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**BLOOD, BLAME, AND BELONGING:
HIV, HEPATITIS C, AND THE EMERGENCE OF
'TAINTED-BLOOD ACTIVISM' IN CANADA, 1985-2000**

by
Michael Orsini, BA, MA

A thesis submitted to
the Faculty of Graduate Studies and Research
in partial fulfillment of
the requirements for the degree of

Doctor of Philosophy

Carleton University
Ottawa, Ontario
October 19, 2001

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***Blood, Blame & Belonging: HIV, Hepatitis C, and
the Emergence of Tainted Blood Activism in Canada,***

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in partial fulfillment of the requirements
for the degree of Doctor of Philosophy

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We are what we have done or neglected to do.
Charles Rosenberg

This dissertation is dedicated to recipients of tainted blood, past and present.

Abstract

This research addresses the emergence of “tainted-blood activism” in Canada using a social movement framework. Specifically, I examine the impact of the ‘political opportunity structure’ on: a) the strategies adopted by tainted-blood activists; b) the negotiation of the movement’s collective identity; and c) the outcomes of protest. One of the objectives of this research is to demonstrate that key “moments” can transform the political opportunity structure. One of these moments, the Krever Inquiry, not only legitimized tainted blood as a political issue worthy of the public’s attention; it also gave shape to this fledgling movement.

The research identifies four major findings that have a bearing on public policy. First, this case demonstrates that public policy analysts need to pay closer attention to the influence of social movements on the policy process. While tainted-blood recipients were a difficult constituency to mobilize, this research demonstrates how they did so successfully and how, in a short time frame, they managed to secure both compensation and the overhaul of the country’s blood system. Second, this research expands our understanding of public inquiries as sites for contestation over meaning. The Inquiry provides a forum for social movement participants to perform the types of rituals that help to move issues from the uncontested to the contested realm. The fact that movement actors use conventional tactics to do so, reinforces the idea that the line separating disruptive from non-disruptive protest is blurred at the best of times. Third, this research raises larger, troubling questions regarding the boundaries of state responsibility in

matters involving citizens' exposure to risk. Increasingly, governments are being called upon to compensate individuals or groups for inflicted harms, and in such cases they must make these decisions in a climate of heightened anxiety among citizens. Fourth, this research underscores the need to expand our understanding of "policy outcomes", which is too instrumental a term to capture the nuanced effects of collective action. While blood activists were able to win compensation, they succeeded also in creating a collective identity for tainted-blood recipients, and they challenged notions of what "sick" people can and cannot do.

Acknowledgements

A dissertation is a lonely journey punctuated by moments of personal triumph, and, more often than not, periods of intense frustration. Fortunately, that journey was made bearable by a group of caring and committed people. My thesis supervisor, Susan Phillips, provided the necessary encouragement during the trying times and stands as a towering model of what a thesis supervisor should be. She believed in my ability, and expressed this constantly, even when I doubted myself and whether this project would ever see the light of day. Committee member Miriam Smith always went well beyond the call of duty and took an active interest in my development as a future academic. And member Manfred Bienefeld, who made economics, dare I say, pleasant, gingerly reminded me that I should step outside of the box from time to time. The financial support offered by the Ontario Graduate Scholarship Program and a doctoral fellowship from the Social Sciences and Humanities Research Council (SSHRC), allowed me to avoid the vicious circle that many graduate students must face as they try to earn enough money to finance the writing of the dissertation.

The support of my closest friends, Francesca Scala, Arslan Dorman and Kiera Ladner, kept me on an even keel. Unlike some of the friends you encounter while in graduate school, they will be lifelong friends. The wisdom and guidance of my parents, Santa and Tony, who rarely asked what the heck I was doing but always expressed their unfailing support, is greatly appreciated. My brother Sammy put up with me for several

years while I was living at home. Nanna and Nonno, two of the best grandparents a person could hope for, inspire me beyond words. My Aunt Mary – Auntie, as she likes to be called – is nothing less than a second mother. My in-laws, Mary and Robert “Squee” Gordon, also demonstrated their love and respect, and allowed their eldest daughter to marry an as-yet-unemployed student. My partner, Victoria Ingeborg Gordon, who blew into my life five years ago as I embarked upon this journey, endured many a long night wondering when her husband would join the ranks of the employed. She also held our relationship together during some personal hardships that newly married couples should not have to endure. Her towering strength, spiritual depth, and intellect have nourished me, and find their way onto every page of this dissertation.

Finally, this research would not have been possible without the assistance of a group of dedicated activists who gave so generously of their time, and who agreed to revisit a painful chapter in their lives. I especially would like to thank Jo-Anne Manser, Michael McCarthy, Dr. Alan Powell, Leslie Gibbenhuck, John Plater, the ‘gang’ in Victoria, B.C. who looked after me while I was visiting, and Carol Romanow, a frontline worker who gave me an eye-opening tour of Vancouver’s downtown East Side. And to those individuals whose voices and thoughts did not make their way into this dissertation, I can only hope that the “story” I have presented does justice to what is clearly a matter of gross injustice.

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We will die. But we will not die quietly or privately.

- Jo-Anne Manser, person with Hepatitis C¹

You can't be a victim and an activist. Once you become an activist, you have learned how to use your rage. When you're still a victim, you're not in touch with your rage or your anger.

- Janet Conners, person with AIDS²

CHAPTER 1

Introduction

It is another rainy July afternoon in Victoria, B.C. as about 100 people assemble in a local church meeting room for HepFest 1999, which is billed as the first local event for people infected with Hepatitis C. While there are many discussions of issues of concern to people living with Hepatitis C – government compensation, life after a liver transplant, coping with combination therapy treatment – it soon becomes apparent that the event is more than an opportunity to acquire up-to-date information. The organizer of the weekend gathering says HepFest 99 is a chance for “heppers” – the term used by some people with Hepatitis C to describe themselves – to carve out a distinct identity, a challenge made increasingly difficult by the diversity of the community of people infected with the virus. Most of the people here this weekend have little in common except for the fact that they contracted Hepatitis C. Some were infected through tainted blood or blood products; others contracted it through injection drug use. Still, others have yet to

¹ Quoted at the inaugural meeting of the Coalition for Blood Injured Persons (Sept. 1998). The group has since disbanded.

² Personal interview with Janet Conners, August 11, 1999, Ottawa.

determine how, much less when they were infected, making it virtually impossible for them to claim government compensation. Nonetheless, leaders of the Victoria organization acknowledge that bringing together this diverse membership is challenging at the best of times, and exceedingly frustrating at the worst.

The audience listens intently to speech after speech from fellow “heppers”. One of them, David Smith, a former leader of a local chapter of the Hepatitis C Society of Canada, tells the audience that developing a positive attitude is key. “You’ve got to be proactive,” he says. “Get rid of the anger. There is no room for that in our lives.”³ His comments incense some of the audience members, who insist that they have a right to be angry. Others in the audience mumble in private that Smith can speak optimistically because he is one of the lucky few who underwent a successful transplant to replace his ravaged liver.

Behind the scenes, the Hepatitis C activist known to everyone here as “Squeaky” is trying desperately to corral the local media into covering the event. One television station, a local affiliate of BCTV, finally relents, and “Squeaky” uses the opportunity to lambaste the incumbent, provincial New Democratic Party (NDP) for failing to advocate for tainted-blood recipients who contracted Hepatitis C. The two members of the NDP who were invited to speak at the conference, one of whom has Hepatitis C, appear a bit perplexed – and offended – by the spirited attack that is captured by the live television camera. While some members privately criticize the group leader for “grandstanding” and

³ David Smith, quoted at HepFest 99, Victoria, B.C., July 1999.

perhaps alienating possible supporters in government, others acknowledge quietly that at least he had the nerve to openly criticize the party.

