Remembering George W. Smith’s “Life Work”: From Politico-Administrative Regimes to Living Otherwise

CHRIS HURL
Concordia University, Canada

JANNA KLOSTERMANN
Carleton University, Canada

ABSTRACT This article revisits activist ethnographer George W. Smith’s intellectual and political legacy, with a focus on his engagement with and conception of “life work.” In the context of the AIDS crisis in the late 1980s and early 1990s, Smith contributed to reframing the way in which AIDS was problematized and confronted. Rather than treating people living with HIV/AIDS as “disease vectors” to be isolated from the general population, as had been the case under the prevailing public health regime, he started his research and organizing from the standpoint of people living with HIV/AIDS – investigating the everyday work that they did in accessing the services that they needed in order to survive. Drawing from archival research, activist interviews and his published works, this article traces how Smith deployed the concept of life work in his research as part of the “Hooking Up” Project, in his public writing in the gay and lesbian press, and in his organizing with AIDS ACTION NOW! in Toronto. Beyond the reproductive labour of individuals in accessing particular politico-administrative regimes, which Smith focused on in his research, we explore how life work can be theorized more broadly to include collective efforts to confront social, biomedical and institutional barriers to living. Hence, in considering Smith’s AIDS activism, we argue that his theorizing and political organizing, taken together, should themselves be seen as forms of life work.

KEYWORDS activism; knowledge; life work; political activist ethnography; sociology

1 Both authors contributed equally to this paper.

Correspondence Address: Janna Klostermann, Department of Sociology & Anthropology, Carleton University, Ottawa, ON, K1S 5B6; Email: jannaklostermann@gmail.com

ISSN: 1911-4788
Introduction

Political activist George W. Smith was a novel social theorist who contributed to the growing focus in Canadian sociology on embodied and social justice driven research through the 1980s and 1990s (D. E. Smith, 2005; Frampton, Kinsman, Thompson & Tilliczek, 2006). Creatively blending ethnographic research with his activism in movements challenging the police repression of gay men and demanding support and treatment for people living with HIV/AIDS, he is often credited with founding political activist ethnography as a distinctive strand of institutional ethnography that takes a movement-embedded approach, beginning from the standpoint of people on the ground to uncover and collectively transform how everyday ruling relations are socially organized (Hussey, 2012; Mykhalovskiy & Church, 2006). His contributions have laid the groundwork for activist researchers working within and alongside social movements in generating movement-relevant knowledge.

There is a growing body of literature recognizing Smith’s political, theoretical and methodological insights and exploring how his ideas can be deployed in social struggles (Bisaillon, 2012; Choudry, 2015; Hussey, 2012; Smith, 2006; Teghtsoonian, 2016). While aspects of his biography have been periodically touched upon (for instance, see Mykhalovskiy & Church, 2006), there has not yet been a study that comprehensively investigates how Smith’s ideas were embedded in his day-to-day work as a social activist. This article builds on existing literature by exploring the contributions of Smith as an AIDS activist through the late-1980s until his death from an AIDS related-illness in 1994. Drawing from his conception of “life work,” we look at how Smith fused together research, social movement organizing and public interventions with the aim of systematically identifying and confronting institutional barriers to treatment, challenging government inaction, and extending the capacities of people to live with HIV and AIDS.

We begin by exploring how Smith developed the concept in his efforts to reframe AIDS as a problem through his research with Eric Mykhalovskiy as part of the “Hooking Up” project. Making what he referred to as an “ontological shift,” Smith (1990) argued that social movement approaches to AIDS were hampered to the extent that they were motivated by “speculative” understandings that attributed “agency to concepts such as ‘homophobia’ or … ‘red tape’” (p. 634). Rather than targeting misguided attitudes or opinions, Smith advanced a materialist approach, engaging in interviews and fieldwork to systematically document the institutional barriers facing people living with HIV and AIDS and preventing them from accessing basic social services. Beginning from the everyday work that people do in order to survive, he was
then able to explicate how this work was coordinated through a politico-administrative regime that presented various biomedical, social, and institutional barriers, differently encountered based on one’s classed, gendered and racialized social location (Mykhalovsky & Smith, 1994). In shifting focus to the work that people do in accessing treatment, we argue that Smith was able to reframe AIDS, from a biomedical status possessed by individuals, to a politico-administrative problem to be confronted through direct action and collective mobilizations.

However, beyond focusing on the work of individuals, we argue that the concept of life work can be expanded to also include the work that Smith himself did in collaboration with other social activists to uncover and confront the institutional barriers to living with HIV/AIDS. In this sense, we argue that life work involves not only the actual everyday work of individuals living with HIV/AIDS under a particular politico-administrative regime, but also the work of generating collective capacities to live differently. To illustrate this, we explore how Smith worked to expose and confront the institutional barriers to living with HIV/AIDS through public interventions. This involved regularly publishing his diaries in the gay and lesbian press, which not only shed light on everyday challenges of living with AIDS, but also contributed to changing the public register through which AIDS was understood and talked about.

