

**Illness Identities and Biological Citizenship:  
Reading the Illness Narratives of Hepatitis C Patients**

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## **Abstract**

A growing number of social scientists are asking important questions about the dawning of a new kind of citizenship – biological citizenship – and its implications for how we understand the relationship between the state and civil society actors. The perspective of biological citizenship can be expanded to include the emergence of illness as a new political cleavage, as an identity through which citizens frame their political demands and challenge authorities for forms of redress. Using the case study of hepatitis C in Canada, this chapter asks whether these new forms of citizenship, rooted in illness identities, undermine other dimensions of citizenship. Is biological citizenship contributing to a new wave of contentious politics which takes as its starting point the citizen's relationship to his/her biological body? Or, rather, must we examine how in the process of contestation, illness activists may reinforce particular ways of seeing and knowing the biomedical body? The illness narratives of Hepatitis C patients also reveal how biological citizens are “made up” from above (by government, scientific and medical authorities) and from below, by patients themselves who work to contest biological and biomedical truth claims. Patients' ability to problematize official knowledge regarding hepatitis C, however, depends on a number of factors, including the social status of infected individuals, in this case whether they were infected through intravenous drug use or through the blood system.

## **Introduction**

Adriana Petryna describes biological citizenship as “a massive demand for but selective access to a form of social welfare based on medical, scientific and legal criteria that both acknowledge biological injury and compensate for it” (2003: 6). As she explains, “the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims” (2003: 5). This chapter asks whether new forms of ‘biological citizenship’ are undermining or reinforcing other dimensions of citizenship, and the possible implications of such a shift for how we understand health policy and politics. Is biological citizenship contributing to a new wave of contentious politics that takes as its starting point citizens’ relationship to their biological bodies? Do these new forms of contention challenge the welfare state as we know it? Garland has questioned, for instance, how thinking of the welfare state as a risk management state shifts our attention away from conflicts over the means of production and towards conflicts over the means of security. In this analysis, the key historical actors are not so much social classes as risk categories...” (2003: 62)

The first section expands upon the idea of biological citizenship, focusing on how the term has been used by social scientists, and situating it in the context of the discourse of the risk society. In the second section, I emphasize the need for narrative approaches to unlock lay understandings of health and illness, and their implications for citizenship. The third section fleshes out some of these ideas in the context of a research project examining the illness narratives of people living with hepatitis C in Canada. We conducted 101 in-depth qualitative interviews with a broad sample of persons infected with hepatitis C throughout the country, including those infected through the blood system, in the course of surgery, or through intravenous drug use. Although we are still in the process of analyzing the interviews, I offer here some general themes that are emerging from the data. Finally, I offer some preliminary thoughts on the policy challenges associated with the emergence of biological citizenship. Before proceeding, I will provide some background on hepatitis C itself.

## **Hepatitis C: A Brief History of the “Other” Virus**

The three most common strains of hepatitis are A, B, and C. Hepatitis A, which is normally transmitted by the fecal-oral route, is highly infectious. It is normally spread through contaminated water and food, and is more

common to developing countries. Unlike the other strains of hepatitis, there are few cases of hepatitis A virus (HAV) being transmitted by blood. Hepatitis B virus (HBV), on the other hand, is transmitted primarily by injection drug use, sexual contact, perinatally (from mother to child), and through blood transfusion. People infected with HBV experience symptoms similar to those infected with HAV, but they are often more severe and longer lasting. While many clear the virus, for a time public health authorities became concerned with those who developed chronic hepatitis but remained symptom-free. As a result, infection through blood transfusion became commonplace as many infected people unknowingly donated blood unaware that they were infected. Before a specific test for HIV was available, blood was tested for the presence of hepatitis B, after it was discovered in the 1980s that as many as 90 per cent of AIDS patients had also been exposed to hepatitis B.

