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Author(s): Corinne Squire
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Partial Secrets

by Corinne Squire

The ability and right to have secrets may be a condition of social ethics (Derrida, A Taste for the Secret), but at the same time the nature of secrets is that they undermine themselves. Once told, secrets are no longer secret but are known. Even to name them as possibilities is to bring them into view as objects of knowledge. Secrets are thus always in some ways partial secrets, but their "openness" also connotes the lack of certainty of any knowledge about them, their evasiveness, their lack of fixity, and hence, their partial character and openness to change. In this article, I explore partial secrets in relation to a 2011 interview study of HIV support in the United Kingdom, where HIV’s relatively low prevalence and high treatment access tends toward its invisibilization. I suggest that in this context, HIV is positioned ambiguously, as a "partial secret," in an ongoing and precarious tension between public knowledge and acceptance of HIV, HIV’s constitution as a condition of citizenship attended by full human rights, and HIV’s being resealed through ongoing illness, constrained resources, citizenly exclusion, and the psychological and social isolation of those affected.

The ability to have secrets may be a condition of ethical social life, as the philosopher Jacques Derrida (2001) argued. This capability is important even though the nature of secrets is to undermine themselves (Derrida 1989). For once told, even to a single person, or merely to oneself, secrets are no longer completely secret but partly known, and they are thus not really secrets at all. Even to name secrets as possibilities is to bring them into view as potential objects of knowledge. Secrets thus always exist after themselves, already betrayed, as what we could call postsecrets or partial secrets. They come into existence, extracted into narratives (Derrida 1995), in a way that performs them while at the same time making them no longer secrets. This “deferred action,” as Freud and Lacan have described it in relation to subjectivity’s development and formation within language (Freud and Breuer 1975 [1895]; Lacan 1977 [1953]), also means that there is no simple present for secrets. The secret that is known, or known about now, belongs to the past. Even as past secrets are declared and made known in the present, other secrets are concealing themselves within that present as parts of the future.

Parts of secrets are always left out of language, history, and subjectivities while still making themselves felt as untranslatable aspects of language, neglected elements within the present, or inescapable patterns of affect. Secrets are thus manifested partially, through their traces, as signifiers of something inaccessible, unknowable, or incomprehensible (Butler 2005; Derrida 1989). They thus secrete themselves in two senses of the word: they are both endlessly concealed and perpetually exuded, showing themselves.

It might seem that there are no good secrets, particularly in relation to a serious illness such as HIV, which is my concern here. In one sense, however, there are no good secrets at all. The secret engagements and marriages and children that are staples of British nineteenth-century novel plots and the reservoirs of loves and contentment, for instance, are also matters of disapproval and shame; the happiness of secret fortunes is obtained and maintained at the expense of others. Any secret thought, such as “I am HIV positive,” betrays, at the least, the sociality of human lives. At the same time, there is no possibility for ethical sociality, for any “good,” without the existence of secrets, which depend at their very simplest on an other that recognizes you—a precondition for ethics itself, within some philosophy (e.g., Derrida 1980 [1967]; Levinas 1969 [1961]). “I am HIV positive,” for instance, said to the self, is a secret expressed to a posited internal other that hears it even if that other does not accept it.

These performances, deferrals, recognitions, and misrecognition that make up the partialities of secrets do not just operate in relation to language, subjectivities, and time. Many other aspects of the contexts of secrets also make and unmake them. Anthropologists have long recognized how social and cultural formations are structured by secrets, how those secrets undo themselves, and how certain kinds of language have secrecy built into them (Piot 1993; Rosaldo 1984). As Manderson, Davis, Colwell, and Ahlin point out in the introduction to this supplemental issue of Current Anthropology (Manderson et al. 2015), anthropologists have also examined the power relations of secrets in relation to their construction, withholding, and disclosure as well as the pat-
terns of surveillance and governance associated with these processes (Brenneis and Myers 1984). They have even considered secrets that are not secrets, "public" secrets, which we know not to know as the basis of established social institutions such that breaks in these patterns release possibilities of understanding and change (Taussig 1999). It is possible to bring together these anthropological perspectives with the philosophical, linguistic, and psychological understandings referred to above by thinking broadly of the temporal, symbolic, and subjective as well as the social, cultural, and political contexts of secrets, all of which make up secrets' multidimensional contexts. "Context" is a useful word here because it gestures to the spaces within texts that help make sense of those texts as well as to the sense making that occurs in spaces apparently "outside" texts (Derrida 1988 [1972]; Squire 2012) in their social, cultural, and poli-
cical "con-texts." Secrets' "context" also indicates to us that temporalities—that is, the pasts that are kerneled in secrets, the presents that expose and constitute them, and the futures that perform and undo them—are "openings" of the contexts of understanding rather than radically separate temporal spaces (Derrida 2001). Moreover, in such a framework, secrets' multi-
dimensional spaces are not unproblematically polysemic. Their dimensions may be incomplete and repetitious, agonistic and conflicted. Their "partiality" carries with it a second sense of the word: secrets are structured by gradients of resources and power; they have interests. Who owns a secret; who hides, gives, or extracts it; who receives or is burdened with it are all contested matters.