Jarad Gibbenhuck, a young boy from Penticton, B.C. who contracted Hepatitis C during heart surgery, delivers a carefully scripted speech while his mother, a tireless advocate and self-professed 'shit disturber', looks on admiringly. Jarad was chosen as the 'poster child' for Hepatitis C this weekend because, members admit privately, his story has the greatest potential to 'tug at the heart strings'.

Few can dispute that this tangled tale of how thousands of Canadians needlessly contracted Hepatitis C and HIV through contaminated blood 'tugs at the heart strings'. While there was never any doubt that transfusions of blood and blood products carried with them inherent risks, few could have predicted the enormity or severity of those risks. A number of factors make the story of tainted blood compelling. First, it has cut a wide swath through most of the industrialized world. Germany, France, Australia, Denmark, the United States, Italy, Switzerland – to name but a few – each country was affected by and responded to, in distinctive ways, the reality that its blood supply was contaminated with HIV. Second, the revelations of another scandal – Hepatitis C – suggest that many countries did not learn from the mistakes they made with respect to AIDS. Third, thanks in large part to the efforts of those injured by the blood system and the media, tainted blood will not be written off in the pages of history as an unavoidable tragedy, but as a "scandal" with important political, legal, and social implications.

While the news that the blood supply was contaminated with HIV began to appear in the late 1980s, the story of Hepatitis-C tainted blood only burst onto the political stage

in 1993 during the *Commission of Inquiry on the Blood System in Canada*. During the Inquiry's hearings, it was revealed that more than 20 times as many Canadians contracted Hepatitis C via tainted blood than contracted HIV. An estimated 2,000 Canadians – the majority of them hemophiliacs – contracted HIV through the blood supply. And, although there is some controversy regarding the exact number of people who contracted Hepatitis C through the blood supply, Health Canada estimated that 90,000-160,000 people received Hepatitis C-contaminated blood between 1960-1992. Of these, approximately 35,000 were still alive in 1998.⁴ In total, more than 150 million people around the world are infected with Hepatitis C, more than 200,000 of these people in Canada alone.⁵

The Hepatitis C story dominated the media in the Spring of 1998, when the federal government announced that it had brokered a deal with the provinces and territories to compensate people with Hepatitis C who had been infected between 1986-1990. The decision angered many people who received tainted-blood, who argued that compensation should not be tied to when someone was infected. During this tension-filled period, there was even speculation that a Reform Party-led motion in the House of Commons on whether to extend compensation to people with Hepatitis C might bring down the Liberal government.⁶ This dissertation will explore how tainted blood emerged

⁴ See the *Report of the Meeting of the Expert Panel on Hepatitis C Epidemiology*, prepared for Health Canada by Dr. Richard Schabas, July 24, 1998. Available online at <http://www.hc-sc.gc.ca/hpb/lcdc/bid/bbp/schabase.html>

⁵ See the *Report of the Meeting of the Expert Panel on Hepatitis C Epidemiology*, op. cit.

⁶ For a brief discussion, see Michael M. Atkinson and David C. Docherty, "Parliament and Political Success in Canada." In Michael Whittington and Glen Williams (eds.). 2000. *Canadian Politics in the 21st Century*. Scarborough: Nelson.

as a political issue, and how people infected with HIV and Hepatitis C through the blood system coalesced to form a fledgling social movement.⁷ In doing so, it will focus on how the politics of *blood*, *blame*, and *belonging* conspired to produce one of the great scandals in Canada's history.

The Politics of Blood, Blame, and Belonging

Blood, Titmuss noted in his pathbreaking book, "is the bond that links all men and women in the world so closely and intimately that every difference of colour, religious belief, and cultural heritage is insignificant beside it... The very thought of blood, individual blood, touches the deepest feelings in man about life and death."⁸ And, in another thoughtful discussion of the cultural significance of blood, Nelkin suggests that it "can stand at once for purity and contamination, vitality and death, community and corruption, altruism and greed."⁹ The idea of tainted blood, she adds, is tied inextricably to these social meanings.

⁷ A word about terminology is in order here. Following discussions with several activists, I have chosen to avoid using the term "victim" to describe people infected with HIV and/ or Hepatitis C through the blood system, unless I am quoting directly from a reference or an interview. The term, it was pointed out to me, wrongly implies that persons who contracted HIV or Hepatitis C were somehow passive. Instead, I use the terms "tainted-blood recipients" or the "blood injured". My decision not to use 'victim' does not detract from the perception among many tainted-blood recipients that they were "victimized" by the blood system.

⁸ Richard Titmuss. 1970. *The Gift Relationship: From Human Blood to Social Policy*. London: Allen and Unwin, p. 15-16.

⁹ Dorothy Nelkin, "Cultural Perspectives on Blood," p. 275. In Eric A. Feldman and Ronald Bayer (eds.). 1999. *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*. New York: Oxford University Press.

Blame, in the context of Canada's tainted blood scandal of the 1990s, refers to the often frustrating attempts by recipients of tainted blood to come to grips with who is at fault, who is ultimately responsible for the contamination of the nation's blood supply. In the discourse of the 'risk society',¹⁰ this ability to lay blame or to find fault is complicated by the sheer number of possible culprits, including governments, both federal and provincial, the Red Cross, some of the consumers' groups that failed to sound the warning bells, and the global pharmaceutical industry. Despite these difficulties, however, some commentators maintain that the guilty parties are readily identifiable.¹¹

And, finally, *belonging* is crucial if we are to understand how people infected with tainted blood forged a sense of belonging – a collective identity – around their perceived feelings of injustice in a relatively short time. This question of identity is important for at least three reasons. First, the discourse around tainted blood changed rapidly when people infected with Hepatitis C – the so-called “forgotten victims” who constitute the primary focus of this study – officially entered the political fray in early 1994 with the founding of the Hepatitis C Survivors' Society (later renamed the Hepatitis C Society of Canada). Prior to 1994, it was widely believed that HIV was the only virus that had tainted the

¹⁰ See Ulrich Beck. 1992. *Risk Society: Towards a New Modernity* (translated by Mark Ritter). London: Sage Publications.

¹¹ Justice Horace Krever, who presided over the Inquiry, was roundly criticized for failing to 'name names' in his final, three-volume report on the tragedy, despite the fact that he had fought and won a bitter legal fight for the right to do so. André Picard, a *Globe and Mail* reporter who wrote a definitive book on the scandal, argued that anyone who read Krever's report carefully enough could identify the main culprits. (See André Picard, “Lots of names, lots of blame to go around,” *The Globe and Mail*, Nov. 27, 1997, p. A8.)

nation's blood supply.¹² Indeed, several persons who attended and appeared before the Inquiry were initially baffled by the mention of Hepatitis C at the start of the Inquiry by Pierre Lavigne, an Ottawa lawyer. The saga of Hepatitis C began quietly when Justice Horace Krever granted standing at the Inquiry to Lavigne, who represented Étienne Saumure, a Quebec man with Hepatitis C whose heartbreaking story would capture instant media attention.