Hepatitis C, previously known as non-A, non-B hepatitis, is also transmissible by blood. Like HBV, HCV can remain in the body for several years without appearing to cause infection. For this reason, hepatitis C is often dubbed the “silent epidemic”. When the hepatitis C virus takes up extended residence in the liver, it quietly reproduces for many years, often without causing any outward symptoms or illness. A common treatment for hepatitis C is interferon therapy, which has helped some patients “clear” the virus. Recently, patients have had greater success with treatment that combines interferon with ribavirin, an anti-viral drug.

Scientists struggled in the 1980s to develop a test to screen for the presence of hepatitis C (still known only as non-A, non-B hepatitis). The National Institutes of Health suggested in the mid-1980s that the use of surrogate testing could eliminate up to half of the infections. A specific test to screen for hepatitis C was not available and implemented in Canada until 1990, but two “surrogate” (or substitute) tests were available to screen for non-A, non-B hepatitis as early as 1974: one measured a liver enzyme while the other detected previous exposure to hepatitis B. In 1986, the same time that U.S. blood banks began using these surrogate tests, the Canadian Red Cross and governments opted instead to study the tests’ efficacy. The U.S. began using surrogate testing in 1986, while Canada continued to insist that the costs of testing far outweighed the benefits. In Canada, it took a highly publicized public inquiry -- the Commission of Inquiry on the Blood System in Canada in 1994-1995 – to raise the public profile of hepatitis C. The Inquiry examined the facts that led to the contamination of the blood supply during the 1980s, in which more than 1,200 people were infected with HIV and another 10,000 were infected with hepatitis C (Orsini 2002). Nationally,

some 250,000 Canadians are presumed to be infected with the virus; worldwide some 170 million people are hepatitis c positive.

### **Biological Citizenship and the ‘Body’ Politic**

Petryna’s groundbreaking work, *Life Exposed: Biological Citizens after Chernobyl* (2003) traces the features of this new “citizenship regime” using a case study of the 1986 Chernobyl disaster in Ukraine, during which tens of thousands of citizens were exposed to radioactive iodine, which has been linked to deadly thyroid cancers in children and adults. Rose and Novas (2005: 440) use the term “to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species”. Expanding upon Petryna’s work, Rose and Novas are interested in how biological citizenship challenges, supplants or intersects with the dominant mode of understanding citizenship as linked to a nation state or territory. A number of forces, they note, be they religious, ethnic, or cultural, have placed the fundamentally national form of citizenship in question. By citizenship projects, they are referring to “the ways that authorities thought about (some) individuals as potential citizens, and the ways they tried to act upon them” (Rose and Novas, 2005: 439). Dominant theorizing about citizenship in the social sciences often draws from T.H. Marshall’s classic formulation of three types of citizenship: civil, political and social rights, with the emphasis often placed on how the three are ‘indivisible’ (Lister 2003).

An attention to biological citizenship opens a space to think about the emergence of illness as a new political cleavage, as an identity through which citizens frame their demands on the state and civil society. This identity is linked to how we related to our biological bodies. Waldby et al use the term ‘bioidentity’ to describe our “common understanding of our bodies as ours, as both supporting and being included in our social and subjective identities” (2004: 1462). While biological citizenship is not completely new -- in the 19th and 20th centuries, citizens understood their allegiance and nationality partly in biological terms, in terms of race, blood lines, or stock – Rose and Novas argue that there are some novel features of biological citizenship in the current age, including different ideas about the role of biology in human worth, about the biological responsibility of the citizen, and about the role of technology and how it intervenes upon the body.

Biological citizenship, they explain, is both “individualizing and “collectivizing”. It is individualizing to the extent that individuals shape their

relations with themselves in terms of a knowledge of their “somatic individuality.” Individuals are at once expected to be prudent and enterprising, actively shaping their destinies through acts of choice. The responsibility for the self is evident, of course, in the discourse of genetics, where genetic knowledge holds the potential to revolutionize societies and empower citizens to take charge of their own health. To “know thy genetic self” becomes a duty of responsible citizenship in the age of risk.

