1. Reflexivity and Dialogue

Drawing on my fieldwork with young subjects (15-20 years old) living with HIV in zones of marginality and social exclusion in Maputo, Mozambique, this article discusses the use of creative methodological tools in medical anthropology research to better understand people’s experiences of illness, body, and subjectivity. This question arises from a methodological consideration of my PhD thesis, in which I examine the politics of adherence to Antiretroviral Therapy and how they affect seropositive teenagers. In this paper, I will focus on a support group that I set up for seropositive young people – a measure made possible thanks to my previous experience in psychology. Although youth’s living experiences have traditionally been reported by referring to experiences of adults (Alderson 2008), in recent years young people have been acknowledged as both social actors and knowledgeable subjects capable of participating in complex research processes (Christensen and James 2000; Hutchby and Moran-Ellis 1998; Prout and James 1997; Skovdal and Abebe 2012).

Looking for ‘child-centred’ research methods, I finally landed upon the perspective of Bakhtin and Holquist (1981), who argued that both research processes and potential socio-ethical implications should be discussed and explored in a dialogue between the researcher and the people encountered in the fieldwork. Moreover, following Skovdal and Abebe (2012), for whom young people are participants of the research, and not merely ‘informants’ and ‘respondents’, I encouraged the teenagers to be in dialogue and relation with me, which in turn enabled them to become active in the research process. Dialogue can, therefore, become a tool to create a potential space in which to discuss and explore how the research can be conducted ethically, creating a space in which socio-ethical issues could be renegotiated during the research process (Skovdal and Abebe 2012). As Jovchelovitch (2007) argues, a criterion for an idealized public sphere should be that participants and researchers meet as equals, with arguments being accepted for their intrinsic relevance and power rather than according to which speaker wields the most power. However, the space for such dialogue cannot be created without an awareness of and reflection on the tensions (for example, power inequalities) that are likely to arise between oneself (as the researcher) and the other (as the participants to the research) during the research process. These tensions are likely to be significantly affected by the socio-cultural context of the research (Skovdal and Abebe 2012). For this reason, reflexivity – as a means through which researchers reflect upon their research practices (Gaskell and Bauer 2000) – was a crucial path in my project.

With this in mind, I reconsidered the willingness of participation in the research as well as the methods that should be negotiated at the beginning and throughout the research process itself. To this end, as Thomas and O’Kane (1998) argue, I sought to ensure that the teenagers I was working with were always able to ‘opt in’ – and also ‘opt out’ – by encouraging them to decide every aspect of the research activities in which they chose to take part. For example, some of the young people preferred to take part in photo-essays, others choose to use story-writing and draw-and-tell techniques, and others
wanted just to participate in group discussions. The teenagers could therefore temporarily withdraw from the research as well as re-join it depending on the available research methods with which they felt more comfortable (Skovdal and Abebe 2012).

2. Art-Based Methods

Fieldwork occurred in Maputo, capital of Mozambique, between October 2016 and February 2018. Besides participant observation in the health centres, I led interviews with relatives of teenagers affected by the HIV virus, socio-health workers, NGO members, and traditional healers. However, the most important place where I conducted my research work was a day centre for people in precarious socio-economic conditions. During the first few months in the centre, it became clear that some of the methods I was employing were not adequate for all participants, and visual methods initially attracted my attention because they offered the possibility of being ‘child-centred’ (Mitchell 2006).

In my research, visual methods like drawings, body mapping, and photographs quickly became crucial ethnographic techniques to work within the support group. When analysing drawings and their implementation, I followed Rose’s (2001) ‘critical visual methodology’, which takes into account not only the content of an image but also the circumstances of its production, circulation, and consumption. The content of the research participants’ drawings – despite not comprehensively showing nor perfectly mirroring their world view – is a departure point for the understanding of what they know or think about a particular topic. The attention to the production of an image, to the ways in which drawings are made and the reasons they are made, entails consideration of the technologies and social relations with which drawings are tangled and the embodied or corporeal aspects of producing marks on a page (Rose 2001). During the presentations of their work to the group, not only do the drawings convey something of how the producer sees, but the ways in which the drawings are seen and consumed by others become a relevant aspect to discuss as well (Berger 1972).