In this article, I endeavor to explore secrets within this framework in relation to material derived from a 2011 interview study of HIV support in the United Kingdom. In this national environment, HIV's relatively low prevalence and current good treatment access and success alongside a recent history of targeted rather than general prevention interventions mean that the epidemic exists in an often invisibilized state, viewed as a rare and manageable long-term illness, despite the continuing difficulties that attend it and its higher prevalence in some localities. It is also frequently seen as a condition whose major difficulties and significance exist elsewhere, predominantly in sub-Saharan Africa (Health Protection Agency 2011; Squire 2013). HIV in the United Kingdom is supposed to be, in the era of treatment optimism and hope for a "post-AIDS" generation, a "postsecret" phenomenon: medically understood, well treated, and therefore no longer stigmatized or concealed. Yet while there is extensive public knowledge about HIV, this knowledge appears to be declining in some groups (National AIDS Trust 2010), and there is strongly constrained personal openness about HIV status outside of clinics, HIV services, and sometimes family members and close friends. Despite effective treatment, HIV continues to be stigmatized, indeed criminalized. Many of its persistently difficult aspects—such as ongoing ill health, HIV-related poverty, entwined citizenship issues for migrants and refugees who are living with HIV (National AIDS Trust 2011), and the inner dialogues that it continues to generate (Irving 2011)—tend to be either ignored or hidden away. In this context, I argue that the "postsecret" is positioned ambiguously in an ongoing and precarious tension between public knowledge and acceptance of HIV and HIV's status as a condition of citizenship attended by full human rights and its becoming reseeded through ongoing illness, constrained resources, citizenly exclusion, and the psychological and social isolation of those affected.

The HIV Support Study

The study on which I draw was the most recent of five interview rounds in my research on HIV support in the United Kingdom. It involved 47 semistructured interviews with people living with HIV. Half of the interviewees were gay or bisexual men, one-quarter were heterosexual, bisexual, and lesbian women, and one-quarter were heterosexual men. Eighteen participants were from African or African Caribbean backgrounds, and the others were from British, other European, Asian, and North and South American backgrounds. All but three participants were taking antiretrovirals (ARVs). Interviews covered medical, social, family, friendship, work, online and other media, and faith support topics as well as self-support, each lasting generally between 1 and 2 hours. These topics were not asked about specifically unless they had not been covered by the end of the interview. Even then, all topics were not always asked about because I stopped interviews after about 2 hours. This was in order to ensure that some interviews did not become life story interviews—which were not asked for, for which consent had not been obtained, and which would work to center the lives of participants on their relations to HIV—and also because, even if participants were enthusiastic, sometimes they got tired. Indeed, some interviewees had considerably shorter interviews for this reason.

The interviews did not ask participants to tell stories. Indeed, they were designed not to entice people into personal specificity of any kind. Requirements to tell stories, particularly personal stories, and to speak subjectively or emotionally are forms of linguistic and social policing that are intrinsic to language and social relations, albeit also varying with linguistic and social specificities. Such narrative requirements overlap to some extent with the elicitation and control of secrets (Derrida 2001). They are frequently the cause of contestation when research, particularly of a life story or of the ethnographic kind, is argued by its participants to have been a form of identity theft or cultural tourism; criticisms of Alice Goffman’s work are a good recent example (Betts 2014; Sharpe 2014). Such narrative demands should be treated especially carefully in situations where, as here, research participants be-

1. For further details, see Squire (2013), chap. 8.
long to a group, that of people living with HIV, whose thoughts, feelings, and actions are already often under strong social, cultural, and political monitoring and control (Craib 2004; Derrida 1995; Nguyen 2010; Rose 2007). In this case, participants were asked by the researcher simply to position themselves in one specific way: as contemporary sources of knowledge about living with HIV and ARVs.

In interviews, participants were asked for their accounts of support in various domains. However, many of those accounts moved beyond short description and took a narrative form (Squire 2013). This tendency may be due partly to the strong research and mainstream cultural currencies of personal stories. At the same time, though, participants seemed to use the research situation as a means of extending, through personal stories, public representation of the overlooked personal suffering, social exclusion, and political neglect around HIV. Intimate disclosure stories of the kinds they told have a long history of gathering people together, broadening their audience, and potentiating action (Plummer 2001). Moreover, stories of HIV have the specific value of “speaking out” about a condition of living that has often been explicitly silenced (Squire 2007).

All papers and other publications were made available to research participants who wanted to see and comment on them. Advocacy and activist groups involved with the research also gave feedback on early analyses. The participants and those more peripherally involved had, of course, many interests more pressing than the research. There were numerous personal, socioeconomic, cultural, and political factors that may have constrained their engagement. Nevertheless, the participants, research assistants, and those otherwise involved strongly inflected the work. At the same time, as the researcher, I shaped it to the greatest extent. In this case, the limits on my understanding, as an HIV negative white British woman, healthy, employed, middle aged, not a refugee, and socioeconomically middle class, clearly have strong effects on the adequacy of the research.

