breakfast, which evokes what Diego felt he had failed his mother. Even though that photo refers to an event that happened in the past, Diego used this *mise-en-scène* to explore how it could be if things would have been different.
Please look at pages 38 and 39 in the Photo Book before continuing.
7. *Mise-en-scène as Evocations for Desired Worlds*

With this *mise-en-scène*, Diego created a representation of when he disclosed his HIV status to his mother, while having breakfast around the dining table. At the time, he didn’t want to want to tell her the purpose of ‘all those visits to the doctor’, until he’d had some time to understand what his HIV diagnosis would mean. That morning, he remembered, there were just the two of them, and this was something that made the situation more difficult, as both of them were upset after his revelation, and his mother did not have anyone else to support her. Diego wanted to use the *mise-en-scène* to represent that event not as ‘it happened’, but as he ‘would like it to have happened’. Accordingly, he dressed the table for a normal breakfast, but this time he included cups and cutlery for each of his siblings, filling up all the spaces at the table. A full table would have been useful for him as his siblings could have supported his mother, and made the experience less painful. Finally, he placed a family photo at the centre of the table, which also served as a focal point for his photo.

As Mary Warnock (1976) explains, memory and imagination overlap and cannot be totally distinguished as both think about things in *absentia*, or as Diego staged, reflect upon things in a different way to the way in which they took place. Diego used this *mise-en-scène* as a manifestation of what Sontag (1978) described as an attempt to contact or claim another reality, as he not only staged the event as he experienced it, but conveyed the way in which the situation could have been better for him and his mother. In this way, imagination creeps into memory and vice versa in one photograph.

This represents an acknowledgement of the original event but also a desire for his experience to have been different, or maybe less traumatic. His photograph evocates an experience of the world not only anchored to memory, but which refers to imagined possibilities of experience that emerge from that subjectivity. In this case, Diego’s *mise-en-scène* departs from an event which is part of his memory, to then emerge entangled with imagination; and accordingly these are present in how it was finally staged.
Fumanti (2015) has suggested that imagination is strongly associated with emotions and feelings, while at the same time ‘with the idea of freedom in the capacity to relocate oneself in the world beyond the constriction of the real’ (p. 126). In this way, imagination operates not only as a form to ascribe meaning, but also as a way to create other possibilities of the real, from which another form of dialogue with past, present and future is possible.

The production of the collaborators’ photographs and the narration they convey leads to an understanding that autobiographical photos are evocations of our experiences in the world, but also of how we would like to experience it or have experienced it. As Radley (2010) stated: ‘photographs are not just pictures91 of the world [as it is], but are also resources for communicating how it might have been and what it could be in the future’ (p. 268). In this way, pictures are not only ways of capturing a portion of the world, or a ‘reproduction’ of a reality or an event, but rather—as Radley calls them—‘mediators that, along with words give shape to ideas’ (2010, p. 268). Through this, collaborators not only provided access to critical events, but also to what those events meant to them and how they would like to shape their lives in retrospect or as a form of fast-forwarding (in the case of Claudio’s photo), giving shape to new understandings of the world. In other words, the collaborators reflected on their own interiority through media and practices (Pink, 2012), which provided a route to knowing for all the collaborators involved.

When Radley characterised photographs as ‘mediators’, he does not only refer to the photograph itself, but rather to the whole process of its creation, which is what allow us to communicate how it might have been or could be in the future. As such, this process of creation involves not only the communication of a specific aspect of a world, but highlights the context and the reflection from which that photograph emerges. This implies that their photos have to be understood in the context of their production, which was a practice embedded in a specific ethnographic context, shaped by methods and

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91 Radley used the word ‘pictures’ to refer to photographs, drawings, paintings or videos.
particular intersubjective encounters without which these images would have not appeared. The photographic arrangements were products of complex interrelations between memory and imagination and engagements with experiences that formed part of a life history, from which polyphonic visual narratives emerged that not only looked at memories, but also re-shaped them.

Photographs are reflexive responses to difficult experiences that had to be socialized in order to achieve their full re-signifying potential. Only in communicating these visual creative accounts were the collaborators able to share with others the emotions they went through and how those experiences (the initial ones and the ones they created) shaped their sense of being in the world. Through this, they were not only working on themselves by creating new memories, but were also able to react publicly to their experiences, addressing whichever viewer they had in mind when creating their *mise-en-scène*. In this way, photographs are not only a collection of individual stories, but rather a material testimony of a social position; the position of the collaborators as part of the group of people who live with HIV in Chile, and how they experience and find ways to contest stigma in their everyday life. In this way, their photographic *mise-en-scène* went from being intimate representations of their memories to becoming evocations, and ultimately visual testimonies of how they re-signified HIV as part of their social conditions.

This connection between the personal and the social began to appear before the exhibitions took place, when the collaborators found a larger sense of purpose in the photo creation: they started to speak not only to themselves and their internal sense-making dialogue, but also to an imagined audience. Among the personal reflections that preceded the photo creation, they started to question who would see their *mise-en-scène*, and from there, their photos also started to speak to this audience: from family to people they have or will never meet. The collaborators also had in mind other viewers: those living with HIV who could have been experiencing similar situations. The question of the
relation between the viewer and the photographer exceeds the borders of this thesis, but the question remains relevant.

The collaborators decided which memories and imaginaries explore, and in this sense, the collaborative *mise-en-scène* gave access to narratives and evocations of experience that were dependent on the collaborators’ agency and upon our continuous challenging of hermeneutic borders. This method does not operate as an independent system to draw upon memories as scientific evidence, but rather offers new possibilities for expression that could not be achieved through only using words or even with other visual methods. Their photos communicate in two formats that complement each other: images and words, which are in a relation of correspondence (and not of contradiction). The images are presented with these two depending upon each other, delivering a clear primary message to an audience who does not have to put together a meaning, but rather can reflect on the new ways of conceiving of the lives of those living with HIV. Words contest silence, and images make visible what was not seen.

As products of intricate relations, these photographs have to be seen in a complementary relationship with words, be it written as in the Photo Book and/or spoken and recorded as in the film, which, given the diversity of these different media, are able to convey particular aspects of the ethnographic context in a more comprehensive way.

These evocations are dependent on the ethnographic context in which they were produced, one which only exists in a specific time and space, in a continuous effort to engage in a non-hierarchical inter-subjective encounter permeated by trust. This process of production shapes the form, depth and expression of the photograph itself; but at the same time these visual artefacts are nuanced by ideas about who will see them (a potential audience); tensions with the past, present and future; and how this will remain as material evidence of a life that can make sense for others living with HIV.
Now, please watch the film on the link https://vimeo.com/267077601 (password HIV_2018), from which questions about reflexivity in film will be raised in the next chapter.
CHAPTER 4

‘The film is like a photo as well, because it reminds you who you were’ – Claudio Letelier, collaborator of this research

Through the hermeneutic reflexivity developed when creating collaborative photographic mise-en-scène, collaborators are able to create evocations of the past, present and future in the form of statements, from which emerge experiences and intimate reflections which also serve the purpose of opening up opportunities for dialogue with others. This indicates that through the creation of autobiographical photos in a collaborative context, people might use these evocations not only as a route for dialogue with the self (in terms of furthering a sense making exploration), but also in relation to an ‘audience’ with whom communication has been interrupted, denied or perhaps never existed.

In this chapter, I suggest that collaborative methods shape the way research outcomes are presented, in particular in the reflexive medium of the film, which emerged from our face-to-face ethnographic encounter in the form of a hermeneutic circle. In this context, my question is concerned with how reflexivity, which is central to our ethnographic dialogue, is used strategically in the film—by upsetting the ‘suspension of disbelief’—as a means of engaging in a critical dialogue with a wider audience. I suggest that reflexivity, as a form of hermeneutic enquiry in the context of film, can be a way of proposing questions which emerge from our practice in the field to a wider audience.

This idea echoes Jean Rouch’s statement that if visual anthropologists continue to hide without revealing aspects of themselves in their work, for reasons of science or ideological shame, ‘they will irrevocably castrate their films and doom them to an existence in archives, where they will be reserved only for specialists’ (1974, p. 43), which ultimately resonates with taking anthropological findings beyond the academic audience, so as to speak to a Public Anthropology. It can be argued that this idea speaks to a Public Anthropology and its ethical frame addresses problems beyond the limits of the discipline,
promoting ‘public conversations about them with the explicit goal of fostering social change’ (Borofsky, 2006)

The concept of Public Anthropology has been questioned because of its lack of recognition of the work of Applied Anthropology and its engagement with the participant community (Rylko-Bauer, 2000). Hymes (1969) suggested that the problem is not between general anthropology and fragmentation, but between a bureaucratic general anthropology ‘whose latent function is the protection of academic comfort and privilege, and a personal general anthropology, whose function is the advancement of knowledge and the welfare of mankind’ (p. 47). While it is not my intention here to engage with the discussion about Public Anthropology and/or Applied Anthropology—as labelling does not change the inspiration of my research—I use the term Public Anthropology since its scope of action is more explicit about fostering dialogue with the public, while Applied Anthropology is conceptually wider, and has a stronger focus on affirmative action and policy making.

But first, we should delineate what I mean when I refer to hermeneutic reflexivity in the context of film. For this, I will explore Jay Ruby’s understanding of reflexivity, analysing how it is used in ‘This is my face’ and for which purposes. Later I suggest that the film emerges from our ethnographic encounter within a collaborative framework, but offers access to the process as well as the ‘product’ (photos). The film complements an understanding of the process of photo creation, which is a central aspect of this interdisciplinary project, while at the same time it seeks to resonate not only in academia, but also reach a wider audience.

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92 In this chapter, I use the title ‘This is my face’ to refer to the film, and not to the whole research project.
1. Reflexivity in Filmmaking

Anthropologists have debated for decades about the relevance of ethnographic film, attempting to define styles of filming (avoiding cinematic strategies or not), scientific stances for visual anthropologists (discussions about focusing on whole cultures or on individuals), discussing its apparent lack of theory, among many other debates. Still today, ethnographic film seems to find resistance among some groups of anthropologists with ongoing debates about it; but also approaches which point to the particular contribution of ethnographic images (e.g. Henley 2000, 2004; MacDougall 1998, 2006; Ruby 1977, 2000; Loizos 1993; Banks 1992; Pink 2006, 2011; Grimshaw 2001).

Building on these discussions and attempting to expand on them, I propose a specific route of analysis, starting with Sarah Pink (2011) who suggested that images and films can never be purely ‘ethnographic’, but rather depend on how they are being seen and analysed by the viewer. While she is concerned about practices and specific ways of knowing through the camera within intersubjective encounters, she suggests that a particular attention has to be placed upon how images and sound are perceived and apprehend by the viewer. By ‘this broad and contextual definition of ethnographic’ visual material, she opens up the possibility for a range of different genres of video, film, photography and other types of images to be ‘ethnographic’ (2011), promoting a wider understanding of ethnographic materials, highlighting the relevance of how these are analysed and not only how they are collected and presented. Following her analysis, I suggest that for this visual material to be ethnographically successful, the audience has to engage with them critically, not only as a ‘product’, but also by questioning its process of creation. I suggest that by presenting a cinematic narrative on screen, but also by being reflexive about the way in which it was crafted, a form of hermeneutic reflexivity can emerge not only among collaborators, but also in relation to an audience.