Second, the question of identity is important as the mobilization of persons infected with HIV- and Hepatitis C- tainted blood occurred against the backdrop of a growing individualization of responsibility for illness. Recipients of tainted blood, while perhaps enjoying popular support among the Canadian electorate¹³, nonetheless had to combat the view that attributes disease to the moral failings of the individual. As medical historian Allan Brandt has argued, "The triumph of a social ideology of individual control marks a powerful denial of our relative lack of control. Because externally imposed risks appear so difficult – if not impossible – to modify, the tendency ... has been to focus on the risks over which individuals do have some modicum of control."¹⁴

¹² This error is reproduced in Feldman and Bayer's recently edited comparative volume on blood scandals. Although they acknowledge that the "questions raised by Hepatitis C make clear that blood feuds did not end with conflicts over HIV," none of the 11 chapters deals substantially with Hepatitis C. ("Introduction," Feldman and Bayer. In *Blood Feuds*, op. cit., p. 15)

¹³ One survey released in February 1998 by the Angus Reid Group found that 87 per cent of the 1,500 people polled felt that the federal and provincial governments had a "moral obligation" to provide compensation to all people who contracted Hepatitis C through the blood system. See "Aftermath of Krever Report," National Angus Reid Group Poll, Feb. 4, 1998. Available electronically at: <http://www.angusreid.com/media/content/pdf/pr040298.pdf>

Third, from the standpoint of theory, a focus on the process of collective identity formation goes a long way toward closing the gaps left by interest group or pluralist approaches, which often fail to illuminate the influence of identity processes on movement strategies and outcomes.

Research Question

This research seeks to explain how elements of the environment external to the blood movement – the political opportunity structure (POS) and the state – influenced: a) the process of collective identity-formation; b) movement strategy and tactics; and c) policy outcomes (successes/failures).

Regarding the first aspect, I am interested in exploring the forms of protest pursued by recipients of tainted blood. Why, for instance, were vocal, physical demonstrations, which are often typical of social movement organizations, the exception, and not the rule? Secondly, I ask how these recipients of tainted blood succeeded in carving out a collective identity from which effective political action could spring. How challenging was this, given that people with HIV and people with Hepatitis C had little in common except for the fact that they were infected by the same blood system? Third, I question the concrete outcomes, such as the extension of compensation packages to those who fell outside of the “compensation window,” namely persons infected before 1986, the year in which screening tests were widely available for Hepatitis C but not adopted.

¹⁴ Allan M. Brandt, “Behaviour, Disease, and Health in the Twentieth-Century United States: The Moral Valence of Individual Risk,” p. 70. In Allan M. Brandt and Paul Rozin (eds). *Morality and Health*. New York and London: Routledge, 1997.

More importantly, I was concerned with the wide gaps in perception regarding successes and failures.

On the one hand, one may argue that Hepatitis C activists succeeded in getting Hepatitis C onto the government agenda, as the compensation issue dominated the media landscape for several months and culminated in a dramatic House of Commons vote on whether to extend assistance to all people who acquired Hepatitis C through tainted blood. Some of the blood activists with whom I spoke in the course of this research, however, felt that their inability to secure compensation for all people infected with Hepatitis C constituted a colossal failure. In attempting to tell this story – one which unfolded in large measure due to the efforts of the Krever Inquiry – I chart the process through which Hepatitis C rose from near obscurity to become one of the most contentious political issues of the day, to disappear only months later from the political landscape.¹⁵

Following Jenson, I treat actors as “simultaneously *subjects of structures and acting subjects* carrying in their practices and meaning systems the possibilities of both social stability and change.”¹⁶ The general question, then, that guides this research may be formulated as follows:

¹⁵ This feeling was echoed in interviews conducted with Hepatitis C activists, some of whom noted that “the issue was basically dead”, as far as government and the public were concerned.

¹⁶ Jane Jenson, “Paradigms and Political Discourse: Protective Legislation in France and the United States Before 1914,” *Canadian Journal of Political Science* XXII: 2, June 1989, p. 236.

How did the “political opportunity structure” expand and/or constrain the mobilization efforts of the movement on behalf of individuals infected with tainted blood?

Tarrow defines such structures “as consistent – but not necessarily formal, permanent or national – dimensions of the political environment which either encourage or discourage people from using collective action.”¹⁷ One of the main problems with the concept of political opportunity is that it is often used to mean everything external to the movement. Therefore, we need to unpack its meaning and identify the most relevant elements of the POS that helped to shape the process of collective action in this case. This requires that we examine the cultural and institutional environment in which tainted-blood activism took place. In addition, focusing on the impact of the POS will allow us to examine the choices that were made with a more nuanced understanding, while avoiding the dangers of environmental determinism. The POS, then, is central to this study, but so is the realization that actors make choices, sometimes cognizant of the constraints and opportunities afforded by political structures, sometimes not. According to Kriesi, the inability of political actors to anticipate shifts in the political environment “means that they have to take the political opportunity structure as a given in their short-term strategic calculations.”¹⁸

¹⁷ Sidney Tarrow. 1994. *Power in Movement*. Cambridge: Cambridge University Press, p. 18.

¹⁸ Hanspeter Kriesi, “The Political Opportunity Structure of New Social Movements: Its Impact on Their Mobilization,” p. 168. In J. Craig Jenkins and Bert Klandermans (eds.). 1995. *The Politics of Social Protest: Comparative Perspectives on States and Social Movements*, Minneapolis: University of Minnesota Press.

It is important to stress that unlike other strands of social movement research which often ignore the state's role in favour of a "cultural" approach, this study focuses on how the state and its various institutions influenced blood activists' 'action repertoires'. Thus, in this case, it was the Krever Inquiry that provided the institutional impetus that led to the formation of the Hepatitis C branch of the "blood activist" movement, in that recipients of tainted-blood formed a collective identity largely on the basis of the injustices clearly documented in the Inquiry report. Our task is to show: a) how this identity was formed; b) how the state helped to shape this identity; and c) how this collective identity influenced movement strategy and outcomes. How, for instance, did the 'frame of injustice' that had initially succeeded in uniting a disparate group of infected individuals, paradoxically also tear it apart? How did efforts to distinguish those deserving of compensation from those who were undeserving problematize the notion of injustice on which the claims of the tainted-blood community had rested?

This dissertation focuses on the mobilization efforts of *social movement organizations* (SMOs) representing persons infected with tainted blood. An SMO has been defined as a "complex, or formal, organization that identifies its goals with the preferences of a social movement or countermovement and attempts to implement those goals."¹⁹ Several SMOs make up the "blood activist movement", a term I use to describe the range of collective challenges that emerged in the wake of the tainted blood scandal by persons infected with HIV/AIDS and Hepatitis C. A social movement organization

¹⁹ McCarthy and Zald, quoted in Sidney Tarrow, *Power in Movement*, 1994, op. cit., p. 135.

should not be confused with a social movement. The latter describes “*collective challenges by people with common purposes and solidarity in sustained interaction with elites, opponents, and authorities.*”²⁰ The term “social movement” includes not only activists associated with formal organizations, but also those in loose networks that work alongside the main social movement organizations, often in uneasy alliances. Practically, the best way to capture the distinction between social movements and SMOs is to say that the latter have offices, telephones, and other organizational features, while social movements “cannot be located in any single place or simply dialed.”²¹

This grouping of political actors includes seasoned political activists associated with both mainstream and militant AIDS activism, as well as those individuals less accustomed to collective protest. As the dissertation explains, this movement of tainted-blood recipients was not necessarily united in its victimhood. There were deep divisions between those infected with HIV, the so-called “authentic victims”, and those infected with Hepatitis C, who had to demonstrate their legitimacy as recipients of tainted blood. Moreover, the tainted-blood scandal, I argue, was instrumental in transforming one of the organizations involved, the Canadian Hemophilia Society (CHS), from a long-standing health-advocacy group to an adversarial social movement organization, which worked both from within the political system and without. By 1994, the organization found itself in the unenviable position of having to deal with three diseases: hemophilia, AIDS, and

²⁰ Tarrow, *Power in Movement*, 1994, op. cit., pp. 3- 4.

