

Chapter 12

Privacy as a Practice: Exploring the Relational and Spatial Dynamics of HIV-Related Information Seeking

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12.1 Introduction

This paper is an exploration of the relational and spatial dynamics of privacy practices in the context of HIV-related information seeking. It is a study of how a specific group of people, African women living with HIV in London, go about “doing privacy” while seeking health information in relation to living with HIV. Based on material (primarily qualitative interviews, but including focus groups and observations) collected as part of a broader research project on Internet use by women living with HIV, the paper explores alternative methods for researching privacy as an embedded and contingent practice. More specifically, it does so in the context of an increasing interest in the use of the Internet as a source of health information for people living with a stigmatised illness.¹ While the literature on privacy has long stressed that what is considered private information is highly contextual,² until relatively recently there has been little in-depth empirical work that attempts to unwrap what constitutes that context across different domains. However, if we are to develop socially sensitive privacy policies and protection mechanisms this is a necessary first step.

During the course of this research when participants spoke of seeking information and support in relation to HIV they supplemented what they were doing and how they were doing it with where and in relation to whom they did it. Therefore, HIV-related information seeking was articulated as strongly relationally and spatially contingent. Building on this we focus on the relational and spatial parameters

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¹Magdalena Berger et al. Internet use and stigmatized illness. *Social Science & Medicine* 61 (2005): 1821–1827.

²Alan Westin, *Privacy and Freedom* (New York: Atheneum, 1970); Irwin Altman. *The Environment and Social Behaviour* (Belmont, California: Wadsworth Publishing Company, 1975); Ferdinand Schoeman, *Privacy and Social Freedom* (Cambridge: Cambridge University Press, 1992); Helen Nissenbaum, *Privacy in Context* (Stanford, California: Stanford University Press, 2009).

of privacy practices. Of particular interest in this is how these parameters were not reducible to or superimposable on traditional demarcations of public versus private spheres. Rather than equating the private with the domestic, participants spoke of how they worked towards making things private across different spheres. From this perspective our focus on privacy is not on privacy as a state – for example, privacy as intimacy – but rather privacy as an accomplishment – for example, privacy for intimacy.³

The paper is structured as follows. The following section gives an overview of the literature on privacy that informed the analysis, combined with a brief background to the empirical case under consideration and an outline of the methods used. Next the substantive portion of the paper is broken into two sections. The first is an exploration of the tension participants expressed around seeking information and support in relation to HIV while simultaneously keeping information about an HIV positive diagnosis private. The second section describes privacy practices in relation to information seeking on the Internet in more detail, and specifically how a sense of place continues to persist and shape online interactions. Given the widely accepted emphasis on the embedded “everyday” nature of Internet use generally⁴ and with regards to health more specifically,⁵ this latter discussion is situated within the broader understanding of the landscape of relationships and spaces developed in the preceding section.

12.2 Background and Context

When faced with health concerns people seek out information and support from a range of sources, such as family and friends, allopathic and alternative healthcare practitioners, books and magazines, and more recently the Internet. These informal and formal help seeking practices, or “lay” referral systems, have long been recognised as important for people’s health.⁶ Numerous factors, such as culture, age, gender, type of illness, formal healthcare infrastructure, income and education have

³Ferdinand Schoeman. *Privacy and Social Freedom* (Cambridge: Cambridge University Press, 1992).

⁴Barry Wellman and Caroline Haythornthwaite. *The Internet in Everyday Life* (Oxford: Blackwell, 2002); Leslie Haddon, *Information and Communication Technologies in Everyday Life: A Concise Introduction and Research Guide* (Oxford: Berg, 2004); Maria Bakardjieva, *Internet Society: The Internet in Everyday Life* (London: Sage, 2005).

⁵Sarah Nettleton et al. “The mundane realities of the everyday lay use of the internet for health, and their consequences for media convergence.” *Sociology of Health & Illness* 27 (2005): 7; Joelle Kivits. “Researching the ‘Informed Patient’: The case of online health information seekers.” *Information, Communication & Society* 7 (2004): 4; Elizabeth Sillence et al. How do patients evaluate and make use of online health information? *Social Science & Medicine* 64 (2007): 1853–1862.

⁶Eliot Freidson, “Client Control and Medical Practice.” *The American Journal of Sociology* 65 (1960): 4; David Mechanic. *Medical Sociology* (New York: Free Press, 1968); John B. McKinlay, “Social Networks, Lay Consultation and Help-Seeking Behavior.” *Social Forces* 51 (1972): 3;

all been suggested as playing a role in how, why and where people search for health information. However, one aspect of information seeking that has received relatively little attention is the tension between that which is sought and that which is withheld. This tension is particularly relevant in the case of stigmatised illness where peoples' unwillingness to disclose information has been shown to have a negative impact on their ability to seek out help.⁷ It has been suggested that the Internet, in enabling people to search for information with relative anonymity, has the potential to be a privileged source of information about stigmatised illness.⁸ In this paper we explore this tension, and use of the Internet in relation to it, in more depth in the context of HIV-related information seeking by African women living with HIV in London.