Finally, we look at how Smith drew from his research and publishing in developing strategies to collectively confront government inaction and get access to new treatments. As a founding member of AIDS ACTION NOW! (AAN!), a Toronto-based direct-action group influenced by the politics of the AIDS Coalition To Unleash Power (ACT-UP), Smith merged ethnographic investigations with direct action in radically extending capacities to live with HIV and AIDS. Centrally premised on what he described as “documents and demonstrations,” his strategic orientation involved both drawing from research to identify institutional barriers that could be targeted through direct action, and using political interventions to gain more knowledge about the politico-administrative regime through which treatments were brokered. In this sense, life work – the work of people getting access to what they need in order to survive – was also enabled through collective mobilizations. As the AAN! slogan goes: “ACTION=LIFE.”

Our analysis draws on empirical material from our previous work with the AIDS Activist History Project, a research project exploring the history of

---

2 AAN! is a Toronto-based community group well-known for transforming the social organization of AIDS treatment in Ontario. AAN! successfully advocated for reworking (and releasing HIV treatments through) the Emergency Drug Release Program, a program centered on releasing drugs on compassionate grounds, and for introducing Ontario’s Trillium Drug Program, a program providing funding for drugs in catastrophic situations that continues to operate today (Shotwell, 2016). AAN! was also involved in opposing calls for quarantine legislation and advocating for the AIDS treatment registry and the National AIDS Strategy.
AIDS activism in the Canadian context. Spearheaded by Alexis Shotwell and Gary Kinsman, the project has been archiving and exploring the experiences of social movement activists who participated in AIDS activism in Canada between the late 1980s and mid-1990s. Drawing on oral history interviews conducted by Shotwell and Kinsman, on Smith’s scholarly and popular publications, and on other primary source materials from the Canadian Lesbian and Gay Archives and from the AIDS Activist History Project collection, we examine how Smith’s notion of life work can be taken up in identifying both the everyday challenges of people face in living under a specific politico-administrative regime, as well as how capacities to live differently can be generated collaboratively and extra-institutionally through struggle.

Putting Life Work in Perspective: George W. Smith and Political Activist Ethnography

Smith is often identified as a key figure in the formation of institutional ethnography (IE), as well as political activist ethnography more specifically (Frampton et al., 2006; Hussey, 2012; Mykhalovskyi & Church, 2006; D. E. Smith, 2005). Working as a student and social activist with Dorothy E. Smith (no relation), he contributed from early on to developing a sociology for people, rather than about them (D. E. Smith, 2005). His materialist understanding of social organization was well expressed, not to mention screen-printed, on his unforgettable “I have made the ontological shift” T-shirt (Mykhalovskyi & Church, 2006). Rather than taking a bird’s eye view, presuming to explain social practices from above, Smith’s (1990) ontological shift was about recognizing himself within the social organization he was seeking to understand – knowing the world from inside its institutions and knowing that people produce their social worlds through their everyday practices and relations. By beginning from the standpoint of people, Smith was then able to render existing institutional arrangements problematic, exposing how institutional practices marginalize and negate the everyday experiences of those that they target.

Smith is often credited with infusing institutional ethnographic methods with social activism, generating a distinctive approach to IE known today as political activist ethnography, which aims to map and transform “the social organization of ruling regimes” through, and in support of, activism (Hussey, 2012, p. 2). In the literature, Smith’s (1990) notion of politico-administrative regimes has often been taken up in understanding “how ruling is organized and managed by political and administrative forms of organization” (p. 637). The emphasis here is how work across various “institutional sites of regulation and control” is orchestrated (Smith, 1990, p. 637). This work is understood as accomplished through “[t]he joining together of the sites of these diverse organizations by various systems of communication, but
especially through the use of documents” (Smith, 1990, p. 637). Following D. E. Smith (1987), the goal is to examine how lived experiences become codified and articulated beyond the realm of the everyday through the deployment of texts.

By mapping out the politico-administrative channels through which ruling relations are coordinated, Smith aimed to help orient the work of social movement activists. As Kinsman (2014, p. 23) put it, Smith’s “theorizing … was related to the questions that were posed by the activism that [he was] involved in.” Smith extended ethnographic approaches by using research to inform social organizing, and activism as a form of knowledge production to inform and contribute to empirical investigations. For instance, in his work as part of the Right to Privacy Committee (RTPC) through the early 1980s, defending gay men from police raids on Toronto’s public bathhouses, Smith (1988a) argued that it was insufficient to simply focus on the homophobic attitudes of individual police officers. Rather, the focus should be on how police campaigns against bathhouses and against gay sex were socially organized through the official work of the police department, which were authorized through bawdy house laws and municipal regulations and actively endorsed and implemented across state agencies. By making visible how police interventions were authorized and coordinated across institutional settings, Smith supported members of the RTPC in confronting the infrastructure enabling police repression of the gay community. Along the way, he also contributed to developing a method through which social scientists could work within social movement organizations to actively transform public institutions. Rather than positioning himself as a neutral observer of existing social forms, Smith made clear that his active engagement from inside and through constant and collective political confrontation made the politico-administrative regime of which he was a part visible to him, facilitating new forms of critical intervention.

