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International Journal of Cultural Studies published online 18 August 2011

DOI: 10.1177/1367877911416884

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Becoming visible, being heard? Community interpretations of first-person stories about living with HIV/AIDS in Quebec daily newspapers

Article

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Abstract

In this article, we highlight first-person accounts of living with HIV/AIDS that have appeared in daily newspapers in Quebec and raise a number of questions about how these accounts are received – who is listening and how? Recent Canadian criminal trials of HIV-positive people who are alleged to have knowingly exposed sexual partners to HIV serve as a conjuncture against which we address the culture of HIV/AIDS testimonials and analyse both production and reception of these stories. Drawing on the VIHSIBILITÉ project, we ask what discursive forms and social conditions are likely to favour media discourses that foster a sense of social solidarity toward people living with HIV/AIDS. We argue that community interpretations of storytelling and closer examination of how testimonials are received may provide new tools for critically conceptualizing how HIV-positive persons can be better heard as they speak about their lives.

Keywords

community, criminalization, disclosure, HIV/AIDS, interpretation, news media, Québec, stories, testimonial

Sometimes people hear so lightly what others say so intensely, and sometimes people hear so intensely what others say so lightly. (Plummer, 1995: 28)

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Strengthening the social positions of PLWHA [people living with HIV/AIDS] reinforces the collective ability to talk about HIV. It also induces changes in the way society regards PLWHA. Of course, the ability to talk is associated with the ability to listen ... (Spire et al., 2008: 5)

First-person accounts of living with HIV are portraits or narratives based on personal experience in relation to being HIV-positive. This article addresses the ways in which such stories have been produced and consumed in the context of public debates on managing the disclosure of HIV status. Our analysis draws from an ongoing research project called VIHSIBILITÉ.¹ The goal of this action-research initiative is to study trends in conceptualizing and reporting the lived experience of HIV-positive people, examining the impact these media representations have on people's lives and assessing the ways in which media testimonials of this type operate as discursive and cultural modes of reasoning about HIV/AIDS. In this article, we highlight first-person accounts by people living with HIV/AIDS that have appeared in daily newspapers in Quebec and raise a number of questions about how these accounts are received – who is listening and how?

Criminal cases in Canada² involving HIV-positive people alleged to have knowingly exposed sexual partners to HIV serve as a conjuncture against which the VIHSIBILITÉ project has addressed a number of questions and issues raised by the production and reception of first-person accounts in newspapers and other media. Under what conditions are people living with HIV able to give public voice to their stories? Understanding public accounts of living with HIV/AIDS as a genre of sexual storytelling, we have analysed the processes whereby HIV-positive people become vocal and visible in the media. The project has also included analysis of the reception of first-person accounts: Who has access to these stories? What cultural, social, and political factors have a bearing on the manner in which first-person accounts are heard and legitimated? What resources are required to do the 'work' of listening? We examine how speakers and listeners interact in relation to these stories in predominant, alternative and at times resistant ways that shape the meaning and social implications of media testimonials and the visibility they accord to HIV-positive people. Our primary interest is in discursive forms and types of social interaction likely to favour supportive and inclusive social environments for people living with HIV/AIDS.

As we discuss in this article, analysis of the VIHSIBILITÉ corpus and the participation of an interpretive community in critically assessing first-person accounts of living with HIV/AIDS in Quebec media has shed light on this 'culture of testimonials'. Our study of public storytelling about HIV/AIDS has brought into focus some of the contradictions that characterize these accounts as narrative modes of representation and reasoning within popular culture and public discourse. In the following pages, we examine several conceptual, practical and ethical issues that arise with regards to the conditions and contexts in which first-person accounts of living with HIV/AIDS are produced and consumed.

Confession, disclosure, and testimonial in contemporary cultures

Inscribed within notions of confession, disclosure and public testimonial have been important features of societies for centuries and have shaped social interactions related

to personal storytelling in a number of ways. Foucault (1978) has shown that since the Middle Ages at least, western societies have established various types of 'confession' as a key ritual or modality relied upon for the production of truth: the development of confessional techniques with the codification of the sacrament of penance by the Lateran Council in 1215 and later during the Inquisition helped give confession a central role in the order of civil and religious powers:

We have ... become a singularly confessing society. The confession has spread its effects far and wide. It plays a part in justice, medicine, education, family relationships, and love relations, in the most ordinary affairs of everyday life, and in the most solemn rites: one confesses one's crimes, one's sins, one's thoughts and desires, one's illnesses and troubles; one goes about telling, with the greatest precision, what is most difficult to tell. One confesses in public and in private, to one's parents, one's educators, one's doctor, to those one loves; one admits to oneself, in pleasure and in pain, things it would be impossible to tell to anyone else, the things people write books about. (1978: 59)

Foucault goes on to argue that the social obligation to confess is so deeply ingrained that we no longer perceive the effects of its power and its constraints. On the contrary, we tend to assume that the 'truth' or 'identity' lodged in our most secret nature 'demands' to surface and be articulated as some sort of liberation. The confessional forms through which people's truths become sayable and visible have thus come to have important implications in terms of social regulation and control. Furthermore, from the instituting of Christian penance to the present day, sex has been a privileged theme of confession. The transformation of sex into discourse alongside the dissemination or reinforcement of heterogeneous sexualities constitutes two aspects of the same deployment of the confessional form: 'they are linked together with the help of the central element of a confession that compels individuals to articulate their sexual peculiarity – no matter how extreme' (1978: 61). It is thus important to critically examine the processes through which people tell stories in confessional form – in particular sexual stories – in order to understand the implications of making oneself visible and heard in this way.