Collaborative *mise-en-scène* seek to elicit reflexivity during the process of image creation, in the form of mutual questions so as to engage in an ongoing dialectic dialogue through
questions, part of our hermeneutic enquiry. In this way, we—as collaborators—engage in the process of construction of images increasing our mutual understanding of the world and of the creative process at hand. As part of that same process, in the context of ‘This is my face’, reflexivity is not produced by looking at images created in the past, or as an ex-post effort to convey reflexive aspects from the editing suite, or by watching a film and being reflexive about it, but rather as part and continuation of the practice carried out in the field as a form of continuous enquiry. Film, as a product that emerges from our encounter, looks at reflexivity from three main perspectives which are mutually shaped: the relevance of reflexivity in the context of film production, how film informs our hermeneutic enquiry to an audience, and how the film as a reflective artefact will foster future dialogue. In other words, how film informs and reflects our collaborative form of hermeneutic enquiry, and how it can strategically continue the aspiration of offering opportunities for new conversations.

As these elements are co-dependent, I argue that reflexivity in the film does not emerge—just as it doesn’t happen in photo creation—by looking reflexively at images at the end of the process, but rather as a constant research practice and can be extended beyond the academic territory so as to speak to Public Anthropology. During the process of photographic mise-en-scène creation we were not trying to foster conversational questions that looked for answers, but rather trying to open up a territory in which to initiate dialogues. In the case of the film, as in the exhibitions, interlocutors for these dialogues can be found beyond research borders, opening up routes for conversation with a wider audience, to which film reflexivity will speak by fostering a critical approach to what they are seeing.

Jay Ruby (1977) suggested that we are usually only presented with film as a product, by focusing the attention of the audience only on the story presented, and with no critical engagement with how that material was produced. In his text “The image mirrored: reflexivity and the documentary film’ (1977) Jay Ruby states that ‘filmmakers along with
anthropologists have the ethical, political, aesthetic, and scientific obligations to be
reflexive and self-critical about their work’, placing at the centre of their practice (and the outcome, the production) an engagement with what is usually not made visible: the process. Following Johannes Fabian’s diagram of producer/process/product (1971), Ruby suggests that filmmakers usually present us only with the product but fail to include the other two components, or simply decide to exclude them. For Ruby, given that documentary is not unbiased, neutral or objective—even though some still describe it in those terms—but rather a manipulation of a symbolic system for specific reasons, all who ‘mediate’ should make clear not only the ‘product’ but how specific questions and answers were formulated, and finally why the findings are presented in a particular way.

Ruby suggested that this mandate should include everyone who manipulates a symbolic system for any reason, and not only visual anthropologists: ‘I am deliberately using general terms because they serve to remind us that the issues raised are not confined to the cinema’, as a way to call attention to the process of production and the producers’ interventions.

Allen (1977) presents a more radical perspective about the need for film reflexivity, arguing that during the process of production, the ‘film’s manipulative nature’ emerges, and that can be contested with reflexive elements which can make the audience aware of its limitations with regard to document objectivity. For Allen, this is central as reflexivity becomes a reaction to counteract ‘the traditional mode of the documentary which emphasizes verisimilitude’ (1977, p. 37), and in virtue of this verisimilitude, many filmmakers prefer not to reveal how they created the film as it might allow access to unpolished parts of the process.

Ruby’s argument about the centrality of reflexivity in the visual and/or anthropological practices implies on one hand a continuous challenge for the ‘producer’ to examine and reveal methods, but at the same time, an implicit idea that the audience needs to be
‘awoken’ in order to engage critically with the film. For some, this might appear as dismissive of the viewer, but given that some filmmakers might want to make their films appear ‘transparent’—presenting it as ‘objective’—the relevance of reflexivity becomes central in reminding us about the craft that lies behind every ‘product’. I suggest that rather than being dismissive of the audience, films should be reflexive as the audience is never a homogenous group of people with the same kind of knowledge about cinematic craft, which becomes even more relevant when attempting to engage with academic and non-academic audiences.

On the one hand, reflexivity speaks to the ethical duty of visual anthropologists to be critical of her/his own work (Ruby, 1977), while at the same time, it provokes a narrative ‘disruption’ (as suggested by some filmmakers) which is a call-to-attention for the audience in terms of exposing and questioning the methods of production. I suggest that this reflexivity can upset the cinematic ‘suspension of disbelief’, promoting a more critical engagement with the process and producers of the film, that shape the way in which a film has been created. This type of reflexivity becomes key so as to engage in a dialogue in the form of a hermeneutic circle, in a way that poses questions that do not necessarily involve answers, but rather create an open dialectic engagement with the film, and what it as an artefact conveys about the world. This hermeneutic reflexivity is not an element that emerges at the end of the film production process, but rather is central to the way in which the ethnographic encounter took place and is a product of collaborative methods.

Even though being reflexive in anthropological films has become much more common in the last few decades, it is not a simple task for visual anthropologists. One of the tensions comes from maintaining a good balance between exposing methodological aspects behind the enquiry, while at the same time, not disrupting the narrative, even for an anthropological audience. Another important tension comes from the conventions of anthropological filmmaking and its aspiration to embrace a more credible approach, which limits explorations of exposing the ‘backstage of film’. But this tension with reflexivity
does not only concern anthropological films, but documentary films as a whole, in which—as stated by Ruby—the audience is presented only with a product, capturing their attention with real life stories, but hiding the process of the film production. The convention is towards an industry that still looks for others people’s stories and does not behave critically enough with its own production processes.

Due to this lack of continuous experimentation with how to reveal the process of production, reflexivity is still slightly limited to certain forms such as participants looking at the camera, researchers being filmed while they film, or ethnographers and documentary makers breaking the convention and appearing on camera, or their voices being heard as a voice-over. For Ruby, these are always deliberate decisions, with the purpose of expanding the attention towards more than just a central narrative, also engaging with the director’s intentions and what takes place beyond that controlled or uncontrolled diegesis.

2. Reflexivity as a Form of Hermeneutic Enquiry

Ruby’s idea of reflexivity does not simply refer to revealing the producer, process and product as a narcissistic operation, but as means of offering the audience a coherent unity between the three elements, and by that finding ways in which the audience can understand the epistemological stances from which those questions are asked, answered and presented (1977). Reflexivity in the way Ruby suggests, refers to an ethical frame that makes ‘transparent’ more aspects of the film to the audience. In this way the director proposes a cinematic engagement not only with the film as a ‘product’, but also with its ‘process of production’ and with the ‘producer’. From the use of reflexivity emerges questions of epistemological engagement and, as such, it is central to understanding what we are confronting as anthropologically valuable material. With the inclusion of reflexive elements we are able to begin to understand how the process of what we are presented with emerges, and how to engage the viewer in a more critical way, be the film
anthropological or not. This opens up vast possibilities in terms of how to present a film to an audience, both in terms of authorship and cinematic experimentation. It is an invitation for filmmakers to make ‘transparent’ the process to the audience, exposing vulnerabilities by opening ways of questioning the project, and its internal mechanisms of creation.

I suggest that is possible to expand beyond Ruby’s idea of reflexivity—as the practice of revealing coherence or incoherence between producer/process/product—and start to think about it as a space for provoking questions to an audience, by disrupting their experience of cinematic comfort. What I suggest here is that rather than trying to hide reflexive elements—or making them less disruptive—these elements have to be reiterated, so as to become part of the film’s unique grammar. This will speak to an audience from whom a more active engagement will be demanded, and opens up the possibility of merging critical but also empathetic borders with them.

This operation results in a film practice in which not only the audience will get to know the mechanisms of the film, but ultimately operates as a way to invite them to also be conscious about the way in which they are critically responding towards it. What takes place here is a relation in which not only an audience is watching the film, but the film aspires to reverse this directionality by looking back at the audience at the same time. In this way, the collaborators who are the ‘producers’ of the film expect to pose questions to the viewer, which lead to future dialogues about how to live with HIV in Chile, as a context in which life stories are silenced. This is a way of opening up opportunities for conversation, creating spaces for further investigations and understandings. Reconsidering Irving’s idea of ‘attempting to reach across a hermeneutic divide during fieldwork’, but in this case applying the concept in relation to film, we can see that the film also ‘opens up the possibility to provoke movements in perception, personhood, and understanding in which someone comes to the realization that life can be seen, felt, and known from another perspective’ (2017, p. 98-99)
Building on this idea of film reflexivity as an attempt ‘to reach across hermeneutic borders’, I will attempt to further reveal how through reflexive elements, the film not only informs us about aspects of its production process, but is also shaped by this encounter, as a tool to open up possibilities for dialogue with others. By exposing strategically how the film was crafted, the audience can engage with the film’s content from a more informed stance about methods, and from there, analyse its ethnographic data and social implications. I will address how reflexivity is conveyed not only from the editing suite, but as a continuous practice that concerns myself, as filmmaker creating a cinematic *mise-en-scène*, as well as the collaborators in the way that photographic images were produced as *mise-en-scène*. The film reveals anthropological findings in relation to HIV and the use of visual methods as autobiographical investigation but also speaks to an audience as a product shaped by negotiations in the field, relations and common aims.

I propose that film can be a tool for hermeneutic reflexivity conveying material from the field as a result of this specific intersubjective encounter and its negotiations, while at the same time being shaped by elements that emerge from its collaborative origin. From an epistemological perspective, what emerges from the film as product of the practice of hermeneutic enquiry is the possibility for further dialogue and discussion, opening up a territory in which further questions can be asked, ultimately expanding upon understandings of the world.

3. Reflexive Elements of Film Grammar

When creating a *mise-en-scène*, the director makes visible (Cook, 1980; Thompson and Bordwell, 2001; Corrigan and White, 2012; Milligan, 2016) certain elements as part of a *diegesis*, as in the case of the collaborators’ photos. By doing that, the director is using her/his power as a form of authorship in order to make visible some elements, and not others, to the audience. In the same way, the film you have just watched is a *mise-en-scène* in itself in terms of its thematic unity; or a series of *mise-en-scène* from the
perspective of each collaborator and each photo. You as the viewer are presented with some elements and not others, accessing situations from a specific perspective, listening to intimate reflections and not others, and so on; and therefore your understanding is mediated by the film, as also happens in ethnographic photography and ethnographic texts.