Because the interviews were semistructured, participant focused, and lengthy, people talked openly and largely on self-determined topics, and so the material provides a broad picture of how the epidemic is lived within the United Kingdom as well as answers questions about “support.” Part of the material’s breadth lies in its narrative elements. For this article, I take as “narratives” sets of symbols, in this case, spoken words and paralinguistic elements, that build meaning by their movement (Squire et al. 2014) and that may occur in parallel, intertwined, or with multiple story meanings developing from the same symbols. This minimal definition takes in a great deal of meaning-making activity within the interviews and allows attention to the ambiguous, contradictory, and partial aspects of narratives. Attending to narratives’ extended and mobile representations thus allows for some understanding of the complexities of secrets within verbal accounts of them. Below, in my analysis, I focus on stories told about HIV as a secret in the United Kingdom context. Each story excerpted exemplifies a story trajectory in relation to secrets found also in others within the set of 47 interviews.

Secrets Hidden by History, Habit, and the Medicalized Present

If secrets are always partial secrets and secrets “after the fact,” it follows that secrecy about HIV is always at least partly over once it has been articulated. However, the ways in which this HIV secrecy is performed and dispersed are, as with other secrets, multiple.

I want to start with an example of how HIV is articulated as a partial secret in relation to three contexts: family and family history, everyday life, and medicine—three realms in which living with HIV very often has to be articulated. For John, a white gay man of British origin in his 50s who had been living with HIV for over 20 years, the field of the HIV secret had become dispersed across these different arenas and had acquired a kind of postsecret character, while still being concealed, in each.

Medical things were never discussed, you know, and everyone hates going to the doctor, so, yeah, but I know (friend’s name) said to me and you know, a lot of my friends have said, “Are you sure they don’t know? Are you sure they don’t suspect something?” And I said “I’m pretty sure” because my mother certainly would confront me, like she did with the gay thing all those years ago, you know, I didn’t have to come out to her or want to come out to her, she just confronted me with it, and she’d have no qualms with—that’ll go through to the answering machine—um, she’d have me, she would, she’d just say “Is there something serious going on here or what?” She would. (Telephone interruption.)

So I don’t know really, but of course they all, I mean I’ve only got one sister/Right/My mum’s on her own now, she’s been on her own for three years but they all have very full lives of their own. I mean although we’ve always been close, we’ve always seen lots of each other/Mhm/ Given the distances involved, um, they’ve not lived through me and I haven’t lived through them/Mhm/And we all know we’ve got, you know, lives of our own and I think that, that helps, even my mum today, you know, she’s far busier than I am a lot of the time. She’s out hopping around all over the place and doing things like that and everybody’s involved with their own lives. I don’t know if, I don’t think my sister’s ever suspected but again, she calls a spade a spade and she’d probably confront me.

... I think also (interviewer name), having kept it a secret for so long, what feels like a massive chunk, which is a

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2. I am grateful to Harriet Anyangokolo, Royce Clark, and Rachel Stovold for their help with this work.
massive chunk of my life/Yeah/that you’d think about it, twenty-three years is a big chunk, um, I’ve got so used to it/ Yeah/that I don’t have to, I don’t think about it any more/ Yeah/you know I just sort of switch automatically/right/um, to not mentioning it, or taking my pills secretly, if my mother sees me swallowing pills, well there aren’t many people in their fifties that don’t take pills, you know, so, they know I’ve got (chronic non-HIV-related condition) for which I have to take (medication) for because my previous ones don’t work, so they know about the (chronic non-HIV-related condition), they know about the (age-related chronic non-HIV-related condition) which I have to take medications for...so they see me swallowing tablets and don’t and wouldn’t suspect anything...

I mean if it ever comes out, I mean, the fact is the way things are, I’m not going to die of AIDS really/Sure/I’m pretty sure/Yeah/I might die of a complication because of the treatments, I might die of cancer, I might have a heart attack. So even when I die if I were to die if you like before my mum, my sister and all that sort of thing, they probably wouldn’t even need to know, you know, if I got cancer or died of a heart attack they’d accept that; you would, wouldn’t you, someone in their fifties.

The kinds of HIV secrets appearing in the above story were common in interviews with people—the large majority of interviewees—who had not told at least some close family members or friends about their status. In John’s account, the secret of his HIV status was partly constituted by retrospective stories about what has already been done in families such as his about secrets generally. Family members may “confront” you and “call a spade a spade,” but some families, like John’s, are not open about illness. Here, the potentially revealed “postsecret” of HIV suggested by John’s friends—“Are you sure they don’t know?”—was at the same time partly resecreted by John’s specific, disease-silent family history.