While recent literature has focused on how researchers can generate knowledge about politico-administrative regimes through social activism (Hussey, 2012; Kinsman, 2006), not as much attention has been given to how people generate capacities to live in, against and beyond such regimes. We draw from Smith’s concept of life work in exploring his later political and intellectual orientation as an AIDS activist through the late-1980s until his death from an AIDS-related illness in 1994. Through this time, Smith developed the concept of life work as a way of making an ontological shift – reconceptualizing problems of living with HIV/AIDS and making public and collaborative interventions to actively extend the lives of people living with HIV/AIDS.

AIDS was organized and imagined as a death sentence. By 1989, more than 2,500 Canadians had been diagnosed with AIDS, and experts estimated that up to 50,000 were infected with HIV, and yet the federal government had done very little (Silversides 2003, p. 190). Under Jake Epp, the federal health minister until 1989, the government focused its energies on prioritizing
palliative care for the infected – helping them die - and preventative measures for the uninfected. AAN! activist Renee du Plessis (2014, p. 3), who worked alongside Smith, recalled that the medical establishment “responded to [a person living with AIDS] not as a person but as a contamination.” However, very little was being done to help extend the lives of people living with HIV and AIDS. Rayside and Lindquist (1992, p. 41) note that Epp “was consistently reluctant to even say ‘AIDS’ out loud, and retained officials, in strategic bureaucratic locations, who adamantly resisted pressure to alter established procedures for responding to the disease.” While government programs, such as the Emergency Drug Release Program had the mandate and managerial infrastructure needed to manage the delivery of experimental AIDS treatments, the government was not actively utilizing them, nor were they actively pursuing clinical trials for new drugs. Consequently, people living with AIDS were often forced to illegally procure drugs from other countries, where they had already been approved (McCaskell, 2016). Moreover, services for people living with AIDS were fractured and, outside of hospitals, not many family doctors or specialists were willing or able to provide treatment.

In this context, Smith and other activists worked to reframe AIDS. As Shotwell (2016, p. 5) notes, “[c]hanging the social imaginary in which HIV meant AIDS and AIDS meant death was necessary to produce the policy, institutional, practical, and medical conditions that would make it possible to live.” This involved multiple forms of AIDS activism. And, for Smith, it centrally involved attending to the complex ways people radically revise and remake their lives and expectations in relation to social life. It was from this starting place that he and other activists shifted, and helped others shift, from seeing AIDS as a fatal disease to seeing AIDS as what he called a “chronic manageable infection” (McCaskell, 2006). As we will show, he moved beyond the prevailing public health discourse at the time – which viewed AIDS as a status possessed by individuals (the AIDS “victim”) and presumed that death was inevitable – to uncover, confront and transform the multiple biomedical, social, and politico-administrative barriers to living with HIV/AIDS.

Rather than beginning by challenging AIDS stigma, Smith started by examining the capacities of people to live with HIV/AIDS, as a way of understanding and confronting how AIDS services were coordinated. Drawing inspiration from the institutional ethnographic work of Dorothy Smith, the socialist feminist “Wages for Housework” movement (Dalla Costa & James, 1972), and the radical research agenda of ACT-UP, Smith advanced an understanding of work that went beyond wage labour, exploring how people must expend time and energy on a day-to-day basis in getting access to the things that they need in order to live. Beginning from the standpoint of those seeking access to treatment, and examining their ordinary work, Smith was able to uncover through his research numerous biomedical, social and politico-administrative barriers people faced.
In the following sections, we explore how Smith’s efforts to transform the social organization of AIDS treatment involved engaging with life work – systematically exposing barriers to living with HIV/AIDS, rendering them problematic, making them public, and organizing concrete material changes for people to live differently. Seeking to understand life work as problematic, we start by exploring Smith’s community-based research with Eric Mykhalovskiy as a part of the Hooking Up Project. We then examine how Smith made public the day-to-day challenges of living with HIV/AIDS via his “Talking Politics” column in Rites magazine. From there, we highlight how Smith collectively confronted the politico-administrative barriers to treatment through social organizing and direct action. Reviving the notion of life work, we then consider how the concept might be extended in understanding the relationship between the individual work that people do under ruling regimes and the collective work that is undertaken by social movements in expanding the capacities to live.

**Hooking Up: Life Work and Poli
tico-administrative Regimes**

These kinds of problems of knowing – of being told one thing but in fact knowing otherwise on the basis of personal experience – provided a starting point for the research that went on to explicate how a regime works. (Smith, 1990, p. 632)

Smith’s research involved starting with people’s encounters with social institutions. The work of “starting with” involved listening in, attending to, and beginning from the standpoint of people most affected. It involved learning about people’s embodied, situated experiences, knowledges and doings as a way to understand the problems they were facing (Mykhalovskiy, 2014, p. 19). Smith (1990) worked with people to identify problems of “knowing otherwise;” problems of being told one thing, but in fact knowing differently on the basis of personal experience. His interest was in how people, when they learn they have contracted HIV or AIDS, must radically revise their lives and expectations and, thus, are “forced to live differently” (Smith, Mitchell [Mykhalovskiy] & Weatherbee, 2006, p. 167). Life work, in this sense, refers to all the time, thought and energy that people with HIV/AIDS put into “the daily living that they depend on.” (p. 168).