In 2009 there were an estimated 89,531⁹ people living with HIV/AIDS in the UK, with people identifying as "black African" constituting the second largest group.¹⁰ In the last UK census there were over 480,000¹¹ people recorded as living in England who self-identified as "black African",¹² (0.97% of the population), over three-quarters of whom were living in Greater London.¹³ Considering these regional discrepancies, it is unsurprising that 53% of the HIV positive diagnoses amongst Africans in the UK have been in London.¹⁴ Moreover, clinics in east London (where most of the interviews and observations took place) treat a large proportion of the female African HIV positive patients in public sector HIV specialist centers, where the majority of HIV care takes place in the UK.¹⁵

Annette Scambler et al. "Kinship and Friendship Networks and Women's Demands for Primary Care." *Journal of the Royal College of General Practitioners* 26 (1981): 746–750.

⁷Shayna D. Cunningham et al. "Attitudes about sexual disclosure and perceptions of stigma and shame." *Sexually Transmitted Infections* 78 (2002): 5; J. Dennis Fortenberry et al. "Relationships of stigma and shame to gonorrhea and HIV screening." *American Journal of Public Health* 92 (2002): 3.

⁸Magdalena Berger et al. "Internet use and stigmatized illness." *Social Science & Medicine* 61 (2005): 1821–1827.

⁹Health Protection Agency. "United Kingdom HIV New Diagnoses to end of June 2009," page 7, New HIV Diagnoses National tables: Table 1, published in June 2009 and available online at: http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1237970242135. Last accessed 23 January 2010.

¹⁰Audrey Prost et al. "Social, Behavioural, and Intervention Research among People of Sub-Saharan African Origin Living with HIV in the UK and Europe: Literature Review and Recommendations for Intervention." *AIDS and Behavior* 12 (2008): 2.

¹¹UK 2001 Census data, <http://www.ons.gov.uk/census/index.html>. Last accessed 12 March 2010.

¹²For the sake of brevity from now on we will use the term African when we mean "black Africans."

¹³Department of Health. *HIV and AIDS in African communities: A framework for better prevention and care*. London, 2004.

¹⁴Gill Green and Richard Smith. "The psychosocial and health care needs of HIV-positive people in the United Kingdom." *HIV Medicine* 5 (2004): 1.

¹⁵Jonathan Elford et al. "HIV in East London: ethnicity, gender and risk. Design and methods." *BMC Public Health* 6 (2006): 150.

Issues around information management have been highlighted as a crucial challenge for people living with HIV in the UK generally¹⁶ and among African women specifically.¹⁷ This was reflected in our research where issues of disclosure, confidentiality and privacy were raised as barriers for accessing health information by the women who took part in the study. The reason usually given for this difficulty was stigma, and while we do not go into the details of this here it is important to note that some of the women who took part in the research had experienced situations – ranging from losing a job to physical abuse – that were deeply upsetting. This is in keeping with an earlier study of a similar group of women where approximately a third of participants reported direct experience of HIV-related stigmatisation,¹⁸ often with profound negative effects on their mental wellbeing. Although we do not elaborate on stigma here, except when it was raised directly in relation to privacy and information seeking, it formed an omnipresent backdrop to the research and has been discussed in relation to HIV in more detail elsewhere.¹⁹ However, one aspect of how participants expressed their experiences of HIV-related stigma that emerged as particularly relevant in relation to health information seeking and Internet use was how they felt an HIV positive diagnosis affected their most intimate relationships.

Like with other stigmatised illnesses, decisions to disclose an HIV positive status occur in the context of specific relationships.²⁰ However, because HIV is a sexually communicable virus issues around disclosure can be particularly complex and difficult within the most personal of these.²¹ In a similar vein participants often expressed how they felt it was crucial for them to maintain privacy regarding an HIV positive status in the areas of life typically associated with the “private” domain: home and family life. Instead of privacy being equated with the domestic sphere where it has traditionally been placed, both in philosophy and legal scholarship, it was distributed across a range of different spaces, most notably, in relation to HIV,

¹⁶Gill Green and R. Smith. “The psychosocial and health care needs of HIV-positive people in the United Kingdom.” *HIV Medicine* 5 (2004): 1; Leslie Doyal and Jane Anderson, “My fear is to fall in love again” How HIV-positive African women survive in London. *Social Science & Medicine* 60 (2005): 1729–1738.

¹⁷Leslie Doyal and Jane Anderson. “‘My fear is to fall in love again’ How HIV-positive African women survive in London.” *Social Science & Medicine* 60 (2005): 1729–1738.

¹⁸Ibid.

¹⁹Angelo A. Alonzo and Nancy R. Reynolds. “Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory.” *Social Science & Medicine* 41 (1995): 3; Paul Flowers et al. “Diagnosis and stigma and identity amongst HIV positive black Africans living in the UK.” *Psychology & Health* 21 (2006): 1; J. Dennis Fortenberry et al. “Relationships of stigma and shame to gonorrhoea and HIV screening.” *American Journal of Public Health* 92 (2002): 3.