I suggest that the way the film is presented in its reflexivity is not only the filmmaker’s decision but also emerges from the ethnographic encounter and the relations created in the field. In this way, one of the most relevant elements is how the film’s reflexivity looks back at the collaborative aspect, or in other words how the collaborative character becomes one of the main reflexive references within the film. The way in which we worked while in the field shaped the way the film was presented, and from there emerged main aspects of the film’s reflexive grammar. In the following sections, I will rely on some ethnographic vignettes to unpack this point further.

3.1 Mirroring *Mise-en-scène*

We were five blocks away from Diego’s last photo location, at *Academia de Humanismo Cristiano* University. While listening to Diego talk about the details of this last *mise-en-scène*, we—the film crew—started to unpack the gear. Diego wanted to create a self-portrait just after enrolling into college, to reflect on HIV as an opportunity to imagine new futures. We discussed the film sequence, in which we would follow him as he completed his registration process: it would start with Diego walking to university, paying his fees, getting enrolled, and finally, taking the picture of him outside in front of the university. Our technical gear was ready, Diego checked he had all the documentation needed, hung the camera on his shoulder and looked at us saying: ‘OK... Action!’ At this point, we were working with photographic and film creation in parallel and intertwined: the actions leading up to his photographic *mise-en-scène* were also the ones we would record to produce visual material for the film.
The chronology of events Diego imagined (walking, enrolling at university and then taking a photo of himself as a new student) would guide the *mise-en-scène* creation, but even though the photographic image portrays his new status as a student, it doesn’t make visible the whole creative process from which that image emerged. The film sequence followed Diego’s actions as planned and reveals the way the photograph was created as well as his reflections, which convey to the audience a moment in which his life changed. (Film timecodes from 00:45:59 to 00:49:16).

By deciding on their photographic *mise-en-scène*, the collaborators were also deciding upon many of the sequences of the film, and what they would say and how they would be seen. In this way, decisions about the photographic *mise-en-scène* directly affected the film.
Still Image 2. Diego looking through the camera, finding the angle for his photographic *mise-en-scène*. Snapshot from the thirteenth sequence of ‘This is my face’ (timecode 00:48:21)

Still Image 3. Next shot in ‘This is my face’ (timecode 00:48:51). Diego moved in front of the photographic camera and is waiting to be photographed. As can be observed, the film camera does not necessarily face the same direction in which the photographic lens is shooting. The two *mise-en-scène* have elements in common, but are different in their competences and in what elements they convey.

Both *mise-en-scène* shared the same protagonists, location and props, but had different objectives: while the photographic camera was looking at evocations of past and future, the film examined how this process of representation was carried out. The photograph in
this case is a visual statement about a moment in the life of the collaborators, while the film evidences the process within which it was made visible and audible for others. In this way, both mise-en-scène emerge from the same collaborative ethnographic context but due to the competences of each media, each mise-en-scène conveyed different aspects of the same encounter. While the still image makes visible an evocation which emerged from a process of mise-en-scène creation that has to be imagined by the audience, the film makes this process visible and audible.

The two kinds of mise-en-scène shared many elements and mirrored each other, but they also furthered the research, allowing the collaborators to have a more active role in the film part of the project. Given this context, Diego giving us instructions about when to start filming was no surprise, and evidenced how the two creative processes were intertwined. Photo and film were part of the same investigation, with cameras as the mechanisms which elicited questions and interactions about the same subject, in order to discover meaning within the images produced. These images as objects of enquiry allowed us to ask questions, not about the events to which they referred, but rather about how we would arrange them as a form of representation (in the case of film) and as evocation (in the case of the photograph).

The elements that constitute the construction of these images are visible in the film. The viewer sees Diego walking towards University, being enrolled while we hear his voice explaining why that moment was important for him, but the audience can also listen to Diego talking to us behind the camera and see me emerging to help him with the making of the photograph (Film timecode 00:48:12 – 00:48:40).
My emergence from behind the film camera does not appear as a narcissistic exercise, but rather as an action demanded by what was taking place in the scene; and it was repeated during the film at many times, becoming part of the way to expose how the photographs were created and who was controlling the *mise-en-scène* of the film. These elements emerged from what the photographic *mise-en-scène* creation required, and are captured by the film with the camera not trying to hide my intervention, but rather revealing it. In this way, the film expands the understanding of the process of creating these photographs.

### 3.2 Upsetting the Viewer’s Suspension of Disbelief

Given that the instructions for the photograph also formed part of the directions for the film sequence, the film followed the logic of the photographic *mise-en-scène* in that there was not just one director but rather a plurality of voices engaging in the process. While the collaborators provided the sequence of actions, the film crew decided from where to film, what to film and eventually how to proceed with that in the editing process. These are sequences that emerge from the photographic creation, and converse with the
collaborators’ ideas of how they want to be seen by an audience, shaping the way the film is structured from pre-production to post-production. As a consequence, the audience are given access to how the cameras are involved in our encounter and how we negotiate and design the visual investigations.

This follows Pink (2011), who says that to be reflexive ethnographic video makers, we need to ‘be aware of how the camera and video footage become an element of the play between themselves and informants, and how these are interwoven into discourses and practices in the research context’ (2011, p.5). The film not only makes visible their photographs, but revealed that the collaborators were the ones to decide which moments they wanted to photograph and the negotiations that took place around that creation. Due to working in collaboration, these negotiations were relevant so as to emphasise it was a conversation about methods.

For example, in the first sequence with Miguel Angel (Film timecode 00:09:40 – 00:13:33) where he wanted to pass me the photographic camera so I could decide the photographic shot for him. As seen in Chapter 3, this dialogue was part of a process of appropriating methods and promoting a sense of authorship regarding the autobiographical images; and as this was his first photograph, he was still not sure how the process would take place. This was an integral part of the methodology of the project, and the film responds to that uncertainty as the audience can hear my voice saying he is the one who needs to make the decision about the shot (Film timecode 00:11:58 – 00:12:22). The film image becomes a bit unpolished and I appear on camera pressing the button for Miguel, once he’d decided from where and how to take his photograph. My appearances—either through sound, image or both—are a continuous occurrence in every sequence throughout the film; and by that continuity and coherence, it becomes part of its internal visual grammar. The following snapshots are just a few examples of reflexive shots in the film, in which the
way our dialogues and relations shaped the way the images produced were made explicit to the audience.

Still Image 5. From the sixth sequence of ‘This is my face’ (timecode 00:21:00) working with Claudio on his photo about not hiding his HIV status anymore.

Still Image 6. From the seventh sequence of ‘This is my face’ (timecode 00:22:18) in dialogue with Oscar, who was arranging his photographic mise-en-scène about his relation to antiretroviral therapy.

93 For more please refer to the following Film timecodes 00:02:14// 00:09:15// 00:11:58// 00:12:38 // 00:17:20// 00:20:32// 00:22:00// 00:27:35// 00:35:49// 00:41:11// 00:45:31// 00:48:11
Still Image 7. From the fourteenth sequence of ‘This is my face’ (timecode 00:53:28) when Diego read a letter at the exhibition and referred to our dialogue while creating the photos.

For some filmmakers the inclusion of reflexive shots can be a complicated task as it disrupts the narrative flow of the film. For example, when analysing his work with ethnofiction in Brazil inspired by Jean Rouch, Johannes Sjöberg suggests that the reflexive material he filmed was hard to include in postproduction: ‘these reflexive shots did however prove to be difficult to include in the narrative when I returned to the editing suite. I realised that these reflexive scenes broke the narrative, and jogged the spectator out of the story’ (2008, p. 238). This resonates with Siska’s (1979) statement about how some reflexive techniques ‘mount an attack on our empathy by under-cutting the "reality" of the characters and actions within the film’ (p. 286). However, Siska recognises that these shots also cause disruption; they serve the purpose of ‘unmasking’ the illusion. Davies suggested that ‘no process is fully reflexive until it is explicitly turned on to the knower, who becomes self-conscious even of the reflexive process of knowing’ (1999, p.7), in this case the way in which the film was produced. Therefore, exactly because reflexive shots break ‘the illusion’, they also provoke a certain distance from the film, upsetting the ‘suspension of disbelief’, and opening more opportunities for the audience to scrutinise what they are seeing.
In this context, reflexivity elicits a particular form of engagement with the film presented. On the one hand, reflexivity satisfies the duty of the visual anthropologist to be critical of her/his own work (Ruby 1977); while at the same time, rather than only provoking a narrative ‘disruption’, offers an attention-call to the audience to engage in a critical sense, not only about the story crafted by the filmmaker, but as a way of being analytical about the way the film was created and the context in which that story is embedded. I suggest that the disruptive element that ‘reflexivity’ brings to the film unsettles the ‘suspension of disbelief’, with the audience asking not only about the coherence between producer/process/product, as suggested by Ruby, but also about how the film is embedded within a wider cultural context, and their ethical position regarding what they are seeing. In other words, reflexivity disrupts certain assumptions about the film’s objectivity, inviting the audience to engage with the ‘product’ from a more active stance, as critical agents.

‘This is my face’ does not hide the process of the mise-en-scène production but reveals it, even though this might obstruct the narrative flow. However, there are some particularities with regards to this project that facilitated the inclusion of reflexive elements. In this research, the film camera does not operate as the main form of enquiry, as it is the photographic camera that is symbolically eliciting questions from the collaborators with regards to their autobiographies. By this, the presence of the photographic camera reminded them of the purpose of our investigation, and in opposition, the film camera does not invoke all the tension of the enquiry in symbolic terms. The collaborators’ main focus was in relation to the photographic camera, which diminished the tension that a film camera usually brings to the field, and as a consequence they were focusing on the scene they were creating much more than on the scene being created for the film. By releasing that tension in part, the division between being in front and behind the film camera becomes less rigid, and reduces the tension in our interactions.
At the same time, we were all collaborating on the project with our priorities focused on the photo-creation; even those of us involved in filming took active part in the photographic process. In this way the ethnographer is not only behind the camera as the observer and creator of a filmic *mise-en-scène*, but is also there taking active part in the photographic actions. Therefore when the ethnographer appears on camera, they are doing so as a way of collaborating in the photo-creation, and as a consequence, they might break the convention of not revealing the space behind the camera. The spectator is confronted with a film in which they can hear and see the individual behind the film camera, and they are reminded of how that subjectivity mediates what they are seeing in every sequence.

Ruby suggested that to be reflexive is to reveal ‘that films, all films, whether they are labelled fiction, documentary, or art are created structured articulations of the filmmaker and not authentic truthful objective records’ (1977, p. 10). In this way, with the consistent emergence of the ethnographer into the film *mise-en-scène*—and its subsequent inclusion after editing—the ethnographer is constantly reminding the viewer about her presence as mediator. As occurred in the photographic *mise-en-scène* which emerged from our encounter in a specific collaborative ethnographic context, the film *mise-en-scène* also emerges from a collaboration.