Second, in the domain of the everyday present, the HIV secret had become a habit of John’s day-to-day life with his family, “a secret for so long” that it had more or less disappeared as a secret for him, with secrecy eroded into habituality. HIV was a secret hidden in plain view (Derrida 1975), an almost-open secret. Indeed, this partial secret constituted an “everyday secret” with which his family, too, might possibly live. Whether or not they do, the conditions for such knowledge—John’s illness history, his open taking of medications, his talk about HIV in relation to others (mentioned in other parts of the interview)—exist in the everyday familial public domain. Does HIV still in this case have any meaning as a secret? Does status secrecy, disclosure or non-disclosure, in such conditions really matter? John’s continuing talk about what has not been said was indeed mostly about the social impact of HIV as a secret, which, while continuing, was for him declining as HIV becomes medically normalized.

This decline in the social impact of HIV’s disclosure or secreting leads us to the third way in which the HIV secret dissipated within John’s story. In his account, the HIV secret was both declared and hidden away within discourses and practices of medicalized living, particularly medicalized aging. Taking pills in one’s 50s conceals but also normalizes HIV treatment, especially at a time when HIV itself has become highly medicalized (Kippax 2012; Nguyen et al. 2011). The HIV secret, like HIV itself in much contemporary discourse, seemed to have been treated away in this case, turned into something else—a “long-term condition” like many others.

As we have seen here, secrets always escape being kept. However, when a secret is dissipated, some residues remain, at the very least in what cannot be said. John’s talk about the dimensions of secrecy around HIV preserves something of the HIV secret’s partial “unsayability” in its very extensiveness, the longue durée of 23 years’ silence, “a massive chunk...a massive chunk of my life...a big chunk”—at the same time that he describes that secret’s partial sociohistorical dissipation. Secrets’ partial natures can, though, be much more explicitly conflictual, as the stories of denied and re-hidden secrets below demonstrate.

The Nonsecret as a Secret

In the story below and in many other accounts, interviewees described HIV as suspected yet secreted by being hidden by a trusted other, usually a relationship partner. Revealed by physical illnesses, by medication and side effects, by the allegations of others, or by the deaths of partners or children, this nonsecret is resecreted by being denied. This does not quite make a secret of it. Once more, HIV manifests as a partial secret. Olive, a heterosexual black African woman in her 50s who has permanent leave to remain in the United Kingdom and who was diagnosed in the United Kingdom about a decade ago, described the later effects of a secret that had been denied and displaced.

Olive: My, my my my husband didn’t tell me. He didn’t say he didn’t anything, even when he was dying, he didn’t say, he just kept on saying, “I am sorry, I am sorry, you will find out.” “What is it?” “You will find out, I’m really sorry but I hope you look after the children,” so I didn’t know. But when I was diagnosed when I was here, I think er, I think “this is what he meant,” (laughs) yeah.

Interviewer: So when he died, did you think it was TB or some other thing or (?)

Olive: Erm, I thought, he was, with him, he kept on saying it was a low blood pressure but the way he was, was he was a big man, he was a big
man, but when he died he was so skinny, so I kept on asking, "can you tell me what are the doctors saying yeah?," no he just say "no, blood pressure is low." "But how come you’re losing weight, losing weight like this?." He was a very, er, he was a big man, very tall six foot, yeah. But the way he was, he was so skinny, () so I so I kept on asking questions because I was suspecting that he might be HIV positive but he said “no,” so (laughs). “Oh,” I said “ok, fine fine” (laughs) yeah.

Interviewer: It’s very hard.

Olive: Yeah, it is really hard, yeah. And, it is difficult, especially to to forgive that time, yeah. It was very difficult, although I tried not, to but it was very difficult. It was like a (germ). That is when the religion helped, (laughs) to forgive, yeah, to forgive him.

Again, this was a secret concealed in plain view. But it was one that had been kept—though only just—by being spoken and then denied again and again (Derrida 1989) rather than by being lived out in various domains, as in John’s account. In this story, the ambiguity of secrets was foregrounded because Olive’s husband repeatedly signaled some other unspeakable secret—not HIV, but something else. HIV was not all of the secret; the secret must be partialled out because there were, indeed, different parts of it. An indirect indicator of this partial nature of HIV as “the secret,” reported by Olive, was the anger of her children, not because of the HIV secret but because their father had had secret girlfriends and had secretly compromised their mother’s life. “HIV positive” thus gestured here toward a field of secrets very imperfectly described by HIV status. It was this spreading field that was so difficult for Olive to forgive, particularly its inclusion of “that time” when her husband could have helped her, their children, and all their futures by disclosing, rather than leaving her with a legacy of falsification that seemed to spread across their lives, “a germ.” Many years later, even with the support of religious explanation, Olive articulated “that time” of the secret by showing its unspeakability, marking it with laughter. In one sense, then, Olive’s husband was right to say that HIV was not “the secret,” but it would be hard to frame HIV status as entirely irrelevant to these other secret, endlessly cogitated-on betrayals and lacks of care.