²¹ John Lofland. 1996. *Social Movement Organizations: Guide to Research on Insurgent Realities*. NY: Aldine de Gruyter, p. 12.

Hepatitis C. In addition, the tainted-blood scandal propelled a new set of actors into the political arena (united under the banner of the Hepatitis C Society of Canada), many of whom were critical of the CHS's efforts to speak for them.

The Commission of Inquiry on the Blood System in Canada

The Commission of Inquiry on the Blood System in Canada (Krever Inquiry) has garnered substantial media attention since it was established in the Fall of 1993.

Appointed by a federal order-in-council to address the events that lead to the contamination of Canada's blood supply, the Inquiry was one of the most extensive, far-reaching examinations of tainted blood commissioned by a government. The Krever Inquiry raised a series of vexing issues that are implicit in scandals of this magnitude, including important, as yet unresolved policy questions regarding who is accountable for the safety of Canada's blood supply. The Krever Inquiry, therefore, constitutes a critical 'moment' in the emergence of 'blood activism' in Canada.

In trying to flesh out a notion of the state as incorporating a "complex of institutions", I argue that the Inquiry structure itself played a pivotal role in shaping the political engagement of tainted-blood recipients. But the Inquiry suffered from an identity crisis of its own in that it was unable to reconcile its role as a "policy-oriented" inquiry (concerned with public input) and as a "quasi-judicial" body intent on allocating responsibility for these events. And it was this confusion that, in part, prevented the Krever Inquiry from developing a mode of investigation that was appropriate for its

mandate, and that might have allowed it to reconcile what political theorist Nancy Fraser has termed the “recognition-redistribution dilemma.”²²

In general, I assess the Krever Inquiry from within Canada’s Inquiry tradition, seeking to understand how the Inquiry’s work was informed and influenced by Canada’s legacy of public inquiries in the same way that Pierson, among others, emphasized the structure of formal institutions and the consequences of previous policy initiatives (policy legacies) to explain the successes/failures of retrenchment policies in the Reagan and Thatcher governments.²³ Traditionally, commissions of inquiry are important sites for public deliberation of some of the most intractable problems confronting society. As institutionalized political spaces, they marshal and clarify the main ideas and identities surrounding those issues. As such they are “one of the several places in which policy analysis and learning might take place...”²⁴ Moreover, along with the conventional institutions of electoral politics and the policy networks linking various interest groups, they provide opportunities for public involvement in policy-making, and forums for generating ideas about policy issues and about ourselves.

In this case, we explore how the structure of the public inquiry and its unclear and sometimes contradictory mandate: a) compounded political strife between and among

²² See Nancy Fraser, “From Redistribution to Recognition? Dilemmas of Justice in a ‘Post-Socialist’ Age,” *New Left Review*, 1995, No. 112, pp. 68-93.

²³ See Paul Pierson. 1994. *Dismantling the Welfare State? Reagan, Thatcher, and the Politics of Retrenchment*. Cambridge and New York: Cambridge University Press.

²⁴ Jane Jenson, “Commissioning Ideas: Representation and Royal Commissions,” p. 39. In Susan Phillips (ed.). 1994. *How Ottawa Spends 1994-95: Making Change*, Ottawa: Carleton University Press.

social movement organizations, and b) complicated representational strategies. As Krever himself remarked: "I am the only person in this room who does not represent a special interest. I represent the public interest."²⁵ Officially, the Commission was charged with "getting to the bottom" of how the blood system became contaminated. Unofficially, however, it sought to give voice to those injured by the blood system, including those who acquired Hepatitis C.

The federal government's decision in December 1989 to compensated hemophiliacs who had contracted HIV via tainted blood, but not countless others who contracted Hepatitis C, helped to create a hierarchy of victimhood.²⁶ Indeed, some people with Hepatitis C are, in retrospect, so disillusioned with the entire process that they argued that the compensation issue was intended to "divide and conquer" because the idea of "no fault" compensation effectively foreclosed discussion of accountability or justice. In fact, Krever was quite unequivocal on this point when he said at the opening of the Inquiry that the Commission

...is not and it will not be a witch hunt. It is not concerned with criminal or civil liability. I shall make findings of fact. It will be for others, not for the commission, to decide what actions if any are warranted by those findings. I shall not make recommendations about prosecution or civil liability. I shall not permit the hearings to be used for ulterior purposes, such as a preliminary inquiry, or Examination for Discovery, or in aid of existing or future criminal or civil litigation.

²⁵ Justice Krever, quoted in Jane Coutts, "Krever proposal on blood report wins support," *The Globe and Mail*, October 21, 1994, p. A7.

²⁶ The final Krever Report urged governments to compensate all recipients of tainted blood, regardless of the type of infection.

As I interpret the terms of reference, the focus of the Inquiry is to determine whether Canada's blood supply is as safe as it could be and whether the blood system is sound enough that no future tragedy will occur. For those those purposes it is essential to determine what caused or contributed to the contamination of the blood system in Canada in the early 1980s. We intend to get to the bottom of that issue, let there be no mistake about that.²⁷

The Inquiry also played a role in problematizing the notion of "victim". Indeed, as the process unfolded, sharp differences emerged over who could legitimately claim the "victim" label. People with Hepatitis C were criticized for embracing the role of innocent victim, since the qualifier "innocent" seemed to suggest that others with Hepatitis C or HIV who were not infected through the blood system were somehow to blame for their condition. However, the "innocent victim" label was espoused not only by people with Hepatitis C. Hemophiliacs who were infected with HIV also portrayed themselves as quintessential 'victims' of government neglect and corporate greed, arguing that the system in which they placed their faith and trust had poisoned them. The message that this sent to HIV-positive members of the gay community associated with the AIDS movement, was that there was an important line separating those who had engaged in "careless" activities (sexual or drug-related) that carried the risk of HIV infection, from others who had mistakenly trusted a system that was supposed to look after their needs. Moreover, tension between the AIDS community and the tainted blood community was

²⁷ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 1, Ottawa: Minister of Public Works and Government Services Canada, 1997, p. 8.

further fuelled by suggestions that “careless” members of the AIDS community were responsible for the contamination of the blood supply in the first place.