The intervention of the ethnographer on camera (through sound and/or image) is different than in other works with reflexive elements, i.e. what can be seen in Jean Rouch’s films, in particular his film ‘Chronicle of a Summer’ (1962), where reflexivity is more carefully crafted. Rouch, who was a great innovator in the development of reflexivity in film, used reflexivity to meet different ends, as he was using filmmaking as the catalyst for his ethnographic research as part of his ‘Shared Anthropology’. By using the camera as catalyst, he focused the tension on the film camera, and every break in convention had to be more cinematically crafted. In our research, film is not used as a catalyst for the bringing about of narratives, but is a technology that mirrors the
collaborators’ photographic practice, and through this they can control to a certain degree the film camera through the photographic *mise-en-scène*. Film, in this case, converses with the photographs from the perspective of the ethnographer who was taking part in that process not just as observer, but as active participant, and as a result, any breaks in film convention do not dramatically disrupt the narrative.

4. Reflexivity and Collaboration

The aspiration of disrupting distances between subjects and the visual anthropologist—as a way of upsetting hierarchies and recognising each other as ‘collaborators’—involved continuous efforts to unsettle power in our relations. From the beginning of the fieldwork, while I was conducting participant observation, I was not only becoming part of the collaborators’ world(s), but also trying to make them part of mine: I was sharing time with them, but also with their families and friends, in the way that they were sharing time with my loved ones. As I had access to their life stories, they also knew mine as my chosen field-site was also the place I come from.

At times, this process was not easy or even that comfortable. In particular, during the production of the first photographs, when they did not feel at ease handling the camera and making decisions about their *mise-en-scène*, I continuously gave the camera back to them, and repeated that they were the ones in charge of those decisions. This happened not only because they were not used to handling a camera (throughout the process the device was always on automatic), but because the act of making decisions unsettled the power dynamics they had foreseen in our relationship.

Sjöberg (forthcoming) has highlighted the adequacy of the concept of ‘negotiation’ when referring to fieldwork as a way of making transparent ‘the intrinsic power relationships of the intersubjectivity’: ‘This term recognizes the integrity of the fieldwork informants and signals the inherent conflict that can arise in a fieldwork situation’ (forthcoming). The
acknowledgement of ‘negotiation’ as an integral part of fieldwork is especially pertinent for Sjöberg when dealing with documentary filmmaking and its potential to infringe upon the integrity of the ones represented. In this context, efforts to dislocate power became relevant not only in terms of negotiations in the field, but also when crafting outcomes such as the film and exhibitions.

These efforts required a coherent and flexible practice, which was relevant in terms of promoting a less hierarchical engagement with hermeneutic reflexivity. This particular dialectical relation became more fluid as power dynamics challenged the status of researcher-subject and increasingly turned into face-to-face negotiations, involving the collaborators in the process of filmmaking, negotiating permissions to film or proposing ideas for shots.

Even though they were not behind the camera, their participation in the filmmaking process was engaged, and they decided to take on roles in the production of our cinematic mise-en-scène. This is why, at the end of the film, the audience do not read a list of credits, but rather a list of collaborators (00:58:15 – 00:58:23). Through this, I am not denying my power as a filmmaker, but rather convey the idea that during fieldwork the film became a common project over which I could not claim all creative developments, as I will expand upon in the following sections.

Before starting the filming of each sequence, the collaborators informed us (the film crew) about the sequence of actions leading to the photographic mise-en-scène, and from that perspective, the film depended on the photographic mise-en-scène creation. The decision of where and how the film crew would move followed the chronology of actions decided by the collaborators, decisions which we might adjust from a technical perspective. In this way, the collaborators defined the internal structure of the film sequences, and the lines between photographic and film mise-en-scène were even less fixed. This level of collaboration exceeded what I predicted at the start of the fieldwork. As mentioned
earlier, at the beginning of the process, those behind the photographic camera struggled to think visually and weren’t sure about how our practice would take place (see Chapters 2 and 3), therefore their collaboration in the final part of fieldwork (indicating when to film, suggesting shots, helping us carry the gear, gaining permissions for us to film, among other things) indicated that the project moved from being an ´invitation´ for someone to take part in it, to something which they felt responsible for.

Throughout the process of filming, and as seen with the creation of the photographs, the collaborators considered an imagined audience to which they could project their stories (see Chapter 3), and in a context of silence and invisibility (see Chapter 1) the success of the film was crucial. The collaborators understood that the photograph creation focused on their autobiographical investigation and culminated with the creation of still images, while the film was concerned with making visible the process, and in this way, the two complemented each other: the film depended on the photo creation, but the understanding of the photograph as a process relied on the film. At the same time, the photograph and film were used as platforms for images and words, directly contesting silence and invisibility.

During fieldwork, the project went from being collaborative in its methods, to becoming collaborative in the way it was continually re-conceptualised, as we had different purposes towards reaching the same outcomes. While mine was mostly academic, theirs was linked to a making sense and creating a new platform on which to be heard and seen: during fieldwork these met in a common project. The photographs made visible the evocations of their autobiography through specific routes: we started with two exhibitions and after the fieldwork was finished, they organised another two in their community centres. The film has other routes of dissemination and offers a different experience to the audience: it has been screened for small audiences so far, and we are organising a premiere in Santiago, to later screen it in festivals and circulate it online.
Reflexivity is a consequence of the way in which we worked collaboratively—a horizontal relationship which implies less control from the ethnographer—and as such, reflexivity moved in unexpected directions. Towards the end of the film, in the sequence of the exhibition (00:51:59 – 00:54:20), Diego reads a letter in which he refers to the film crew as the people who ‘asked me to repeat part of my life’, and how that made sense for him through practice. Through this, Diego also reveals the methods through which the film emerges: he is not only exposing us to the audience in the exhibition room, but is also calling attention to the film audience in the ways in which this film was created.

As a result, the reflexive aspects of the film emerge through our interactions (which aspired to being horizontal and collaborative) and unsettle the ways in which reflexivity is usually presented: from the back of the camera to the front, from the director and not from the participants. Being reflexive is a consequence of how we engaged during the field, and is also expressed in different directions as we all took an active part in the filming. In ‘This is my face’, reflexivity doesn’t have just one direction, or only come from the voice of the director, as the power dynamics are, to a certain extent, challenged, and the roles and boundaries less fixed.

5. Limits to Collaboration

Although the level of collaboration exceeded what was expected during the filming, many elements made it difficult to maintain this during post-production. The start of editing coincided with my return to the UK, and geographical distance became a difficulty when trying to keep a high level of collaboration. The dilemma of how to sustain a steady commitment with the project when new conditions arise—such as distance or time constraints—is an aspect I underestimated.

Before my departure, I asked collaborators to identify if there was any part of the filmed material they did not want to appear in the film, but all said they were satisfied with the
rushes they had seen. I asked for specific ideas on how we should edit their stories and whether they were willing to be actively involved in the editing process. Diego and Claudio said they would like to, while Oscar and Miguel were more reluctant to take part, and limited their availability within the process.

Despite their different stances, I sent them all an initial written version of the script, and waited for their responses, but with no luck. I thought perhaps the written words did not appeal to them, and tried with images by editing a first version of their sequences and sending it to them. This time Claudio and Diego replied saying they were happy with the sequences they watched, but didn’t provide ideas about how we should move forward with the process. It became clear that with our displacement in space, the particular kind of relationship we’d shared in the field—one based on face-to-face collaboration—had been disrupted and needed re-adjustment.

The fact that the documentary film could not be as collaborative during editing reveals that many elements need to be considered when attempting a project such as this. Considerations such as geographical limitations, the duration of the project, time constraints, and transitions from one media to another (in this case from photographs to film), became relevant when carrying out this research. Working collaboratively is not only methodologically challenging, especially in terms of managing relationships with the collaborators, but it also demands an active engagement with the project. To work within this framework implies pushing the limits of roles and responsibilities, pushing the dichotomy of researcher-informants and its associated hierarchies, and at the same time demands flexibility when collaboration needs to be re-adjusted.

For example, when the collaborators didn’t answer their emails or didn’t provide detailed input, this did not mean they were no longer interested in taking part in the project. After talking to them, it became clear we had to accommodate our work system to adapt to new circumstances and the limitations of time and geographical distance.
Collaboration is not a methodological framework that attempts to establish relations within a utopic relation of equal commitment and unproblematic relations of power. On the contrary, it demands constant negotiations in the form of everyday efforts to dislocate power dynamics, involving patience, flexibility and translation into other modes and formats, from all those collaborating. It responds to the aspiration of working together from a particular set of ethics in which hierarchies are challenged and roles are not totally fixed, offering the opportunity to those involved to bring experiences and knowledge together, and giving meaning to a collective effort, in which a sense of authorship is shared.

Inspired by Jean Rouch´s idea of screening back the film to the participants, I sent the collaborators a first cut, as editing time was running out. Although I didn’t intend to record their feedback as a form of gathering ethnographic material (as Rouch did), it was an opportunity for them to see the material before anyone else. At that point, our collaboration took place over the phone, via email and all sorts of other digital forms of communication, and therefore the film you have seen was not only seen by them, but emerged from our conversations during fieldwork and after it. These are extracts taken from their verbal feedback:

‘It made me emotional, to see all that have gone through and I think it can be useful for others’94 – Oscar (13th October 2017)

‘I feel proud of having gone through all that. With time, all my experiences from that period make much more sense’95 – Diego (14th October 2017)

‘I think it shows really well what we went through, in our individual paths with the project’96 – Miguel Angel (17th October 2017)

‘I look at myself in the film and realise how far I’ve come. The film is like a photo as well, because it reminds you who you were’97 – Claudio (14th October 2017)

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94 ‘Me emocionó ver que todo lo que pasamos es una historia que le servirá a otros’
95 ‘Siento como orgullo de que hayamos vivido todo eso, porque con el tiempo me hace cada vez más sentido haber pasado por allí’
96 ‘Yo creo que muestra muy bien lo que vivimos todos, en nuestros caminos individuales con el proyecto’
As has been suggested by Rouch, getting involved with participants and dislocating the hierarchies and limits inherent in anthropology for such a long time has become a ‘stimulator of mutual awareness (hence dignity)’ (1974, p. 44). In this way, engaging with many voices in a non-hierarchical encounter can expand the borders of the project or even move beyond them. This can be observed when understanding that even though the collaborators had less of a presence during the editing process, they were taking the project a step forward on their own terms: Miguel Angel and Oscar took the photographic exhibition and presented it to their organisations, while Diego and Claudio ran a series of workshops with serodiscordant couples using photography as a tool to tell their stories. They had taken the project and made it their own, evidencing their active commitment with what had been created in collaboration and what was learned from it.