From the moment I began using visual methods, some issues of representation, translation, and power started arising, as I became aware that enabling young people’s perspectives through drawings and photography required more than giving them the tools. As I mentioned before, it requires an awareness of the conditions under which those visual images are produced and viewed; furthermore, the directions given by an adult to the young people raise issues of power with regards to the broader adult-child relation in society, as well as to me as a foreign researcher.

Following Mitchell (2006), I agree that the power hierarchy, implicit in an interaction where an adult ethnographer asks a child, or adolescent, if she or he would like to draw or take a picture, is impossible to eliminate. Mitchell argues that in this case, drawing is not an inherently child-centred activity, but one in which relationships of power, authority, and difference need to be acknowledged and integrated into the analysis (Mitchell 2006). Mitchell further argues that there might be a potential for bias if we expect that children, for example from North America, who are expected to talk about themselves constantly and at length and who are socialized to express their individuality, are taken as the standard for all children’s narratives (Mitchell 2006).

During my experience in Mozambique, I found that the viewpoints of young people were rarely asked in the society – neither expressions of their feelings, nor of their individuality. Drawing was not always seen as a pleasurable activity, and it sometimes presented the risk of infantilizing the teenagers,
creating a barrier to youth empowerment. Furthermore, drawings are not a substitute for youth’s voices, and the absence, muting, or fragmentary nature of explanations of their images should encourage researchers to be particularly cautious about over-interpreting their images (Mitchell 2006).

3. Making Up the Group

In the day centre, which is run by a few Catholic congregations, the nuns expressed the need to create a ‘safe space’ where young seropositive people could express their difficulties and build their self-esteem.

The creation of a support group was aimed at building trust and intimacy with the participants, so that they would feel confident in sharing their experiences. For instance, during one of our last sessions, Augusto told me: ‘In the beginning, no one believed so much in this group, but now we do! We’re feeling comfortable now’. Building a safe context takes time but allows the participants to talk openly about sensitive issues in their lives — issues they would never discuss otherwise or struggled to share. While I treasure the many benefits of such a trusting and open context, I found myself questioning whether they were disclosing things they may not have intended to, or about which they were not emotionally prepared to — e.g. the HIV status of other family members (Cree et al. 2002). I initially decided to invite them to speak about pills, without directly using the term HIV. This choice was made since, during my first months of fieldwork, I realized that in many cases the disclosure of the HIV status had been done in a light way, and many were still deny or confused about their HIV status. My role, identity, and participation in the research was discussed throughout our encounters. Though my double position as researcher and psychologist was clear to the nuns of the centre, I was concerned about the group’s participants’ understanding. Although the meaning of ‘researcher’ was not so clear to them, and for most of the time they regarded me as a nun, the fact that they were part of a research project was explicit from the beginning, and a formal consent form was signed by them and their families. This understanding was gradually deepened throughout the meetings. Below is an extract from one of the initial group sessions, as we explained to a new member what we were doing in our meetings:

Researcher:  This is not just a support group but also research. Do you know what research (investigação) is?
Augusto:  Sister, you are a researcher?
Pedro:   A secret researcher! (Um investigator secreto!)
Researcher:  Not really a secret one! But I’m not a sister – you know that, right? We can speak about all kinds of things here. If you give me your permission, I will write some of the things you are telling me in a book that can help others to feel better. What do you think about me writing about it, without using your names?
Angelina:  That’s fine, but you will always be a sister to us.

I took a few months before deciding to start our sessions. I was already meeting with teenagers at the day centre individually, and I waited until I was sure that what I was building was a safe space. Many matters gripped me: Am I increasing the stigma already present in their lives? Will it actually be useful? Will they participate in the group? Will I be up to it?
I started feeling a sense of inadequacy due to the mere fact of conducting research in a field that involves working and coming into contact with extreme suffering. In my experience, becoming an active participant in my research came naturally, and my tendency was to try to improve the lives of the young people encountered – to alleviate their problems and try to avoid avoidable deaths, even if the feeling was not being able to do enough. For this reason, the psycho-social support group that I set up for young people was always a priority with respect to the collection of ethnographic data.