²⁰Valerian J. Derlega et al. “Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis.” *Journal of Health Psychology* 7 (2002): 4.

²¹Kathryn Greene et al. *Privacy and Disclosure of HIV in Interpersonal Relationships* (New Jersey: Lawrence Erlbaum Associates, 2003).

the clinic and the community support group. Thus, the “intuitive” boundaries of what constitute the private and the public shifted in relation to HIV in this research.

Critiquing the dichotomy between the private and the public has been central to feminist writing and political struggle.²² Indeed, some feminists have explicitly criticised privacy as being dangerous for women as it can be used as a means and justification for covering up domestic violence and subjugation.²³ Others have suggested that although notions of privacy can be subject to abuse this is not necessarily the case.²⁴ In our research the need for rethinking the public/private divide emerged as being salient in the sense that privacy should not be considered as necessarily associated with the domestic domain, but rather that it needs to be “exploded”²⁵ across numerous domains, people, practices and objects. However, this exploding does not, as in Catharine MacKinnon’s original suggestion,²⁶ amount to the dissolution of privacy. Instead privacy shifts from being associated with a specific place towards being associated with practices that enact different places and spaces of relative privacy. What we mean by this will be discussed in more detail in the substantive discussion below, but first it is necessary to outline our approach to privacy.

Since Warren and Brandeis’s early definition of privacy as the “right to be let alone”²⁷ researchers have been grappling with how to delineate this elusive concept. While this research has extended our understanding of privacy there is still no unified definition of what privacy is. In this paper we draw on and extend two broad conceptualisations of privacy:²⁸ a dialectic one, as proposed by Irwin Altman²⁹ and that of privacy as contextual integrity, proposed by Helen Nissenbaum.³⁰ In the former privacy is seen as a process of selective control of access to the self, an idea that has been elaborated on further in work on information disclosure.³¹ However, our focus within this discussion is not on disclosure per se, an area that has been

²²Carole Pateman. *The Disorder of Women* (Stanford, California: Stanford University Press, 1989), 118.

²³Catharine MacKinnon. *Toward a Feminist Theory of the State* (Cambridge, Mass: Harvard University Press, 1989).

²⁴Anita Allen. *Uneasy Access: Privacy for Women in a Free Society* (Totowa, New Jersey: Rowman and Littlefield, 1988).

²⁵Catharine MacKinnon. *Toward a Feminist Theory of the State* (Cambridge, Mass: Harvard University Press, 1989).

²⁶Ibid.

²⁷Samuel Warren and Louis Brandeis. “Right to Privacy.” *Harvard Law Review* 193 (1890).

²⁸There are many different versions of what privacy is, of which these are only two. In selecting these we are not suggesting that this is all that privacy entails, but simply that these versions of privacy emerged as particularly appropriate in the context of this research.

²⁹Irwin Altman. *The Environment and Social Behaviour* (Belmont, California: Wadsworth Publishing Company, 1975).

³⁰Helen Nissenbaum. *Privacy in Context* (Stanford, California: Stanford University Press, 2009).

³¹Sandra S. Petronio. *Boundaries of Privacy* (Albany, New York: State University of New York Press, 2002); Kathryn Greene et al. *Privacy and Disclosure of HIV in Interpersonal Relationships* (New Jersey: Lawrence Erlbaum Associates, 2003).

covered extensively in relation to HIV/AIDS,³² but on the privacy practices participants adopted while seeking HIV-related information and support, practices which sometimes, although not always, facilitated situations participants felt were conducive for the disclosure of an HIV positive status. In the latter, Helen Nissenbaum argues that questions of privacy are tied to specific contextual norms that are not dichotomised by a public versus private distinction, but are distributed across a plurality of different spheres of life.³³ Building on this in our particular case of HIV-related information seeking we examine how relational and spatial parameters form part of these contextual norms.

12.3 On Method

Not only is privacy notoriously hard to define it is also difficult to study. One of the methods traditionally employed, as exemplified by the work of Westin,³⁴ has been the survey. There is, however, an increasing awareness that this only captures a specific, and often narrow, vision of what privacy entails. As a consequence of this limitation, different approaches, such as grounded theory,³⁵ experiments,³⁶ and diary methods,³⁷ have been adopted to study privacy. Despite these methodological developments, concerns persist with regards to how we should best study privacy in relation to Internet use. These include how to conduct research on privacy sensitive individuals,³⁸ how to avoid prompting an increased privacy sensitive response by the

³²Sandra S. Petronio. *Boundaries of Privacy* (Albany, New York: State University of New York Press, 2002); Jonathan Elford et al. "Disclosure of HIV status: the role of ethnicity among people living with HIV in London." *Journal of Acquired Immune Deficiency Syndromes* 47 (2008): 4; Rosalie Corona et al. "Do Children Know Their Parent's HIV Status? Parental Reports of Child Awareness in a Nationally Representative Sample." *Ambulatory Pediatrics* 6 (2006): 3; Martha B. Lee and Mary Jane Rotheram-Borus. "Parents' disclosure of HIV to their children." *AIDS* 16 (2002): 16; Valerian J. Derlega et al. "Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis." *Journal of Health Psychology* 7 (2002): 4.; Kathryn Greene et al. *Privacy and Disclosure of HIV in Interpersonal Relationships* (New Jersey: Lawrence Erlbaum Associates, 2003).