6. Beyond an Anthropological Audience

As suggested earlier, the creation of a film with consistent reflexive elements is not an ‘accident’ of editing, but rather the result of planning in order to make the film ‘transparent’ to the audience by revealing the process and producer (Ruby, 1977). The way that ‘This is my face’ (in its film form) was crafted is the product not only of my decisions as a visual anthropologist, but also of the ethnographic negotiations with collaborators, and therefore is permeated by that inter-subjective encounter. In those encounters, what emerged were more than questions about how to create the mise-en-scène, but also questions about what to do with those images once they became objects that could be seen by others, which also shaped how the reflexive aspect was crafted. Therefore I suggest that reflexivity is formulated not only as a cinematic exercise of ‘transparency’ with the audience, as defined by Ruby, but it also responds to other itineraries and intentions, beyond revealing methods and producers.

97 ‘Me miro allí y me doy cuenta todo lo que he avanzado. El documental es como una foto también, porque te recuerda donde estabas’
When we discussed how to frame the outcomes of the project (in the exhibitions and documentary film), it was agreed that we should try to reach a wider audience, in order to convey a deeper understanding of the particular difficulties experienced by people living with HIV in Chile, and by that promote a dialogue about a topic that had not yet been properly addressed in that country. In order to reach this wider audience, the exhibition and the film had to be presented in a way the audience could not only understand, but also engage with and question. This reveals that collaboration is not only an ethical frame that informs fieldwork from an academic perspective, but also permeates the design of research outcomes in dialogue with the concerns of the participants.

This is why, for the exhibition, the texts that accompany the pictures were personal and accessible accounts about the events that inspired each photo. The exhibition was not focused upon the photographs from a technical perspective, but on conveying the potentials of this visual tool to work on life events from a reflective perspective within a collaborative framework. In this way, visitors at the exhibition were able to approach the images and text together, learning about their life experiences and the methods that informed the creation of those photographs simultaneously.

In the case of the documentary film, we worked with the same objective of reaching a wider audience by delivering a visual work that promoted a reflective approach to their stories. This permeated the way the film was assembled in the editing suite, as a continuation of the work we carried out in the field. There are some codes in the film you might have recognised as not being part of the standard of ethnographic filmmaking, such as the use of music, or a more active filming style that does not rely on fixed observational shots, which serve the purpose of reaching beyond an academic audience, while promoting a critical engagement with methods through the constant use of reflexivity. A chronological narrative structure that unfolds, with an active editing pace and an attractive visual style were some of the strategies used to make visible life experiences and ways of knowing; which follows Rouch’s understanding that ethnographic film should
be created for the largest possible audience (1974). Rouch asked himself ‘for whom and why we create ethnographic films’, and suggested that it is ‘absurd’ to condemn ethnographic film to a closed information circuit, such as merely to university networks or scholarly societies: ‘the time has come for ethnographic films to become films’ (1974, p. 43). Rouch’s idea that films could surpass the boundaries of academia, and be seen by many others, has also been the purpose of this project, as a way of promoting dialogues that more fluidly connect academia and society, and which speak to Public Anthropology. This aspiration emerged from our encounter in the field, which encouraged dialogue as a way to promote social change, as suggested by Scheper-Hughes: ‘If anthropology cannot be put to service as a tool for human liberation why are we bothering with it at all?’ (2009, p. 3).

Film reflexivity as a way of looking back at the audience, reminds the viewer to take a critical position towards what they are seeing, not only in reaction to scientific methods, but also in terms of the stories the film offers to the audience. Reflexivity invites a critical stance, but the angle from which this emerges depends on the subjects who are part of the audience; in this way, the viewers engage with the film from their own subjectivities, which cannot be fully controlled by the filmmaker, but only provoked. If the filmmaker is successful in her/his attempt, the audience would be able to engage in a dialogue from the academic to the social and vice-versa, expanding understandings of what people are living through and how they make sense of their lives.
SUMMARY AND CONCLUSION

The written outcome of ‘This is my Face: Audio-visual practice as collaborative sense-making among men living with HIV in Chile’ has introduced and analyzed the use of ‘collaborative mise-en-scène’ through reflexive film and photography practices, as a methodological tool to promote further sense-making of a biographical disruption. Collaborative mise-en-scène refers to the inter-disciplinary research method that promotes reflexivity during the creation of photographic images in which collaborators explore life experiences, while the researcher creates her/his own mise-en-scène about the collaborators’ process of autobiographical investigation.

These mirroring practices promote a mutual engagement of mutual question as a way of eliciting reflexivity about the images they are producing. In this way, collaborators engage in the process of autobiographical image-creation and ask questions of each other about the expressive coherence between what they want to convey in the photograph, and how that is being translated to the arrangement they are creating. The centrality of recurrent questions underlines the fact that the mise-en-scène they are producing, and the photograph that emerges from it, are not produced by random actions, but rather they are confronted with the distinction between ‘making’ a photograph and ‘taking’ one. By promoting this reflexive approach as collaborators, this method highlights the importance of a specific type of hermeneutic reflexivity as central to the whole process, not simply an ex-post practice in the context of interviews or film production.

The use of reflexivity and a sense of authorship were also promoted by the inclusion of some basic elements of Aristotelian poetics (plot structure of beginning-middle-end) and the Russian formalist practice of estrangement (Shklovsky, 1917), which ultimately facilitated their transition from ‘protagonists’ to ‘directors’ of their own representations.

98 Which follows Ansel Adams’ idea that you don’t take a photo, you make it (quoted in Jaar, 2016).
From our combined practice in the field emerged two exhibitions (one in Santiago, and one in Manchester), one feature documentary film, one Photo Book and this written text.

In this text, I presented how people living with HIV in Chile confront stigmatisation as a fundamental part of their lives. In order to understand this ‘biographical disruption’ (Bury, 1982) which is described by them as a ‘fracture’, they engage in inter-subjective encounters in order to make sense of what they are going through after diagnosis. Given the persistent occurrence of stigma, the assessment of its potential emergence becomes an everyday practice, a way of attempting to control, as best as they can, the consequences of disclosing or even talking about HIV. In this way, men living with HIV in Chile engage with other peers in conversations in which they share experiences and reflect on them, as a practice of simultaneous collective and individual learning. However, given the acceptance of stigma in Chile, and the lack of support from the authorities beyond biomedical considerations, people living with HIV have limited spaces and opportunities at their disposal through which to socialise and understand the impact of their biographical disruption.

In their encounters, they are sometimes confronted with the insufficiency of words in expressing what they are going through, as many of their experiences deal with suffering or trauma from life events that are beyond comprehension (Caruth, 1995; Gilmore, 2001). Despite the success or not in expressing their experiences in words, these remain ‘central to all social life’ (Irving, 2007) and therefore relevant but methodologically challenging for anthropologists. I conducted an initial period of participant observation while looking for potential collaborators, which allowed me to identify the centrality of inter-subjective encounters in terms of creating experiential and reflexive knowledge to make-sense of their biographical disruption.

After that initial period and departing from Irving’s idea of creating new forms of collaborative research when attempting to understand the experience of illness (ibid), we
began to finally explore visual representations of experiences. In this context, the use of collaborative *mise-en-scène* was informed by participant observation, but also has an interventional character: by promoting further reflection and sense-making through the use of visual means, this provided further possibilities for their expression and investigation, and eventually dislocated the limitations of talking about HIV in only a few select places.

Sense-making in the field of social cognition is understood as the ‘creation and appreciation of meaning’ (De Jaegher and Di Paolo, 2007, pp.488), which emerge as a consequence of continuous reflection and adjustment in relation to the self and others. Departing from this definition, sense-making is conceptually framed for this project as the creation of meaning in the form of understanding and re-signifying life events in the context of a life history. This project attempted to expand the usual conditions for sense making, by providing visual means as opportunities for expression and reflexivity about their autobiographical accounts, and also by the creation of an ethnographic context that facilitates the emergence of life narratives and its investigation.

From conversations with the collaborators, in particular from the first workshop organized for this project, there emerged a personal and collective analysis of how they make decisions about disclosing their status to others (even others living with HIV), and the tactics used to manage the tensions that come with disclosure.

From this workshop varying perspectives also appeared on how to create trustworthy accounts, from which the idea of speaking to an audience was discussed and reflected upon. This intention of speaking to a wider audience is informed by ethical considerations about how they could consider the research as an opportunity to challenge misconceptions about HIV, in which personal and political implications were entangled.
In the workshop, we engaged in a continuous dialogic practice in the form of mutual questions, from which they decided which events they wanted to work on and how they wanted to represent them. But our practice also became a kind of negotiation about the shape of the research; which emerged when discussing what autobiography meant to them and how they wanted to address it in the context of narrating their own experiences. From here, we attempted to reach across hermeneutic borders, in the Heideggerian sense, so as to promote reflexivity and a sense of authorship, and as a way to dislocate power in the context of our practice. The practice of hermeneutic reflexivity was an element shared by all collaborators (both researchers and participants) as opposed to the more orthodox unidirectional practices (from the researcher) which highlights that sense-making emerges partly out of the practice of expressing, questioning and re-signifying.

These mutual questions, as a practice-based form of hermeneutic enquiry, became the main way to foster reflexivity while being engaged in the process of creating collaborative *mises-en-scène*, through which they ‘made’ photos, rather than simply ‘taking’ them. Collaborators were able to take control of their *mise-en-scène* through the articulation of the Aristotelian beginning-middle-end, and in the practice of ‘making strange’ or ‘*étrangeté*’, a term coined by Shklovsky (1917) as a way to disrupt familiar relations with objects, places and people. This disruption of ‘everyday familiarity’ allowed them to think about the elements they wanted to include in their photographs as ‘signifiers’, rather than as mere objects of their everyday life. In this way, the collaborators approached life events from the perspective of being the directors of a *mise-en-scène*, rather than directly confronting the memory of that event.

By having a collaborative and experimental character, this practice-based research was open to continuous adjustment and negotiations, using mutual questions as tools for promoting a form of hermeneutic reflexivity. In this way, the creation of a specific type of ethnographic context and relationship was fostered, not only to promote the emergence
of narratives, but also to shape the practice by discussing the components and arrangements of the images.

Through our mutual questions, while engaging in the collaborative *mise-en-scène* creation and the experimental character of our investigation, the collaborators expanded the method beyond the initial aim of this project: to offer possibilities for an exploration of autobiographical self-representation. Instead of representations, what emerged were evocations of experiences located in the past, present and future, in the form of statements (Radley, 2010) about what it means to live with HIV for the collaborators, in which memory and imagination emerged as ‘physical partners’ (Casey, 1976).

During the creative process, the collaborators appropriated methods and reshaped their practice as a means of taking their images beyond the relation that took place during the photo production, and open up a dialogue with their loved ones, others living with HIV, and the general public. In this way, their *mises-en-scène* are products of complex interrelations between memory and imagination, and between themselves and others as statements about a life history that look not only at past experiences but also re-shape meanings so the process of creation ultimately becomes a new experience.

The relation of film and photography offered the possibility of engaging in visual practices that mirrored each other by sharing the same objective: to create images about their autobiographical investigation. Photography and film bring to the project their specific media competences, in relation to the context and the purpose with which we were using them. While photography was the tool for autobiographical investigation, film was the media for investigating the process in which the photo was created and embedded.