In effect, tainted-blood recipients were implicitly classified according to the way in which they were infected (transfusions, use of blood products) and the type of infection (HIV, Hepatitis C or, in some cases, both). At the inquiry, there were representatives for people who contracted Hepatitis C (Hepatitis C Society of Canada), for people with hemophilia (the Canadian Hemophilia Society), and for those who contracted HIV through transfusion (the HIV-T Group). Those who were infected after receiving transfusions of blood components (red cells, platelets, or plasma), usually in the hospital and often in the course of surgery, are referred to as occasional users of the blood system. In contrast, hemophiliacs who use factor concentrates (blood products that are used to treat hemophilia) are considered frequent users of the blood system. Severe hemophiliacs depend on these products to treat their frequent bleeding episodes. In 1985, blood system officials had developed “triage criteria” to deal with the problem of having separate stocks of factor VIII concentrate that were heat treated and not heat treated. Heat-treated factor concentrates were “heated” to kill viruses and bacteria in a manner similar to the pasteurization of milk. According to one account, it was agreed that: “Heat-treated factor VIII concentrate would first be reserved for hemophiliacs who had never been exposed to untreated blood products; next, it would be made available to hemophiliacs who had been treated least with such products or had received only cryoprecipitate. Young hemophiliacs

would receive priority.”²⁸ This “Schindler’s List”, as some hemophiliacs liked to refer to the triage program, was not needed, however, as “only one million of the 15 million units the CRCS (Canadian Red Cross Society) received at the time were ever distributed, presumably in an effort to use stocks of untreated material that otherwise would have had to be recalled and destroyed.”²⁹

Opportunities and Frames

In developing a social movement perspective on tainted blood, I attempt to overcome the “reification problem” that is described by Benford as a tendency among social movement scholars to speak “about socially constructed ideas as though they are *real*, as though they exist independent of the collective interpretations and constructions of the actors involved.”³⁰ Benford identified three ways in which this problem manifests itself in the literature. First, when speaking about movements, identities, ideologies and frames, there is a tendency to “anthropomorphize” them, as if the movements are doing the “framing”, “interpreting”, and “acting”, when it is movement participants who engage in these activities. “Social movements do not frame issues; their activists or other participants do the framing.”³¹ Second, many social movement analysts neglect the role of

²⁸ Norbert Gilmore and Margaret A. Somerville, “From Trust to Tragedy: HIV/AIDS and the Canadian Blood System,” p. 139, in *Blood Feuds*, op. cit.

²⁹ Norbert Gilmore and Margaret A. Somerville, “From Trust to Tragedy...” p. 139, in *Blood Feuds*, op. cit.

³⁰ Robert Benford, “An Insider’s Critique of the Social Movement Framing Perspective,” *Sociological Inquiry*, Vol. 67, No. 4, November 1997, p. 418.

³¹ Robert Benford, “An Insider’s Critique of the Social Movement Framing Perspective,” p. 418.

human agency, forgetting that social movements are neither monolithic nor do they “speak” with one voice. They are made up of actors who interact, cooperate, and react. And third, reification leads to the neglect of emotions. This is partly due to the influence of the rationalist paradigm of resource mobilization theory, which emphasizes the role of organizations and the incentives they offer to movement participants. In our haste to paint a “rational” account of collective action, Benford argues that we mistakenly treat movement actors as “Spock-like beings, devoid of passion and other human emotions.”³²

One of the gaps in the literature on collective identity is an explicit consideration of how such identities come into existence. Moreover, most discussions focus almost exclusively on non-state actors, and neglect the policy implications of identity strategies. In contrast, the state’s role in the construction of identity represents a crucial starting point for this study. In order to facilitate such an understanding, I adopt a view of the state as a complex web of relations. Scholars working within the historical institutionalist framework have also attempted to grapple with this question, with varying results.³³ Tainted-blood activists did not confront a monolithic state. Rather, their example demonstrates how states are differentiated, how different branches of government send mixed signals to non-state actors. As Allison has demonstrated in his analysis of the Cuban Missile Crisis, the claim that monoliths “perform large actions for large reasons

³² Robert Benford, “An Insider’s Critique of the Social Movement Framing Perspective,” p. 419.

³³ See, for instance, Sven Steinmo, Kathleen Thelen, and Frank Longstreth (eds.) 1992. *Structuring Politics: Historical Institutionalism in Comparative Analysis*. Cambridge, England: Cambridge University Press.

must be balanced by the appreciation that (1) monoliths are black boxes covering various gears and levers in a highly differentiated decisionmaking structure and (2) large acts result from innumerable and often conflicting smaller actions by individuals at various levels of bureaucratic organizations in the service of a variety of only partially compatible conceptions of national goals, organizational goals, and political objectives.”³⁴

For instance, it was difficult to determine whether Chrétien’s Liberal government spoke with one voice on the Hepatitis C issue. Interestingly, there is some debate about which government department was responsible for the tainted blood file. Officially, at least, the Ministry of Health was responsible, but a former Federal Health Minister complained bitterly in a personal interview that the effective “lead” department was the Ministry of Justice, specifically the department’s “merciless” legal team that led the

³⁴ Graham T. Allison. 1971. *The Essence of Decision: Explaining the Cuban Missile Crisis*. HarperCollins Publishers, pp. 5-6. Allison provides a useful illustration of how the three theoretical models – Rational Actor (Model I), Organizational Process (Model II), and Governmental Process (Model III) – to understanding the Cuban Missile Crisis differ: “A central metaphor illuminates the differences among these models. Foreign policy has often been compared to moves and sequences of moves in the game of chess. Imagine a chess game in which the observer could see only a screen upon which moves in the game were projected, with no information about how the pieces came to be moved. Initially, most observers would assume – as Model I does – that an individual chess player was moving the pieces with reference to plans and tactics toward the goal of winning the game. But a pattern of moves can be imagined that would lead some observers, after watching several games, to consider a Model II assumption: the chess player might not be a single player but rather a loose alliance of semi-independent organizations, each of which moved its set of pieces according to standard operating procedures. For example, movement of separate sets of pieces might proceed in turn, each according to a routine, the king’s rook, bishop, and their pawns repeatedly attacking the opponent according to a fixed plan. It is conceivable, furthermore, that the pattern of play might suggest to an observer a Model III assumption: a number of distinct players, with distinct objectives but shared power over the pieces, could be determining the moves as the resultant of collegial bargaining. For example, the black rook’s move might contribute to the loss of a black knight with no comparable gains for the black team, but with the black rook becoming the principal guardian of the palace on that side of the board.” (*The Essence of Decision*, p. 7)

attack against the Krever Inquiry's ability to single out individuals and institutions in its final report.

From the perspective of social movement theory, this case is useful in elaborating not only the process of collective identity but how it relates to movement fragmentation, as well. How the blood activist movement succeeded in creating a collective identity is an important theoretical question, but of equal importance is how this translated into successful/ unsuccessful movement strategies. Do movements "succeed" only if they can engage in normal politics (if they become institutional players), or can they work both inside and outside the system? As Fainsod Katzenstein convincingly shows, the inside/outside distinction may be misleading, if it presumes that actors working within the system have lost their radical edge, while treating those on the margins as "authentic" radicals.³⁵ In fact, her study of feminist activism inside the institutions of the Church and military demonstrates that feminists, while perhaps eschewing the traditional model of disruptive protest that is often romanticized in social movement scholarship, have "challenged, discomfited, and provoked, unleashing a wholesale disturbance of long-settled assumptions, rules, and practices."³⁶ Institutionalization may offer "wider opportunities for disruption" if movements refuse to play by the established rules.

Recognizing, however, that an "opportunity unrecognized is no opportunity at all," it is crucial to determine "the shared meanings and definitions that people bring to

³⁵ See Mary Fainsod Katzenstein. 1998. *Faithful and Fearless: Moving Feminist Protest inside the Church and Military*. Princeton, NJ: Princeton University Press.

their situation.”³⁷ Social movement theorists refer to these as “framing processes”, the “ideational” dimensions of collective action; scholars of new social movements have addressed this issue under the broader rubric of identity. It is insufficient, therefore, to chart solely the opportunities available to movement actors; rather, one must examine why, given the opportunity to do so, recipients choose to mobilize or not.