The notion of life work was developed in the Hooking Up project, a project conducted by Smith and Mykhalovskiy, with support from Douglas Weatherbee who was involved in writing the proposal. Starting from the standpoint of people living with HIV/AIDS, the study investigated the everyday work that people with HIV/AIDS do to “hook up” with health and social services. The research centered on making visible how people’s life work was coordinated through “institutional course[s] of action over which they have limited control” (Smith, Mitchell [Mykhalovskiy] & Weatherbee
Smith said that it was “a sociology for people living with HIV/AIDS” (Mykhalovskiy & Church, 2006, p. 80) – for people who were exhausted from running around, trying to survive. As AAN! activist Chuck Grochmal put it, “I spend about a week every month running around from institution to institution. … AIDS isn’t the only thing that’s making me feel like shit … I’m exhausted just running around” (cited in Silversides, 2003, p. 146).

Between 1990 and 1994, Smith and Mykhalovskiy trekked around the city to conduct 120 interviews with people living with HIV/AIDS, service providers and government administrators (Mykhalovskiy, 2014). They set out to understand the everyday, embodied, situated work people do to look after themselves (and others), opening up how that work is connected to the work of others, such as family, friends, significant others, doctors, social service workers or public officials. Mykhalovskiy (2018, personal communication) recalls that they used the notion of life work to methodologically orient their research. Initially, they framed it as a means of gathering open narratives from those they interviewed about the work involved in living with HIV. They asked people about the life work they did around the house – caring for themselves, preparing food and looking after their apartments. However, Mykhalovskiy (2018, personal communication) also notes that these kinds of questions didn’t do the “methodological work they were hoping for.” Consequently, they shifted to focusing more on institutional access to treatment as those questions “got people to talk rather generously about the state of their health, what they were doing with their doctors, which then moved our interviews into other institutional spheres” (Mykhalovskiy, 2018, personal communication). Focusing on questions of access, the research then centered on making visible how people’s everyday social experiences were coordinated through “institutional course[s] of action over which they have limited control” (Smith, Mitchell [Mykhalovskiy] & Weatherbee, 2006, p. 177).

Investigating the institutional relationships through which access to treatment was brokered, the project revealed social relations of class. Mykhalovskiy (2014) – who assumed responsibility for the research after Smith passed away – recalled the project made visible how “people who were most marginalized, and who in fact needed most of these services the most, were actually excluded as a feature of how the system operated and functioned” (p. 20). The research opened up a visceral contrast between those with differing social circumstances, resources and supports, making visible how “what they were able to do or not able to do” depended a great deal on the “fine grained” as well as on the “real texture of people’s lives” (Mykhalovskiy, 2014). The Hooking Up project made clear that social organization manifests locally, intimately, relationally and quite differently for people in different social locations.

From this perspective, living with HIV/AIDS was reconceptualized as a complex organizational problem, in which class-based exclusions were
reproduced through mundane professional practices and institutional procedures. Mykhalovskiy (2014, pp. 20-21) provides an example:

…to get family benefits you had to be designated ‘permanently unemployable’ and HIV was a categorical eligibility for that, but you needed to have a doctor… first of all, you needed to know that you could do it. You needed to disclose your HIV to somebody in the caseworker system, which lots of folks wouldn’t do because they were scared. And you needed to have a physician fill out a form that said that you were permanently unemployable. So, you needed to have a physician, right. Or you needed to have a physician you had a relationship with, who you could approach to ask that. And if you could do that when you had an AIDS service organization behind you in a network, it happened much more easily than if you tried to do it alone. And you needed to have a file. You needed to have a medical file so the doctor could justify the claim through medical language and medical discourse – because I can say, ‘Yes, you can’t work anymore.’ Or you needed to find a doctor who would just do it and there were many who would. But you could see how those possibilities were all structured in terms of social class, in terms of social location, and they produced class relations themselves.

Through their research, Smith and Mykhalovskiy called attention to the agency and activity of people living with AIDS and HIV who were active in producing the social relations of which they were a part (Frampton et al., 2006; Kinsman, 2018). They rendered visible the skills and knowledge involved in producing one’s health or doing health work (Kinsman, 2018; Mykhalovskiy & McCoy, 2002; Mykhalovskiy, 2008). They also clarified how this work was mediated by state agencies and social institutions. By mapping out these institutional channels, and identifying the points of blockage and exclusion, Smith and Mykhalovskiy argued that activists could at the same time establish a much more precise roadmap for social organizing. Taking life work as a starting place, they were then able to uncover the biomedical, social, and institutional barriers to living with HIV/AIDS taken in plural, rather than reducing them to a single identity or status. As Mykhalovskiy (2014, p. 7) notes:

… it wasn’t as though the concerns were just about treatment narrowly defined as this little box. It was their whole lives that were entering into these conversations, and it was never just simply about a particular issue … It was more about – my life is falling apart and I don’t have a house; I don’t have a place to live. And all these things were intersecting.

Beginning from these everyday issues taken together provided a means of reframing AIDS. It shifted focus from an ideological understanding of AIDS as an identity or stigma to the multifaceted material problems of living with AIDS.

