Working paper

Title: Critical reflections on the ethical challenges of researching the lives of people living with HIV

Author: Cesare Di Feliciantonio (School of Geography, Geology and the Environment)

1. Introduction

In summer 2018 I attended a workshop on 'risky methods' in an English university. The workshop was not supposed to be an introduction to 'risky methods' (i.e. involving sensitive topics or people in disadvantaged situations), but an opportunity to discuss tricky issues in-depth among experienced researchers. During one of the activities of the day, one of the facilitators talked about their experience with fieldwork, suggesting explicitly that you don't want to become friend with research participants, you need to establish and keep rigid boundaries, otherwise the situation can be harmful for both the participant and the researcher. Please bear in mind that the own fieldwork experience the speaker referred to involved participant observation in people's homes and everyday lives for a sustained period of time. Given my engagement with feminist and queer geographies and research methods (Di Feliciantonio, 2017; Di Feliciantonio and Gadelha, 2017; Di Feliciantonio, Gadelha and DasGupta, 2017), I asked them how to keep such rigid boundaries and when and where these boundaries exactly end, is the last day of fieldwork a final farewell? Their reply was that you need to remind everyday to your research participants that what you are doing is work, you are not their friend. In relation to boundaries, their suggestion was to change your telephone number once the fieldwork is over in order to prevent participants to get in touch with you as 'friends'. Beyond the impracticality of the suggestion- you can change your phone number but you cannot change your work email address or office location- I felt deeply disturbed by these suggestions, especially coming from someone who is supposed to be a critical geographer whose work relies mostly on ethnography. How can we predicate to enter people lives (physically), stay with them for weeks or even months and then change telephone number in order to avoid personal contact? This was certainly not the first time I heard very 'conservative' positions on fieldwork and the relationship between researcher and researched; however, this time my sense of bothering lasted for days. What disturbed me so much in these words?

In this paper I unpack my sense of discomfort provoked by the words of this fellow geographer by relating it to the ethical boundaries we are increasingly 'strongly encouraged' to follow when doing research on 'sensitive' topics, like gay men living with HIV in the case of my current research project. As a matter of fact, at the time of the workshop I was going through the ethical approval for my research project, so I realized how ethical procedures, as formulated by universities and funding bodies, were the source of my distress for the words I heard at the workshop. In terms of institutional practice, the speaker was probably acting in the best way possible! Risk mitigation sounded accurate, the 'right distance' clearly marked, the positionality of the researcher fully transparent. Is this one of the final results of the 'ethical creep' (Haggerty, 2004) determined by the increasing expansion of ethical committees

and reviews? Shall we leave the contribution of critical, feminist and queer scholarship on situated knowledges and the relationship between researcher and researched (e.g. Browne and Nash, 2010; Gibson-Graham, 1994; Katz, 1994; Nast, 1994; Rose, 1997) to the abstract level of theoretical speculation, while incorporating the prescriptions of committees built around a positivist mode of knowledge and the biomedical sciences (e.g. Chadwick, 1997; van den Hoonard, 2011) into our own fieldwork practices?

The paper addresses these questions through the lenses of critical perspectives on the rationalities behind ethical committees and their guidelines, showing the limitations they pose to the research efforts of critical scholars, notably in the relationship with research participants, the process of knowledge production, and the life experiences and positionality of the researcher. In emphasizing the threat posed by ethical committees on our research efforts, my aim is not to downplay their relevance, but to push towards a rethinking of some of their main instances in order to make them open to critical approaches including research on 'sensitive' topics with 'risky' subjects. This way, the paper responds to the call of those scholars who have studied the negative impact of formal, bureaucratized ethical guidelines and commissions over scholarship in 'unsafe' fields and based on participation, among others (e.g. Church, Shopes, and Blanchard, 2002; Crow et al, 2006; Hamilton, 2002; Hemmings, 2006; van den Hoonard, 2011). In the case of human geography, Dyer and Demeritt have argued that "the prevailing medical model of research governance is unsuited to human geography (and by extension to other social sciences as well) and that its wholesale and indiscriminate application will create more problems than it solves" (2009: 48).