In an increasingly confession-oriented world, specific patterns of sexual storytelling have proliferated and developed rapidly in the 20th and 21st centuries. Among these are stories of sexual suffering, surviving and surpassing – including HIV/AIDS narratives – that have taken on an especially important role in popular culture and are common in the press, in biography, on television talk shows, in photography exhibits, in therapy groups, in social science, etc. Plummer's sociology of coming out stories (1995: 81–96) and rape stories (1995: 62–80) provides a range of examples. Similar issues are dramatized in the 2008 film *Milk*, in which the heroism of gay rights activist Harvey Milk is linked to the emergence in the 1970s of a new understanding of coming out as a political act:

Gay people, we will not win our rights by staying silently in our closets.... We are coming out. We are coming out to fight the lies, the myths, the distortions. We are coming out to tell the truths about gays, for I am tired of the conspiracy of silence, so I'm going to talk about it. And I want you to talk about it. You must come out. (in Van Sant, 2008)³

To this notion of a confession that brings liberation can be added forms of testimony that are seen to bring support or 'relief'. The trauma associated with being silenced, invisible or carrying things untold is also expressed in the sexual testimonies of women who have been raped or abused. Over the past 40 years, radical feminist therapy has embraced and deployed this culture of testimonials. As depicted in popular films such as *The Accused* (Kaplan, 1988), the sharing of women's first-person stories of sexual suffering and survival is now a familiar practice and has contributed in significant ways to feminist organizing and support in relation to sexual violence:

Hence a body of listeners and seers became, as part of our movement, an institution. We created rape protection centers. Women sat and listened as another woman who had just been raped told her story. *She was heard*. And this was healing of a festering wound, even to those of us who had never been raped, because such is the nature of a community or a movement. (Griffin, 1979, quoted in Plummer, 1995: 51)

In responding to rape with new approaches and a new discourse, the exchange of stories within specific contexts of listening contributed to action and *was* a form of action. What became important was not simply the stories themselves but the intersection of the production of stories with their reception, leading to new understandings and new forms of interaction.

From face-to-face to written, audiovisual and now digital formats (Gillett, 2003; McLagan, 2003), 'finding a voice' and 'telling one's story' have been increasingly emphasized within political and social movements focused on the rights of citizenship and demands for equality:

Rights and responsibilities depend upon a community of stories which make those same rights plausible and possible. They accrue to people whose identities flow out of the self-same communities. Thus it is only as lesbian and gay communities started to develop and women's movements gathered strength that stories around a new kind of citizenship became more and more plausible. The nature of our communities – the languages they use, the stories they harbour, the identities they construct, the moral/political codes they champion – move to the centre stage of political thinking. (Plummer, 1995: 150)

For Plummer, then, an important aspect of movements and communities that have emerged and organized in relation to sex and, in particular, in relation to sexual suffering is the 'community of stories' that often underpins the demand for rights. Both as individual stories and as collective tales recounted within communities or movements, confessional forms of public testimonial constitute a genre of sexual storytelling that links the public expression of these stories to processes of social change, suggesting that the roots of this genre can be found in classic confessional narratives of redemption and transformation.

Similarly, many first-person media accounts of women and men living with HIV are 'personal experience narratives of the intimate' (Plummer, 1995: 19) that have contributed to social change in various ways. Yet if sexual storytelling has been an important catalyst for reflection and action in relation to a range of issues, Foucault's analysis of the disciplinary and discursive dimensions of sexuality reminds us to examine the processes

of social regulation that also characterize confessional cultures. This must be taken into consideration when assessing the resistance or transformation associated with the production and reception of media accounts of living with HIV/AIDS and the culture of testimonials within which first-person stories are situated.

Producing first-person accounts of living with HIV/AIDS

Shame may prevent the story being told, pride may lead to it being shouted. (Plummer, 1995: 28)

People living with HIV have various motivations for providing media testimonials: to educate the public, to challenge stigma, to express themselves creatively, and to rearticulate categories of knowledge and relations of power. In Québec, those who decide to go public and talk to the media about their HIV-positive status are frequently driven by community activist goals of enhancing social understanding and dismantling the stigma and prejudices associated with HIV/AIDS (Mensah and Gauvin, 2010). Media reporting, in turn, can incorporate first-person accounts for varying reasons: to set agendas (Dearing and Kim, 2008), to humanize a storyline, to sensationalize it,⁴ to corroborate factual data, to 'normalize' the epidemic, or to provide narrative continuity that illustrates complex issues by dividing them into sequences of events (for example, the story of how a person was exposed to the virus may be used to illustrate who else may be at risk). First-person testimonials can also provide important opportunities for personal development, education, access to support and services, and the expression of solidarity in relation to shared concerns.

