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# (Un)Ethical Boundaries: Critical Reflections on What We Are (Not) Supposed to Do

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Building on critical readings of the rationalities behind ethical committees and their guidelines, this article analyzes 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 recent research with gay men living with HIV in England and Italy, I show how research participants have contested the General Data Protection Regulation guidelines I was following in relation to the use of pseudonyms and the depersonalization of data and the sharing of interview transcripts. Questioning the fixity of the position of the researcher and the research participants assumed in ethical guidelines, the article explores the impact of the encounter with research participants on the researcher's life course well beyond data collection and analysis, emphasizing the need for a different care ethics. **Key Words:** care ethics, critical geographies, general data protection regulation, institutional ethics, positionality.

In summer 2018 I attended a methodological workshop about the challenges posed by doing research on sensitive topics or with subjects in disadvantaged situations. 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 friends with research participants, that 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 fieldwork experience the speaker referred to involved participant observation in people's everyday lives for a sustained period of time. Given my engagement with feminist and queer geographies and research methods (Di Feliciano 2014, 2017; Di Feliciano and Gadelha 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 your research participants, every day, 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 from getting in touch with you as friends. Beyond the impracticality of this 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 a fellow 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 our 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 I was bothered by the advice for days. What disturbed me so much in these words?

In this article 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 recent research. As a matter of fact, at the time of the workshop I was going through the ethics approval for my research project, so I realized how ethics 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 ethics 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., England 1994; Gibson-Graham 1994; Katz 1994; Nast 1994; Rose 1997; Browne and Nash 2010) 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 Hoonaard 2011) into our own fieldwork practices?

This article addresses these questions through the lenses of critical perspectives on the rationalities behind ethics 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 ethics committees on our research efforts, my aim is not to downplay their relevance but to push toward 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. The article follows the footsteps of fellow human geographers who have constructively engaged with institutional ethics (e.g., Cahill, Sultana, and Pain 2007; Elwood 2007; Martin and Inwood 2012; Price 2012; Eriksen 2017), as well as those of scholars across the social sciences who have studied the negative impact of formal, bureaucratized ethics guidelines over scholarship in “unsafe” fields and based on participation, among others (e.g., Church, Shopes, and Blanchard 2002; Hamilton 2002; Hemmings 2006; van den Hoonaard 2011).

The reflections included in this article have mostly emerged in relation to my recently completed research project about the life choices of gay men living with HIV in England and Italy. The project relied on different methods (a survey; biographic interviews; interviews with service providers; media discourse analysis); among them, the biographic interviews were the ones posing more risks because they involved me sitting down with the participant for hours. Whenever possible, I followed the guidelines of the biographic narrative interpretive method (see Wengraf 2001); that is, the interview was realized in two parts. In the first one, I only asked a general question about the participant’s life, so the participant was free to talk about whatever they wanted, for as long as they wanted. In the second interview, I asked questions based on what had (not) been said previously. Participants were free to use objects or pictures that they felt the need for in order to narrate their life history as they wished. In the case of participants struggling with the chronological sequence of the events they discussed, we used mental maps of time and space. Before starting the interview, I gave the participant the opportunity to ask me any questions that they felt could make them more comfortable in the interview. Quite (un)surprising, most of the time their questions were vaguely about the research project and much more about my positionality and my personal interest on the topic. The most frequent were the following: “Are you gay?”; “Where are you originally from?”; “Why HIV?”; “Are you poz?”; “Does your partner live with HIV?”; “Are you always so candid about your HIV status?”. This brief introduction to some of my research routine is aimed at contextualizing the ethical issues discussed in the article in order to better understand some of the challenges faced in the field, notably, how participants might be interested in aspects of the researcher’s life beyond the research itself.