Olive’s account also shows how a secret is transitive: it is always kept by someone specific, or between specific people, and away from specific other people. This is part of its context. Yet the boundaries of such transitivity are mobile: a secret is not fully owned by anyone, nor is it entirely withheld from or told to another. Language connects people, albeit imperfectly, and those who are closely connected may “have no secrets” from one another. Here, the person who asked about the HIV secret, within a long-established relationship, trusted the assertion that there was no such secret—though perhaps not entirely. The revelation of the secret later awakened the prior, suspected but trustingly refused knowledge. It is hard, “especially to forgive that time,” Olive said. This was a difficulty not of self-blame but of reframing interpersonal and social parameters of trust and communication in the wake of a secret held to some degree in common and across time.

It is not surprising that the epistemologically problematic, historically complicated, and spreading secrets of “that time” had intense later effects for Olive. The secret of “that time” was indeed a “germ” whose intractability and deferred action offers some parallels with the viral processes of HIV itself.

A Secret That Is Not a Secret: A Secret That Must Be Told

In 2011, more frequently than in previous interview rounds in the late 1990s and 2000s, participants insisted on the importance of speaking out about HIV. They described it as no longer a secret because knowledge of it has become available, yet it is something that has been resecreted because of stigmatization, even in a time of good and effective treatment, and that has to be countered actively, because allowing it fuels destructive exclusions of many kinds. This was particularly characteristic of the stories of some more recently diagnosed interviewees, who often reported having few psychosocial HIV services available to them, something that earlier-diagnosed interviewees remarked on as a change from the strong advocacy and activist HIV environment of the 1980s and 1990s (Squire 2013). Here, for instance, are excerpts from an interview with Zack, a white gay man in his 30s of non–United Kingdom European origin diagnosed in 2010.

Zack: It’s only something which is in my blood and it’s contained and it’s monitored, well monitored. And, they don’t need to make me feel sick when I am not sick, I’m not ill. Some things need to change, as with the perception of HIV positive needs to change. And, I said before, erm, before we recorded (laughs) that scientifically, we are miles ahead of the people’s perceptions of HIV, because they fear me and I don’t scare anybody.3 So, I can be careful, you know, I mean everybody should be careful. So, I don’t know, that’s the thing and, but I think we also need, because most of us are, and I know that from, erm, forums, online forums where HIV-positive people
organizations (Squire 2007). In pursuing prevention and work-

ing against stigmatization, such open talk has indeed been
described as the “invisible cure” (Epstein 2006). This undoing
of a harmful secret makes HIV “visible” not by producing
a visually healthy from an unhealthy body, as medical care
often does, but by speaking out about the nature of HIV it-
self. In these accounts, as in Zack’s own story, visual knowl-
edge can be unreliable and can hide HIV status away as a
secret—although not when HIV owns itself by writing itself
out, as on the “HIV positive” t-shirt.

At the beginning of Zack’s account, writing out, or speak-
ing out, about HIV positivity, was not a matter of telling a
secret so much as of redefining HIV as something that can-
not and should not be signified as a secret. “It’s contained
and it’s monitored,” and perhaps not even as an illness any-
more. It is not to be feared, not to be the subject of self-blame
or remorse; it will not change your life or your friends; “there
is no difference between me and a person, or you.” A secret
is only a secret if there is something extraordinary that must
be concealed; here, speaking of HIV indexes and displays its
contemporary ordinariness as a condition.

For Zack, an open secret about HIV, like the one arguably
at play in John’s family, is as bad as a closed one: HIV has
to be spoken out. However, not everything gets said, even
in such open speech. In Zack’s story and many that were
similar, HIV remained difficult to deal with medically despite
the dramatic improvements; new friends reacted unpredict-
ably; stigma was experienced and feared. Not everything
is cured, then, in erasing the secret by speaking out. HIV
remains potentially, and partly, secret, just as not everything
appears on the apparently revealing surface of the visible
(Jay 1995). Zack’s specification of the “HIV positive” t-shirt as
a way of performing “speaking out” was embedded in such
ambiguities. Wearing this t-shirt is a polysemic performance;
the shirt itself is an empty signifier. The field within which
the performance takes place provides a set of likely mean-
ings. For some, wearing the t-shirt is a political rather than
personal act, of varying strength; for others, the t-shirt is just
a t-shirt. For yet others, the t-shirt may be worn precisely
because it says nothing about one’s own status while enabling
one to talk about HIV with the people around one (Squire
2013). For some people, like Zack, this bodily performance
could be a personal declaration as well as an incitement to
politics. Similarly, Nelson Mandela’s wearing an “HIV posi-
tive” t-shirt at a time when the South African epidemic was
largely unspoken, or spoken of as conspiracy, triviality, or
poverty, was a political but also, given his own speaking out
about HIV-affected family members, a personal act. The poli-
tics of such an act are also not fixed. The 1980s Benetton ad
that displayed the muscular, healthy-appearing torso of a
man with “HIV +” tattooed on one bicep, a kind of flehmen
version of the t-shirt, was understood by many HIV activists
as a minimization of a then-fatal illness. In 2000, Mandela’s
“HIV positive” t-shirt, by contrast, was positioned as part of
the struggle for treatment access in Africa and is now part of
the recently established “Museum of AIDS in Africa.”