Research on first-person accounts of living with HIV has provided several perspectives on the modes in which personal stories about HIV/AIDS are typically produced. Some of this research has looked at the narrative structure of such stories and their literary, textual or filmic forms. For example, Chambers' (1998) critical analysis of AIDS video autobiographies produced during the first decade of the epidemic explores the relationship between the authors and readers of works that were largely stories that white, middle-class gay men told as they died. Chambers' considers these stories to be acts of revolt because the authors choose to confront rather than merely succumb to the disease. In choosing to bear witness, AIDS autobiographers refused to become victims of their circumstances. The experience of reading AIDS diaries becomes an act of mourning in which readers participate in the postmodern anxiety of authors who undertake not only to die as they write, but to write about their dying. Other literary (Delvaux, 1999) and filmic (Waugh, 2009) analyses of the production of AIDS testimonials suggest that, in addition to raging against death, such stories seek to reject the shame and guilt imposed by society and dismantle the process of being 'othered'.

From this perspective, HIV/AIDS storytelling operates as a flow of power/knowledge. Testimonies that take on a memorial aspect tend to recount experiences of trauma while also involving a search for the truth of past events. The veracity of stories about marginalized communities and their relationship to mainstream society is seldom if ever questioned and such stories take on power through this 'truth'. Nonetheless, such acts of recounting and witnessing remain open to critical examination. The idea that readers necessarily acquire knowledge of 'the truth' through reading stories about living with (and dying from) HIV/AIDS is subverted when one considers the changing dynamics of

HIV/AIDS epidemiology, the heterogeneity of stories being told by men, women, youth, and transgendered people and the possibility for multiple interpretations of literary texts, film and video. Narratives of remembering and overcoming, for example, can be shaped by other arcs in which the 'truth' about a person's identity and experience is located along a spectrum of HIV-exposure categories and focuses on the question: How did you acquire HIV (Mensah, 2003)? This can constrain the capacity of the story to surpass confessional preoccupations and categorizations. Such considerations make it important to critically question the positionality and ethical dimensions of first-person accounts that proclaim the truthfulness of one's tragic demise.

The production of stories about living with HIV/AIDS has been examined as well in terms of the negotiation of a stigmatized identity (Clark et al., 2003; Cusick and Rhodes, 1999; Derlega et al., 2002, Klitzman and Bayer, 2003; Letteney and LaPorte, 2004; Racicot et al., 2011; Shelley et al., 2006; Serovich, 2000; Siegel et al., 2005). Many factors make it difficult for people to tell others that they are HIV-positive due to the ways in which this kind of disclosure labels them as an 'infected person'. A significant body of research deals with disclosure (the act of informing others about one's HIV-positive status) in the context of families, interpersonal relationships and sexual relations. This work focuses on understanding the motivations behind disclosing one's HIV status and the impact of revealing this information to others. One such study compared the disclosure experiences of a group of HIV-positive women before and after 1996, the year combination therapies were introduced (Siegel et al., 2005). This research showed that the re-conceptualization of HIV/AIDS as a treatable disease (in regions of the world where people have access to affordable anti-retroviral treatment) had little impact in terms of reducing feelings of responsibility, guilt and shame when disclosing HIV status to a sexual partner. Other research has refuted the hypothesis that the disclosure of HIV-positive status to sexual partners increases the likelihood that people will adopt safer sex practices.⁵ Research on the processes and implications of disclosure, however, have rarely addressed or assessed public storytelling about HIV/AIDS and the use of media by people living with HIV.

A number of other studies have focused on the capacity of first-person accounts by people living with HIV to have a positive influence on media audiences, for instance by providing information about prevention and testing (O'Leary et al., 2007) or contesting stigmatizing attitudes (Fuller, 2003; Ibañez-Carrasco, 1995; Kennedy et al., 2007). First-person stories about living with HIV/AIDS are considered here in light of the contribution they make to public education, affirming the identities and experiences of HIV-positive people in ways that can challenge homophobic, sexist, ethnocentric, racist or HIV-phobic preconceptions. Paxton's (2002) study of the impact of public disclosure on 75 HIV-positive speakers from 20 countries in Africa and the Asia-Pacific region, for example, showed that people who became community HIV/AIDS educators were frequently motivated by an interest in decreasing stigma and stopping new infections. A majority of study participants felt that speaking out in public was liberating and rewarding, and contributed to reducing discrimination. Telling one's story in public led to greater well-being and reduced stress. The paradox of publicly disclosing one's HIV status is that the risk one incurs of experiencing stigma also permits a psychological release from burdens of secrecy and shame. Paxton recommends that governments and

community organizations provide better support, counselling and training for those who choose to go public about their experiences as a person living with HIV/AIDS.

For many community-based HIV/AIDS organizations, the production and circulation of first-person accounts in the media is a challenging issue because media outlets with a range of motivations regularly solicit these organizations in search of people to interview and because organizations themselves frequently use testimonials as advocacy and public education strategies. This deployment of first-person accounts raises a range of practical and ethical issues. It is important to recognize the motivations for the production of first-person accounts clearly vary and instrumental views of first-person accounts as tools for public education provide but one perspective on what these accounts mean and why they are important. Other forms of first-person storytelling about HIV/AIDS, and non-journalistic work in particular, can clearly have different aims that are more critical, resistant or subversive. In the following section, we look more closely at the VIHSIBILITÉ corpus and how the project's interpretive community has critically assessed first-person accounts of living with HIV/AIDS in Quebec media, the varying motivations for their production and reception, and the conditions and contexts within which they are situated.