## Ethics Guidelines and the Research Participants

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Originated in the medical context, ethics 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 be “a powerful, knowing agent who assembles a scientific methodology that is always of potential harm to the researched” (Martin and Inwood 2012, 7). The participant therefore needs to be protected from possible harm through protocols and informed consent procedures. Though these assumptions appear important in medical research because of the physical risks involved, they appear at least inopportune in the case of social research because it “does not involve any risks beyond those encountered in everyday life” (Dyer and Demeritt 2009, 55). For Dyer and Demeritt (2009, 48), “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.”

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 European Union since 2018. In line with the GDPR, for my project I was advised by one anonymous ethics 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 ethics 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 doubts or questions, 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 ethics procedures and 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 ethics requirement openly contested by at least two research participants 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”—that is, the nondisclosure of HIV status in order to avoid social condemnation—still represents a widespread situation (Berg and Ross 2014; Di Feliciano 2020); being out of that closet and speaking 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 programs 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 ethics committee) “knows better” might therefore appear as a form of silencing. The concerns expressed by the research participants in my project resonate with several observations made by fellow social scientists about research participants feeling offended by ethics guidelines. For instance, one of the researchers interviewed by van den Hoonaard (2011) “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” (117).

These examples express one of the main problems behind the conception of current ethical guidelines: Power is conceived as singular and unidirectional, with the researched always having less power than the researcher because they are somehow vulnerable or socially inferior (Shea 2000). These assumptions collide with the reflections of those geographers researching elites or policymakers, showing how they have little power or influence over the subjects of their research (e.g., Schoenberger 1992; McDowell 1998; England 2002). 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 held by an individual can be automatically transferred to any social context, including the interview (e.g., Pile 1991; Smith 2006). For instance, McDowell (1998) has discussed how she presented herself to interviewees differently on the basis of “visual and verbal clues” (2138).

However, this kind of reflexive approach often seems to reiterate the idea that the researcher is fully able to understand all of the power relations shaping the social world and the space of the interview (Rose 1997). Thus, self-reflexivity has become a sort of routinized exercise in academic texts in social sciences in which scholars are required to be (apparently) self-reflexive to be considered critical. However, as discussed by Di Feliciano and Gadelha (2017), “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 decentering our subjective positions” (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.

### **Can the Researcher Learn from Research Participants?**

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As anticipated in the previous sections, current ethics guidelines rely on a positivist assumption of knowledge originated for the biomedical sciences: 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 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 (1999), “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’” (221). Against this perspective, an increasing 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 ethics guidelines seen, among others, as Eurocentric and individualistic, emphasizing the authority of

participants (e.g., Kitchin 1999, 2001; Kindon and Latham 2002; Sanderson and Kindon 2004). According to Manzo and Brightbill (2007), the adoption of a participatory ethics requires rethinking the dimensions of representation, accountability, social responsiveness, agency, and reflexivity involved in the research process. Discussing the experience of one participant in their London-based participatory project on young people's experiences of home, Dickens and Butcher (2016) highlighted the importance of conducting research that supports participants' aspirations and rights to develop their own voice through negotiated, specific conditions of visibility that challenge conventional ethics concerns around anonymity.

However, there is a dimension often missing in these perspectives; that is, the impact of the encounter with research participants and the knowledge produced by them over the researcher, their life course, and their future research. Two recent papers by Wimark (2017) and Fois (2017) represent exceptions to this lack of engagement. To reframe the relationship between the research process, emotions, and the life course 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 *känsloupplävelse* (i.e., emotional experiences shaping life course 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 centered around *social pathways*, *turning points*, and *transitions* and *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" (Fois 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 life course of the researcher, collides with existing ethics guidelines and the (emotional) distance between researcher and researched as prescribed by the workshop speaker discussed earlier in the article.