As a product that emerged from our hermeneutic and reflexive encounters, the film reveals aspects of the process of production in which those photos were created, in which the collaborators dialogue revealed not only a product, but also the film’s producers and
its process of production (Ruby, 1977). This idea of reflexivity was pushed beyond Ruby’s definition of the term, underlining the presence of a specific film grammar that upsets the audience’s ‘suspension of disbelief’ as a way to engage and propose questions to an audience. In this way, reflexivity in the context of film is not an ex-post activity exercised from the editing suite, but rather is a continuous practice that starts in the field and projects its question beyond ethnographic encounters.

The film is not only informed by our practice of hermeneutic enquiry, it also shapes the way in which the film was shot and edited, giving a wider audience access to the process of creating the photographs and film. Informed by our practice and following Pink’s (2011) idea that images and films should not be restricted by an ‘ethnographic’ category, but rather that the character ought to be determined by the viewer, the film attempts to serve as a platform to initiate dialogue and does not restrict itself to a specific anthropological category.

In this way, the use of particular cinematic techniques and reflexivity in the film follows Rouch’s ideas about the need for ethnographic filmmakers to reveal themselves in their work and not ‘doom them to an existence in archives, where they will be reserved only for specialists’ (1974, pp.43). This speak to ideas of Public or Applied Anthropology, and their intention of disciplinary and academic breaching so as to ‘foster public conversations about them with the explicit goal of fostering social change’ (Borofsky, 2006), as well as to Participatory Action Research (Fals-Borda, 2001) which aims to ‘articulate knowledge production and transformative action’ (Johnson Martinez Guzman, 2012, pp.405). These ethical considerations become much more relevant when conducting research with people who are in difficult conditions, as their narratives and understandings of the world are not part of the hegemonic discourse.
1. The Centrality of Hermeneutic Reflexivity for Sense-making

I argue that from the methodological tool of collaborative mise-en-scène creation emerges the centrality of reflexivity not only as an individual activity, but as part of inter-subjective encounters based in mutual questions, which is a practice-based form of hermeneutic enquiry central to the sense-making process. This process, although interventionist in its character, provided a context from which we engaged in a practice-based form of hermeneutic reflexivity, in the form of mutual questions about the mise-en-scène creation, and not about the events they were based on. Our dialogical relation based on this mutual enquiry about the images, revealed that sense-making does not emerge from the articulation of reflexivity as an individual practice, but relies significantly upon encounters with others and the socialisation of experiences that might appear as part of those encounters.

I also suggest that this form of hermeneutic enquiry using visual means promoted disruptions of power in which collaborators went from being the ‘protagonist of their stories’—those who act and are affected by the action of others—to the position of ‘directors’—the ones who provided a vision about the events and its meaning. By creating evocations of their life experiences, and with memory and imagination emerging together throughout the process, they could establish new relations with those life experiences by re-shaping its meaning.

In other words, I propose that sense-making as an central element in confronting a biographical disruption does not only appear as a consequence of an internal dialogue with the self, but also has an equivalent social component. In this way, sense-making as the creation of meaning about life events is not a process that solely takes place in the form of individual inaccessible dialogues, but also depends on having opportunities to express these internal utterances to others, who can ask further questions or provide alternative perspectives. The engagement in this hermeneutic circle elicited new reflections from other collaborators: what they received from their interlocutors were not
closed answers, but rather more questions or new perspectives which expanded mutual understandings.

By engaging in a collaborative *mise-en-scène* creation about critical life events, the collaborators engaged in this practice-based form of hermeneutic enquiry from which questions were asked about the coherence of the image in progress. From here, they engaged with the *mise-en-scène* creation not as a form through which to report their life events, but as a way to understand experiences and provide meaning to them, in relation to their lives. In this way, their photographs are not representations but evocations, as they provide access to much more than a re-construction of experiences. Rather, they allow us to access a visual system that informs us about what these experiences mean to them, and how they are entangled with ideas about the past and futures in the context of their life continuity.

Considering that some of the collaborators of this research had lived with HIV for more than twenty years, and others only a few months, their sense-making processes were at different stages. For example, Miguel Angel and Oscar, who received their notification more than ten years ago, had gone through a long period of reflection by which they had re-signified some of their life events; where Diego and Claudio had recently engaged in this process. Regardless of this disparity in terms of years following their diagnoses, what emerged from our engagement in the collaborative *mises-en-scène* was that the process of sense-making was in constant transformation. This can be recognised in the fact that all of them thought their engagement in the process provided new perspectives about their life events and relations, as if their sense-making process was still being re-shaped.

After the photography exhibition, the collaborators reported that even though ‘re-calling difficult experiences required courage’ (Diego, film timecode 00:53:45), it was also after
the process of the *mise-en-scène* creation that some of those experiences started to resonate with their lives in a different way, to signify something different\(^{99}\):

Oscar: ‘When I see my photos, I realized that I have been through so many things, but that at the end it’s what speaks highly of me.\(^{100}\)’

Diego: ‘Because we walk through a past difficult to remember, its in that journey that we can build our own narrative, our particular struggle.\(^{101}\)’

Gato: ‘Even though I feel exposed by the photos, It is also liberating, because I don’t feel shame anymore. Now, I can just show who I am.\(^{102}\)’

Collaborative *mises-en-scène* became a research method to investigate sense-making outside the familiar spaces and means for expression, which emerged through our encounter and would not exist otherwise. Given the persistence of stigma in Chile, collaborative *mises-en-scène* offered a means for sense-making outside the material and spatial restrictions they face in support groups, limitations which complicate their opportunities to understand their biographical disruption.

On the one hand, it offered a visual means for expression which can partially satisfy the insufficiency of words, or establish a relation of complementarity. This is particularly relevant when thinking that some experiences they investigated were still out of the realm of comprehension, never mind of expression. It also revealed that this process of sense-making is not necessarily attached to specific places or relations, but rather it can emerge when an appropriate context and relations that foster reflexivity are in place.

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\(^{99}\) From the last sequence of the film (Timecode 00:49:20 – 00:57:38)

\(^{100}\) ‘Cuando veo mis fotos me doy cuenta que he enfrentado tantas cosas difíciles, pero al final eso habla bien de mí’

\(^{101}\) ‘Porque caminamos a través de un pasado que es difícil de recordar, es ahí donde construimos nuestra historia, nuestra pequeña lucha’

\(^{102}\) ‘A pesar de que me siento expuesto, es una exposición positiva. Es liberador porque no siento vergüenza. Ahora puedo mostrar lo que soy’
2. Additional Social Elements of HIV Sense-making

A particular element that emerged from the experience of collaborative *mise-en-scène* creation with men living with HIV was the collaborators’ intention to project our practice beyond our encounters. The fact that all of them felt compelled to push this agenda in our conversations and practice, it indicates that this aspiration for ‘social’ projection have to be explored further. I suggest that this element emerges as a response to their perception of social stigma as the main cause for their biographical disruption, and also as the central element that obstructs their opportunities for sense-making.

One of the aspects that became prevalent in their narratives when conducting the *mise-en-scène* creation responded to the question: ‘For whom are we doing this?’, by which they assigned significance to their practice beyond our autobiographical investigation. One way to answer this question is to understand that they wanted to speak to others living with HIV and who might be experiencing similar situations of stigma, and given the fact that we were producing images (photographs/film) that could be seen by others, they assigned a ‘meaning’ to the project itself considering its potentialities:

‘My experiences can help others who are just starting this journey of living with HIV. To say yes, I can live with this illness, and you can achieve many things in life’ - Oscar (Film timecode: 00:50:55)

What Oscar expressed during the opening of the exhibition was also shared by all the collaborators while working on this project. During the first workshop, when they created a first tentative list of life events to explore, Diego left a written message at the end of his list: ‘I will remember these moments as experiences for me, and as lessons for others’. A year after that workshop, and after a preview for people living with HIV at the George House Trust in Manchester, a woman asked me if we could have a chat while dragging me to where Diego’s photos were displayed. She said she could relate to all the feelings of loneliness after being diagnosed. While pointing to Diego’s photo of the phone booth
from which he made his first phone call after diagnosis (Photo Book, page 41), she said ‘I am still alone in this’, as at that point she had not yet called anyone. However, she explained that seeing others who have gone through similar circumstances made her understand that eventually she will call someone as well.

The experience of the exhibition in Manchester shows that a biographical disruption after a HIV diagnosis, can be still felt as an isolating experience in different parts of the world, after more than thirty years of the crisis in the 80s. At the same time, this conversation exposed that there are certain commonalities in what it means to live with HIV which surpass regional boundaries, contexts and intersectionalities. At the same time, living with the virus remains an individual and unique experience, as it depends upon a personal sense-making process within specific material and socio-historical contexts.

As indicated earlier, the collaborators wanted to speak to others through their photographs as a way of promoting a further dialogue, or maybe to create a dialogue that in some cases had never existed before. From their responses to the question ‘For whom are we doing this?’ also emerged an intention to open spaces for dialogue with others who do not live with HIV, who can sometimes make judgements, relying on a lack of knowledge about the virus. In this context, the aspiration of promoting opportunities for dialogical encounters with them, is also as aspiration to re-frame their ideas about what it means to live with the virus today. By this, images open up the possibility to contest stigma by ‘normalising’ the fact that people live with HIV, in the same way that other illnesses are normalised. This is a tactical approach with the purpose of changing the way HIV is perceived, reducing the disruption caused by stigma, and ultimately opening up more opportunities for sense-making:

‘In my photos, there are things that will make sense for others, even people who are not living with HIV. Like a dinner table ready for breakfast is a
place that many people can relate to. And that is something everyone can understand, that my medical history doesn’t make me different to others’ – Diego (Film timecode 00:56:20)

This statement and all the data collected in this research in relation to stigma and the need to ‘normalise’ people living with HIV, leads to the conclusion that three decades after the first HIV diagnosis in Chile, there is a disparity between how the impact of the virus has changed in relation to the bio-medical aspect (effective and free antiretroviral therapy), and its consequences in relation to stigmatisation locally.

Considering this, the process of creating these photographs became an opportunity to, on one hand, investigate their experiences as part of their autobiographies, but it also provided a platform for them to present and re-present themselves in different ways to how they had historically been depicted. What emerged here are more than images of experiences in a context in which they are still subject to potential stigmatisation, but ‘evocations’ of potential worlds, which became more tangible through the practice. These are central to their intention to reach across empathetic borders with others outside the HIV community.