In March 2017, after several meetings with other psychologists who were following and observing support groups organized by other clinical centres in Maputo, I eventually decided to set up the group. Together with the nuns, we decided to start on a Wednesday, since on this day the centre was closed to the public, allowing some privacy and avoiding interruptions or questions from other members of the centre. The group was characterized by a great flexibility in regards to schedule and space: members could arrive when they chose to, for instance after school, and attending was not mandatory. This flexibility proved to be powerful in the creation of a safe space. However, the admission of new members during the following months compelled me to explain our rules again, and the different arrival times often slowed down the activities.

4. Structure and Activities

The group meeting started at 9 a.m. and continued until 12.30 p.m. These hours accommodated different school time schedules. Each sessions had three different moments: the icebreaker, the main topic, and food.

During the icebreaker, we would usually sit in circle. I would invite participants to describe a good thing and a bad thing that had happened that week. Sometimes the conversation began without my intervention. Taking into account the shared stories, we chose a central topic for the session. Below is an extract from an icebreaker moment:

Researcher: How was the week? How are you feeling?
Augusto: I’m not very well. They [the doctors] told me it’s gonna pass – they gave me cough syrup and pills.
Alvaro: I’m feeling a bit better. Yesterday was not a good day. I started feeling dizzy and I started to vomit. I was at school and I asked to go back home.
Researcher: How do you feel when these things happen at school? Does anyone give you trouble? Does this happen often?
Angelina: It’s happened a lot to me.
Pedro: I don’t go to school the day after.
Alvaro: I didn’t vomit in the classroom but I felt a bit ashamed.
Researcher: It’s normal to feel like that, but feeling bad is something that happens to everyone. What do other people say?
Augusto: Some of them say bad things.
Pedro: Others feel pity for you, I don’t like that. 60 students that pity you! Imagine if someone arrived and told you, ‘She is sick, I feel bad for her’. I don’t like that.
Alvaro: I already feel pity for my cousin. In the streets of our neighbourhood people beat her up; she fainted. She is 14 years old. When she woke up
she had forgotten everything that had happened, she had lost her memory.

Researcher: Sometimes we forget things that were bad, these things escape our memory. Do you think there are things that you don’t want to remember?

Pedro: I have forgotten getting hit. I forgot a lot of things, not everything. When I woke up I was in the hospital.

Angelina: I was sick, I had headaches and a cough. People in the school told me to go home but I didn’t want to, I wanted to study.

Pedro: My week was terrible! I had diarrhoea and headaches. When the weather is cold my head hurts a lot but when it’s hot it hurts more! Cold hurts inside and hot outside.

Among the main topics that we discussed there were explications of HIV, CD4, and viral load; treatment and difficulties in adherence; treatment at the health centres; stigma at school and with family; traditional medicine, religions, and beliefs; reimagining the past, present, future; friendship, love, and sexuality.

The last half an hour of our meetings was dedicated to the important moment of sharing food. As the participants arrived to the meeting right after school or would be going to school afterward, it was important to eat properly, especially concerning the taking of antiretroviral treatment. During the first session we decided that everyone would alternate being in charge of bringing food and drink for the whole group. I usually gave a small amount of money to the one in charge to buy the ingredients for the meal – e.g. cake, pasta, chicken. While research compensation has been a fundamental, albeit controversial, element of the health research apparatus for decades (Dickert and Grady 1999), in particular for structurally vulnerable populations, in my work it engendered a sense of responsibility towards others in the group, affecting other aspects of group relationships. Nobody lost money or did not fulfil their task. During the convivial setting people talked about food, cooking, and in particular about appetite. One of the aspects characterizing advanced states of HIV-positive young people is lack of appetite. Therefore, cooking for oneself and for others, talking about ingredients and recipes, turned into a pleasant experience. One day, while speaking of the positive aspects of the group sessions, Mauro told me, ‘The good thing about the group is that it gives us an appetite!’ Below, an excerpt on the matter of lack of appetite:

Researcher: Sometimes a headache can come from the lack of food.
Pedro: …lack of appetite.
Researcher: What is the difference between lack of food and lack of appetite?
Angelina: When you don’t have food in your house, or when you have food and you don’t want to eat – that’s lack of appetite. We have food at home; I lose weight from my lack of appetite.
Augusto: Sometimes I don’t have food at home. [Others agree with his affirmation]
Angelina: If I’m not feeling well, I don’t want to eat. I can eat two spoons and I’m full.
Researcher: Sometimes we don’t like eating, sometimes we don’t like what we have to eat. That’s okay but it’s also good to try to eat something to feel better.
Pedro: Angelina, you are so skinny! We want you to eat these two bananas that are here! Actually, you can have mine too.
5. Photovoice

During this project I was inspired to implement the use of cameras from the auto driven interviews technique used in particular by Clark (1999) and Clark-Ibáñez (2004). I reframed the methodology to adapt it to the group context in Maputo suburbs.

The term ‘auto driving’ refers to an interview ‘driven’ by the informant, who sees or hears their own recorded behaviour and explains or comments on that behaviour (Heisley and Levy 1991). Butler’s (1994) research and his studies show that ‘auto driving’ can increase the researcher’s access to the experiences of young people. Auto driving brings a ‘perspective of action’ as the interviewee attempts to make the visual material meaningful to the outsider (Heisley and Levy 1991), allowing the participants to retain some control of the interview. Their own photographs shape the topics included, and their own commentary of the photographs preserves youths’ right to interpret material in their own way (Clark 1999). Because of its ability to portray behaviours in context, as well as to explore the meaning of those behaviours to the actors, the ‘auto driving’ technique allows children and teenagers to visually show and tell important aspects of their lives (Clark 1999).

For all these reasons I decided to introduce cameras into the project, still being aware that the imbalance of power between the researcher and the young people remains and has to be included in the analysis. While you are giving oral instructions to the child, encouraging her to show what it is like to have an illness through picture-taking, as Clark pointed out, you are also directing the child to take pictures of some part of their world, preventing them from feeling free to take photos of whatever they want (Clark 1999). For example, the photo of where the antiretroviral treatment was being held was my instruction. In this case, therefore, you cannot consider this photo as necessarily representing their daily life.

Although most of the young people had never taken a photograph, they understood the basic principles of operating a camera and required few instructions. Most of them completed the project within two weeks after receiving their camera others took a while longer, and some lost their cameras. It was also challenging to attempt to give them few directions as possible regarding what to photograph.

I presented the project ‘Quem sou eu?’ (Who am I?) as a project in which they could show how life was to a stranger through photographs. During the first session, each of us made a roundup of our daily routines in order to think together about what aspects could eventually be important to capture. Two suggestions were given by me during this session. The first was about taking pictures of where they keep medicines, in order to analyze aspects of treatment, and the second was a discussion about the ethical dilemmas of taking pictures of strangers, which could potentially violate privacy and confidentiality (Gold 1989). In particular, we discussed some of the potential dangers of taking photographs of people without their consent, and together we agreed that they should have to ask before taking a picture and completely avoid taking photographs of people in situations that they believed could be potentially embarrassing for the person photographed. Together we also decided that they should not take pictures in hospitals and that if they wanted to take a picture at school, they would always have to ask for permission from the teacher. In the end, they decided unanimously not to take pictures at school out of fear that classmates might steal the cameras.
Photographs were eventually presented during the group sessions as a sharing activity that could reveal new meaning and experiences.

In Figure 1, Angelina showed us a normal meal in her house. While describing the picture (and the situation), she stressed out the fact that her inappetence had to do also with the lack of variety presented in the household fold – in this case *xima*, a polenta made from corn flour and tomato sauce.