Further, Smith’s political project not only involved uncovering how social relations of treatment were actually organized, but also involved identifying
absences and oversights, gaps in service delivery that needed to be filled. Kinsman (2014, pp. 9-10) shared:

There was nothing that actually allowed for people in catastrophic situations to actually get access to drugs and treatments. It just wasn’t how it was organized. … In a certain sense, what George thought AIDS ACTION NOW! should be about was – we need to put that in place. We need to get that organized so that drugs and treatments could actually get into people’s bodies in terms of the social relations of treatment, not simply the social relations of research. So, that became a really profound way of orienting what AIDS ACTION NOW! was doing, especially in this early period.

Smith wasn’t simply describing rhythms and materiality of everyday life, nor was he simply explicating the social organization of HIV/AIDS treatment as it is. His project centrally involved engaging with and remaking the social relations of which people living with HIV/AIDS are a part. As we will explore, Smith was concerned with developing the capacity to actively reimagine and reorganize social relations of care.

Talking Politics: Diary of an AIDS Activist

A central component of Smith’s work involved publishing everyday accounts in the gay press, fostering counter-publics through which the “problem” of AIDS could be differently imagined and engaged with (Warner, 2002). In making life work public, he reframed the way in which AIDS was problematized, shifting from an identity or stigma carried by individuals to exposing the biomedical, social, interpersonal and institutional barriers to living with HIV/AIDS. Smith wrote newsletter and magazine articles in The Body Politic, Rites Magazine and in AIDS ACTION NEWS!; his Rites feature known as “Talking Politics” or “Talking Politics: Diary of an AIDS activist” is of particular interest to this inquiry, as it offered a medium through which ordinary experiences of living with AIDS could be presented, rendered problematic and collectively transformed. Rather than making himself an object of study, Smith used the diary form to locate himself within the social, while also problematizing how people’s experiences are constituted socially.

While a few of his articles are in essay form, other “diary entries” give a glimpse of particular days in his life, describing his oft-mundane work as an AIDS activist. From making phone calls to designing buttons, riding trains and bumping into others, Smith expressed his own standpoint and captured some of the ways he brought the social into existence through his work. He

---

1 Rites magazine was a leftist, feminist publication produced in Canada from 1984 to 1992. It promoted lesbian and gay liberation, while addressing bisexual and trans questions. AIDS ACTION NEWS! was a newsletter published by members of AAN! Smith published several columns between 1987 and 1988 that do important work to contextualize and make public the experiences and struggles of people with HIV/AIDS.
carefully documented his experiences and struggles along with the experiences and struggles of other people living with HIV/AIDS:

Dear Diary: / April 22\textsuperscript{nd}, 1988 / A chance encounter with a friend on Yonge Street today. He looked thinner than the last time I bumped into him. He told me they had just diagnosed lymphoma of the liver. He’s going to start going in for treatments next week. When he told me about the diagnosis, I really didn’t know what to say. What can anyone say? He’s dying of AIDS. (Smith, 1988d, p. 7)

Describing a chance encounter, he expanded possibilities of interpretation beyond exaggerated, sensational, spectacular accounts of AIDS wreaking havoc and beyond accounts of “willfully promiscuous activists” (Smith, 1988e, p. 8) or “diseased, violent and dangerous” (Smith, 1987, p. 4) people with AIDS. Smith rejected the “heterosexual view of AIDS as a disease caused by reckless gay men, bent on an immoral lifestyle, who pose a serious threat to public health” (Smith, 1988e, p. 8). Instead, he framed AIDS as a problem of social and material organization – highlighting how it arises in the situated practices of people as they interact with others and with social institutions.

Significantly, Smith extended others’ work – drawing inspiration from ACT-UP and the 1983 “Denver Principles” – to both reconceptualize AIDS as a manageable chronic condition as opposed to a fatal illness and to portray people with AIDS as “survivors” as opposed to “victims” (People with AIDS Coalition, 1983, p. 8). While representing AIDS as a fatal disease invited palliative care, hospice care and psychosocial support for the dying victims, reimagining AIDS as a chronic manageable condition invited aggressive treatment for survivors. Here’s a relevant example from one of his diary entries:

Sent a copy of “AIDS Treatment News” to John this week. It had an article on people surviving with AIDS. He’s had KS [Kaposi Sarcoma] for about four years now, but still goes to work every day. Lately he’s been on chemotherapy which is helping. He’s coming to think of himself as a “survivor.” There is increasing evidence from the US that some people are living a lot longer with AIDS than expected. The Canadian medical establishment doesn’t appear to be very interested in these developments, however. AIDS doesn’t seem to be a disease doctors are interested in getting out and fighting. (Smith, 1988d, p. 19)