³³Helen Nissenbaum. *Privacy in Context* (Stanford, California: Stanford University Press, 2009).

³⁴Alan Westin. "Social and Political Dimensions of Privacy." *Journal of Social Issues* 59 (2003): 2

³⁵Anne Adams and Martina Angela Sasse. "Privacy in Multimedia Communications: Protecting Users, Not Just Data." In *People and Computers XV – Interaction without frontiers*, edited by Ann Blandford, Jean Vanderdonck and Philip D. Gray (Lille: Springer, 2001), 49–64.

³⁶Alessandro Acquisti and Jens Grossklags. "Losses, gains, and hyperbolic discounting: An experimental approach to information security attitudes and behavior." 2nd Annual Workshop on Economics and Information Security- WEIS'03 (2003); Kai-Lung Hui et al. The value of privacy assurance: A field experiment. *MIS Quarterly* 31 (2007): 1.

³⁷Denise Anthony et al. "Privacy in Location-Aware Computing Environments." *IEEE Pervasive Computing* 6 (2007): 4

³⁸Carina Paine et al. "Internet users' perceptions of privacy concerns and privacy actions." *International Journal of Human-Computer Studies* 65 (2007): 526–536.

inclusion of explicit privacy references³⁹ and the persistence of a “privacy paradox” in which a discrepancy is noted between reported and actual behaviour.⁴⁰ Although we do not seek to resolve these issues, building on a belief that “robust intuitions about privacy norms” are rooted in the texture of peoples’ lives⁴¹ our approach here is to situate questions of privacy within broader narratives of information seeking, narratives which are in turn situated within wider experiences of being diagnosed and living with HIV.

Although narrative interviews have a respected pedigree in medical sociology and anthropology,⁴² our aim was not to collect and analyse privacy narratives per se. Instead our goal was to contextualise questions of privacy in relation to health information seeking within broader narratives of living with HIV. As part of a wider study on Internet use and HIV, 41 women from a range of sub-Saharan African countries including Angola, Burundi, Gambia, Ghana, Kenya, Nigeria, Sierra Leone, Somalia, South Africa, Uganda, Zambia and Zimbabwe participated in the research. They were recruited at one of three HIV specialist centres in east London where they were receiving treatment and care. Rather than asking participants about privacy directly, they were prompted to talk about their experiences of living with HIV. The first part of the interview (which lasted between 30 minutes to 3 hours, with an average of 45 minutes) was unstructured with participants talking retrospectively about their experiences of looking for information and help, online and off, in relation to their health from the point they were diagnosed to the present. In the second half, specific questions were asked about their history of and current use of the Internet. Participants’ levels of Internet access and use differed greatly, ranging from daily broadband access via personal laptops to sporadic access on terminals at Internet cafes.

The majority of the participants were interviewed in a private hospital room, although some, depending on their preferences were interviewed at their homes or in community support groups. In some cases more than one interview was conducted. Most of the interviews were audio recorded, then transcribed and analysed, but in the cases where research participants were not comfortable with the interviews being recorded simultaneous notes were taken instead. The interview transcripts and field notes were analysed thematically throughout the course of the research and issues raised by participants were included in subsequent interviews. Initial coding was used to highlight areas of pertinence to privacy. Although the words

³⁹Adam Joinson et al. “Measuring self-disclosure online.” *Computers in Human Behavior* 24 (2006): 5.

⁴⁰Carina Paine et al. “Internet users’ perceptions of privacy concerns and privacy actions.” *International Journal of Human-Computer Studies* 65 (2007): 526–536.

⁴¹Helen Nissenbaum. “Privacy as Contextual Integrity.” *Washington Law Review* 79 (2004): 119–157.

⁴²Arthur Kleinman. *The illness narratives: Suffering, healing, and the human condition* (New York: Basic Books, 1988); Arthur Frank. *The wounded storyteller: Body, Illness and Ethics* (Chicago: University of Chicago Press, 1995); Michael Bury. “Illness narratives: fact or fiction.” *Sociology of Health and Illness* 23 (2001): 3.

“private” or “privacy” were brought up relatively infrequently by the interviewees associated words, such as “confidentially”, “disclosure”, “safe”, “free”, “comfortable”, were regularly used, and issues of stigma, disclosure and confidentiality were omnipresent. More detailed thematic coding was then carried out on this “privacy aware” data in order to generate an in-depth understanding of how participants spoke about “doing” privacy while searching for health information.