The practice of collaborative mise-en-scène as a method means (relationally, contextually, materially) fostering the collaborators’ own evocations and access to how they create meaning around their experiences. Sense-making as a continuous process is embedded in an entangled system of relations within themselves, with others and the socio-historical context in which a biographical disruption takes place. As a practice that extends in time and is permeated by conversations with the self and others, it is not fixed or conclusive because it’s constantly re-shaped, re-framed, and re-signified whenever new critical questions arrive.
Certainly, there are memories that remain hidden, which are not ready to be explored, or to be shared and discussed. However, this project has promoted a specific type of relation with memory and imagination, articulating both as a way to explore sense-making in a moral context in which they were in control of how those memories were brought into the present and how to establish dialogues with futures. By dislocating the way in which they refer to their memories, by reflecting on potential representations and not on the events itself, they were able to think about their personal sense-making process from a different perspective, one in which new opportunities could be considered. In that way, and considering that memories are inherently part of one life history and interconnected, this investigation might resonate with those memories that were kept hidden, and not visually explored in this project.

3. Collaborative Mise-en-scène and Other Sense-making

This project has been challenging in its execution, in particular because of its experimental and interventional character. Although this aspect created a rich ethnographic context, it sometimes offered too many opportunities for practice, and by that pushed us to choose certain elements over others, which ultimately shaped the research. However, despite some complications (such as underestimating the importance of face-to-face interaction during the editing of the film; or Jaime and Herman deciding to leave the project earlier), the project has been successful in promoting further understanding of sense-making in its inter-subjective form. It has also offered new images and evocations of experiences of men living with HIV in Chile, which would not have existed without the reflexive and collaborative visual engagement that this research proposed. These images and the film can be still analysed further, paying attention to elements that we discarded not because of their lack of interest, but simply for the sake of framing the analysis.

This method does not operate as an independent system to access memories of past events in the form of scientific evidence, but rather offers possibilities for practice and/or
research about sense-making through its representations in film and photography, embedded in a specific type of ethnographic relation of hermeneutic reflexivity with collaborators. It can be adapted, de-constructed and re-created, which is central when considering that it can be implemented as a practice and/or research method across a wide variety of conditions.

However, this method is suitable not only for conducting further research about biographical disruptions (produced by a medical diagnosis), but about sense-making in a more general frame: as the reflexive process of making meaning. As such, it can be applied to other contexts, other processes of sense-making, and using other types of media. For example, we used an analogue photo camera in order to promote a reflexive photographic practice, in which collaborators had to consider the arrangements they created before shooting, outside of the almost limitless storage capacity of digital cameras. In this context, the use of analogue and not digital was not an only an aesthetic choice, but most importantly, was one of the elements that helped promote reflexivity during the practice.

However, future implementations of the method to specific conditions of the field-site and available material conditions need to consider that media in this case is not only another means for expression, but are part of a practice that implies a reflexive way of knowing. In other words, what should remain central for any adaptation of this method, is the centrality of reflexivity as a hermeneutic practice that fosters a coherence between what collaborators want to express and what they are representing in their mises-en-scène.

Based on these grounds, I would suggest that the adaptation and implementation has to be carried out by a practitioner/researcher who knows the craft of the media being implemented, and not by someone who is experimenting for the first time. Cameras for film and photography are technologies by which collaborators (including the researcher,
for more clarity) engage in the same activity, and by sharing a focus in the same objective, they can ask relevant questions of each other when new knowledge emerges. If someone who is unfamiliar with the use of a camera conducts research of this level within collaborative exploration, it would bring an uncertainty to the practice, or even create tensions between collaborators by disrupting the creation of their *mises-en-scène*. A researcher/practitioner who understands how to handle the media in changing conditions can ask relevant questions so as to initiate a hermeneutic dialogue; but can also put her/his knowledge at the service of the collaborators’ expressions. The same criteria concerning practitioner/researcher suitability should be considered for any other type of media/discipline (e.g. painting, animation, theatre) adapted for the implementation of a specific type of collaborative *mise-en-scène*.


This project responds to certain ways of doing in anthropology, focused on the use of orthodox methods with an overreliance on participant observation, and the production of outcomes for academic audiences only. In this sense, the project is aligned with what Salazar and Pink (2017), in relation to their Future Anthropologies project, describe as those that seek to ‘derail mainstream social and cultural anthropology from an insular and inward looking single-discipline route that threatens to exacerbate its isolation and incapacity to participate and intervene in the major worldmaking activities of our times’ (pp.3).

This practice-based research is situated in an intersection of public, interdisciplinary, collaborative and interventional strands of anthropology, as a way of proposing a specific way of engaging with anthropological practice. While maintaining its critical center and ethnographic inspiration, it proposes a specific type of relation with collaborators embedded in specific ways of knowing, based on dialogue, reflexivity and experimentation, with outcomes that can reach beyond an anthropological audience.
This project has described the creation of an ethnographic context in which the collaborative creation of images provides ways of knowing about sense-making processes which do not only fit with an arrival narrative. This can be controversial in relation to the non-interventionists tradition of anthropology, but I suggest that inter-and-transdisciplinary approaches offer opportunities to foster reflexivity as a continuous practice, not only of the domain of the researcher but also of the participants, from which unexpected opportunities for relations and ways of understanding the world emerge. This on-going adjustment of the practice can be perceived as a source of uncertainty, not only about its impact on the shape of the research, but as a type of relation that demonstrates that the gaze is directed in both ways.

How this method will be adapted by other practitioners/researchers in the future remains unknown, and as yet unsolved is the extent to which collaborators will push what learned in the field. But there are glimpses: Diego and Claudio have taken elements of their collaborative *mise-en-scène* using mobile phones with other zero-discordant couples, while Miguel Angel and Oscar have presented their photos at other HIV organizations. A film premiere in Chile for the general public will take place at the end of this year, and we are planning to produce a new project of film and photographs with women living with HIV.

The consequences of our practice upon future relations and tactics in confronting stigma has yet to be considered after some time, but so far it seems the impact of our practice exceeds the scope of this PhD, as what we have experimented with is being taken further in our future practice, in potential common projects and in our life journeys.
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Films

APPENDIX

Transcriptions and translated texts of the exercise called ‘I was, I am, I will be´

Oscar

<table>
<thead>
<tr>
<th>Spanish</th>
<th>English</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yo fui niño</td>
<td>I was a child</td>
</tr>
<tr>
<td>Yo soy adult</td>
<td>I am an adult</td>
</tr>
<tr>
<td>Yo seré viejo</td>
<td>I will be old</td>
</tr>
<tr>
<td>Yo fui estudiante</td>
<td>I was a student</td>
</tr>
<tr>
<td>Yo soy un trabajador</td>
<td>I am a worker</td>
</tr>
<tr>
<td>Yo seré jubilado</td>
<td>I will be retired</td>
</tr>
<tr>
<td>Yo fui vendedor de dulces en la micro</td>
<td>I was a candy seller on the bus</td>
</tr>
<tr>
<td>Yo soy peluquero</td>
<td>I am a hairdresser</td>
</tr>
<tr>
<td>Yo seré el dueño de un local de negocios</td>
<td>I will be a business´ owner</td>
</tr>
</tbody>
</table>

Diego

<table>
<thead>
<tr>
<th>Spanish</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Yo fui el extremo de tu carne</td>
<td>I was the border of your flesh</td>
</tr>
<tr>
<td>Yo soy los restos de la cena familiar</td>
<td>I am the family dinner´s leftovers</td>
</tr>
<tr>
<td>Yo seré el silencio al interior de tu pieza</td>
<td>I will be the silence inside your room</td>
</tr>
<tr>
<td>Yo fui el niño de papá y mamá</td>
<td>I was the boy of mum and dad</td>
</tr>
<tr>
<td>Yo soy su exilio</td>
<td>I am their exile</td>
</tr>
<tr>
<td>Yo seré el final de su circuito</td>
<td>I will be the end of their circuit</td>
</tr>
<tr>
<td>Yo fui el que salió descalzo</td>
<td>I was the one who went out barefoot</td>
</tr>
<tr>
<td>Yo soy el que espera tras la puerta</td>
<td>I am the one who wait behind the door</td>
</tr>
<tr>
<td>Yo seré quien se aparezca como un fantasma</td>
<td>I will be the one who appear like a ghost</td>
</tr>
<tr>
<td>Miguel Ángel</td>
<td>Claudio</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Yo fui un niño solitario y llorando que llama a su mamá</td>
<td>I was another baby for my grandmother</td>
</tr>
<tr>
<td>Yo soy la soledad del cosmos</td>
<td>I am what I think when I am drawing</td>
</tr>
<tr>
<td>Yo seré las alas que se extienden y vuelan sobre el mundo</td>
<td>I will be a sensible person</td>
</tr>
<tr>
<td>Yo fui la boca cubierta con una cinta adhesiva</td>
<td>I was the boy that never played football</td>
</tr>
<tr>
<td>Yo soy un cofre abierto y lleno de misterios</td>
<td>Yo fui una guagua más para mi abuela</td>
</tr>
<tr>
<td>Yo seré la libertad encarnada en mi ser</td>
<td>Yo soy lo que pienso cuando dibujo</td>
</tr>
<tr>
<td>Yo fui un alma inocente picoteada por pájaros hambrientos</td>
<td>Yo seré una persona consciente</td>
</tr>
<tr>
<td>Yo soy una expresión de sentimientos y emociones que son estrellas</td>
<td>I was an innocent soul pecked by hungry birds</td>
</tr>
<tr>
<td>Yo seré la luz que se propagará por dentro de mí mismo</td>
<td>I am the expression of feelings and emotions, which are stars</td>
</tr>
<tr>
<td></td>
<td>I will be the light spread from within me</td>
</tr>
</tbody>
</table>

<p>| Yo fui una guagua más para mi abuela                                       | Yo fui la niña que jamás jugó a la pelota                                |
| Yo soy lo que pienso cuando dibujo                                          | Yo seré una persona consciente                                           |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>I am the spoiled child who looks like he will never stop being a boy</td>
<td>Yo soy el regalón de la casa y el niño que parece que jamás dejará de serlo</td>
</tr>
<tr>
<td>I will be a professional working for others</td>
<td>Yo seré un profesional al servicio</td>
</tr>
<tr>
<td>I was the one scared to tell the truth</td>
<td>Yo fui el que tenía miedo de contar la verdad</td>
</tr>
<tr>
<td>I am lucky</td>
<td>Yo soy afortunado</td>
</tr>
<tr>
<td>I will be brave</td>
<td>Yo seré alguien valiente</td>
</tr>
</tbody>
</table>
First tentative list of life critical events

Copies of original written texts. Including transcriptions and its translations.

1.- Diego

Los días en que presumo me infecté. Carreteando solo en el centro, patético.

Foto: Tomando cerveza en un parque.

(The days in which I suspect I got infected. Partying by myself at the city centre, pathetic).

Photo: Drinking beer at a park).

El correo que le envié a Claudio.

Foto: El mensaje de facebook.

(The email I sent to Claudio.

Photo: The message on facebook).
La semana que me pidieron usar mascarilla.

Foto: La mascarilla junto a mis libros.

(The weeks in which I was ask to use a face mask.
Photo: The face mask next to my books).