Recognizing that language invites social action and has real material and social consequences for people’s lives, Smith underscored that AIDS isn’t necessarily fatal and that people living with it can survive (Smith, 1988c, p. 11; Smith, 1988b, p. 9; Smith, 1988d). He made clear that surviving is a matter of social organization; it hinges on the Canadian medical establishment, on new developments and on the interests of doctors. Surviving involves concrete, practical work – ordinary activity and collective action to make and remake the social relations of which we are a part.
Underscoring the principle, borrowed from ACT-UP New York City, that “ACTION=LIFE,” Smith’s writing modeled a radical way of orienting to social organization that grasped that life is socially mediated and, in turn, political. Rather than abstracting people’s experiences, importing foreign concepts or speculating about how people are set up, Smith attended to how the social is produced in the activities of people – how society is an outcome of the work of organizing relationships with other people. These social relationships of course include the Canadian medical establishment, yet Smith (1983) also attended to informal lived relations and to the “actual social organization of life.” For example, Smith (1988d) described the difficulties of renting space for AIDS organizations, noting, “[a]s soon as the landlord knows AIDS is involved, it is impossible to get a lease” (p. 19). He also problematized relations between people living with HIV/AIDS and medical professionals, underscoring the need for “proper hospital care” (1988d, p. 7) that ensures people have the right “to treatment they and their physicians think might be useful” (1988d, p. 19). Speaking of his friend Jack, Smith (1988b, p. 9) wrote:

His former doctor seems to be more interested in a professional lifestyle than in dealing with patients with HIV illness. As a rule this gay doctor only spends 7 minutes per patient – the lowest limit OHIP can be billed for. It seems he wants the most from the medical insurance system. It seems even some gay doctors have difficulty putting the health of their patients first. … Do patients with life threatening illnesses have an automatic right to treatments they and their physician believe to be beneficial, especially if these treatments have been shown to be effective? … In the case of PCP, for example, do doctors have to tell a patient that the anti-leprosy drug, dapsone, is equally as effective as aerosolized pentamidine in controlling PCP, or, for Toronto patients, that pentamidine is available in Buffalo?

Making visible the unregulated and unaccountable practices and career relations of medical professionals, Smith made clear that people could end up with a doctor who is “more interested in a professional lifestyle” or one who is withholding treatment information.

What is striking to us is that Smith offered a more expansive understanding of the relationship between everyday life and the political – rendering problematic interpersonal relations and tensions that arise in practice and deeply shape people’s lives. Smith (1990) wrote that we should read texts “not for their meaning as such – although this is important – but for how they organize people’s lives” (p. 642). With two dashes bookending the phrase “although this is important,” Smith noted that understanding social organization hinges on understanding what texts do, as well as what they mean. Grasping the importance of social meanings and of language in use, Smith didn’t write simply to educate, inform or provide evidence. The diary entries are socially significant in that they popularize alternative epistemological frameworks – shifting from HIV/AIDS as a stigma to living
with HIV/AIDS as an everyday problem, while also inviting aggressive treatment, proper care and opportunities to survive, live longer and live well. Attending to life work helps us to appreciate how Smith offered a different register for speaking about and living with AIDS, while expanding our understanding of social organization. Smith used an informal mode of writing to depict people’s ordinary, yet vital, life work, to render lived social relations problematic, and to challenge the fundamental categories upon which the social order relied. He produced new forms to get people in sync for the possibility of transformation – pulling people in, establishing solidarity for political action, and clearing space for direct action and social organizing centered on extending people’s lives.

Documents and Demonstrations: From Research to Mobilization and Back Again

Uncovering the everyday institutional barriers to living with HIV/AIDS through the Hooking Up Project and making them public through his diaries published in the LGBTQ press, then generated new targets for political organizing. Life work, for Smith, expanded beyond the individual challenges in surviving day-by-day, to cultivating collective capacities to live differently. Working with AAN!, Treatment Information Exchange (TIE), and Community AIDS Treatment Information Exchange (CATIE), organizations which he helped to found in the late 1980s and early 1990s, Smith fostered infrastructure that could confront and transform the dominant politico-administrative regime.

Over the span of three years, from 1988 to 1991, AAN!’s organizing efforts moved from a three-point list of demands, primarily focused on drug approval and treatment access, to generating and mobilizing around a complex set of demands that targeted federal, provincial, and municipal agencies on a wide array of issues, including increased access to social services, housing and drugs for low income people, standards of care for hospitals, prison and immigration reform, public programming specific for women, and support for people living with HIV/AIDS in developing countries (among other issues identified in The Montreal Manifesto, 1989). Broadening and diversifying their focus, Smith and other members of AAN! generated the capacity to mobilize around life work and around diverse barriers to living. Through a diversity of tactics, including “demonstrations, street theatre and guerilla press conferences,” the group confronted these issues, “garnering sympathetic media attention and, ultimately, public support” (Hosein, 2010, p. 11).

AAN!’s approach to mobilizing was informed by Smith’s materialist orientation which identified institutional barriers to living with HIV/AIDS by beginning from everyday practices. In fostering collective capacities to live with HIV and AIDS, the approach brought research and activism together,
cultivating a symbiotic relationship which involved both “documents and demonstrations.” Hosein (2014, p. 9) notes:

...George Smith came up with the phrase ... “documents and demonstrations.” It’s not just good enough to have a demonstration for rage or anger that you’re feeling, but you’ve got to ask, what is your demonstration going to accomplish? How is it going to help us move forward? Yes, you demonstrate because you’re angry. That’s fine. But what are your aims for the demonstration? Is it to get media attention? Is it to educate key stakeholders? Is it to do something else? Is it...” You know, da-da-da. And so we always had to have a policy document to go with our demonstration. Now, that policy document might just be a page with key issues, but our demonstrations became eventually guided by our policy documents so they worked together.