12.4 Exploring the Relational and Spatial Dynamics of Privacy

12.4.1 *Practices of Demarcating HIV and Non-HIV Places*

There are few places within which space and time are as overtly marked out as the settings of contemporary medical care,⁴³ and an HIV clinic is no exception. There are different wards, different waiting rooms, whole areas marked with large staff only signs, rooms which require security passes to access and others that require codes. Who gets access, when and where, is not static. Patients and staff move between these spaces, and this movement changes over time. Where patients and staff have access, where they go and do not go, is neither trivial nor arbitrary and the HIV patients who took part in this research expressed this strongly when they spoke about seeking and receiving HIV treatment and care. Building on this, our aim in this section is to describe how rather than speaking about public and private places in general, participants distinguished between HIV and non-HIV places in particular. This distinction was enacted and maintained in various ways as was made clear while carrying out the interviews, as illustrated below in the case of Frances.⁴⁴

Frances is a patient who was introduced to the first author by a nurse as she had expressed a willingness to take part in the research. However, after reading the information sheet she said, “I am happy to talk to you, but I am not HIV positive.” Frances had been approached to take part in the research explicitly because of her HIV positive status and she had accepted this status in front of the nurse. Yet barely 5 minutes had passed and a short corridor traversed before her status had changed, before she was no longer HIV positive to the researcher. Not to the doctors and nurses, but to the researcher. We were still technically in the same location as when we were introduced, but when alone Frances made it clear that outside the hospital she was no longer an HIV patient. Three weeks later, when Frances was interviewed again, she appended not being HIV positive with a spatial specification: “when I leave this place I am no longer HIV positive.” What this draws attention to is the way in which privacy was articulated by participants as spatially specific, and yet

⁴³For a historical description of how this has changed within British general practice see David Armstrong. “Space and Time in British General Practice.” *Social Science & Medicine* 20 (1985): 7.

⁴⁴All names have been changed as have any details that could indicate the identity of the women who took part in the research.

the salience of this spatiality was not necessarily bounded within a given location. Rather, participants demarcated these different places through the management of physical geography, but also interpersonal relations.

The reason Frances had chosen this particular hospital was its distance from where she lived: “I just wanted to get out of my borough. You know where not anyone is knowing me from my borough. So I decided to come here. I could have gone to Barking,⁴⁵ but I preferred this hospital.” For Frances, who has only disclosed her HIV status to her partner and the healthcare staff directly involved in her care, the physical distance between her house and the clinic was one of the ways in which she protected her privacy. This practice of physical distancing was not unique to Frances. A number of other research participants travelled long distances to seek out treatment and care in order to maintain a separation between places in which they were HIV positive and ones where they felt they simply could not be. Interestingly, in medical geography, an area where issues of space and health are of central importance, access to healthcare services is normally measured based on proximity to people’s homes,⁴⁶ yet here, for privacy reasons, a certain distance between healthcare services and other relevant locations such as home and work was seen as desirable rather than detrimental for access. Of course, not all participants selected hospitals far from where they lived, but what they did do was employ a range of demarcation practices in order to keep different spheres of life separate. These practices became particularly visible when, as above, they emerged as apparent contradictions or paradoxes. They could also be seen in the case where participants resisted changes to these demarcations, as discussed below.

12.4.2 The Difficulty of Moving Between HIV Places and Non-HIV Places

By that time I am here (department of sexual health), but before coming here I was in big fight. I said I am not coming here. I said to them anything they want to do to me should be in the private place because I don’t want to see my country people because they will pick up phone and tell my family and friends back home and my daughter will not be able to be in peace. So I said I am not coming to this building, this particular building I will never ever come here. They talk to me and they take me to one room in this building.

In the excerpt above, Wendy one of the research participants, speaks about her difficulty in receiving treatment in the department of sexual health after being diagnosed during pregnancy. As pregnant women in the UK are routinely offered HIV tests it was unsurprising that a number of the women interviewed for this research had moved from the antenatal clinic to the HIV clinic, a move they often described as extremely traumatic. In the former they were focussed on being an expectant mother, where in the latter they shifted to being an HIV patient. One of the key things Wendy

⁴⁵Name of hospital referred to changed.

⁴⁶Robin A. Kearns and Alun E. Joseph. “Space in its place.” *Social Science & Medicine* 37 (1993): 6.

objected to in this transition was being seen at the department of sexual health by people from her country. In Frances's case the demarcation between HIV and non-HIV places was centred on physical distancing, while in Wendy's the nested rather than Euclidian nature of these demarcations is more apparent. Although Wendy resisted moving between the antenatal clinic and the department of sexual health in a hospital in east London, the implications of this resistance, for her, stretched in a widening arc that included Africa.

This particular nesting of locations occurred frequently. Participants distinguished between Africa and the UK, within the UK between home and hospital, within the hospital between the different departments, and within the departments between different people. Although these distinctions did shift over time, once they had been made a great deal of work was required for the old demarcations to be replaced by new ones. In Wendy's case it took time, persuasion and care on the part of the healthcare practitioners for her to become happy to attend the HIV clinic. This resistance related to physical movement between departments as well as the distribution of her information. Wendy did not want her information to be distributed between departments unless it was absolutely necessary. She even objected to it being visible when she was receiving in-patient care at the hospital. Underpinning this local resistance to the distribution and display of information was a diffuse and constant fear of people "back home in Africa" finding out about an HIV positive status. This separation between HIV in London, where treatment and care was possible, and HIV in Africa, where people were dying, highlights how decisions around what and where to keep things private were not only embedded in specific locations, but nested within broader socioeconomic factors.