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 the Catalan capital. After a few interviews, I realized that all of 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; stigma, violence, and abuse combined with the will to 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 ("The Mental Health of PhD Researchers Demands Urgent Attention" 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. At such an already difficult time, I also found out I was HIV-positive. Though an analysis of my personal journey through the HIV diagnosis goes beyond the scope of this article, 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 to me somehow the path to follow in order to go through what I was experiencing and the constant sense of failure I was feeling. VR (Italian living in Barcelona, aged 31–35) was probably the research participant I could see myself in (background, education, self-narrative) the most, so the interview with him was particularly inspirational, notably the following extract (among many):

You see yourself going down, down, you are ashamed of yourself, you feel like you have no one to really talk to because after all you don't want to really talk to yourself, and you feel like you are going even further down, but you see it and somehow you don't want to stop it. (...) One day, at a very precise moment, and I can tell you I recall exactly that moment, you say, "That's enough, I can't go further down." (...) That's when the current path I'm on restarted. (...) I'm not a fool, my path is not linear, I have never known linearity in my life, some days are very difficult and all the shit returns to the surface, but I know what I need to do, I know where I want to go, I know where I want to be with myself.

While I felt unable to speak to the people closest to me in everyday life, I found in VR and the research participants' life histories a sort of companionship, so I listened to the interviews over and over, finding inspiration on how to approach what I was living. 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. The boundaries between research (or the field) and personal life were crossed, bringing me to rethink the ethics of research beyond existing guidelines (for a discussion on boundary crossing in ethnographic research,

see Zhang 2014) in ways that could account for my emotional investment in the research as well as for the specific needs of research participants beyond the abstract principles of anonymity and informed consent.

Which *responsibility of care* do we have toward ourselves and research participants in specific situations? How do we acknowledge the needs and issues of others in the research process, thus emphasizing that the research is an encounter with people who might have different boundaries and requests? These questions resonate with the call for a *care ethics* raised by an increasing number of scholars in human geography (e.g., Lawson 2007; Conradson 2011; Ritterbusch 2012; Askins and Blazek 2017). According to Lawson (2007, 3), “Care ethics begins with a social ontology of connection: foregrounding social relationships of mutuality and trust (rather than dependence). Care ethics understands all social relations as contextual, partial, attentive, responsible and responsive.” Acknowledging the central role of emotion in care relations, Askins and Blazek (2017) proposed a project based on *caring with* as an affirmative ethics generating relationships around social justice, “a conscious political stance enveloping practices of caring-for and -about collectively as a cornerstone of our academic identities, presents and futures” (1098). These contributions emphasize how any research project is situated and relational; therefore, ethics guidelines that do not acknowledge these characteristics 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 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 helped them to reconsider their attitude toward talking about themselves. The following series of texts received by Thomas, one of the research participants living in Milan, reveals the intensity and ambivalence of the emotions generated by the interview:

*I am not sure I want to do the second part [of the interview], is it a problem? This is a bit too much for me* (text received right after the end of first interview)

*Thanks Cesare, yesterday was really important* (text received the following day)

*I am so happy to do this, it has helped me to figure out some things* (text received in response to my

invitation for the second interview some weeks after the first one)

Being aware of how difficult it 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 in order to deal with the complex array of emotions faced by research participants. Since the start of data collection for the project, I had research participants texting me about very different topics or in moments of self-doubt about the most disparate things. For instance, one night I received a long message from 1904, clearly under stress, asking suggestions on how to hide antiretrovirals in his upcoming trip to Dubai.<sup>1</sup> What should I have told him? Because the interview was over, should I have not answered his questions? When does the responsibility of care toward research participants end? These questions address the issue of exiting the field(work), a theme of increasing scrutiny across the social sciences (e.g., Reeves 2010; Michailova et al. 2014), including human geography. In one of the milestone papers on the topic, Katz (1994, 72) argued that she was “always, everywhere in ‘the field’” and that her position as a woman and an ethnographer was constituted of “spaces of betweenness.” The fieldwork cannot be bounded geographically or temporarily; it cuts across different times and different scales (Nast 1994; Di Feliciano and Gadelha 2017).