Like Hosein, other members of AAN! elaborated on the significance of documents and demonstrations. Brown (2014) emphasized it was about more than “making noise” (p. 17), while Kinsman (2014) highlighted the importance of cultivating collective agency. As he put it, “you could write the best documents in the world, but without the agency or the force to bring them about or to get people to hear them or listen to them this was not going to go anywhere” (Kinsman, 2014, pp. 14-15). McCaskell (2014) also reflected on Smith’s conceptualization of documents and demonstrations, saying, “[y]ou had to have the capacity to frame things and shape it in a way that bureaucrats could understand it and figure how it could become actionable, as well as providing the political pressure on the street to make sure that they didn’t forget about the whole thing” (p. 16). Activists highlighted the importance of generating the capacity to confront an increasingly diverse array of political, institutional and professional barriers that were hindering people living with HIV/AIDS from getting what they needed to survive.

The approach centrally involved using research to develop more effective forms of activism and organizing, while also using activism and organizing to learn about and deepen understandings of social organization (Kinsman, 2014, p. 9). As Smith (1990, p. 664) noted:

The constant political confrontation between AIDS ACTION NOW! and its respective, politico-administrative regime, often designed on the basis of the analysis as it had so far developed, continued to orient my collection and examination of data. The ongoing analysis of the data was intended to extend my working knowledge of a regime. In every instance, this involved the acquisition of the knowledge people working in the setting had, with the kind of reflexivity that entailed. My ethnographic work, in this respect, was intent on describing, from inside, the social organization of a world that was constantly emerging, and one of which I, too, was a member.

Through research, Smith identified a growing number of issues to mobilize around, generating an increasingly precise roadmap of the barriers and
blockages that prevented people from living with HIV/AIDS. The research undertaken by Smith and members of AAN! – from the Hooking Up project to medical research on the latest treatments (Hosein, 2014) – informed their increasingly comprehensive list of demands, and framed collective action, including street protests and public actions. The relationship can be thought of as reflexive; demonstrations generate knowledge for analyses and documents, just as analyses inform demonstrations (Kinsman, 2014).

AAN! was well-known for transforming AIDS treatment and service access, for example, by protesting against inhumane practices (such as clinical trials, quarantine camps), advocating for the release of drugs, and demanding changes to Ontario’s drug benefit program (Barnett, 2014; Shotwell, 2016b). Their demonstration at Toronto’s City Hall in May 1988, which involved burning an effigy of the federal health minister, is one fitting example that helps us to think about the political possibilities and limits of using life work as an analytic. The aim of the demonstration was to push for treatment access and for the use of the Emergency Drug Release Program (McCaskell, 2016), and to mobilize people from the Canadian AIDS conference, which was in town, to show opposition to the inaction of the federal health minister, Jake Epp. Drawing from a range of tactics, including a die-in, banner unfurling, march and effigy burning, the demonstration was a way to reframe AIDS as a problem, shifting focus from AIDS as a “death sentence” to collectively identify and confront the politico-administrative barriers to living with HIV/AIDS as exemplified by the health minister’s inaction. Activists underscored “EPP=DEATH” and “ACTION=LIFE.” It was a remarkably effective action as activists were later told that Prime Minister Brian Mulroney had asked Epp into his office to ask why people were angry enough to burn an effigy of him in Toronto (Kinsman, 2018). In framing this action, Smith understood that social transformation involved “captur[ing] the zeitgeist of the moment” (McCaskell, 2014, p. 7) – using collective forms of activism to ready people for change and cultivate alternative social relations (such as the formation of CATIE).

Yet, while the 1988 demonstration shows the political utility of organizing around life work, it also highlights a tension between exposing the range of institutional barriers that people confronted in living with HIV/AIDS and mobilizing around particular, concrete issues. While Smith’s investigations contributed to understanding the multitudinous material, interpersonal, institutional, cultural barriers to living with AIDS, there was the lingering question politically in terms of how to make these barriers legible and actionable. In interviews with the AIDS Activist History Project, Smith is often identified as a figure that focused more on a narrow and targeted approach to political organizing, and this was certainly evident in his response to the effigy burning. McCaskell (2014, p. 12) recalled how the demonstration was “one of the precursors to later tensions” in AAN!. He described how, while Smith endorsed the effigy burning that was part of the demonstration, Smith was critical of the inclusion of a “KKKanada” sign on
the front of the effigy. In Smith’s view, the sign “confuse[d] people,” “wasn’t up to the standards of design,” and lacked a clear focus (McCaskell, 2014, p. 12). It critiqued the state at the ideological level, without exposing how racism and settler colonialism operated through specific institutional practices that could themselves be identified and confronted.

So, while Smith’s engagement with life work was relatively open, on the one hand – aiming to uncover multiple, complex problems to living with HIV/AIDS – in developing collective capacities to actively overcome these barriers, he emphasized the need for focus, discipline, and a degree of restraint, when it came to confronting particular social problems. This was contentious, because by seeking to achieve focus, AAN!’s work centered some people, perspectives and social problems and not others. At times this came at a cost; it meant narrowing the focus, foreclosing on some forms of expression, and decentering some social or political issues (Barnett, 2014; du Plessis, 2014; McCaskell, 2014). This was also an enduring object of debate, as the organization moved from its narrow three-point agenda for access to treatment to account for the varied challenges to living under the politico-administrative regime.