Regarding the process of collective identity formation, the study asks: How were recipients of tainted blood represented? How did they represent themselves? How did the representational strategies of people with HIV/AIDS differ from those of people with Hepatitis C? I am particularly concerned with the gap between how recipients of tainted blood viewed themselves, individually and collectively, and how they were represented by their representatives and in media discourses. HIV-positive hemophiliacs, for instance, struggled to forge distinct identities and avenues for representation in an epidemic that, in Western industrialized countries, remains linked to a gay-male identity. Unlike homosexuals, hemophiliacs did not have a rich activist tradition from which to draw. This absence of an activist legacy was far more pronounced in the case of people with Hepatitis C, whose links to activism were almost non-existent. In personal interviews many revealed that even a small demonstration proved an organizational nightmare.

³⁶ Mary Fainsod Katzenstein, *Faithful and Fearless*, op. cit., p. 7.

³⁷ Doug McAdam, John D. McCarthy, and Mayer N. Zald, “Introduction,” p. 5. In McAdam, McCarthy, and Zald (Eds.). 1996. *Comparative Perspectives on Social Movements: Political Opportunities, Mobilizing Structures, and Cultural Framings*. Cambridge, UK: Cambridge University Press.

Methodology

It became clear early in the research that in order to gain deeper insight into the strategies employed by activists, the tensions between leaders and rank and file members, and the constraints and opportunities they believed either impeded or facilitated collective action, I would need to interview activists associated with the blood movement. Although many of the questions that guided the interview process were informed by theory about how structures constrain or provide openings for movement challengers, a growing body of theory recognizes that the perceptions/attitudes of individual activists vis-à-vis the opportunities available to them are important, as well. Conducting semi-structured interviews allowed me to construct a narrative of activists' experiences within the movement and of their perceptions of successes, failures, and, overall, of their capacity to effect change. To this end, personal interviews were conducted with about 30 activists in Toronto, Ottawa, Montreal, Vancouver, and Victoria. In order to gain a richer understanding of the tensions within the movement itself, I interviewed not only group leaders, but rank and file members as well, some of whom clashed publicly with their leaders. Finally, I conducted interviews with five federal government officials who were acquainted with the Hepatitis C file, with Justice Horace Krever, as well as with two newspaper journalists who covered the tainted-blood scandal.

In addition, I draw on the use of primary documents, the most significant of which are the Krever Inquiry's 500,000 pages of transcripts, as well as dozens of newspaper reports and documents prepared by some of the organizations represented at the Inquiry.

Overview of Chapters

Chapter 2 provides a discussion of the cultural context of blood, as well as an historical overview of key developments that preceded the tainted-blood saga, as a means to anchor the discussion that follows. This section looks at significant changes in the handling of blood and blood products, and in the relationship between clients/consumers and those officials charged with responsibility for the blood system. Finally, a brief overview is provided of three key moments in the blood scandal: initial demands for compensation for people infected with HIV-tainted blood and the announcement of the federal government's Extraordinary Assistance Plan (1987-1989); the creation of a public inquiry (1993), and the emergence of 'blood activism' generally and that branch of the movement representing persons infected with Hepatitis C. In addition, attention is paid to tensions within the broader community of persons with Hepatitis C and HIV who were infected through other means than tainted blood. Here I deal with questions regarding the organizational makeup of the Hepatitis C Society of Canada, and any changes to it, and how they have affected modes of collective action. Since no definitive study of the Society exists, it is constructed with the help of interviews and other supporting documents. While the Hepatitis C Society of Canada emerged as the key representative for recipients of Hepatitis C, it was not alone in advocating for people with Hepatitis C. The Canadian Hemophilia Society, a long-established consumer voice for people with hemophilia, initially carried the torch for people with Hepatitis C, sometimes to the frustration of people with Hepatitis C, some of whom believed the organization was

trying to expand its fiefdom and control of blood-related policy issues. Moreover, Hepatitis C patients who were unhappy with the direction of their national organization continued to exert pressure, albeit with the help of newly formed networks of interaction.

In **Chapter 3**, I review some of the main theoretical strengths of social movement theory (SMT), in addition to those elements of the theory less important to my study. I also justify my choice of SMT to explain the emergence of blood activism, and outline briefly its advantages over an interest-group approach. One component of this discussion is devoted to examining the role of collective identity, which is often ignored by interest-group theorists in favour of a more instrumentalist approach. And while sidestepping the often stultifying debates over social movement 'newness', I nonetheless explain my choice of incorporating the work of those associated with this branch of theory, and argue that the 'old' suggestions about what constitutes the 'new' in new social movement theory are insufficient to explain the movement in question. I locate "blood activism" among a host of contemporary political actors calling upon the state to compensate them for harms inflicted upon them directly or indirectly through government and/or institutional neglect. The 'blood-injured' are but one example in a growing list of victims of the "risk society". This chapter also introduces and expands upon the notion of 'political opportunity structures' (POS), and highlights some of the problems in isolating those factors that comprise such structures. I discuss briefly the four elements of political opportunity relevant to this study: the institutional framework, the presence or absence of elites and allies; the influence of political values and ideas, and the openness of/ and access to the political system.

Using the framework set out in the previous chapter, **Chapter 4** elaborates the particular political opportunity structure facing tainted-blood recipients. I expand upon the salient elements of the POS identified in Chapter 3. I argue that while one element of the POS – the Inquiry process itself – expanded the field of opportunities for tainted-blood recipients, it also channeled protest toward less-threatening (non-confrontational) ends. Moreover, the tainted-blood scandal, I suggest, was instrumental in transforming one of the organizations involved – the Canadian Hemophilia Society – from a traditional health-advocacy group to an adversarial social movement organization. In addition, the Inquiry catapulted a new set of actors, united under the banner of the Hepatitis C Society of Canada, into the political arena. These two developments are especially interesting as they call into question some of the Canadian literature on public inquiries, which argues that inquiries operate to quell dissent and to co-opt the parties involved. The final section of this chapter examines the impact of media coverage on the framing of political opportunities.

In **Chapter 5**, I provide both a detailed theoretical discussion of collective identity processes, and a descriptive account of the process of collective identity formation within the Hepatitis C movement organizations. In asserting the crucial role collective identity plays in influencing both movement formation and success, I stress that its role must be understood within its proper context. Specifically, tainted-blood activists did not face the types of problems commonly associated with movement actors attempting to forge a collective identity. Unlike other movements that often face a challenge from non-movement actors who may adopt the identity the movement helped to spawn, but who

eschew active participation in the movement (one may identify as a feminist but not with the feminist movement), activists consistently tried to fashion an identity that accommodated as many tainted-blood recipients as possible, as a means to lower the costs associated with assuming an otherwise negative identity. In contrast to much of the literature on the subject that treats collective identity as a putatively positive process, activists faced added pressure in recruiting others because many were reluctant to identify as people with Hepatitis C. I argue that part of this failure must be attributed to the activists' inability to fully utilize the "injustice" frame they had developed. Blood activists had only limited success in demonstrating to would-be supporters that the scandal was a result of willful action, and not simply an unfortunate accident. In addition, unlike tainted-blood recipients who contracted HIV, people with Hepatitis C struggled to position this "new" disease as an important public health concern, not to mention debilitating disease. HIV-infected blood recipients did not have to make the case that AIDS be taken seriously. The AIDS movement had previously succeeded in solidifying this claim.