The idea that different privacy norms and expectations are applied in different "spheres of life" is not a new one.⁴⁷ In this research these spheres were not only defined in relation to specific places – the HIV clinic, the community group, the home, the Internet cafe, the GP surgery – but also nested in much broader socio-political networks. It is in the creation of these networks, and the spaces of possibility they engender, where the relevance of the feminist injunction that the personal is the political can be seen most clearly. While Catharine MacKinnon claims that "to see the personal as political means to see the private as public" and that "the very place (home, body), relations (sexual), activities (intercourse and reproduction), and feelings (intimacy, selfhood) that feminism finds central to women's subjection form the core of privacy doctrine",⁴⁸ this is based on the equation of privacy as intimacy, as domesticity, rather than for intimacy, for domesticity, and for multiple other worlds. "Exploding" the private does not have to necessitate its destruction, but rather a splintering into multiple interrelated private spheres.⁴⁹ And

⁴⁷Ferdinand Schoeman. *Privacy and Social Freedom* (Cambridge: Cambridge University Press, 1992).

⁴⁸Catharine MacKinnon. "Feminism, Marxism, Method, and the State." *Signs* 8 (1983): 656–657.

⁴⁹Catharine MacKinnon. *Toward a Feminist Theory of the State* (Cambridge, Mass: Harvard University Press, 1989), 190.

it is in understanding how these spheres came into being and are maintained, that we can develop a richer understanding of privacy as a relational concept.

As one might expect these demarcations, and the manner in which they were made, changed over time. In a similar way to the unfolding of a stigma trajectory,⁵⁰ changes in participants' health and life experiences resulted in changes in what they considered HIV or non-HIV places. As such, privacy practices not only took place within these demarcations, but also were performative of new ones. In the excerpt below, Wendy describes how this happened in relation to the department of sexual health becoming a place in which she was comfortable receiving treatment:

Before I met Dr. Thompson⁵¹ and Angela [another doctor] it was a big trouble. I said I don't want to see any of them. They said why? I said no I don't want to see them because it is better I die because I am nothing now. Because this is not going to heal up, so its better I die, so I don't want to see anybody. Lucy [midwife who initially told Wendy about her HIV positive diagnosis] was very very nice. She would drive, go to my house, talk with me, bring all sorts of things, to talk to me, go to this home treatment people, bring the head of the home treatment people to my house. She went there about three times on her own. And that was the time she get me to come here and before I come here again, when I came to hospital it was very bad again. We went to the antenatal because I tell them I am not coming here, so we went to the antenatal in one of the doctors room and when I went there Dr. Thompson was there, but before Dr. Thompson came it was a black lady supposed to take back my blood test and as soon as I realised it was a black lady and I said no! I don't want anyone of that colour to look after me. I was shouting. They said why? I said no. Because I don't know where she is from.

As can be seen above it took a great deal of work to make the department of sexual health a safe HIV place for Wendy. Healthcare practitioners provided reassurances of confidentiality and specific interpersonal relations were developed over time. Moreover, Wendy explained how her initial aversion to people from her country treating her gave way after a while once she got to know individuals. Often these processes of her becoming familiar with people involved her checking for explicit privacy indicators such as badges of identification and evidence of professional status.

12.5 Privacy Practices and HIV-Related Internet Use

12.5.1 *Putting the Internet in Its Place*

Up to this point we have articulated a sense of place as an important parameter for privacy in offline HIV-related information seeking. Additionally, we highlighted that this sense of place did not simply mirror existing physical locations. Instead of being self-evident "safe" HIV places were brought into being through practices

⁵⁰Angela A. Alonzo and Nancy R. Reynolds. "Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory." *Social Science & Medicine* 41 (1995): 3.

⁵¹All healthcare practitioners' names have been changed.

such as the use of privacy indicators, reassurances of confidentiality, practices of care, specific interpersonal relations and disclosure. The word place is usually used to indicate an actual physical location.⁵² Moreover, it is often a place with very specific associations and meanings, in the sense of “anthropological place”.⁵³ In this section we take this sense of place and look at how it interacts with online information seeking.

While the fact that the Internet is not removed from people’s lives, that it did not “fall out of the sky,”⁵⁴ is well recognised in the privacy literature, most research on privacy in relation to the Internet focuses on privacy on the Internet. Although this remained important in our research, another aspect to privacy and Internet use emerged, that of privacy when using the Internet. Where participants used the Internet mattered for privacy, as can be seen in the example below:

Interviewer: “Do you have Internet access at home?”