Below is an extract about the medication shown in Figure 2:

*Augusto (showing pictures): Here is where I keep all the medicines; here I am with the medicines.*

*Pedro: Me and Augusto have the same disease, so we take the same things. My mother told me that I’ve had it since I was a child, Augusto I don’t know. I have been very sick since I was three years old.*

*Angelina (speaking about Augusto’s picture): This cream here is for the wounds, when you have wounds on your body you apply it after a bath.*

“The door of the house, which has fallen”, Figure 3, was taken by Pedro, who unfortunately loss his life a few months after this shot. He stated that through the picture, he wanted to demonstrate the lack in privacy he had in his house. While his aunt shouted at him to take drugs, one of his biggest fears was his serological status being discovered by neighbours.
Figure 2: ‘The drugs table’ (not used in the exhibition). Author: Augusto.

Figure 3: ‘The door of the house, which has fallen’. Author: Pedro
This sharing moment revealed how some issues and interpretations might have otherwise remained dormant in face-to-face interviews (Clark-Ibáñez 2004). I found that even if the images didn’t contain new information, they could trigger meaning for the interviewee to communicate something that might not have otherwise been expressed (Collier 1967; Schwartz 1989).

This is also present in two photos that for ethical reasons I cannot show. Edson was very shy and not a great speaker; others always joked about how quietly he spoke. During the presentations of the pictures, we all realized – especially him – that he was an amazing photographer. His works show that that he was living in a happy and safe family context – probably also the reason for his undetectable viral load.5

Moreover, I found that showing pictures could function both as a form of advocacy and a way of mentalizing sick states considered transitory. Alvaro showed me two powerful photos that he had decided to take of himself. One showed him very skinny and hunched over, taken in a period of his life when he was very ill with tuberculosis and Kaposi sarcoma. In the other, he was well dressed, listening to music, at the school entrance. He told me that he wanted to capture these two important moments of his life to remember how ill he was and how, with medication, he got better. ‘It is important for me but also for others, others in my condition. They have to understand that you can get better, you must not break down’.

6. Body Mapping

Body maps can be broadly defined as life-size images of the human body, while ‘body mapping’ is the process of creating body maps using drawing, painting, or other art-based techniques to visually represent aspects of people’s lives, their bodies, and the world they live in (Gastaldo et al. 2012). Body mapping is a way of telling stories, much like how totems contain symbols with different meanings, but whose significance can only be understood in relation to the creator’s overall story and experience (Gastaldo et al. 2012). It originated in South Africa as an art-therapy method for women living with HIV/AIDS in 2002 (Devine 2008; MacGregor 2009; Weinand 2006). The method evolved from the Memory Box Project designed by Jonathan Morgan, a clinical psychologist from the University of Cape Town, South Africa.6 Jane Solomon later adapted this technique to create body mapping, through a narrative process reflecting on living with HIV/AIDS. Since then, body mapping has evolved as a research methodology, but still today there has been no substantive literature to guide the creation and analysis of the rich visual and oral qualitative data that body maps, and body mapping, provide as products and processes, respectively. As Solomon (2002) argues, body mapping has the potential to engage and enable its participants to communicate creatively through a deeper, more reflexive process. Body mapping can be used as: a therapeutic tool, a treatment information and support tool, a research tool, and advocacy tool.

I reviewed the body mapping activities found in Solomon’s original body mapping guide and selected those which had the potential to illustrate my themes (see Table 1-2).
Another crucial aspect of the adaptation of body mapping to my research purposes was time. The original body mapping guide encourages allocating at least five full days of working time, or approximately 30 hours, to complete each body map. Since our activities were done once a week, alongside others group tasks, the body mapping exercises therefore continued for a couple of months.