The ability to identify and confront different barriers to living with HIV and AIDS was itself conditioned by collective capacities. And, in fact, many of the tensions faced by Smith and AAN! through the late-1980s and early-1990s involved strategic questions in determining which problems the organization had the capacity to effectively confront and transform through the fusion of documents and demonstrations. Starting from the capacity to live with HIV/AIDS as an open and politico-administrative problem meant that as certain obstacles were overcome, new challenges became apparent. The challenges of life work continually open up new vistas for thinking about what it means to live and flourish.

Conclusion

Revisiting the notion of life work, we have touched on Smith’s contributions as an ethnographer, writer and activist, who contributed to radically and methodically transforming social movement activism, feminist social research, and the social organization of living with HIV/AIDS in Canada (Brown, 2014; Hosein, 2010; Hosein, 2014; Kinsman, 2014; McCaskell, 2014; Mykhalovskiy, 2014). We surveyed Smith’s work to extend the lives of people living with HIV/AIDS – investigating people’s everyday life challenges through his research, reframing the way in which these problems are discussed in public writing, and actively confronting the barriers that he identified through direct action. Speaking to how life work can be extended to these different areas, our analysis has much to offer activists and researchers committed to investigating and transforming the social organization of everyday life (Brulé, 2015; Butz, 2015; Chewinski, 2017;
At a time when AIDS was framed as a death sentence or a disease vector to be isolated from the general population, Smith moved beyond focusing on AIDS as a biomedical entity or condition to generate a different way of seeing and engaging with AIDS as a social problem. Making an ontological shift, he began his research and organizing from the standpoint of people living with HIV/AIDS – examining the ordinary work they did and identifying the professional, institutional and political barriers to treatments necessary for survival. In this sense, he should be viewed as a fellow traveller of ACT-UP, as well as an early pioneer of patient-centred, embodied health movements and research focusing on the social determinants of health (Brown, 1997; Epstein, 2008; Gould, 2009).

Attending to life work, or to the ordinary work people do, provides an important contribution to feminist explorations of reproductive labour, and the theoretical toolbox of institutional ethnography. As many researchers are aware, examining people’s intimate or everyday practices, and framing them as work, provides a powerful starting point for explicating how the social is produced (Diamond, 1992; Doucet, Lee, Cattapan & McCay, 2016; Mykhalovskiy & McCoy, 2002; Mykhalovskiy, 2008; Nichols, Fridman, Ramadan, Ford Jones & Mistry, 2016; Sevigny, 2012; Watson, 2016). Smith’s project aligns well with the work of feminist scholars who are committed to making intimate or reproductive work public, and clarifying how that work is central to social production or to projects of social justice (Coulter, 2016; Doucet, Lee, Cattapan & McCay, 2016; Hall, 2016; Watson, 2016). Understanding how the capacity to live is, in part, mediated by all the work that people do engaging with public institutions helps to extend the notion of reproductive labour to state-society relationships. In this sense, engaging with the politico-administrative regime, and the web of material practices that make it up, is itself constitutive of the capacity to live.

That said, our study also invites a fuller understanding of life work. Considering Smith’s research, public writing and activism as forms of life work illuminates how the concept can be extended – directing attention to the ongoing, living, day-to-day activity of individuals, as well as to the role of social actions and movements in cultivating both individual and collective capacities to live. Smith was committed to remaking the “actual social organization of life” (Smith, 1983, emphasis added). Part of what is interesting here is that life work is not just about institutional relations or individual endeavours. Rather, it also involves the collective capacities to identify, confront and overcome biomedical, social and politico-administrative barriers to living with HIV/AIDS. Ultimately, life work reflects not only the actual everyday work of living under a particular politico-administrative regime, but also generating capacities to organize things differently.

Thus, Smith’s project can also serve as a useful political intervention in reframing our understanding of social activism. Through his strategy of
documents and demonstrations, he has been able to make a forceful interjection in social activism, arguing that activists should aim to be more materialist in their approach to social problems. Beyond ideological orientations towards activism that target the ideas or beliefs of public officials, the notion of life work provides a method for how activists can systematically expose and target the mundane, everyday practices underpinning oppressive relationships and collectively imagine and develop new avenues for survival and flourishing. Rather than just using demonstrations as a means of blaming public officials, then, life work provides a means of fostering alternative ways of living in, against, and beyond the politico-administrative regime. As our study makes clear, Smith’s life is testament to how life work can also generate capacities to live differently – meaningfully and collectively imagining and developing new avenues for survival and flourishing.

Acknowledgements

We would like to express our gratitude to Gary Kinsman, Eric Mykhalovskiy and anonymous reviewers for their generative feedback, and to both Alexis Shotwell and Gary Kinsman for their mentorship and work with the AIDS Activist History Project. Thanks also to Sarah Rodimon for feedback on an earlier draft.

References


---

*Studies in Social Justice, Volume 13, Issue 2, 262-282, 2019*