Producing and consuming first-person accounts of living with HIV/AIDS: examples from Quebec newspaper coverage

The VIHSIBILITÉ project was initiated in 2004 with a search of the electronic databases of Quebec's four major daily French-language newspapers (*La Presse*, *Le Devoir*, *Le Soleil* and *Le Droit*) using HIV/AIDS-related keywords, yielding 12,754 articles published between 1993 and 2004. Computer-assisted analyses were conducted on this corpus using qualitative data analysis software (SATO, ATLAS.ti). A subset of articles that contained French-language equivalents of the term 'testimonial', or in which people living with HIV were quoted, was extracted ($n = 1144$), enabling selected newspaper articles to be segmented into information units (IU): sequences of words, phrases or paragraphs from which specific meanings could be discerned. Based on this sample of articles, our study made apparent certain characteristics of first-person accounts of living with HIV/AIDS in daily news coverage.

We found that first-person accounts of living with HIV/AIDS were frequent within news coverage of HIV/AIDS over the 10-year time period covered by this corpus. Quotes from people living with HIV (499 IU) appeared significantly more often than those of other spokespersons such as doctors, scientists and researchers (125), advocates (34), community organizers (17), media professionals (19), politicians (13), colleagues (5) or church representatives (3). Accounts by HIV-positive men appeared more often than those by HIV-positive women's (107 IU by 51 men vs. 83 IU by 44 women), and HIV-positive people in general tended to be described as 'activists' or 'victims'.⁶ People living with HIV also tended to be depicted in terms of personal characteristics such as age (e.g. young), civil status (e.g. married) and racial categories (e.g. black, aboriginal), as well as in terms of HIV-exposure categories/identities such as heterosexual contact (e.g. heterosexual, sex worker), blood transfusion, same-sex practices (e.g. gay, homosexual, lesbian), vertical transmission (e.g. mother) and injection drug use (e.g. addict, heroin

user, drug user). Over time, media accounts in this sample tended to use two common tropes to 'coax' the provision of and shape the production of testimonials about living with HIV. Initially (1993–7), the most common thread for inviting and organizing an HIV-positive person's story was 'How did the person acquire HIV/AIDS?' More recently (1998–2004), storylines have tended to focus on 'To whom did that person disclose his or her HIV status, and how?' These tropes suggest that first-person accounts within this corpus have been shaped by discursive forms and practices that hearken back to confessional modes. First-person accounts within this corpus tend to privilege certain 'truths' about the experience of living with HIV/AIDS – for example, notions of the infection as a lurking secret that may or may not be disclosed – while serving to categorize the people providing these accounts based on how they were exposed to the virus (for similar examples, see Orsini and Scala, 2006).

Because 'tellings cannot be [understood] in isolation from hearings, readings, consumings' (Plummer, 1995: 25), research undertaken through the VIHSIBILITÉ project has also focused on people on the receiving end of testimonials. An advisory committee was formed early on in the project to assess concerns from various contexts – community-based, institutional and professional – related to news coverage about HIV/AIDS. As an ongoing interpretive community, this committee participates in analysing research results, planning joint responses to these results and proposing directions for further analysis. 'Interpretive communities' is a concept that implies, from a cultural studies standpoint, that readings of a text are culturally constructed (Fish, 1980). From this standpoint, a text does not have meaning outside of a set of cultural assumptions regarding what it means and how it should be interpreted. The interpretation of articles collected within our newspaper corpus, then, is dependent upon each reader's experience within one or more communities, each of which is defined by a distinct epistemology and specific concerns.

In February 2008, the project's interpretive community was expanded through a day-long workshop held in order to facilitate discussion and debate regarding the visibility and portrayal of people living with HIV/AIDS in the media and to exchange ideas about how to foster a better social climate and reduce HIV-related stigma and discrimination. Of the 29 participants,⁷ a significant proportion identified as HIV-positive and three had previously provided testimonials to the media about living with HIV. Participants were divided into small groups of four to five people in order to analyse two distinct samples of media clippings from the broader VIHSIBILITÉ media corpus. The first sample consisted of 10 front-page stories published between 1988 and 2004 that contained first-person accounts of the experience of living with HIV.⁸ This portion of the collective interpretive work undertaken in small groups was thus oriented by an historical overview of media coverage from the past. The second sample discussed in small groups included four clippings published two weeks prior to the workshop that dealt with a court decision in Québec in which an HIV-positive woman was accused of assault for not having disclosed her HIV status to her former partner.⁹ This case was particularly controversial because the former partner had initially been charged with domestic assault against her. He was acquitted of this charge after claiming in court that she had failed to disclose her HIV status to him prior to their having sex (resulting, according to his claims, in his becoming upset and violent). No claims were made indicating that the man had contracted HIV. The woman subsequently faced her own trial on assault charges and was found guilty. Our collective

interpretation of this more recent media coverage focused on issues that the criminalization (in some circumstances) of the non-disclosure of HIV-positive status may raise for people who give media testimonials about living with HIV/AIDS.

For each article in these two samples, participants were invited to read the article and discuss the following series of questions:

In your view, how are men and women living with HIV portrayed in the article? Does this portrayal encourage an open-minded attitude? Does it encourage prejudicial attitudes?

What is your perception of the place accorded to the voice of people living with HIV within the article?

Do the experiences (cited or reported) within the article encourage a sense of social solidarity with people living with HIV? Do they bear some relation to your own concerns?