In relation to research on sensitive topics—as in the case of my research—Watts (2008) connected the issue of exiting the fieldwork with the emotional impact of conducting ethnographic research in a cancer drop-in center as a lone researcher. Facing the death of research participants made him “aware of the importance, within sensitive qualitative research of this kind, of self-care strategies and establishing a support network where feelings of distress can be unloaded” (Watts 2008, 10). Following similar concerns in relation to research on violence, Lopez and Gillespie (2016) called for the recognition of a “buddy system” in research as a practice of *caring with* one another, their call informing “the need to reform academic structures through enriching the ethics review process to consider the impacts of the research *on the researchers*, not just on those we study” (1698). Sharing her own experience with vicarious trauma in ethnographic geographical research about bushfires in Australia, Eriksen (2017) invited ethics committees to consider the researcher’s mental health, possibly through liaising with professional and organizational development services and workplace health and safety units. Taken together, these contributions address the need to reform institutional ethics in order to account for the vulnerability of the researcher, meant here, in line with Behar (1996), as their emotional involvement with the research subject.

## Conclusions

In line with critical studies about institutional ethics, in this article I have shown how the positivist, biomedical conception of the research process in ethics guidelines can have a negative impact on research participants who might perceive their voices erased by these institutional practices. Using examples from my recent research with gay men living with HIV in England and Italy, I have shown how research participants contested the GDPR guidelines I was following in relation to the use of pseudonyms and the depersonalization of data and the sharing of interview 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 toward research participants required by specific research projects. Building on 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.

Following several examples within human geography (e.g., Elwood 2007; Price 2012; Lopez and Gillespie 2016; Eriksen 2017), my discussion of the negative impact of existing ethics guidelines is not aimed at suggesting to reject them outright. Human geographers have contributed to the debate on institutional ethics in a critical but constructive perspective, avoiding to frame it as a mere roadblock. Reflecting on the different assumptions behind institutional versus participatory ethics—the former assuming that problems and risks can be fully anticipated, the latter framing ethical dilemmas as situational—Elwood (2007, 331) noted how “for university-based researchers it is increasingly not a matter of choosing one or the other, but developing ways of practicing both simultaneously in spite of their contradictions.” Price (2012) pushed the dislocation of the boundaries between institutional and participatory ethics even further, inviting fellow geographers to see the institutional review boards “as an interconnected collaborator among many versus an insular ‘other’ to the research process” (39). Building on her own experience as institutional review board chair, Price (2012) offered some practical suggestions on how geographers might constructively engage with ethical committees, notably by (1) volunteering to serve on them in order to challenge the overrepresentation of members from the biomedical sciences; (2) becoming familiar with the regulations in order to identify gaps; and (3) helping committees with the interpretation of existing guidelines which are often vague. Price defines these strategies as part of a “politics of place” (2012, 40) that has the ability to reshape institutional practices and therefore the

working conditions of fellow researchers, potentially at multiple scales. Price's suggestions are compatible with the reforms of institutional ethics invoked by Lopez and Gillespie (2016) and Eriksen (2017) discussed in the previous section. Their calls are based on the acknowledgment of the emotional impact of the research process over the researcher, an issue usually ignored within existing ethical guidelines.

Rather than a bureaucratized, time-consuming and box-ticking exercise, ethics reviews should be an inspiring moment of professional growth to reflect upon the multiple and complex implications (on research participants, on different publics and society more generally, on ourselves) of our research practices not just during the official life span of a project but also in its aftermath. These implications cannot be fully anticipated as prescribed by existing guidelines but require a more flexible and open approach. I believe our academic community—as critical geographers and social scientists—owns all of 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 ethics practices (e.g., among researchers 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/holding power versus researched/in need of protection. At the same time, additional resources might be destined to support researchers through their emotional and mental health needs in multiple forms, whether it be the buddy system envisaged by Lopez and Gillespie (2016) or the professional services discussed by Eriksen (2017). These would be useful steps toward the recognition of the situated and relational character of social science research as well as the need to assume *care* (for ourselves and others) as the core principle of our research practices. ■

## Note

<sup>1</sup> United Arab Emirates is one of the countries in the world where there is a full travel ban for people living with HIV. See <http://www.hivtravel.org/Default.aspx?PageId=143&CountryId=189> (last accessed November 9, 2020).

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