The reflections included in this paper have mostly emerged in relation to my current research project about the life choices of gay men living with HIV in England and Italy. The project relies on different methods (a survey; biographic interviews; interviews with service providers; media discourse analysis); among them, the biographic interviews are the ones posing more 'risks' since they involve my sitting down with the participant for hours. Whenever possible, I follow the guidelines of the biographic narrative interpretive method (BNIM; see Wengraf, 2001), i.e. the interview is realized in two parts. In the first one, I only ask a general question about the participant's life, so the participant is free to talk of whatever they want as long as they want. In the second one, I ask questions based on what (not) said during the first part. Participants are free to use objects or pictures that they feel the need for in order to narrate their life history as they wish. In the case of participants struggling with the chronological sequence of the events they discuss, we use mental maps of time and space. Before starting the interview, I give the participant the possibility to ask me any question that they feel could make them more comfortable in the interview. Quite (un)surprisingly, most of the time their questions are vaguely about the research project and much more about my positionality and my personal interest on the topic. 'Are you gay?' 'Yes.' 'Where are you originally from?' 'A small town in central Italy but I lived in Rome for many years; since the end of 2017 I have moved to England where the research project is officially located.' 'Why HIV?' 'Because I think it still has a great relevance in the life experiences of gay men and in a preliminary study I found out that several gay men tend to move out after being diagnosed with HIV.' 'Are you poz?' 'Yes I am since 2015.' 'Does your partner live with HIV?' 'No, he is negative.' 'Are you always so candid about your HIV status?' 'Only if openly asked and if I feel safe in disclosing it.' This brief introduction to some of my 'research routine' is aimed at contextualizing the ethical issues discussed in the paper in order to better understand some of the challenges faced in the 'field', notably the ways participants might be interested in aspects of the researcher's life beyond the research itself.

2. Ethical guidelines and the research participants

Originated in the medical context, ethical guidelines have often been described as 'paternalistic' by researchers in the social sciences (e.g. Flowers, 1998; Hamilton, 2002; Sieber, Plattner and Rubin, 2002; van den Hoonaard, 2011). As a matter of fact, they assume the researcher 'to know better' what is good for the participant who therefore needs to be protected from possible harm through informed consent procedures. While these assumptions appear extremely important in medical research because of the physical risks involved, they appear at least inopportune in the case of social research since it "does not involve any risks beyond those encountered in everyday life" (Dyer and Demeritt, 2009: 55). In his book (2011), van den Hoonard shows how some groundbreaking studies in the social sciences realized between the 1970s and the 1990s would have not been approved by current ethical guidelines. The protection of the participant is strictly related to issues of privacy, anonymity, and data management, becoming the object of a very careful scrutiny in new regulatory systems like the recent General Data Protection Regulation (GDPR) implemented in the EU since 2018.

In line with the GDPR, for my project I have been advised by one anonymous ethical reviewer to share interviews transcripts with participants only through encrypted, password-protected files. The password should be agreed at the moment of the interview in order to avoid hacking. When going through the information sheet and the ethical guidelines before an interview with a research participant in Milan in late 2018, I explained this procedure. The participant- aged over 60 and uncomfortable with advanced informatics procedures- looked confused while I was giving him this information. Asked whether he had any doubt or question, he asked me quite directly: 'so are you telling me that you can't send me the transcript via email?' In response I repeated the information about the password-protected, encrypted file and he said: 'so you are telling me that you can't send me the transcript via email!'. From there we started a very warm conversation about ethical procedures, the need to guarantee the privacy and anonymity of participants; he understood my discomfort with existing guidelines, but still consenting to be interviewed. One of the most interesting things he said was that it had taken him many years to get to own his life history and be able to talk openly about it, he had nothing to be ashamed of so he was irritated by some rule saying that to access his own interview he needed a special password that he knew he was not going to remember (research diary, November 2018).

Another ethical requirement openly contested by at least two research participants to my project has concerned the use of pseudonyms and the depersonalization of data. The tone of contestation was very similar to the one mentioned above, participants expressing discomfort in not being able to see their real names next to their life histories. For gay men living with HIV the 'second closet' still represents a widespread situation (Berg and Ross, 2014; Di Feliciantonio, 2018); being 'out' of that closet and speak openly about their own condition and lives can therefore represent an act of liberation and empowerment for some. It is not a coincidence that several community organizations of people living with HIV have deployed programmes to support people who are willing to speak publicly about their status. For those who have struggled to deal with HIV, their sexual orientation or other issues but have now managed to be able to be open about them, being said to be in need of 'protection' because the researcher (or the ethical committee) 'knows better' might therefore appear as a form of silencing. The concerns expressed by the research participants to my project resonate with several observations made by fellow social scientists about research participants feeling offended by ethical guidelines. For instance, one of the researchers interviewed by van den Hoonaard "mentioned how the women she interviewed 'were deeply insulted' by her mandated use of consent forms that had to be signed. She was considered a part of the problem the women were fighting against" (2011: 117).