In the large-group discussions that followed, a range of viewpoints were expressed. Some of the clippings evoked divergent and contradictory readings and opinions among participants. Rather than aiming for unanimity or consensus, these exchanges allowed for a variety of perceptions and meanings of news media discourse to be identified and discussed. In particular, contrasting interpretations of the 2008 court case led to emotionally charged debates with regard to the criminalization of non-disclosure and the respective roles of the media and of people living with HIV in relation to this issue.

Workshop participants then went on to define the type of media coverage they felt could best foster a social environment that was supportive toward and inclusive of people living with HIV. Participants felt that such coverage should educate: it should be informative, neutral in style and tone, and grounded in fact. Journalists were thought to have a responsibility to be adequately briefed on the subject of HIV/AIDS so as to present a range of perspectives on the issues and events dealt with in their stories. Media coverage should also take care to properly situate experiences and issues as fully as possible with reference to broader interpersonal, cultural, social, economic and political contexts. Coverage should avoid an overemphasis on categorization by giving voice to the diversity of people living with HIV and to a range of personal experiences. In particular, categorizations that set up classes of 'innocent' versus 'guilty' victims and media coverage that portrays different groups of people living with HIV as being in opposition to one another should be avoided. Collective issues raised by organizations that promote the rights of people living with HIV should instead be emphasized. Media accounts that expose injustices, increasing public awareness of the stigma and discrimination that people living with HIV/AIDS face on a daily basis (and educating the public more generally about HIV/AIDS), were identified as crucial. Finally, media coverage should facilitate access to contexts where people living with HIV/AIDS will be well received by specifically mentioning services and support that are available in the community.

The 2008 workshop brought into focus in a preliminary way some of the key meanings and social implications of first-person accounts of living with HIV/AIDS in Quebec newspapers, as well as patterns and dilemmas in the ways speakers and audiences interact in relation to these stories. In the next section, we examine broader characteristics of

these accounts and the culture of testimonials within which they are situated. Addressing the social and cultural challenges and injustices that are often highlighted in first-person accounts requires analysis both of the forms and conditions within which these accounts are produced and of the social interactions associated with their circulation, consumption and reception.

Why talk about a culture of testimonials in relation to HIV/AIDS?

Cultural Studies approaches consider cultural texts and contexts in light of historical forces and power relations articulated through social change and popular media formats (DuGay et al., 1997). Central to this field of inquiry is the idea that discourse intimately affects everyone in complex ways because the ideological work of the media 'hails' us toward a dominant system of meaning (Althusser, 1970). Since any message carries a multitude of potential meanings, attempts are made to affix a particular meaning such that it is privileged above others. Yet media messages remain polysemic and interpretations differ depending on various factors. The range of viewpoints and divergent readings of media coverage expressed by those participating in VIHSIBILITÉ's interpretive community provide one example. First-person accounts of living with HIV constitute a diverse range of cultural texts co-constructed in various contexts and various ways by those who produce and circulate and those who receive and consume these texts.

Numerous scholars have taken an interest in the forms and social interactions associated with storytelling and in the characteristics of narrative more generally. As Richardson observes, 'narrative is both a mode of reasoning and a mode of representation' (1997: 28). She emphasizes the centrality of narrative to social experience based on the ways in which narratives produce knowledge and meaning, establish connections between events, and provide perspectives on *how to understand the world* (reasoning) and *how to tell about the world* (representation). The frequency of first-person accounts of living with HIV/AIDS within the VIHSIBILITÉ corpus, and the accompanying emphasis on exposure categories and questions of disclosure, point to specific ways in which these accounts have operated as modes of narrative reasoning and representation in Quebec media.

Plummer's study of sexual storytelling (1995), focused on how stories told in public are embedded in particular regimes of the visible and the sayable, provides a way to analyse the culture of testimonials associated with HIV/AIDS. Plummer's framework is helpful in unpacking the various levels that comprise public storytelling about HIV/AIDS and in identifying some of the contradictions that characterize these accounts as modes of representation and reasoning within popular culture and public discourse. In Plummer's framework, four levels of social interaction typically characterize public storytelling about sex and these can also be seen to characterize the culture of testimonials associated with HIV storytelling. First, there are the storytellers themselves, those involved in producing stories such as HIV-positive authors who inscribe themselves within a first-person discourse about HIV/AIDS – narrators, those who write novels or autobiographies, film their lives, photograph themselves, give interviews or publish personal blogs on the internet. Closely allied to tellers are a second type of producer, the 'coaxers, coaches and coercers' (1995: 21) who momentarily exercise a certain power to

provoke people to tell their stories. Coaxers and their like listen and interrogate. They probe, send out questionnaires and solicit. They are researchers, interviewers, curators, journalists, therapists, and friends and relatives who incite people to tell stories they might never have told before and coach them to tell their stories in a certain way. Third, consumers, readers and audiences ('witnesses to the witness') interpret the stories that are told and make sense of them. How these audiences do the 'work' of listening is crucial to understanding the nature and implications of any culture of testimonials. Consumers of first-person accounts may be attentive and sensitive – they may identify. Alternatively, they may be indifferent or turn a deaf ear. They may consume first-person accounts in relative isolation or they may do so through a community, real or imagined, of class, race, gender, experience or taste.