Chapter 6 focuses on the outcomes of protest (both concrete and less tangible), and presents a theoretical as well as practical explanation of how and why events unfolded as they did. Apart from the obvious outcomes that might be of concern to students of public policy, such as the compensation victories, this chapter underscores the need to pay closer attention to the less-obvious outcomes of protest. For instance, did activists succeed in articulating new meanings onto disease? Did they transform or challenge commonly held assumptions about the proper role of "sick" people in society?

Moreover, what impact did protest have on governments in their interaction with movements and organized interests? Finally, I discuss the particular strategies pursued by blood activists, and explain the factors that may have contributed to success in some areas and failure in others.

Chapter 7, the concluding chapter, restates the dissertation's main findings, and explores the possible implications of this study for future research in which social movement theory is applied to Canadian cases. In addition, it makes a plea for greater attention in the Canadian context to the interaction between institutions and social movement organizations, especially as they relate to the study of public policy. Implicit in this discussion is a critique of social movement theorists who neglect the role of institutions in providing both the context and grounds for collective action. Contrary to suggestions that social movements bypass the state, this study is concerned with how new configurations of state power influence both movement identity and strategy, and hence outcomes. Finally, the chapter demonstrates how the four main avenues of this research – the political opportunity structure, the role of collective identity, the strategies of movement activists, and the outcomes of protest – are closely intertwined and inform one another. That is, identity informs strategy, and strategy helps us to explain outcomes. The political opportunity structure is not immutable, however; it is affected by and affects the other factors.

The Appendix provides a detailed chronological overview of key moments in the tainted-blood scandal.

The story of blood is one of metamorphosis, of a liquid that became symbolically transformed as society learned how to deconstruct and manage it.

- Douglas Starr

CHAPTER 2

Seeing Red: Blood in Culture and History

The tainted-blood scandal took on the particular significance that it did because it was steeped in the cultural and historical roots of blood. Before we can understand the mobilization of blood activists, then, it is necessary to examine in greater detail some of these roots. Science, for instance, has focused on the objective and biological substance of blood, which has three types of cellular components and a liquid component, or plasma. Beyond science, there are many underlying questions about blood's enduring social meanings. The first section of this chapter considers some of these meanings, focusing on four metaphors of blood identified by Nelkin. The second section turns to a discussion of key developments in the history of blood and blood-borne illnesses, including the advent of AIDS and Hepatitis C, and in the history of transfusion medicine. The third section narrows the focus to consider the distinctive features of the Canadian blood system. Finally, the last section provides a brief chronology of three key moments in the scandal: the initial struggle over HIV-related compensation (1987-1989), the announcement of a formal inquiry (1993), and the mobilization of people infected with HIV- and Hepatitis C-tainted blood (1994-1999).

Blood as a Symbolic Resource

Within cultures from the ancient to the present, blood has been assigned a unique, almost mystical, importance. The Ancient Egyptians reportedly bathed in blood “to refresh their powers,” while in Australian tribes sick, old men drank the blood of young men for rejuvenation.³⁸ For centuries, says Titmuss, “blood has been regarded as a vital, and often magical, life-sustaining fluid, marking all important events in life... and its loss has been associated with disgrace, disgust, impotence, sickness and tragedy... From time immemorial, it has symbolized qualities of fortitude, vigour, nobility, purity, and fertility.”³⁹

According to Nelkin, blood metaphors typically center on four related themes:

First, blood is defined as an essentialist substance, the essence of personhood, the basic life force.

Second, blood – and the exchange or donation of blood – is an important symbol of community and solidarity.

Third, metaphors of blood are a means to represent the prevalence of danger and risk.

Fourth, the concept of pure blood contains associations that extend well beyond the properties of a biological substance to include references to social relationships and moral as well as physical contamination.⁴⁰

Examples abound of the first metaphor, from the eucharistic doctrine of Roman Catholicism (bread and wine symbolizing the body and blood of Christ) to former

³⁸ Richard Titmuss, *The Gift Relationship*, op. cit., p. 15.

³⁹ Richard Titmuss, *The Gift Relationship*, op. cit., pp. 15-16.

⁴⁰ Dorothy Nelkin, “Cultural Perspectives on Blood,” p. 275, in *Blood Feuds*, op. cit.

Romanian dictator Nicolae Ceausescu's penchant for "harboring little boys in his castle both to brainwash them with his political ideology and to periodically draw blood from them for his own rejuvenation."⁴¹ In the Japanese press, for instance, blood-type analyses are used to predict personality and behaviour. And in parts of Japanese society, "blood type determines personal character" and acts as a "template of identity."⁴² Recently, controversies over the Human Genome Diversity Project (HGDP), which seeks to develop a genetic map of the world's 400 indigenous populations, have underscored the wide chasm between scientific and essentialist meanings of blood. Scientists working with the project contend that the HGDP may yield important insights into rare, genetic diseases and help in the development of pharmaceutical products. Representatives of some indigenous communities believe, however, that the project constitutes a "pernicious form of biopiracy" that will ultimately undermine indigenous communities.⁴³

The second metaphor, of blood as a symbol of community and solidarity, marks bonds of kinship and social solidarity. In common parlance, for instance, we refer to "blood brothers" or "blood ties" as shorthand to describe or evoke feelings of kinship. For some, this metaphor was shattered as it became apparent that the so-called "gift of life" was little more than a "gift of death" for those who had the misfortune of relying on blood or blood products to stay alive. Blood previously united donors with strangers, and still

⁴¹ Dorothy Nelkin, "Cultural Perspectives on Blood," p. 276, in *Blood Feuds*, op. cit.

⁴² Dorothy Nelkin, "Cultural Perspectives on Blood," p. 276, in *Blood Feuds*, op. cit.

⁴³ Dorothy Nelkin, "Cultural Perspectives on Blood," p. 279, in *Blood Feuds*, op. cit.

figures prominently in advertising campaigns by blood collection organizations, including the recently formed Canadian Blood Services.

Although blood and its components are now commercial products, for some time the donation of blood represented one of the highest forms of altruism. Donating blood served a good beyond the individual stranger or strangers who could benefit from it; it represented a contribution to the public good. The explosive revelations of tainted blood shattered this well-worn image, and ruptured the fragile link between donor and community solidarity. If blood indeed united communities, the revelations of tainted blood would serve to fragment them, to say nothing about the negative impact this would have on blood-collection agencies' ability to recruit blood donors.⁴⁴ This was especially pronounced in countries such as Canada, where blood donation remains a truly altruistic act. The practice of paying donors for their blood, especially when those donors may be engaged in high-risk activity, has been roundly criticized. One study, for instance, found that paid donors in the U.S. were derided, and seen as morally suspect.⁴⁵

The third metaphor, blood as a symbol of danger, gained currency within the highly charged discourse of tainted blood. As cultural anthropologist Mary Douglas has argued, however, the idea of the polluted body is rooted firmly in history. Some 30,000 prostitutes and women suspected of being prostitutes, for instance, were incarcerated in

⁴⁴ Numerous Canadian newspaper articles reported on these new-found problems faced by the country's blood-collection agency, which coped with severe blood shortages in the wake of the tainted-blood scandal.