These examples express one the main problems behind the conception of current ethical guidelines: power is conceived as singular and unidirectional, the researched always having less power than the researcher because somehow vulnerable or socially inferior (Shea, 2000). These assumptions collide with the reflections of those geographers researching elites or policy-makers, showing how they have little power or influence over the subjects of their research (e.g. England, 2002; McDowell, 1998; Schoenberger, 1992). Moreover, the increasing adoption of the Foucauldian perspective on power- seen as circular, mobile and diffuse (Foucault, 1982) – has led critical geographers to rethink the relation between the researcher and the researched as complex, rejecting the idea that the power detained by an individual can be automatically transferred to any social context, including the interview (e.g. Pile, 1991; Smith, 2006). For instance, McDowell has discussed how she presented herself to interviewees differently on the basis of "visual and verbal clues" (1998: 2138). However, this kind of reflexive approach often seems to reiterate the idea that the researcher is fully able to understand all the power relations shaping the social world and the space of the interview (Rose, 1997). This way, self-reflexivity has become a sort of routinized exercise in academic texts in social sciences, scholars required to be (apparently) self-reflexive to be considered critical. However, as discussed by Di Feliciantonio and Gadelha, "self-reflexivity cannot be considered as the final scope of our epistemological and methodological efforts, (....). The fieldwork experience cannot be reduced around the 'self-reflexivity' of the researcher, a complex web of power relations need to be taken into account when decentring our subjective positions" (2017: 276). To achieve the goal to decenter the researcher's position as fully self-reflexive subject in the research process, we need to question the mechanisms of knowledge production, notably the idea of the academic as the only 'producer' of knowledge who knows 'more' and 'better' than research participants.

3. Can the researcher learn from research participants?

As anticipated in the previous sections, current ethical guidelines rely on a positivist assumption of knowledge originated for the biomedical sciences: the knowledge (based on the ideals of truth and objectivity) is produced by the researcher who is always in a position of power over the research participants, used to extract data. I'm not trying to argue that social sciences have inherently taken the distance from such a model of knowledge. On the contrary, the traditional idea of the fieldwork across the social sciences was based on the study of a (geographically and socially) distant 'other' (Sluka and Robben, 2012). In this perspective, 'going native' becomes the *other* to what 'proper' research should be; as acknowledged by Fuller, "the inclusion within the research of the 'researcher as person' is interpreted as an apparent inability to distance him/herself from the events in which (s)he is participating, ultimately undermining the authority of the voice of the 'researcher as academic" (1999, p. 221). Against this perspective, an increased number of scholars have called for the adoption of participatory methods and approaches as a way to challenge the separation between researcher and researched by involving participants in some or all stages of the research process, from research project design to dissemination (Pain, 2004).
Scholars engaged in participatory research have challenged the main assumption around the process of knowledge production behind current ethical guidelines seen, among others, as Eurocentric and individualistic, emphasizing the authority of participants (e.g. Kindon and Latham, 2002; Kitchin, 1999, 2001; Sanderson and Kindon, 2004). However, there is a missing dimension in these perspectives, i.e. the impact of the encounter with research participants and the knowledge produced by them over the researcher, their lifecourse and their future research. Exception to this lack of engagement is made by two recent papers by Wimark (2017) and Fois (2017). To reframe the relationship between the research process, emotions

and the lifecourse of the researcher, Wimark (2017) has relied on the interrelation between *känsloläge-* i.e. emotional positioning originated from one's position in the life course- and *känsloupplevelse-* i.e. emotional experiences shaping lifecourse trajectories. Emphasizing the need to rethink the timescale of the research process far beyond the fieldwork, thus including also the researcher's life course, Fois (2017) has proposed a systematic analytical framework centred around *social pathways*, *turning points* and *transitions & trajectories*. In her own words, this framework "stresses the importance of the researcher and his/her cultural, social and institutional background; captures the turning points that affect the research process and how they shape the research(er) life course; and reflects on the ethnographic process beyond the fieldwork transition" (2017: 426). Building on her framework, what I want to suggest in this section is that such a reframing of the timescale and the impact of the research process, based on acknowledging research participants as co-producers of knowledge who influence the lifecourse of the researcher, collides with existing ethical guidelines and the (emotional) distance between researcher and researched as prescribed by the workshop speaker earlier in the paper.

In the case of my research, the encounter with research participants and their knowledge has impacted deeply on my life course and my research trajectory. The focus on HIV within my research arrived accidentally. In 2014 I was in Barcelona for the official fieldwork of my PhD and, given my interest in queer migration, I was conducting a parallel study on Italian and French gay migrants in Catalan capital. After few interviews, I realized that all the guys I had interviewed were living with HIV; thanks to not having institutional requirements because this was an independent project, I decided to focus only on gay migrants living with HIV. The interviews were emotionally challenging but also empowering, with stigma, violence and abuse combined with the will the reinvent one's life and establish new emotional ties.