Plummer extends his framework to include the broader social context within which stories are told and testimonies given. The meanings of these stories are never fixed, but emerge out of a changing stream of interaction between producers and consumers in shifting contexts. In Canada, for example, the social environment in which first-person accounts can be offered by HIV-positive persons has changed over time. Since the late 1990s, HIV/AIDS has been somewhat 'normalized' as a chronic and treatable infection in places where treatments for HIV are accessible and affordable. Over roughly the same period, the non-disclosure of HIV-positive status in the context of sex has been criminalized in Canada (Adam et al., 2008). Decisions of the Supreme Court¹⁰ have established that failure to disclose HIV-positive status in some situations can constitute 'fraud', removing the element of consent from a sexual relation. This opens the way to a conviction for assault (although recent lower court decisions have signalled that future jurisprudence may take a different direction).¹¹ The ways in which court decisions have made certain types of HIV-related disclosure legally mandatory in Canada raises important questions. What is the impact in terms of how first-person accounts of living with HIV are told and heard more broadly in the society? One key concern is that an overemphasis on criminal sanctions to obligate HIV-related disclosure in some situations may do little more than perpetuate stigmatizing attitudes towards people living with HIV/AIDS and could make it more difficult for people to tell stories that need, for many reasons, to be told.

Disclosure, of course, can occur in many contexts: within personal relationships (to lovers, partners, spouses, children, friends and other family); in the workplace (to an employer, other employees, or clients); to health and other service providers (physicians, emergency services, dentists, social workers, insurers, etc.); in an institutional setting (prisons, schools, etc.), and to the general public via the media. Moreover, regardless of whether or not people living with HIV choose to disclose their status, someone else may decide to disclose this information to others, with or without the HIV-positive person's consent. Disclosing HIV-positive status tends not to be easy and can have both beneficial and negative implications. With troubling frequency, people living with HIV (and in a substantial number of cases, members of groups associated with HIV/AIDS) are refused employment or dismissed from their jobs, evicted from housing, refused insurance, barred from entering other countries (Bisaillon, 2011), abandoned by partners, provided insufficient access to reproductive health services (Loutfy et al., 2009), denied the possibility of adoption, rejected by family and lovers, and in some cases violently attacked (Abrahams et al., 2005; Hawkins et al., 2009; Human Rights Watch, 2004). Documented around the world, a social climate

of this type with regards to HIV/AIDS boosts the incentives for people to remain silent or to avoid being tested for HIV, and helps to explain why people living with HIV may be quite hesitant to disclose their status publicly to the media.

In a recent study that dealt with the disclosure experiences of some women living with HIV, researchers found that, for participants in the study, managing the *secret* of one's HIV status on a day-to-day basis was consistently described as a heavy burden (Racicot et al., 2011). Obstacles to disclosure included fear of rejection, fear of being judged and fear of causing significant others to experience worry. These women deployed much energy in the enactment of dissimulation strategies such as hiding their medication, invoking another illness (e.g. high blood pressure) to explain regular medical check-ups, avoiding contact with family members, avoiding AIDS service organizations and not having conversations about HIV. Many women described creating two distinct social identities according to context. An identity as an HIV-positive person was reserved for contact with community-based organizations and services. Another identity, detached and distinct, was adopted in most other social contexts outside of the community sector and served to protect the women from having to disclose their HIV status in these contexts.

The dynamics that shape public storytelling about and disclosure of HIV status can be compared to those of public conversations. As Baker et al. (2002) note, a private conversation is one where the participants can exercise control over who is included and who is excluded. Private conversations provide important opportunities to explore sensitive, intimate, confusing and important topics about oneself, others and the world by limiting the social context in which the conversation takes place. Often it is more risky to talk about certain issues in public, and public conversations tend to expose those who engage in them to challenges less present in private interactions with family and friends. 'In public conversations, what is said becomes open, in varying degrees, to everyone. Just one "outsider" can turn a private conversation into a public one' (Baker et al., 2002: 5)

The potential risks associated with having information about one's HIV status open to everyone, and the complications that may or may not arise when one or more 'outsiders' or additional listeners turn private conversations about HIV into public ones, render public accounts of living with HIV/AIDS into a particularly charged yet oddly silent/silenced social and discursive terrain. As an action-research project, VIHSIBILITÉ has emphasized the development of process for critically and collectively assessing this terrain. While the project has led to a number of tangible 'products', a method of engagement and collective interpretation has been one of the main outcomes. The project's initial assessment of first-person accounts of living with HIV/AIDS in Quebec daily newspapers has shown that these accounts favour specific modes of narrative reasoning and representation (such as the categorization of HIV-positive people by exposure category and the depiction of HIV as a 'lurking' secret). The collective process of critical assessment developed through the project has provided ways for an interpretive community to grapple with regimes of the visible and the sayable specific to HIV/AIDS, and to assess discursive forms and levels of social interaction associated with public accounts of living with HIV/AIDS and the culture of testimonials within which these accounts are situated.

As noted above, public accounts become such through the presence of additional listeners (just one 'outsider'), and a key focus of our project has been the conceptualization and critical assessment of the reception of testimonials. In the next and concluding

section, we provide several examples of how the role and effort made (or not) by those on the receiving end of first-person accounts about living with HIV/AIDS is shaped by a range of tensions and dynamics. Analysis of the culture within which first-person accounts are produced and consumed brings into focus both the details of specific types of disclosure and testimonial and the broader social worlds through which these accounts circulate.