Biological citizenship is collectivizing in the sense that we see an increasing number of groups organized around a ‘biological conception of shared identity’. Patients are no longer willing to be merely patients; they are becoming active in gaining recognition for their condition, or challenging the stigma that is associated with illnesses or conditions that are medicalized or pathologized. In other cases, they are challenging ‘science as industry’ and ‘science as procedures’, as Steven Epstein has said of AIDS treatment activists or contesting -- albeit with differing degrees of success -- the strict separation between the expert and the lay public (Epstein 1991). This citizenship operates in what Rose and Novas term “a political economy of hope”, in which “(b)iology is no longer blind destiny or even a foreseen but implacable fate. It is knowable, mutable, improvable, eminently manipulable. Of course, the other side of hope is undoubtedly anxiety, fear and dread at what one’s biological future... might hold” (Rose and Novas 2005: 442).

I understand the process of contestation in three ways. First, from the perspective of the patient, patients grapple with and sometimes resist the illness label, and refuse the identity attached to a hepatitis C diagnosis. Second, persons with hepatitis C may challenge the institutions of science and medicine with regard to the severity of hepatitis C, countering the claim sometimes heard that a little knowledge can be a dangerous thing if that knowledge provokes unnecessary anxiety. Patients may do this by becoming “citizen experts” – learning and becoming conversant in the language of medicine as a way to interrogate or challenge scientific knowledge from a position of authority. Third, contestation can occur at the collective level when individuals band together to politicize their illness experience. While it would be incorrect to suggest that support groups that are not focused on advocacy are apolitical, it is nonetheless important to pay closer attention to those instances when patients frame their own experiences in terms of broader notions of injustice. A collectively felt sense of injustice may underscore the fact that harms may be inflicted through professional or policy responses, not solely as a result of the illness itself. In this sense, contesting the official line may be the wise choice, and can contribute to

collective mobilization if such contestation is capable of uniting a disparate group of individuals united only by a medical condition.<sup>1</sup>

### **How Narrative Matters**

In public policy terms, narrative analysis has generally centered on examining “the issue-oriented stories told by policy actors, using such analysis to clarify policy positions and perhaps mediate among them. Work of this sort analyzes the structure either of the policy and agency stories told by various actors or of their content, allowing comparisons across different versions” (Yanow 2000: 58). Traditionally, the analysis of story telling has been viewed from the perspective of strategic (or self-interested) policy actors seeking to influence or shape the policy agenda with their “version” of events. Such analyses clings to a pluralist vision that the act of including more voices in the policy process is somehow sufficient; whether those voices are heard or actually contribute to policy making is less important.

Among social scientists interested in health, while there has been less attention to its policy implications, narrative approaches to understanding illness have been usefully developed and refined (Williams 2000; Ezzy 2000). Narrative analysis in health has not been without its challenges, however. As Morris notes (1998: 251), “medicine... not only avoids narrative but treats it with a disdainful mixture of hostility and contempt.” Evidence Based Medicine, with its gold standard of the double-blind, randomized clinical trial, leaves little room for narrative. At best, qualitative studies might complement the more ‘robust’ findings derived from quantitative studies. “Anecdotal” evidence, however, is viewed as incapable of matching the rigour, objectivity, and reliability of evidence-based approaches.

Arthur Frank’s classification of three types of illness narratives (restitution, chaos and quest narratives) is widely regarded in the literature. As Frank makes clear, illness narratives do not conform to one type. Indeed, in many cases, all three types are told, depending upon where the patient is on his/her journey. The three narratives should be viewed as “patterns in a kaleidoscope: for a moment, the colours are given one specific form, then the tube shifts and another one emerges” (Frank 1995: 76). In contemporary culture, *restitution* narratives cling to a belief in ‘restorable health’. For

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<sup>1</sup> My thanks to Steve Kroll-Smith for the useful suggestion and reframing of this discussion.