In 2015 I was back in Rome to focus on completing my PhD. The mental health challenges posed by completing a PhD in neoliberal academia are well documented (Nature, 2019). Driven by the desire to excel as expected by people around me, I was extremely anxious, almost obsessed with work and the need to write. In such difficult time, I also found out to be HIV-positive. While an analysis of my personal journey through the HIV diagnosis goes beyond the scope of this paper, I want to stress how I found a major source of support in the life histories of the research participants I had interviewed in Barcelona; their actions, words and stories became a sort of guidebook for me, indicating me somehow the path to follow in order to go through what I was experiencing and the constant sense of failure I was feeling. While I felt unable to speak to the people closest to me in everyday life, I found in the research participants' life histories a sort of companionship. Thanks to this process of learning and self-discovery I decided to continue the research work started in Barcelona, making it my main research interest, thus turning my academic career and profile.

This process has led me to rethink the ethics of research beyond the current guidelines and towards an *ethics of care*: being aware of how difficult can be to talk about your HIV status in relation to your life, I understood the need to fully reject the idea of 'right distance' as prescribed by the workshop speaker. Since the start of data collection for this project, I have had some research participants texting me about very different topics or in moments of self-doubt about the most disparate things. What should I have told them? Because the interview was over, should I have not answered their questions? Which *responsibility of care* do we have towards research participants in specific situations? Should we not acknowledge the needs and issues of others in the research process, thus emphasizing that the research is not just about ourselves but is an encounter with people who might have different boundaries and requests? I am addressing these questions to emphasize how any research project is situated and relational, therefore ethical guidelines that do not acknowledge this relational character of the research process limit our possibilities as critical researchers, eventually hurting

research participants. A different ethics of care in the case of my research involves acknowledging that some research participants might not have anyone to talk to or have never been able to fully share their life histories. This makes the interview a very cathartic moment for some participants; it is no coincidence that some interviews lasted more than five hours and that several participants have texted me multiple times after the interview to thank me for the possibility to fully express themselves, emphasizing how the interview was a very empowering moment that has helped them to reconsider their attitude towards talking about themselves. These examples fit well with feminist and poststructuralist analyses of the research process; as brilliantly theorized by Gibson-Graham (1994), the social identity of both the researcher and the researched makes the research process but is also made by it.

Conclusions

In a recent paper published in this journal, Miles (2020) argued that institutional and ethical boundaries did not limit intimate and meaningful encounters with research participants in the case of his research with gay men in London, where he decided to interview participants exclusively in public spaces in order to have "a productively intimate meeting that would not cross the boundary into an erotic one as it was down to any institutional ethical requirement" (p. 76). For Miles, institutional ethical review boards "can foster productive, boundaried intimate research" (p.78). Even though Miles' argument appears to be at odds with those contributions in feminist geography and geographies of sexualities stressing the importance of sexual desire and emotions in the research process (e.g. Bain and Nash, 2006; Cupples, 2002; De Craene, 2017; Valentine, 2002), I think his self-reflexive account is important because of its honesty in relation to the boundaries decided by the researcher. On the same time, his support for existing ethical reviews fails to question their bases. Building on critical studies about ethical guidelines and committees, in this paper I have shown how their positivist, biomedical conception of the research process can have a negative impact on research participants who might perceive their voices erased by these institutional practices. Using examples from my current research with gay men living with HIV in England and Italy, I have shown how research participants have contested the GDPR guidelines I was following in relation to the use of pseudonyms and the depersonalization of data, and the sharing of interviews transcripts. Moreover I have shown how these guidelines fix the position of the researcher and the research participants, not addressing important issues around the ethics of care towards research participants required by specific research projects. Following the post-structuralist and feminist reading of Gibson-Graham (1994) as well as recent contributions by Wimark (2017) and Fois (2017), I have shown how the encounter with research participants impacts the researcher's life course well beyond data collection and analysis. In my case, the knowledge shared with me by research participants has allowed me to go through one of the most difficult times of my life, reshaping my academic career.

By discussing the negative impact of existing ethical guidelines, my agenda is not aimed at scrapping them: ethical guidelines are extremely important, there are situations with a strong and clear power imbalance between researcher and researched that require careful scrutiny. However I think the current bureaucratized system does little to really address those imbalances, while making 'risky' research in specific fields (e.g. sexualities) and based on critical approaches extremely difficult to pursue. I believe our academic community- as critical geographers and social scientists- has all the necessary tools to promote a professional self-regulation of ethical issues that might need to be considered on a case-by-case basis. Rather than spending great resources in supporting and reproducing the 'ethical creep' (Haggerty, 2004), universities and funding bodies might better manage their resources by implementing light, peer-reviewed ethical practices (e.g. among researcher working in the same field or using the same research methods) that do not limit our research efforts,

acknowledging the complexity of the research process, beyond the automatic distinction researcher/knowledge producer/detaining power *vs* researched/in need of protection.

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