Relatively normal? Navigating emergent sensitivity in generating and analysing accounts of ‘normality’

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Abstract

This article describes methodological and ethical issues associated with examining discourses of ‘normality’ in the context of the normalisation of HIV and relationships. It considers how sensitivity was anticipated, encountered and managed in the recruitment of participants and during research interviews, discussing the implications of these in this project. It reflects on the tensions present when generating data on topics externally deemed to be ‘sensitive’ but considered ‘normal’ by participants. In doing so, it has wider relevance for research on experiences that were once prohibited but are now considered normative in some settings, such as gay marriage. However, highlighting the importance of ‘the normal’ in notions of stigma, it concludes that potentially any research project that examines or questions ‘normality’ may give rise to sensitivity, emphasising the importance of reflexivity in assessing and managing sensitivity throughout the research process.

Key words

HIV, serodiscordant relationships, sensitivity, normalisation
Sensitive research is often defined by its engagement with topics that intrude into the private sphere, or those that relate to non-normative, taboo or stigmatised subjects (Dickson-Swift et al., 2008; Lee, 1993). Despite the methodological challenges posed by research which provokes sensitivity, it has proven to be a rich seam for sociological investigation, partly because the sensitivity itself signals phenomena of social significance (Dickson-Swift et al., 2008; Lee, 1993). At the other end of the spectrum, the everyday and the ordinary have also been the focus of a significant sociological literature (Jacobsen, 2009). In contrast with a traditional sociological focus on the unusual or deviant (Lee, 1993), a sociological examination of the ‘normal’ has merit precisely because it is often overlooked (Scott, 2018). Researching the ‘normal’ is associated with methodological challenges, because its taken-for-granted nature means that it is often hidden or unseen but it is rarely associated with the challenges of sensitive research. However, as the other papers in this collection attest, problems associated with sensitivity can also arise in otherwise uncontroversial research (see Tilley et al. and Robb in this issue). Recognising the importance of context for making research sensitive (or not), Lee suggests considering the conditions in which sensitivity arose in the research process rather than seeking to define sensitivity only in terms of its subject matter (Lee, 1993). This approach shifts the focus from the subject of research towards its conduct.

Here we adopt Lee’s approach to consider how sensitivity arose in relation to questions of normality drawing on interview data and reflexive journal entries from a qualitative investigation into the lived experience of thirty gay and bisexual men living in the UK who have a different HIV status to their partner (Witney, 2020). Here, reflexivity refers to an examination of both the researcher’s relationship to the data (Finlay, 2011) and the influence of epistemological commitments on the research (Braun & Clarke, 2019). We
explore how competing discourses of HIV stigmatisation and normalisation produced sensitivity in the research encounter and reflect on how its emergence was managed. Finally, we outline the methodological implications for other researchers working in subject areas which bridge processes of normalization and stigmatization.

Relationships where the partners have different HIV statuses (known variously as serodiscordant, sero-different or ‘magnetic’ relationships) have been the focus of medical and sociological study since early in the HIV epidemic (Mendelsohn et al., 2015). Serodiscordant relationships were considered sites of significant transmission risk, particularly with evidence of inconsistent condom use in sexual activity (e.g., Prestage et al., 2009). As a result, such relationships have been subject to stigma (Persson, 2013). However, recent medical research has demonstrated that effective antiretroviral therapy prevents sexual transmission (‘treatment as prevention’ or TasP), even in the absence of other methods of prevention (Rodger et al., 2019). While some point out the potential of this ‘medical breakthrough’ to make subordinate the complex social aspects of the epidemic (Nguyen et al., 2011) others have taken this as an opportunity to reframe serodiscordant intimacy, as safe and legitimate (Philpot et al., 2018) and normalise HIV in order to address stigma (Prevention Access Campaign, 2017).

Goffman (1963) highlights the importance of notions of normality in both creating and resisting stigma. Research with serodiscordant couples has shown that treatment underpins a sense of normality and sameness with other couples and thus may be key in addressing the experience stigma (Hughes, 2017). However, normalised discourses of HIV do not go uncontested and stigmatising tropes still dominate broader social discourse (Walker, 2019). Thus people in serodiscordant relationships often remain silent about their
circumstances to avoid stigma (Persson, 2008). Contemporary serodiscordant relationships occupy a space between normalising and stigmatising discourses, with partners drawing on these and their own experiences to articulate new ways of ‘doing’ serodiscordant intimacy (Philpot et al., 2018). In this article, we argue that in the context of an ongoing processes of normalisation and continued stigmatisation, sensitivity can emerge in unexpected and novel ways. This paper draws on reflexive journal entries generated during TW’s PhD research project and is hereafter written in first person singular. However, as TW’s supervisor and collaborator, PK worked closely with TW on framing the problem and developing the concepts presented in the article and inputted substantially into drafts.