Frank, these narratives fulfill two important functions: “For the individual teller, the ending is a return to just before the beginning... For the culture that prefers restitution stories, this narrative affirms that breakdowns can be fixed” (Frank 1995: 90). People living with chronic illness, however, “can find it difficult to tell a story which does not appear to have a happy ending” (Kilty 2000: 17-18). This is especially relevant for people with hepatitis C, the majority of whom will develop chronic hepatitis, with which they may have to live for 30 or 40 years. Hepatitis C is not chronic in all patients; some clear the virus, while others may become acutely ill and die as a result of end stage liver disease. The *chaos* narrative, which is often hidden, has been referred to as “the anti-narrative of time without sequence, telling without mediation and speaking about oneself without being fully able to reflect on oneself” (Frank 1995: 98). The third form of illness story is the *quest* narrative, in which a person faces suffering head on in the belief that they were destined to learn something from the illness experience. In their search for alternative ways of experiencing illness, quest stories may include becoming politically active, forming a patients’ rights group, attending support group meetings, or helping others who may be in a similar situation.

### **People with Hepatitis C as Biological Citizens**

When we examine the illness narratives of Hepatitis C patients, we can see how a risk discourse simultaneously downplays their health concerns, while magnifying their responsibility. In its written submission to the Krever Inquiry (the government-sponsored Commission of Inquiry on the Blood System in Canada), the Hepatitis C Society of Canada claimed that the Canadian Red Cross and the Canadian Liver Foundation attempted to discredit people with Hepatitis C, by painting all sufferers as “druggies”. Emphasis was placed on their reckless behaviour, including intravenous drug and alcohol use. In addition, not only were people with hepatitis C singled out as reckless risk-takers, many were told not to worry about the “benign” virus. A common theme expressed in interviews with patients was one of profoundly mixed messages – hepatitis C was at once viewed as deadly serious but also no cause for alarm; in general, many patients were told there was little cause for concern. At the same time, several patients mentioned that their doctors inquired about how they were infected, asking specifically whether they were current or former drug users. For those who experimented with drugs when they were younger, the question forced them to revisit a painful chapter in their past. For those with no history of drug use (ie:



recipients of tainted blood), the idea that they would be lumped in with “drug users” caused – and continues to cause – great anxiety.

While patients were assured that the virus would not adversely affect their health, the reactions they encountered from friends and family alike suggested otherwise. As one woman testified at the Inquiry into the tainted blood scandal, “Most of our friends headed for the hills because they were scared they could get it by sitting in the room with me. Parents at my son’s school would not let him into their homes. I feel like a leper.” (Joyce M., quoted in Powell 1996: 25) People with hepatitis C find themselves in the unenviable position of being both marked by risk and erased as individuals whose health concerns are considered minor or non-life threatening.

It is perhaps not surprising that persons with hepatitis C have had to work hard to attract attention, whether from their doctors, the media, or governments. For many years, HCV moved slowly and discretely through the Canadian population. By comparison, contracting HIV was seen as a virtual death sentence. While people with HIV were able to tap into the wellspring of activism that previously animated gay liberation and helped to mobilize communities around fighting AIDS, people with hepatitis C continue to struggle to carve out a distinct identity, a struggle that has been frustrated by the heterogeneity of the group and by challenges from those who continue to view hepatitis C as a minor medical problem.

One of the key findings emerging from the data relates to how the experiences of people with hepatitis C are structured by the nature of their infection. Those who were infected in the course of sharing drug injecting equipment are not only qualitatively different from those who were infected through tainted blood (generally, IV drug users spoke of having had difficult life, often marked by poverty, illness, family trauma) whereas those infected through tainted blood, while not carbon copies of one another, conform to the stereotype of middle class respectability. This, it turns out, affects how respondents reacted to and are dealing with life with hepatitis C, or to use the words of William Gamson, how they constructed their “injustice frame” – in this case, the degree to which they politicized the origins of their diagnosis (Gamson, in della Porta and Diani, 1999: 70). Those infected through drug use often spoke of not being surprised that they were infected, noting that this was the price one paid for choosing a “dangerous” lifestyle:

**Interviewer:** You know how you got it?

**Respondent:** I figure I got it from Tammy (pseudonym) I would say. But with an understanding that I would. We were partners. We were doing the hardcore drug thing. Everyday we had to shoot each other up. We’d mix our drugs together. We had unprotected

sex our whole relationship and I knew from the beginning that Tammy had hep C. I had that sense I'm in this with her. If I end up with it with her we're going to be together and that's what happening with us. So we'll go through whatever struggles we go through together. So it could have been through unprotected sex but was more likely from making up, not sharing like taking a needle from her arm and putting it on mine but...

As a result, they do not express anger or resentment with respect to the failure of others to take seriously their health concerns, even though they recount harrowing tales of being bounced from one doctor's office to another looking for someone willing to treat them, or of finding out they were positive and never receiving proper follow up, much less an information pamphlet to take home. In addition, how drug users found out they were infected was critical. For some, testing was required as a condition of entering treatment for heroin addiction at a methadone clinic. Dealing with a positive hepatitis C diagnosis then became part of a comprehensive plan to get one's house in order, "getting clean". Treatment clinics provide a support system, albeit a short term one, for someone dealing with the trauma of a hepatitis C diagnosis. Others were not so lucky, finding out by accident in the course of a visit to an emergency ward or a walk-in clinic.

Conversely, tainted blood recipients were often indignant about their situation, claiming that they were indeed "authentic victims"; they did everything they were supposed to do, they were law-abiding citizens, and did not deserve to be infected with tainted blood. Dealing with the stigma associated with hepatitis C was particularly difficult for tainted blood victims, and many expressed concern that this was related to the overwhelming incidence of hepatitis C among drug using populations.

An overwhelming majority of respondents discussed a range of issues related to treatment, which for coding purposes are grouped under the headings: choosing treatment, life under treatment, and life after treatment. With regard to the first, "choosing treatment," respondents' decisions to opt for treatment were influenced by a number of factors, including positive encouragement from friends, family and/or health care professionals, a generally positive attitude toward conventional medicine, a desire to see treatment as part of a wider, comprehensive attempt to "put their life together again" (mainly IV drug users). In addition, many respondents mentioned the discovery that they had a "good genotype", one of the six strains of the virus that have been identified, as motivating their decision to go ahead with treatment. Genotypes 2 and 3 are easier to treat than Genotype 1, although

Genotype 1 is more prevalent in North America (about 70 per cent of patients) than Genotypes 2 and 3 (roughly 14 per cent of patients). Patients with genotypes 2 and 3 are almost three times more likely than patients with genotype 1 to respond to therapy with alpha interferon or the combination of alpha interferon and ribavirin. Furthermore, patients with genotypes 2 and 3 undergo a 24-week course of combination treatment, whereas patients with genotype 1 require 48 weeks of treatment. Although most of the persons interviewed had undergone or were in the process of being treated, for the minority who did not undergo treatment, being told they had a “bad genotype” – a strain of the virus that is more difficult to treat – played a large role in their decision to reject treatment. In some cases, the respondents spoke of the decision being made for them, by their doctors, who actively counseled them against this. For the others who rejected treatment but not for reasons of genotype, a lack of faith in conventional medicine, a concern about the seriousness of the side effects, and a history of depression or mental health problems, were all cited as reasons.

When asked what life was like under treatment, patients described a bewildering array of symptoms, including trouble sleeping, depression, lethargy, “brain fog” (short term memory problems, difficulty remembering seemingly mundane details), lack of appetite, hair loss, diminished sex drive, gastrointestinal problems, and “interferon rage” (anger issues that can lead to wild outbursts, violent behavior, and sometimes suicidal thoughts). For many who underwent treatment, “life after treatment” is qualitatively different from life before, in the sense that they felt unable to return to the life they had before being diagnosed with hepatitis C, even though they may have been living with hepatitis C for much longer. The ‘new normal’ is nothing like their previous life, although this reality is not easily accommodated by the health care system, which treats these patients as success stories. For those who were treated successfully, assurances that they had cleared the virus were met with skepticism as they still felt unwell.