Emma: “I don’t use it at home ‘cause you know I don’t want people to see’. Sometimes, you know, I just go, you know, to the business centres, cyber cafes. Because I don’t like to go down because the computer is in the kitchen. We put it in the kitchen. And you know because of the boys in the house, they are in school, they use the computer all the time. So I said this week I have to get a laptop so I can stay at home and I can do anything I want. And I am going to lock it up, you know because they are kids, I can’t tell them. So next week I will get a laptop for myself.”

Many contemporary conceptualisations of privacy have been developed based on the assumption that the home is, or at least should be, a private place.⁵⁵ Yet, in our research whether the home was demarcated as a private HIV place depended on a range of factors influenced by the socioeconomic circumstances of the participants, family arrangements and disclosure status. In the excerpt above Emma, who has not disclosed her HIV positive status to anyone apart from her partner, spoke of how she was not comfortable using her home PC for HIV-related information because it was situated in the kitchen and shared with her children. For her, in relation to HIV, she would rather go to an Internet cafe to find information about HIV. In Emma’s case an apparently public place of Internet use became, when compared to her home, relatively private. This apparent inverting of the private and the public was extremely common amongst research participants and often the home was considered the least private place with regards to HIV. In many cases, like Emma’s, this

⁵²Stuart Shapiro. “Places and Spaces: The Historical Interaction of Technology, Home, and Privacy.” *Information Society* 14 (1998): 14.

⁵³Christine Milligan. “Location or dis-location?” *Social & Cultural Geography* 4 (2003): 4.

⁵⁴Adam Joinson et al. “Measuring self-disclosure online.” *Computers in Human Behavior* 24 (2006): 5, 242.

⁵⁵Stuart Shapiro. “Places and Spaces: The Historical Interaction of Technology, Home, and Privacy.” *Information Society* 14 (1998): 14.

was primarily because participants did not want family members, friends or house-mates finding any evidence of them searching for HIV information online, and so they went elsewhere to use the Internet even when they had access at home:

I don't use it a lot [the Internet] because I share the computer at home and the bookmarks stay on. I can use the computer at home to find things not related to HIV, but for HIV things I go to the Internet cafe.

However, the relationality of these demarcations needs to be stressed. It was not that the home was not deemed private, but rather it was not deemed private in the context of living with HIV. For the women who took part in this research the Internet of the home was markedly different from the Internet of the cyber cafe, of the library, of the community support group. More importantly, and what is so interesting about these different Internets, is that their relative privacy or publicity were emplaced. The practices of demarcation, discussed earlier, impinged not only on face-to-face information seeking, but also online. However, even when the home was not considered an HIV place participants did sometimes use the Internet in relation to HIV there and when they did so they used a variety of mechanisms to increase the relative privacy of this use. In the following section we discuss two prominent examples of this: deleting and depersonalising.

12.5.2 Practices for Making Internet Use Private

Some participants used the Internet at home even when they did not consider the home an HIV place. In these cases, they spoke of practices they adopted in order to make their use of the Internet in relation to HIV private, the most common example of which was to delete any evidence of their use – to render it invisible.

The problem with HIV is that you can't really, that is me, well I am talking on my behalf. I find it hard asking people, but I can go like on the website and ask Google, ask whatever I want to ask about it. I am not good with computers but sometimes I try because I have a family and my children are teenagers and they don't know my status. So I have to find a time whereby they are not even in the house so they don't look at what I am searching for. If I am finished I make sure I delete the history, the history of the website I was on so they don't say oh my God mum was, who was looking at this?

For participants, like Grace above, use of the Internet at home for HIV-related information was relatively private as long as they felt comfortable they could delete the evidence of that use. Therefore, use of the Internet was only considered partially private – something that you did covertly and not too prolifically, something that had the potential to be private. Yet, the ability to bring this potentiality into being was highly contingent on your familiarity and comfort with computer technology. In some cases, however, the removal of evidence of Internet use in relation to HIV was not necessary even when participants had not disclosed their status to the people they lived with. In these cases instead of deleting or hiding evidence of HIV-related Internet use participants depersonalised that use.

The most common mechanism for depersonalising HIV-related Internet use was to associate it with something else, most typically work or studies. For example Olivia, who has not told her teenage children about her HIV status, felt comfortable using the Internet in relation to HIV at home because of her position as a nurse: “I feel safe to use the Internet. Being a nurse if anybody was checking I am covered, because I am a nurse and I need to know what goes on”. It was not the act of searching for HIV information that was at stake here, but its legitimisation. A number of participants were working as or studying to be healthcare professionals in the UK and they developed a sense of privacy by disassociating their search for HIV information from themselves. What this draws attention to is that the affect of associations on privacy are not always threatening, but can also be a form of protection. So while Wendy resisted going to the department of sexual health because of its association with sexually transmitted infections and HIV, Olivia uses her position as a nurse to associate her interest with HIV with work and hence prevent this interest from being interpreted as personal. Instead of keeping her HIV status private she turns her interest in HIV into something public in order to keep it private. This highlights how in some case people actively leverage the entanglement of private versus public information as a means of privacy enhancement.