**Nothing to see here: An initial encounter with ‘normal’ sensitivity**

My first encounter with sensitivity occurred before I had recruited any participants and before the study had received institutional ethical approval. Though I was in the process of preparing an ethics application that outlined the potentially sensitive nature of the interviews I was planning, this focused on ‘traditionally’ sensitive aspects, such as relationship intimacy and a stigmatised health condition, or the potential ethical implications of interviewing couples together and apart. There is a large body of research on HIV and relationships, with serodiscordant relationships forming a significant proportion of this literature; I was confident that this project was academically and ethically sound. However, I had not considered that the research question itself would give rise to sensitivity. Yet a chance encounter with someone who could have been eligible to participate in the research vividly brought that possibility to life, as the following research diary extract illustrates:

*I was at a friend’s birthday party enthusiastically talking with some people I had met for the first time that evening about my research on serodiscordant relationships and how interesting I found the topic. As I was talking, I noticed another partygoer on the periphery of our conversation, arms folded, stern faced; a stark contrast to the others. “There’s nothing*
interesting about our relationship, I don’t know why you need to do a study. My boyfriend is positive, he’s on treatment and that’s it. Our relationship is normal,” he said. Despite me agreeing and explaining that my motivation for doing the research was to describe the reality – and normality – of serodiscordant relationships, his hostility remained.

Reflecting on this experience, I felt sheepish. In my enthusiasm I was concerned that I had inadvertently used stigmatising language. I worried that, as someone who was not in a serodiscordant relationship myself, my interest in the subject was not legitimate. Although I reassured myself that these concerns were unfounded, I could not fully answer the potential participant’s charge that by selecting serodiscordancy as something worthy of study, I was problematising the relationships I sought to examine. I had not considered that participants might object to the idea that their relationships were legitimate objects of study. In the context of a stigmatised condition such as HIV, notions of normality become entwined with discourses of stigmatisation and de-stigmatisation (Hughes, 2017). My research could potentially upset this balance and, in doing so, re-enact the social stigma potential participants were resisting. Lee (1993) also highlights how, irrespective of the topic, becoming the subject of research can itself be stigmatising. This experience began a process of reflection on, and navigation through, the normality (or otherwise) of HIV at the core of discourses of normalisation that were central to my enquiry, in dialogue with institutionalised understandings of sensitivity and research ethics.

Investigating a ‘new normal’?

The first impact of the experience above was on my framing of the research and recruitment for the study. Although sampling participants from a particular population can be time consuming (Boynton, 2017), after an initial recruitment call yielded no responses at all, my concerns about potential participants’ resistance towards participating in my research were compounded. Various guides and guidelines (Dickson-Swift et al., 2008; Lee, 1993;
The British Psychological Society, 2014) stress the importance of respecting participants’ autonomy, making research voluntary and ensuring participants understand their right not to take part in research. But while these guidelines recognize that people who could take part may choose not to, they do not provide guidance on the potential range of meanings attached to participants not taking part, nor how researchers should respond to non-participation.

Although a lack of participation could be explained by an ineffective recruitment strategy, non-participation in an activity can also be conceived of as an act of resistance (Scott, 2018). The experience of a hostile reaction from a potential participant loomed large. In response to an imagined participant who was reluctant to become involved in a study that might be embedded in ‘old’ stigmatizing narratives of HIV, I focused my recruitment materials on the change and progress in HIV treatments and HIV prevention, and emphasised the need for research to reflect this new situation. However, attempting to avoid sensitivity and stigma by writing the recruitment materials this way firmly allied the study with ‘normalised’ discourses of HIV. The following extract from the participant information sheet shows how I constructed ‘treatment as prevention’ as a normalising phenomenon through its impact on transmission risk:

A lot of research into mixed-HIV-status relationships has focused on sex and risk before the role that treatment can play in preventing transmission was fully understood. ‘Treatment as prevention’ provides an opportunity to look again at this subject, but also to move away from looking at risk alone and to consider the broader experience of being in a relationship.