The general experience was of viewing this chronic illness as an instance of biographical disruption” -- “where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury 1982: 69). Bury identified three aspects of disruption that are critical in understanding chronic illness. The first involves a disruption of ‘taken for granted assumptions and behaviours, or the “what’s going on here?” phase. Second, he identified disruptions in the “explanatory frameworks” used by people, which force individuals to question their own sense of self and engage in processes of “narrative reconstruction”. Third, at a practical level, there is a disruption that involves a mobilization of resources in order to adjust to the “new normal”. As a chronic illness, hepatitis C forces you to

rethink your identity, how you understand your relationship to others. In addition, it is important to stress, however, that the disruptive qualities associated with chronic illness may be overemphasized, especially if one considers patients for whom a hepatitis C diagnosis is simply one in a string of disruptive moments in their lives. Indeed, in these cases, what is most striking is the disease's inability to provoke the much expected disruption. As Williams notes (2000: 50) in an important critique of the concept of biographical disruption, the term itself fails to take account of those instances in which an illness fails to register its requisite disruption among individuals: "Health ...may indeed be an important moral category which few if any of us wish to relinquish, but the biographically disruptive nature of illness is perhaps most keenly felt amongst the privileged rather than disadvantaged segments of society."

There is a presumption that good citizens concerned with their health will be roused to action upon discovering that they are infected with a potentially debilitating virus. In some cases, however, hepatitis C competes with other issues or problems that are vying for attention. For instance, one respondent spoke of her inability to distinguish her hepatitis C symptoms from being what she called "dope sick":

**Interviewer:** For someone who has little understanding of Hepatitis C, can you describe what it is like to live with this condition?

**Respondent:** Oh yeah. I did a lot of drugs. I just started cleaning up like 2 months ago. In the summer, I cleaned up this summer but I was drinking and stuff. I don't know, I always just like, I get nose bleeds a lot, well I used to. I'm not doing too bad now. Like when I was doing drugs I would always get nose bleeds and it's kind of hard to tell the difference between being dope sick and being Hep sick. Like when you wake up in the morning and if you're tired or not, you don't really know which one it is, kind of thing.

**I:** What's dope sick?

**R:** The most intense pain you could possibly imagine in your whole life.

**I:** Like your body hurts?

**R:** Oh yeah.

**I:** Is that like a craving?

**R:** No, it's your whole body gets sick. Cuz I'm with a lot of users, so... and you just get the shakes and the shivers and pukes and shits

and hot sweats, cold sweats. It's the most intense pain you could ever feel in your life.

(Personal interview, Woman, 19, Halifax, N.S., Feb. 25, 2005)

Stigma and ignorance emerged as a significant concerns for people living with hepatitis C. This is not surprising given the fact that the majority of new infections are found in injection drug users. The attitudes of others vis-à-vis people with hepatitis C are reminiscent of the attitudes toward people with AIDS in the early years of the epidemic. And in the Canadian context, the fact that hepatitis C first entered the public lexicon in the wake of the tainted blood scandal, meant that hepatitis C always struggled in the shadow of HIV. The blood scandal was both a blessing and a curse for persons with hepatitis C. Hepatitis C acquired the stigma that is still associated with HIV/AIDS; at the same time, however, the media reminded the public that AIDS was a greater public health threat than hepatitis C. There is an overwhelming sense that hepatitis C can not win: they are branded as a result of the association with HIV/AIDS, while at the same time this association with AIDS means this virus is always on the losing end of the battle of the viruses.