From disclosure to testimonial: connecting social worlds

Making oneself visible and heard as an HIV-positive person has a number of political and social implications that require examination. This article has explored several questions regarding the meanings and processes whereby HIV-positive people become visible in the media. The role and impact of audiences, listeners – the people on the receiving end of these accounts – has emerged as a key aspect of the cultures of testimonials associated with this mediated and public visibility. In her speech on behalf of people living with HIV/AIDS at the opening ceremonies of the 2006 International AIDS Conference in Toronto, an activist from Indonesia outlines some of the stakes raised by this issue:

empowerment or involvement is not just giving testimony. I refuse when people only ask me to give testimonies.... I do not want to just be listed in the report of a meeting. [Applause] Now friends, are you hearing the words or are you really listening? I want to be more involved and I negotiate it. (Iskandar, 2006)

Cultural analysis of HIV/AIDS testimonials provides conceptual resources for grappling with the complexities of reception, in part by clarifying what distinguishes testimonials from less public acts of disclosure. Managing disclosure on the interpersonal level is a day-to-day challenge for a majority of people living with HIV/AIDS and the term ‘disclosure’ carries a certain weight that it is helpful to unpack. From the Latin *claudere* (‘to close’) – disclosure meaning therefore ‘to unclose’ – the connotations of shame and menace associated with this word can recuperate the ways in which, from the beginning of the pandemic, HIV-positive people have been situated within a framework of guilt and innocence. Disclosure suggests an individualistic approach to HIV, focusing our concern on the ostensibly central fact of a hidden infection and the obligation to reveal it. Media accounts of criminal cases related to the disclosure of HIV status can reduce the issue to competing accounts of who did what to whom and guide HIV-related public discourse toward a collective spectatorship of unseemly revelations rather than toward other types of more engaged witnessing. Disclosure evokes a notion of reception – of the listener – as not really directly involved, a detached and silent observer to a disconnected, individualized revelation. As another term and concept for first-person accounts, the testimonial has quite different resonances and dimensions of reception and engagement. For example, testimonials perhaps more easily connote (or perhaps ‘provoke’) a participatory response and practice.

These resonances are evident in the testimonial forms and practices central to the history of AIDS activism. During the 1980s and early 1990s, alternative AIDS media – in particular activist film and video – self-consciously sought to engage audiences in

contesting dominant representations of AIDS and attesting to the overlooked experiences of people living with HIV/AIDS.¹² As Hallas (2003) notes, one of the central objectives of media-savvy AIDS activism at that time was to produce new witnesses to the pandemic rather than mere spectators of it. Although activist AIDS testimonials have faded in potency in recent years, and in their heyday had only limited success in establishing the terrain for an alternative public engagement with HIV/AIDS, the potential and the imperative remain for concepts and practices of testimonial to be fashioned and mobilized for current purposes.

Ibañez-Carrasco (1995) has argued that testimonials stand out from other genres and practices of telling one's story because of their potentially destabilizing qualities. As his analysis suggests, the idea of disclosure focuses attention inward on the question of 'What is this person revealing/hiding?', whereas testimonials invite the gaze outward and respond to a richer, broader range of questions such as 'What is this person's story?' and 'How does this story relate to broader social worlds and to multiple truths about sexuality, intimacy, power or risk?' Whereas the idea of disclosure seems more closely associated with an impulse toward disconnection, testimonials can connect speakers and listeners in unanticipated ways, generating new discursive forms and new patterns of social interaction. The VIHSIBILITÉ project, a study of the specific culture of testimonials in Quebec related to daily news coverage and of other comparable examples elsewhere, has allowed for an assessment of predominant and alternative ways for speakers and listeners to be interconnected around first-person accounts of living with HIV/AIDS.

Funding

This research received funding from the Social Sciences and Humanities Council of Canada.

Notes

- 1 The VIHSIBILITÉ project aims to develop a critical understanding of the meanings conveyed by media accounts as well as the interpretations that can be made by communities involved in the production and reception of media discourses. Our methodology is twofold: first, the compilation and coding of a media corpus composed of newspaper articles published in Quebec since 1982, and, second, the formation of an interpretive community composed of participants from community-based, institutional and media sectors. The project has recently turned its attention to questions related to the production and reception of first-person accounts by people living with HIV that have appeared in non-journalistic media forms (film, video, photography, theatre, the Internet, etc.). Information on the project is available at: www.vihsibilite.uqam.ca
- 2 According to Edwin Cameron (justice in the Supreme Court of Appeal of South Africa, activist, human rights lawyer, and the first public office holder in his country to disclose HIV-positive status), Canada has filed criminal charges against more people with HIV per capita than any other country (Cameron, 2010).
- 3 Speech by Harvey Milk at 1978 San Francisco Gay Pride Parade, on the ninth anniversary of Stonewall (as portrayed in Van Sant, 2008).
- 4 Sensationalistic media coverage of AIDS has been recurrent since the early years of pandemic. In 2005, for example, an HIV-positive Canadian woman was charged with aggravated assault in what was described in the media as a 'military sex scare' (*CBC News*, 24 March 2004, 23 April 2005) focused on the Canadian Forces base in Borden, Ontario. Media accounts tended