Reflecting on these materials later in the research process, I recognised that although my motivation for communicating my research in this way was primarily a pragmatic response to a perceived distrust or suspicion in my project and an attempt to manage or mitigate sensitivity, it also led to me adopting a very visible position within a process of social change which I hoped to study through the research. While locating myself within a social constructivist ontology which eschews the concept of objective or unbiased positions, I
later became concerned as to whether emphasising one position, while attempting to examine experiences from a range of alternative positions, closed down rather than opened up the focus of my enquiry: did couching my research within normalizing discourses imply an invitation for positive stories of relationships in which HIV was not an issue? Would this potentially alienate those for whom this did not ring true and make them less likely to participate in the research?

Navigating potential stigma

Whether or not it was due to the new strategies I deployed, ultimately, this recruitment approach was successful and I interviewed several participants. Bearing in mind my previous experience, even when piloting the interview schedule, I became sensitized to suggesting to participants that serodiscordancy was not normal. This led me to approach the question of its relevance in an indirect way during interviews. Although a focus on the everyday was theoretically and methodologically justified in my research, when I explained this to participants, this often served as an opportunity for me to stress that I wasn’t ‘just interested in HIV.’ This further reinforced to participants my focus on serodiscordancy as something part of the everyday and thus ‘normal.’ Consistent with this approach, I constructed the interview schedule to ask open questions about serodiscordancy in the context of a broader understanding of participants’ everyday relationship experiences. However, on reviewing the recordings and transcripts from the interviews, as well as my own reflection on the experience of conducting the interviews, I noticed I departed from the question construction in the guide when it came to asking participants about their experiences of serodiscordancy, instead deploying phrasing which suggested an ambivalence towards the relevance of HIV to their relationship.

[Interviewer] Erm, and so we’ve talked about a few, kind of, factors that
influence your relationship, or make it what it is. I kind of have to ask, what role does HIV play in your relationship, if anything?

Individual interview 14-01

I reflected that this phrasing helped me demonstrate to participants that I did not automatically assume that HIV was important in the everyday experience of a serodiscordant relationship. This allowed me to position myself as open to the response that it was not relevant. In order to remove potential sensitivity from the research encounter I also introduced a rhetorical distance between myself as the embodied interviewer asking the questions, and the (distant) creator of the interview schedule, ‘I have to ask.’ In later interviews, I increased this distance, bringing in an additional party to the interviewer-participant dynamic, the university. In presenting the institution as not just a passive supporter of research but a powerful governor of its conduct and my employer, I foregrounded obligations often invisible during research encounters in order to minimise my agency in the conduct of the interview.

[Interviewer] There’s some general topics, there might be some stuff that you’ve got to say, there might not be. [but] if we don’t talk about HIV I’ll probably get sacked from my studentship!

Couple interview-06

Joking with participants that I was obliged to ask about HIV in order to keep my job, signalled my ambivalence about its relevance while also retaining it as a topic of discussion in the couple interview. Despite the fact that in this instance the participants laughed with me, even in jest, I suggested that the reason we were discussing the topic was not because of its relevance to the research, but because of a need to satisfy the institutional requirements. Although the phrasing of these questions could be considered poor interview technique, or potentially deceptive, I reflected that in the context of the interview these were techniques which helped to maintain rapport with participants, many of whom had already spoken about
how little HIV featured in their day-to-day relationship. These rhetorical ‘fig leaves’ that I adopted during the research process further helped me position myself as a sympathetic researcher who was sensitive to the idea that viewing serodiscordancy as non-normative was linked to stigmatizing discourses of HIV. Adopting the view of the interview as a social interaction and applying Goffman’s analysis of the management of identity (1963) emphasises the importance of creating ‘normality’ through the interaction in order to manage stigma. The importance of these strategies was further emphasized when I began to analyse interview data, in which the contested nature of normality was a key factor for participants in relation to how they talked about their relationship with others (Witney, 2020). The idea of serodiscordancy being a normal, untroubled state was underpinned in participants’ accounts by biomedical discourses which construct HIV as rendered unthreatening or irrelevant by antiretroviral treatment. Whether others were already familiar with these ideas was a key factor for many participants in deciding whether to discuss their serodiscordancy or not. Thus navigating the contested nature of ‘normality’ in the context of serodiscordancy appeared to be a crucial consideration for participants, and underscored the importance of my drawing on and emphasizing discourses of normality in presenting the research to potential participants and throughout the research process.