El nerviosismo de entrar al Lucio Córdova.

Foto: Los cigarillos que apagaba fuera del lugar.

(The anxiety before entering Lucio Cordoba Hospital.
Photo: Cigarettes I put out, outside that place).

Las caminatas alrededor de Toesca para comprender la situación.

Foto: La pasarela de Vial.

(The walks around Toesca to understand the situation.
Photo: The footbridge at Vial).
El frío que había en la sala donde me dieron el resultado.
Foto: La sala vacía.
(The coldness at the room where I received my test results.
Photo: The empty room).

El día que le conté a mi madre durante el desayuno.
Foto: La taza de té y el pan que dejó sobre la mesa.
(The day I told my mother, during breakfast.
Photo: The tea and bread she left on the table).

El viaje en metro después de saber que tenía VIH.
Foto: El metro de noche, vacío.
(The journey on the metro, after learning I had HIV.
Photo: Metro by night, empty).
La primera vez que fui a buscar medicamentos.

Foto: La bolsa llena de pastillas y condones.

(The first time I went to get my medication.
The bag full of pills and condoms).

La llamada que hice al salir con mis resultados.

Foto: Un teléfono público.

(The call I did after receiving the results.
Photo: A public telephone).

La seguridad que sentía viviendo en pareja.

Foto: Un departamento con la tele encendida a media tarde.

(The certainty I felt when I was living with my partner.
Photo: A flat with a TV on at the evening).
Espero escribir un libro de poemas sobre esta experiencia.
(I hope to write a poetry book about this experience).

Espero algún día esta enfermedad y otras no conlleven un estigma.
(I hope one day this illness and others do not carry stigma).

Voy a dejar de tomar pastillas pensando en los errores del pasado.
(I will stop taking the medication while thinking about mistakes from the past).

Voy a recordar estos momentos para aprender y dejar a otros mi experiencia.
(I will remember these moments to learn from them and later leave my experience to others).
Planeo en un momento dejar de existir con miedo.

(I am planning to one-day stop living with fear).

Espero escribir de esta experiencia y utilizarla.

(I hope to write about this experience and use it).
2. - Claudio

1) Octubre 2014. Me parece que mi ex me oculta algo, veo que se toma unas pastillas que me había mostrado.
   (October 2014. I think my ex is hiding something from me, I see him taking some pills he had showed me).

2) Mensaje de Facebook que me manda Diego contándome que el examen del VIH le salió positivo.
   (Facebook message in which Diego tells me his HIV test came back positive).

3) Encontrarme con el Diego después de esta declaración, ir a Redoss y estar con él sin importar nada.
   (Meet Diego after his message, go to Redoss and to be with him without caring about anything else).
4) Un día en que pedí permiso para un “trámite” fui a Redoss solo desde Ñuñoa a Conchalí, me hice un mapa pero no pude tomarme el examen.
(The day I asked for permission to do some “paperwork” but I went to Redoss by myself from Ñuñoa to Conchalí, I drew a map. But I couldn’t get tested)

5) El día en que me tomaron el examen, salió negativo. Afuera de Redoss me puse a llorar porque encontraba injusto todo lo que le pasaba a Diego, me vuelven a llamar y mi examen estaba indeterminado, debía esperar un mes para saber.
(The day I got tested, it came back negative. Outside Redoss I cried because I felt it was unfair what Diego was going through. I got called again because my test was ambiguous. I had to wait another month to finally get to know).
6) “El mes de espera” sentía la inseguridad de Diego de ponerme en riesgo, nuestro primer intento no funcionó, él no quería ponerme en riesgo.

(“Waiting month” I felt Diego’s fear of putting me at risk. Our first try didn’t work. He didn’t want to put me at risk).

7) Junio, acompañé a Diego a Redoss y me vuelven a tomar el examen rápido. El Lucho se demoró caleta. Me pidieron pololeo en un patio muy otoñal y cuando Lucho llega me muestra las dos rayitas que señalan positivo.

(June, I go with Diego to Redoss and I got tested with the quick test. Lucho took a long time. On a autumnal garden, I was asked to be his boyfriend, and when Luis comes back he showed me the two lines that indicated the result was positive).

8) Juntarme con mi ex, después de contarle el resultado, me pide perdón y se sorprende de mi serenidad en el parque San Borja. Su examen también salió positivo.

(Join with my ex, after telling him the result, he asks for forgiveness and he is surprised by my serenity in San Borja. His test also came out positive).
(Meet my ex-boyfriend, after telling him about my results. He asked me to forgive him and he is surprised about my calm at San Borja Park. His test also came back positive).

9) Muchas tomas de sangre, entre ellas un PPD (tuberculosis), 3 días después tuve que ir solo al hospital a la lectura de este examen, salió positivo, aparte tenía tuberculosis, me ponen una mascarilla y me sentí horrible, solo, enfermo, y en ese momento me di cuenta que esto ya es más grave.

(Many Blood tests, among them a PPD (tuberculosis), three days after I had to go to the hospital to learn the results, it came back positive, I had tuberculosis, they gave me a face mask and I felt terrible, alone, sick, and in that moment I realised that this was much more serious.

10) Después de la lectura, Diagonal Paraguay ahora soy yo quien pone en riesgo a Diego, tomo las cajetillas de cigarro de mi mochila y espero los días para tomarme las radiografías de los pulmones y salir de la duda.

(Immediately after the results, Diagonal Paraguay is now I, who put Diego in danger. I take the cigar sleeves from my bag and wait for the days to have the chest x-rays of the lungs and leave the doubt.)
(After getting the results, Diagonal Paraguay Street now I am putting Diego at risk, I take out the cigarettes from my backpack and I wait for days to get X-Rays on my lungs and finally get to know).

11) El día de la radiografía, desee no seguir conociendo el hospital, mi familia ya sabe y espero los resultados.
(The day of the X-Rays, I wished I didn’t have to visit more places at the hospital, mi family knows and I wait for the results).

12) 2 de Octubre. El momento en que tengo que ir al hospital y me dicen cuál es mi camino y tratamiento, voy a empezar la etapa en que la enfermedad se me aparece todos días ya que ahora es solo un fantasma.
Y sabré lo que es vivir de verdad con esto.
(2nd October. The moment when i have to go to the hospital and they informed me about my options of treatment, I will start a new phase in which the illness becomes an everyday presence, until now is only a ghost.
And I will know what it means to live with it).
3. Miguel Angel

1. El día en que me notificaron como VIH+.

Pablo, mi pareja de aquel momento, me acompañó. No tuve tiempo para llorar ni bajonearme, porque él en todo momento me tiró para arriba. Foto: 2 hombres jóvenes abrazándose. Uno apoya al otro. (Puede ser un primer plano detalle de sus caras juntas).

(The day I received my HIV notification. Pablo, my partner at that time was there with me. I didn’t have time to cry or get depressed, because he cheered me up all the time. Photo: 2 young men, hugging each other. One supports the other. It could be a close-up shot of their faces together).

2. Recuerdo que en un principio me complicaba conocer a alguien y decirle que era VIH+.

Recuerdo a uno en especial, Rodrigo, que nunca quiso tener relaciones sexuales conmigo por el VIH. Foto: Una cama desordenada, sobre ella un condón sin abrir (picado). A cada lado del condón, un hombre desnudo, inmóvil.

(I remember that at the beginning it was complicated to get to know somebody and disclose that I was HIV+. I remember one in particular, Rodrigo, who never
wanted to have sex with me because of the HIV. Photo: A messy bed, on top of it an unopened condom (oblique angle).

3. Mi situación siendo VIH+ y diabético. La diabetes me tiene harto; ser diabético es lo peor, no así ser VIH+. Foto: Mi cama, el velador, sobre la alfombra medicamentos, jeringas, frascos de insulina (estoy sentado en la orilla de la cama). (My situation of being HIV+ and diabetic. I am fed up with diabetes; to be diabetic it’s the worse thing, unlike being HIV+. Photo: My bed, bed side table, on the carpet some medication, syringes, insulin doses (I am sit at the edge of the bed).

4. Recuerdo cuando intenté suicidarme. Estaba en la posta, en una camilla. El doctor me interrogó sobre mis enfermedades. Él salió y le contó a mi mamá sobre mi VIH. Foto: Mi mamá sentada en el sofá. Yo acostado con mi cabeza sobre las piernas de mi mamá. Yo leyendo en voz alta un libro sobre el VIH. (I remember when I tried to commit suicide. I was at the hospital, on a stretcher. The doctor questioned me about all my illnesses. He went out and told my mum...
about my HIV. Photo: My mum sit on the sofa. I am lying down, with my head resting on my mum’s legs. I am reading out a book about HIV).

5. Mi actual trabajo de prevención del VIH en la discoteca. Foto: Yo conversando con alguien, entregando folletos y condones en la disco.
(My current work on HIV prevention at the night club. Photo: Talking with somebody, giving away leaflets and condoms at the club).

6. Actualmente uno de los medicamentos para el VIH provoca que mis ojos se vean amarillos. Eso me produce pena, porque siento que la gente me mira raro y todos me preguntan.
Foto: Yo en una piscina o en la playa, con aguas cristalinas, totalmente desnudo.

6. Actualmente uno de los medicamentos para el VIH provoca que mis ojos se vean amarillos.
Eso me produce pena, porque siento que la gente me mira raro y todos me preguntan.
Foto: Yo en una piscina o en la playa, con aguas cristalinas, totalmente desnudo.
(Currently one of the HIV medications make my eyes look yellow. That makes me sad because I feel people look at me with suspicion, and everybody ask me about it. Foto: Me, on a swimming pool or at the beach, with crystalline water, completely naked).

4.- Oscar

Lo difícil fue vencer el estigma que se creó en mi propia familia. Sobre todo cuando iba al baño y mi madre iba detrás limpiando todo y desinfectando con cloro.

(It was so difficult to fight my own family’s stigma. Especially when I was going to the toilet, and after that my mum was cleaning everything with bleach.

No poder besar a mi hija por miedo a contagiársela por la falta de información que existía 20 años atrás y lo feliz que me sentí cuando lo pude hacer.
(Being unable to kiss my daughter because of the fear of passing HIV to her. 20 years ago there was so little information, so when I could do it for the first time, I was so happy).

3) Lo feliz que me siento haciendo prevención en la radio.
   
   (I feel so happy when I can talk at the radio about HIV prevention).

4) Trabajando en el Hospital Sotero del Río en consejería entre pares conteniendo a personas recién diagnosticados y enseñando con mi propia vivencia que se puede seguir viviendo.
   
   (Working at Sotero del Río hospital in peer-to-peer counselling, giving support to people who are newly diagnosed, and showing them-through my own experience-that you can carry on with your life).
5) Habituarme a tomar mis remedios en forma constante. Horarios ya que fue lo que más me costó.

(It was not easy to take my medication everyday, in particular get used to the timetable).