- towards depicting the woman as a promiscuous and infectious sexual predator and some reports inaccurately suggested she had been charged for 'spreading' HIV rather than for not disclosing her HIV-positive status to partners, with whom she had engaged in unprotected sex (*Canadian Press*, 27 March and 29 March 2005; *CTV News*, 30 March 2005; *Toronto Sun*, 31 March 2005).
- 5 In surveys of the literature (Simoni and Pantalone, 2004: 111–12), research results on this questions have varied, with anywhere from 50 percent to 90 percent of participants in a range of studies reporting that they do disclose being HIV positive to at least some sexual partners. Perhaps surprisingly, in some studies, about half of those who reported disclosing their status also reported having unprotected sex with the partners to whom they had disclosed (D'Angelo et al., 2001; Kalichman et al., 2002; Marks and Crepaz, 2001; Marks et al., 1994).
 - 6 Accounts of female seropositive 'activists' outnumber accounts of male activists (30 IU = 10 women vs. 17 IU = 5 men). 'Victim' was used to describe almost as many women as men (8 IU = women, 11 IU = men, 2 IU = neutral).
 - 7 Participating organizations in the VIHSIBILITÉ project's interpretive community included representatives from the community sector (Action Séro Zéro, Association des intervenants en toxicomanie du Québec, Camp Positif – Catholic Community Services, Canadian AIDS Treatment Information Exchange, Centre d'Action sida Femmes, Coalition des organismes communautaires québécois contre le sida, Collectif d'artistes Chambr'Amie, Comité Projet Action Sida Femmes, Fréquence VIH, L'A.R.C.H.E. de l'Estrie, Maison du Parc, Maison Plein Cœur, Stella) and from the institutional sector (Centre maternel et infantile sur le sida de l'Hôpital Sainte-Justine, Institut Simone de Beauvoir de l'Université Concordia, Service de lutte contre les infections transmissibles sexuellement et par le sang du Ministère de la santé et des services sociaux du Québec, Unité de recherche sur la santé des femmes de l'Université d'Ottawa).
 - 8 The stories that were analysed were:
 - Noël A (1992) Le mythe et les faits. La campagne de prévention manque la cible. *La Presse*, 22 février, p. A1.
 - Chartier J (1994) Les médecins au banc des accusés? Le Dr Réjean Thomas dénonce l'incurie de ses confrères envers les séropositifs. *Le Devoir*, 28 septembre, p. A1.
 - Pelchat M (1994) 'Un don de mort'? Témoignages pathétiques à l'enquête sur le sang. *La Presse*, 17 septembre, p. A1.
 - Clément O (1994) Une maladie d'amour. *La Presse*, 1 décembre, p. A1.
 - Breton B (1994) Le sida, c'est la fin des projets. Caroline et Suzanne vivent avec la mort depuis sept ans. *Le Soleil*, 1 décembre, p. 1.
 - Boisvert Y (1995) Un séropositif acquitté de tentative de meurtre. *La Presse*, 21 février, p. A1.
 - Bouchard A (1995) Métier TR. TR comme travailleur de rue. Un Pepsi, si tu viens le prendre avec moi ... *Le Soleil*, 3 juin, p. 1.
 - Paré I (1996) Le prix de la vie: l'assurance cauchemar. Dès janvier, des malades atteints du sida risquent de ne plus pouvoir assumer leurs factures de médicaments. *Le Devoir*, 30 novembre, p. A1.
 - Voisard A-M (2003) Pour que cesse l'opprobre. Des sidéens laissent tomber le masque afin de sensibiliser le public à leur combat contre la maladie ... et les préjugés. *Le Soleil*, 1 décembre, p. 1.
 - Touzin C (2004) Une bataille de plus pour les sidéens. Ils réclament des traitements gratuits pour contrer les effets secondaires de la trithérapie. *La Presse*, 29 novembre, p. A1.
 - 9 The four articles were:
 - Myles B (2008) De bourreau à victime; de victime à criminelle. *Le Devoir*, 15 février, p. A4.
 - Leduc L (2008) Condamnée pour avoir caché sa séropositivité à son partenaire. *La Presse*, 15 février, p. A6.
 - Santerre D (2008) Agression sexuelle. Indignation. *Le Journal de Montréal*, 15 février, p. 26.
 - Routy J-P (2008) Une victime du VIH devenue criminelle. Conséquences catastrophiques pour le dépistage du VIH. *Le Devoir*, 18 2008, p. A7.

- 10 Two specific Supreme Court decisions, *R. v Cuerrier* (1998) and *R. v Williams* (2003), served to confirm the manner in which unprotected sex can be interpreted as assault, upholding what has now become a legal obligation for people who are living with HIV (or have reason to believe they may be HIV positive) to disclose their actual or possible HIV status in certain circumstances. For more information, see: www.aidslaw.ca.
- 11 See for example *R. v Mabior* (2010), in which the Court of Appeal of Manitoba ruled that in a case where a person's viral load was undetectable (for example, when anti-retroviral medications are taken as prescribed under medical supervision), there was no significant risk of transmission, no duty to disclose HIV-positive status and no grounds for a charge of assault (see Canadian HIV/AIDS Legal Network, 2010).
- 12 This approach also encompasses additional genres such as autobiographical film of the last two decades and the virtual archives of the 21st century. HIV/AIDS testimonials here point to the dynamic link between activist and artistic milieus, whereby first-person accounts reflect the creative expression of people living with HIV. For further discussion on this issue, see Waugh (2009).

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