These two examples of practices for rendering Internet use private focus on privacy when using the Internet, but what about privacy on the Internet? In order to illustrate this we turn to cases where the home was considered more straightforwardly private in relation to HIV; where the participants lived alone or with people who knew their HIV positive status. In these cases there was typically more overlap between the designation of domesticity with privacy, and this filtered through to the privacy practices participants adopted when using the Internet. It is important to note, however, that this overlap was not given simply as a characteristic of the technology, but dependant on whether they were living alone, whether they had children, whether they had an Internet connection and whether they could use it on their own or had someone they trusted who could help them. And in cases where the Internet was used in homes considered HIV places, other forms of spatial and relational privacy dynamics emerged, which we discuss below using Harriet’s particular case as an example.

12.5.3 Places and Spaces of Privacy Online

Harriet lives alone and has a laptop with an Internet connection that she uses regularly in relation to HIV. She does not only search for information about HIV medication, but subscribes to newsletters, reads up on research and has even contacted doctors via e-mail to ask questions and get quotes regarding treatment. It would appear that she is comfortable about using the Internet in relation to living with HIV and is not too concerned with issues of privacy. Yet, through two interviews and an analysis of an information-seeking diary, a more nuanced sense of her perceptions and practices around privacy on the Internet emerged.

Harriet was happy to search for information across a range of websites but had a strong preference for trusted sources of information, such as NAM.⁵⁶ Her two most frequent methods of finding information online were to put queries into Google and click through the websites that came up, or to go directly to sites she knew and trusted. She e-mailed doctors and kept in contact with people from her HIV community support group, but when it came to meeting new people online, as shown in the excerpt below, she was more wary. This opens up a range of questions with regards to the relationship between offline HIV places and online spaces.

Interviewer: “You said you go to the community support groups to speak to people who have had the same experiences as you; do you ever do that online?”

Harriet: “No I don’t do that online, because online you know I don’t want to expose myself to people who don’t know me. I don’t want to chat to someone I don’t know [pause], because you know it’s not a secret, HIV is stigmatised, someone will come in like an HIV person and yet they are not. And they will get everything, chat, chat, chat, the next thing, before you know it’s on Facebook and everywhere.”

Interviewer: “But you feel at the community support group its ok?”

Harriet: “It’s ok because these are positive people [pause], why should they be malicious? They are suffering like me. So that community I don’t mind exposing myself to them, no problem, they are like me, I am like them.”

Even in purely online interaction the importance for a sense of place for privacy persists. While Harriet is happy to e-mail the people she has met at a community support group and chat to them online she does not trust people she has only met online. In addition to trust relations developed offline persisting online, Harriet’s description of her Internet use in relation to HIV was broken up into the designation of specific HIV spaces. These online spaces often, but not always, had a strong connection with an offline place (the community support groups for example), and a strong preference for trusted information sources emerged most notably amongst research participants who had been using the Internet for a while in relation to their HIV health concerns and questions. The majority of these were based in the UK: the NHS choices website,⁵⁷ NAM, i-Base⁵⁸ and Avert,⁵⁹ but participants did use sites from other countries such as The Body⁶⁰ in the US. However, while they felt this information was useful for them they also felt it was often not relevant, both

⁵⁶National Aids Manual. <http://www.aidsmap.com>. Last accessed 2 November 2009.

⁵⁷<http://www.nhs.uk/Pages/HomePage.aspx>. Last accessed 2 November 2009.

⁵⁸<http://www.i-base.info/>. Last accessed 2 November 2009.

⁵⁹<http://www.avert.org/>. Last accessed 2 November 2009.

⁶⁰<http://www.thebody.com/>. Last accessed 26 May 2010.

culturally as it was more US centric, but also medically as the healthcare services and treatments being discussed were sometimes not applicable to the UK context.

12.6 Conclusion

Through the situated case of HIV-related information seeking by women living with HIV in London, this paper explored some of the relational and spatial dynamics of privacy when using the Internet for health in the context of a stigmatised illness. In examining how participants spoke about these practices the persistence of a sense of place in relation to privacy and the Internet emerged. However, this sense of place was not one that was simply geographically bounded but delineated through sets of relations and associations that often challenged traditional notions of Euclidian space. Rather than being reducible and super-imposable on physical locations the salience of place for privacy was in how it was actively performed by participants and those around them.

We discussed these relational and spatial dynamics in more detail in relation to practices of demarcating, deleting, and depersonalising. However, each of these practices deserves to be explored in more detail in relation to privacy, both online and off. Using narrative interviews we demonstrated that it is not sufficient to talk of the Internet as a source of private information without situating it within a broader understanding of different “spheres of life”. Privacy practices on the Internet are informed by where the Internet (or often more aptly the computer in question) is placed as well as the specificities of online spaces. These are in turn embedded within broader socioeconomic and political circumstances. This draws attention to how being able to make the Internet “private” involves work that is contingent on where you live and your pre-existing knowledge, opening new avenues for research on privacy in relation to different aspects of people’s lives and different technologies.

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