### **Unravelling the Policy Implications**

A shift to new forms of biological citizenship has direct and indirect implications for public policy. It is directly related in the sense that it calls upon the state to expand our understanding of public policy, that is, the nature of state intervention in the economy and society. And it is indirectly related in the sense that changes in how citizens construct their citizenship duties/obligations and demands will have an impact on how they view their role as participants in policy processes. While biological 'citizenship projects' expand the boundaries of the political, and contribute to the shifting terrain of contestation, it would be premature to reduce these shifts to negative or positive effects, as new forms of citizenship rooted in biology "cannot merely focus upon strategies for making up citizens from above" (Rose and Novas 2005: 441). Citizenship is also influenced by strategies from below.

Second, biological citizenship may be altering the character of collective mobilization and vice versa. Paul Rabinow, for instance, has alerted us to the proliferation of "biosocial groupings", which are defined as "collectivities formed around a biological conception of shared identity" (Rabinow, in Rose and Novas 2005: 442). Support groups, patient

organizations, and the like exist for a number of conditions, illnesses, and diseases, some of which are recognized and accepted by medical and scientific authorities, while others remain marginal or hotly contested within official medical or scientific discourses, such as Multiple Chemical Sensitivity Syndrome (see Kroll-Smith and Floyd 2000). There are other instances, however, in which scientifically acceptable conditions (such as hepatitis C), which may not be the subject of contestation within official circles, struggle to become contested on the political stage. For some asthma sufferers and activists, for example, asthma offers an opportunity to mount wider challenges around environmental and transit-related issues, all in an effort to politicize asthma (Brown et al. 2003). British sociologist Frank Furedi has argued, for instance, that this politicization is related to the idea that illness “is a normal state, possibly even more normal than being healthy. We are all now seen as being potentially ill; that is the default state we live in today” (Furedi 2005).

Finally, biological citizenship can open up spaces for the articulation of “politicized illness experiences”, focusing attention on the wider political-economic forces that structure health. While this may appear to be a positive development, official recognition of a disease or illness may do little to reduce the incidence or magnitude of the problem, if it does not attend to the underlying factors that produced the problem in the first place.

### **Concluding Thoughts**

This chapter has attempted to introduce the term “biological citizenship” to the study of health policy and politics, but it should be clear that the implications of such new forms of citizenship extend beyond the field of health. I conclude with three broader questions raised by the hepatitis C case, but can only sketch the contours of possible responses to these questions. First, does biological citizenship supplant other dimensions of citizenship? Certainly, the mobilization of citizens along disease or illness-specific lines casts in a different light debates about universal citizenship rights. It forces us, as well, to recognize that “politicized illness experiences” may fast become the next wave of “contentious politics”. To be sure, there are dangers associated with one disease constituency being pitted against the next in the never-ending race for recognition, but as some health social movements have shown, there are enough social justice links between seemingly disparate movements to suggest that this is by no means a zero-sum game. One movement’s efforts to secure policy or value change need not necessarily harm the efforts of other movements to achieve success.

Second, do we need new analytical tools to understand the important shifts under way in how “biological citizens” in the age of risk, an age in which we have seemingly lost the ability to control our exposure to a plethora of risks? In the case of hepatitis, one will recall, paradoxically, people with hepatitis C found themselves in the unenviable position of being both marked by risk and erased as individuals whose health concerns are considered minor or non-life threatening. The health concerns of hepatitis C patients have been consistently downplayed, while their responsibility (for getting infected in the first place, especially in the case of IV drug users and for making “responsible” treatment decisions) has been magnified.

Third, how do new forms of contention by “biological citizens” challenge the architecture of the welfare state? While biological citizenship has the potential to empower citizens to become acquainted with their biological identities and challenge the truth claims of biomedical knowledge, we should be cautious about its emancipatory potential to reframe the public policy landscape, and with it the role of citizens and the welfare state itself. While this shift may influence how we understand fundamental categories such as life and death, how citizens interact with each other and with authorities is structured by existing power relations, as well. When, for instance, patients challenge biomedical knowledge or science, they may, in the process, reinforce the supremacy of scientific or medical knowledge, or valorize particular ways of knowing, even though this may be unintentional.

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