I analysed the mapped stories in their entirety, including the process of creation (verbatim and field notes), the body map itself, and the narratives that accompany it (testimony and key aspects), as Rose’s (2007) methodology suggests. As shown in pictures 5, 6, and 7, during the creation process the children were able to paint over their body and free to alter their body shape in whichever way they wanted. In the pictures, the marks on their body – related to the HIV status and useful in speaking about stigma – were covered during the last session, when decorating the body. The young people were attracted to, and initially engaged by, this work. However, during the final discussion about whether or not to show their work in the exhibition, they preferred to ameliorate them first. With a potential of over-interpretation, I initially thought that they didn’t want to show their body maps with the marks, so as not to disclose their status. Actually, their explicit motivation was purely an aesthetic one. This is why, in the final work, the drawn bodies were embellished and covered with many layers of colour (Figure 8).
Figure 4: These three painted hands represent the support network. I asked participants whom they ask for help if they may have a problem related to school, health, or other issues. Interestingly, only one of them identified a doctor as an important figure in their network. Author: Pedro.

Figures 5, 6, and 7: The creative process of Augusto. Photo by the author.
Figure 8: The final body mapping of Carlo.
Final Reflections

The works produced during the support group sessions were exhibited during the International Day of the Fight Against AIDS, on 1 December 2017 (Figures 9 and 10). The exhibition took place on an open day at the centre, alongside other exhibited works and without specifying which authors were seropositive. However, the group members wanted to be active ‘coordinators of the exhibition’ and sought to explain their work to the visitors. This raises some concerns on the contradiction that often occurs in the Mozambican society on HIV public disclosure. On one side, young people are advised to keep their status secret by families and health workers to protect them from stigma. On the other side, they are empowered to have a normal life and not to be ashamed of their status. However, it has been a very important act of giving back, where they had a chance to show their abilities and stories to the public, and consequently also to themselves.

Visual arts are useful if we consider that they mitigate, in part, the often demanding issues that researchers face during fieldwork. Through visual arts, for instance, I was able to gain insight into certain aspects of youth reasoning, thinking, aspirations, desires, and ways of handling particular issues. I explored several key themes, including support networks, emotions, and experiences with pain through a critical examination of participants’ visual and oral narratives. It also became an important therapeutic tool, as it helped to analyze and discuss critical aspects related to stigma, adherence, and self-esteem. However, photovoice and body mapping do have some limitations. First of all, they cannot be considered techniques per se, but instead are tools that can complement other research methods, such as individual and family encounters. Secondly, researchers should be cautious in using the ‘visually arresting’ images – e.g. poverty context – rather than focusing on what might be meaningful for the interview participants (Orellana 1999). For example, I noticed my own tendency of preferring images and paintings that, as an outsider, I found unique or aesthetically beautiful but that were meaningless for the young people I was working with. Finally, I think that during the research process, we as researchers should remain critical and reflective about what actually is in practice a ‘child-centred research’, and especially avoid any over-interpretation of youths’ arts works.

Picture 9: The exhibition. Photo by the author.
References


Notes

1 The serostatus is the state of either having or not having detectable antibodies against a specific antigen, as measured by a blood test (serologic test). For example, HIV seropositive means that a person has detectable antibodies to HIV; seronegative means that a person does not have detectable HIV antibodies (https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/1632/serostatus).

2 Most of the young people were affected by HIV through vertical transmission, defined the infection from mother to child during gestation, delivery, or breastfeeding. This means that the HIV status is gradually revealed around the age of 10. This has not always happened in the best way, leaving children in a limbo, confused about the real condition they may be affected by.

3 To protect the identity of the participants, all the names in the article are pseudonymous.

4 Viral load and CD4 cell count are the two surrogate markers of antiretroviral treatment (ART) responses and HIV disease progression. A viral load test shows how much HIV there is in a small sample
of blood. CD4 cell count gives an indication of the health of the immune system (https://www.aidsmap.com).

5 The lower the amount the better. The aim of HIV treatment is to reduce the viral load to a level that is too low to be measured by standard tests. This is called an ‘undetectable’ viral load.

6 The Memory Box Project was a therapeutic technique for women with HIV/AIDS to record their stories, providing a keepsake for their loved ones in a handmade memory box.

7 For ethical reasons, even though I had their permission, the day centre exhibition was the only occasion in which I showed participants’ pictures with people. For other presentations, I have decided to use just photographs without people as subjects.

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