Interviewer: What would help people not ( ) what
would you change?

Zack: Ah, what would (I) change? Erm, well,
that HIV positive people should come out of the
closet, basically. I was thinking of the, erm, I
mean I commented online and quite a few people
found that really stupid, but, I mean, there was
Annie Lennox, she has a campaign, so she wears
a t-shirt and it says “I’m HIV positive” and then
on the back it says “fight the stigma, fight AIDS,
fight the stigma.” So, you have to fight the stigma,
and I thought, perhaps we could create a flash mob
or, you know, or like, or a jogging group,
and we go running with that t-shirt; that is when
people would think, “oh my God he’s HIV posi-
tive, and is he jogging?” Because, I know a lot of
people, especially gays that go and look at you
and say “hmm, you’ve got an AIDS face,” because
if you have a fat here or your eyes are this way or
that way then you have HIV. People go by the
looks, I mean how can they be so stupid? There is
such misconception, misinfor- mation, and the
only way is that, I think, people have to know us;
see what we do, see what we can do, and we are
doing fine. There is no difference between me
and a(nother) person, or you, I mean, there is
no, nothing. People have really stupid ideas in
their brains.

This and many other stories of speaking out, or plan-
ing to speak out, were interesting to hear at a time of HIV’s
often-noted invisibilization in the United Kingdom and in
the context of the narrated unreliability of visual signs of
HIV and ARVs. These features were both commonly discus-
sed by people who had lived in high-prevalence African
epidemics when little was being said publicly about HIV
and when testifying about the condition openly was often
(as to some extent it still remains) a priority for HIV orga-
nizations (Squire 2007). In pursuing prevention and work-
In Zack’s story, the different modalities of the secret—silent or spoken, written, visual—indicated its complex epistemology. The sophistic simplicity of a secret that is not one if it is not kept becomes more problematic as Zack’s narrative continued. It transpired that it was active speaking against HIV as a secret that dispersed the imperative to hide it. Some secrets, like that of HIV status, do indeed, in this account, need to be worked against quite directly.

A Secret That Is Not a Secret

We have already seen, in John’s and Olive’s accounts, that HIV as a “secret” may be parted out or may extend into different fields and may attenuate into the habits of everyday lives and memories of the past. It is not just that secrets cannot be entirely told; it is also that telling a secret does not only involve revelation or the opening up of what is hidden. Telling secrets is also a remembering or reframing of things that are not thought or talked about, that are concealed in less various, often unthought ways. These are social secrets, which may not even be framed as secrets, as appeared at the end of Yann’s interview, when the interviewer asks him whether there is anything that they had not talked about.

Do you know, I’m surprised about the things we have, things I had forgotten about, things that were brought up, but also for the future I’ve found it quite helpful in a way because in thinking there may be some scope in the future going back to (HIV support organization 1) where I’ve not been involved with for a while/mhm/and um yeah so I’m grateful for that . . . the final thing that I do have to mention that has just come into my head is the immense amount of stigma that still exists amongst health professionals about HIV. There still is a huge amount of work to be done in this area. Because again, just because it’s not talked about so much, you know, I’ve heard um colleagues, er (in health) let’s say even doctors say “oh be careful he’s HIV positive”. As if, OK . . . I didn’t really need to know that you know (that person is) HIV positive or they’re Hepatitis B positive. It didn’t affect what I was doing and kind of felt, I’ve heard these recently from (health professionals). So that kind of again, I have an insider’s view of, and this point of view how people look on this. I don’t know what it’s like on the general side but I know on the (profession 1) side there is still a quite a lot of probably misinformation and possibly some degree fear/mhm/of doctors and other health professionals dealing with clients who are HIV positive. And that’s it, that’s definitely all.

Here, Yann, a white gay man in his 40s of non–United Kingdom European origin, diagnosed in the mid-2000s, and himself a health professional, used the length, personal orientation, and space for complexity within the interview to explore, when the interview was coming to an end, some possibilities for support groups that he knew about from past experience and had secreted by forgetting and to name the discriminations that happened within health practices that were secrets hidden in plain sight within his everyday work experiences.

There were many other examples in the interviews of aspects of HIV secreted by being overlooked: doctors’ carelessness or lack of resources, instances of stigma that had been hardly thought about, difficulties of living with ongoing side effects, and difficulties with living with increasingly constrained resources, particularly for HIV-positive asylum seekers and undocumented migrants who, given time, started to detail the life calculations and compromises that they had to engage in around food, transport, social support, and sending money home. These elements of living with HIV were, one could say, socially constituted secrets, publicly unspoken and psychically shut away, and partial in their character, both because they are relatively accessible but also because they are easy to predict, made up as they are by gradients of power. This conjunction of structural and affective determination is perhaps constitutive of “public secrets” (Taussig 1999). It seemed as if such social secretings away were being intensified by the resource shortages and discourses of market and austerity with which HIV-positive people are now living, within which the social value accorded to gratitude, belt tightening, lack of entitlement, and marketized thinking increasingly rendered difficult aspects of HIV unsayable.