**Discussion**

I have explored how unexpected sensitivity emerged during a research project in relation to issues of ‘normality.’ I argued that it centres on the position of serodiscordant relationships in relation to discursive tensions generated by discourses of normalization of HIV, rather than being related to the ‘sensitive’ subject of HIV and relationships itself. My experience of the research, first becoming aware of an unexpected sensitivity, consciously and unconsciously managing it during the research and reflecting on it during analysis, has led to my
understanding of the crucial role that ideas of normality play in creating and counteracting stigma and thus in creating or diminishing sensitivity. Beyond the specific context of this research, the issues discussed here may be relevant for researchers active in settings or subject areas where discourses of normality are deployed to claim equality for or the validity of stigmatised identities, such as Muslim identity among teenagers in Australia (Harris & Karimshah, 2019). However, in exploring my responses to the emergent and dynamic sensitivity, I am not suggesting a blueprint of techniques to manage such research. Instead, I am highlighting the importance of both personal and epistemological reflexivity (Braun & Clarke, 2019; Finlay, 2011) on the part of the researcher with regard to the way in which competing discourses of normal/not-normal are articulated during each stage of the research process.

Claims to normality are often a feature of arguments for equal treatment of minorities and have been deployed in narratives about gay and lesbian foster carers (Hicks, 2005), the validity of same-sex relationships (Heaphy, 2018) and the othering of minority ethnicities (Harris & Karimshah, 2019). Punch (1994) argues that researchers must do more than simply respect their participants or treat them with courtesy; they should actively work to elucidate imbalances of power and work towards eliminating them. I share a commitment to empowering participants (Tisdale, 2004) and recognise that enabling participants to share their stories in their own words can play an important part in shaping norms and addressing stigma (Persson et al., 2016; Plummer, 1995). Yet the experience of this project highlights the embeddedness of researchers within social power relations. Thus the benign intent of an individual researcher cannot on its own address or compensate for wider social processes of stigmatisation and normalisation. This stresses the importance of engaging with sensitivity beyond ‘tick box’ definition within ethics applications and highlights the need to be attuned
to participants’ concerns about all aspects of the research, up to and including the research question itself. Furthermore, by approaching sensitivity as an emergent phenomenon that is interpreted differently by institutional ethics committees, researchers and – importantly – participants this analysis foregrounds the power inherent in defining and ‘fixing’ definitions of sensitivity. It also demonstrates how formal definitions of sensitivity are navigated, negotiated and resisted in practice. This highlights how concepts of ‘sensitive’ and ‘normal’ are not mutually exclusive binaries but can co-exist as lenses through which to better understand lived experience (Hathaway et al., 2011).

In the context of normalized or normalizing phenomena, this article underlines the importance of reflection on and engagement with the discourses of normality that participants are negotiating in and, in particular, the relevance of these to issues of stigma and accompanying sensitivity. Although it is important that researchers retain their freedom to critique both stigmatising and normalising discourses, it is also important to consider the dynamics of power relations and stigma in deploying criticism of normalisation.

More broadly, the issues discussed here point to a methodological tension between the way in which researchers and ethics committees construct their research participants and the way in which participants construct themselves. As well as the stigmatising potential of being researched itself, Lee points to the role that implicit assumptions about research play in the potential for divergent interpretations to arise between the researcher and researched; a study seen as problematic by one group can be thought innocuous by another (Lee, 1993). However, drawing on Goffman (1963) and the importance of the presentation of ‘normality’ in avoiding stigma, illustrates how research that positions participants as outside normative bounds has the potential to generate stigma. This phenomenon is often most immediately obvious in studies engaged with ‘sensitive’ topics, but could arise in any study in which questions of normality are at stake. This analysis disrupts ‘static’ approaches to
understanding sensitivity in the research process traditionally used in ethical assessment and highlights the need for a more nuanced and reflexive approach to assessing and managing sensitivity throughout the research process.
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(Cross references with articles within the special issue to be added at typesetting/proof stage)


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