Parts of a Secret Cannot Be Told: When a Secret Is Not a Secret

We have already seen traces of secrets, remains of them that cannot be articulated or spoken out simply, manifested in the complexities and elisions of interviewees’ accounts: John’s story of his outspoken family, silent about HIV; Olive’s signaling of the impossible past with her laughter; Zack’s declarations of how things should be but are not always. Some aspects of living with HIV remain recalcitrant to speech, shut away by the excesses of the experience. Even though they can be indicated, they cannot be fully opened up, as Olive and many others described, when they followed unambiguously positive accounts of living with HIV and treatment with briefer, allusive accounts of what does not work, what hurts, and what has been lost. Olive described herself as empowered, accepting her status, helping others, and doing well, medically, on ARVs. Later in the interview, though, she describes considerable difficulties.

Olive: Yeah, for me, it was, it was, it (ARV) was, it was OK for me. But with him (doctor) the, he said he found the, he say, I don’t how he explained it, in my blood, when they take blood, that the dosage was very high, yeah, yeah. In the blood, it was, it was showing that the dosage was very high for me. Because I was feeling more, the side effects were dizzy, tired (and stuff like that, that
Olive does not and cannot tell fully, even when she speaks about it, as here, the daily hidden abjection of the side effects. These aspects of her life are noted and then put aside for the rest of the interview. They are secreted, although they are not surrounded by the signifiers of secrecy—alternative terms, silences, taboos, weighty emotionality.

Sometimes, such untellable things are not marked so clearly. Susan, for instance, a heterosexual black African woman in her 40s diagnosed in the mid-2000s and with an asylum claim pending, almost immediately left behind the present, hardly spoken condition of her absent, missed children to talk about a planned future of disclosure and a long-gone habitual past. Susan’s children are with her sister in her country of origin. She has been in the United Kingdom for 11 years. I asked a question about how she managed to live so well; this was a bad question. Looking away at something I could not see, Susan was suddenly filled with emotion about things she could not really talk about. She mentioned some conditional future plans and some aspects of the past, but this was clearly not an account of the whole history of the preceding 11 years or the full present condition of missing her children.

Susan: You just, it’s not easy./mhm/It’s not easy. I just try to be positive./mhm/it’s not easy, at all, at all. It’s not easy. (looks away, pause) I’m sorry. It’s OK . . . Because, I have been away this long, even if now I decide to go and I fall ill, I’m ill. I haven’t even had the courage to tell my children. Now you, () when they see you poorly, what do you tell them, when they see you poorly? How do you start, and how, they are children, I have not been with them for the, like (my last one), I left him when he was only eight years old. So you go, and you start saying, "oh, I need your help to look after me." It’s not right. You haven’t been there for them and now you (need) to be there for you./mhm/It doesn’t make sense. So that is why I am still stuck around here, hoping one day things will go better.

Interviewer: Were you working when you came here?

Susan: Yeah, mhm, though I wasn’t supposed to work. (laughs) But I was working, and I think it is the work that made me get even more sick because I used to work 14 hours, in about three different jobs, because I had children back home to look after them.

This is a story that, less explicitly than Olive’s, indicates an area that cannot be told about—what happened and is happening with Susan’s children, to whom she cannot return without forfeiting her asylum claim and consequently her current assurance of HIV treatment, health, and being a help to her children rather than a burden on them. Nevertheless, this story also marks out that area, taking it out of secrecy while still leaving much within it bracketed as secret. This is also, though, a story that starts to move onto other secrets—about citizenship status, for instance. This was something that commonly happened and that was particularly the case when participants were describing difficult aspects of their lives around migration.

One Secret Leads to Another

Not only are secrets never really secrets, because they are always brought into knowledge by being formulated as such, they are always secrets after the fact. Secrets are also often never really told, because, as we have just seen, aspects of them may remain resistant to formulation, so that a part or a kernel of the secret always remains and may get transmitted, still unknown (Abraham and Torok 1994). Another element of this deferral is that secrets are mobile. Talk of one leads to another, as in Olive’s story of her husband’s chain of concealed deceptions. In longer interviews, participants often moved from HIV stories to stories of other kinds of intimate suffering (Plummer 2001). Penelope, for example, a black African woman in her 40s diagnosed in the early 2000s whose asylum status was pending, described, like Susan, difficult and often unknown aspects of the lives of her children, separated from her for over a decade and themselves hiding difficult parts of their lives from her.

(My daughter is) still in (country of origin), yes um. I tried to bring her but it didn’t work out and then I thought I thought she was in primary school there going to secondary school so I had not looked for a place for her be-
cause I thought it was going to be possible [to bring her] but it didn’t. I had to go back to my cousin again and beg her to take her so she took her, and then at one time she beat her up, with um you know a ruler? she beat her, my daughter never told me, she beat her and she put salt, my daughter never told me, I didn’t know about it until she went to visit at my sister. That’s when they saw the scars and asked her and then she told them that my cousin had beaten her and she had stolen some money from her, she didn’t want me to send her money, but I said when I was going to school my parents use to give me a 50 cents at least you know so. And a, every time it was holiday she [cousin] would call me and say “where is she going where is she going to go for holiday?” so I said, “where would she go?” you know, so last year she went to visit her aunt you know. Then, so I asked her [aunt] if she can if she could stay with her, so that’s where she is now, um my sister yeah . . . but I feel I haven’t been there for my children you know and my son died in his sleep and I understand he was fasting. I don’t know what for and a, I dunno they told me at one time he wanted to commit suicide, he was also ill, he had diabetes, and I regret having I told him to look after his sister you know and I regret having told him that because I don’t know why he wanted to commit suicide you know seeing the people in Africa who are HIV.

For Olive, a chain of HIV-related secrets accreted sadness when it moved from her husband’s HIV status to her relationships and family life. For Susan, too, the secret’s expansion from HIV to her relations with her children aggregated pain. This narration of HIV meanings moving from status to children and family was common in HIV-positive migrants’ stories, compounding the weight of the secret. It happened in Penelope’s account very explicitly and intensely because of the narrator’s children’s partly known suffering. Here, the secret of HIV spread from status toward the unspeakability of children’s abuse and loss as well as their absence. Even though Penelope spoke about these things, she knew only imperfectly how the son thought—particularly about HIV, which had perhaps been signaled to him by the injunction to “look after” his sister, rather like Olive’s husband’s hope that she “look after the children,” and which may have influenced his mental health, his suicidal ideation, and perhaps his fasting. Her story also tells something of her daughter’s long-held secret about her lack of money, her theft, and her subsequent ill treatment, revealed only by the visible scars on her body, and held within the secret of Penelope’s sadness, which is really unspeakable, something to which Penelope returned again and again, about which she was never able to say enough.

As in John’s story, Penelope’s account disperses the secret of HIV over the fields of family life and history. However, for John, such dispersion lightened the secret because the fields of dispersal were positive in nature—an accepted family silence, the continuing ordinariness of everyday HIV life, and the medical assimilation of HIV to other chronic illnesses. For Penelope, though, the secret’s dispersal intensified pain, because for her, the fields of dispersal took in the hostility of family members and the suffering and loss of children. HIV here was a secret that—as perhaps for Susan, although more intensely—became more dangerous to the narrator as it stretched out its meanings. It is important to note that both these interviewees were talking in the context of unresolved citizenship status and family separation. For interviewees talking after citizenship and family reunion, like Olive, the space of HIV-associated secrets, however painfully extended, had reduced and become contained after these events.

Conclusion

If talk about secrets leads to more talk about secrets, as here and in many of the interviews, we can read such talk as helpfully exploring the parameters of public silence that constitute and maintain sociohistorical secrets. This process seems particularly important for the contemporary United Kingdom HIV epidemic, which many study participants reported as invisibilized and isolating, a kind of punishing social sequestering of the ill, especially the poor and ill (Squire 2013; Wacquant 2009). However, even if such processes start to constitute a new and more open, mobile framework of secrets, this does not mean that everything can be said and all secrets gotten out into the open. These explorations are always happening retroactively, at a time when other secrets, elsewhere, are being constituted. We have seen, too, that secrets give rise to other secrets; they change history and change with history; they are difficult to know about because they are negations that deny themselves (Derrida 1989); they have a mobile transitivity; they are contradictory because once mentioned, even if denied, they are to some degree known; they are often played out between conflicted fields; they are, to sum up, partial. Moreover, stories about secrets demonstrate—even in their bringing secrets such as those surrounding HIV into language and even when HIV secrets are being dispersed and normalized—what is being left out. They register a kernel of meaning that cannot be reached into with words, that is wondered about in speculative, conditional past tenses or just glimpsed if you do not look directly at it, off to the side, in a glance or a laugh.

While it is extremely important to recognize and work for the retelling and reconstitution of the fields of HIV secrets, as many of the research participants were indeed doing, it is also valuable to recognize the residues of meaning that continue to be secreted, in both senses of the word, that is, hidden and also extruded, within these HIV stories, from John’s ongoing talk about a status secrecy that at the same time he said did not matter to Penelope’s repeated, inevitably failed efforts to articulate the sadness of HIV’s familial ramifications. It is this resecuring—rather than only the “defacement” of secrets—that
"makes the energy in the system both visible and active," as Taussig (1999:3) put it. For these remainders of secrecy indicate the irreducibility of events that by their singularities generate, again and again, the new contexts of the future (Derrida 2001). They are a helpful marker of elements of the HIV field that do not fit with its contemporary de-secrectizing normalization, such as ongoing illness and pain; stigmatization and isolation; the history of the epidemic itself, and its ramifying effects; and HIV’s intersections with other, contemporary conditions of suffering and constraint. Perhaps, too, they indicate to us some of those broader aspects of subjectivities—habits of thinking and feeling, ambiguity, specific emotions such as grief and guilt—that are increasingly falling out of line with contemporary technologies of open, homogeneous, improvable, and governable subjects.

References Cited