⁴⁵ See Martin J. Kretzman, "Bad Blood," *Journal of Contemporary Ethnography*, January 1992, pp. 416-441.

barbed wire camps during the First World War to stem the rate of syphilis infection among soldiers.⁴⁶ But, as Brandt observes, "What began as an attempt to save the health and efficiency of the American fighting man was eventually transformed into a comprehensive program to rid the nation of vice, immorality and disease."⁴⁷ Nelkin relates how ideas about dangerous blood have been used to stereotype not only prostitutes, but also women in general, especially in relation to menstruation. Medical accounts treated menstruation as a disease of dirt and defilement.

Finally, the myth of pure blood dates back several centuries. Although disease was often attributed to bad blood, blood purity was supposedly linked to other factors, such as race, social position, and ethnicity. During the height of World War II and despite an increasing demand for blood, the U.S. resisted blood donations from African-Americans for fear they would "mongrelize the nation." The U.S. Congress finally relented, but once accepted, blood from black donors was segregated from other donors' blood. The myth of pure blood also pervaded discussions of immigration policy in the U.S., where the palpable fear of mixing blood justified restrictive immigration practices in the 1920s. As Nelkin argues, "Blood language is a way to express political anxieties about the threat of foreigners to national borders."⁴⁸ Interestingly, she notes, the U.S. has

⁴⁶ See Allan Brandt. 1987. *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*. New York: Oxford University Press.

⁴⁷ Allan Brandt, *No Magic Bullet*, p. 52.

⁴⁸ Dorothy Nelkin, "Cultural Perspectives on Blood," op. cit, p. 286.

also been on the receiving end of this xenophobia. In Canada, the argument for self-sufficiency had been fuelled by the suggestion that Canadian blood was somehow cleaner than American blood because Canada did not rely on paid donors. And indeed, the recent allegations that plasma collected from high-risk prison inmates in Louisiana and Arkansas was used to manufacture blood products for Canadian hemophiliacs, only reinforces these anti-American sentiments. It is ironic that due to the recognition of the wide incidence of high-risk sexual activity and drug use among inmates, U.S. officials suspended the use of prison plasma at least two years before Canada did.

The History of Blood and Blood-Borne Illness

Canada's tainted blood scandal is littered with tales of missed opportunities, deliberate avoidance, and scientific uncertainty, each of which is rooted in the history of how nations have handled or mishandled blood and blood products. But were it not for great medical strides in transfusion medicine, it is unlikely that HIV and Hepatitis would have contaminated the blood supply. I now turn to a brief examination of the development of transfusion medicine.

The Development of Transfusion Medicine

The history of transfusion medicine dates as far back as the 17th century, when the first animal-to-human transfusion was performed in France by Jean-Baptiste Denis, one of Louis XIV's physicians.⁴⁹ Denis believed at the time that he could cure a "madman",

⁴⁹ See Douglas Starr. 2000. *Blood: An Epic History of Medicine and Commerce*. New York: Harper Collins Publishers.

Antoine Mauroy, by transfusing him with the blood of a calf. Starr offered a descriptive reenactment of the famous procedure:

At precisely six in the evening on December 19, according to the doctor's report, an associate opened a vein in Mauroy's arm, inserted a silver tube, and drained off about ten ounces of blood. He then inserted the other end of the tube into the leg artery of a calf and allowed about a cupful of the calf's blood to flow into the man. The doctor hoped that the calf's blood 'by its mildness and freshness might possibly allay the heat and ebullition of the (patient's) blood.'⁵⁰

At first, observers, including Denis himself, were shocked by the results. The man who had previously exhibited violent fits of rage, who beat his wife repeatedly, "had dramatically – almost magically – been cured." This was followed by a second seemingly successful transfusion. Within a few days, however, the patient had reverted to his "normal" state of swearing and wife beating. Against his better judgment, Denis agreed to perform a third transfusion using calf's blood, but his patient's violent fits of shaking prevented him from completing the procedure. The next night, Antoine Mauroy died. The wagons began to circle around Denis, even though he had never actually carried out the third transfusion. Mauroy's wife buried her husband before an autopsy could be conducted to examine the cause of death. All eyes were on the doctor, who became the victim of a smear campaign within France and in Britain, which had long complained that it pioneered transfusion medicine. During a high-profile trial launched by the patient's wife, it was revealed that after a particularly brutal beating, the wife began "putting

⁵⁰ Douglas Starr, *Blood*, op. cit., p. 3.

certain powders in his soup.” The patient had died, not from the attempted transfusion, but from arsenic poisoning.

Despite this, however, the die had been cast. Smarting from the negative repercussions of the incident, the French Parliament, followed by the British, decided to ban all transfusions involving human beings. It took more than a century and a half before doctors in London were able to perform the first successful human-to-human transfusion. Even then, the results were not nearly as successful as doctors had hoped. A British doctor, for instance, transfused 12 patients, five of whom died. Few knew at the time why the transfusions were yielding such mixed results. Researchers had yet to discover that there were four different blood types.

By the second half of the 19th century, transfusions were becoming popular again. But the modern era of transfusion medicine did not begin until the early 20th century. Interestingly, it was another Frenchman, this time living in New York, who took centre stage. Dr. Alexis Carrel, who had left France to work for the Rockefeller Institute for Medical Research, was called upon to save the life of a newborn baby girl who desperately needed fresh blood to stop blood that was oozing from her nose and mouth. After some prodding, Carrel relented and agreed to try the procedure. He transfused the baby with blood from her father. After several failed attempts to suture the father’s artery to the small vessel in the baby’s leg, Carrel finally connected them. Soon after, they noticed a “a little pink tinge at the top of one of the ears... Then the lips, perfectly blue, began to change to red. Suddenly a pink glow broke out all over its body, almost as if she

had been placed in a hot bath. The baby began to wail.”⁵¹ What few doctors, including Carrel, realized at the time was that the doctor’s choice of the baby’s father as the transfuser meant the difference between life and death. Doctors, who had no knowledge at the time of blood types, were unaware that the girl had survived because her father had a compatible blood type. Three blood types – A, B, and C (later renamed O) – were discovered in 1900, by Viennese researcher Karl Landsteiner, who later won a Nobel Prize for his work. A couple of years later, two of Landsteiner’s colleagues discovered a fourth, AB.

Word of the promising results of transfusion medicine spread throughout much of the world, and it couldn’t have come at a better time as the world was preparing to go to war. Although there were some successful transfusions performed during World War I, it was not until the Spanish Civil War (1936-1939) that the potential of transfusion medicine would be realized. Norman Bethune, a Canadian thoracic surgeon, was responsible for much of these pioneering efforts in battlefield transfusions. He suggested something that had not been attempted before: “collecting blood from civilians, storing it in bottles, and shipping it to the front. The doctors who performed transfusions during World War I had relied mainly on donors-on-the-hoof – the blood came forward, in effect, in a person. Most doctors considered stored blood too novel and dangerous for war.”⁵²

⁵¹ Douglas Starr, *Blood*, op. cit., p. 36.

⁵² Douglas Starr, *Blood*, op. cit., p. 78.

The wartime effort to aid wounded soldiers also signalled a growing role for both the Red Cross in the collection of blood, and Toronto-based Connaught Laboratories, which had stunned the medical world in 1922 with the discovery of insulin. Following the raid on Dieppe, in which an estimated 1,500 soldiers were killed or wounded, the Canadian population sprang into action. The Canadian Red Cross, which had been incorporated as a charitable organization in 1909 but not given any formal responsibility for the collection and distribution of blood, launched a major blood-donor drive. By 1943, Canadians had donated more than half a million units of blood to the Red Cross, a dramatic increase from the previous year.

No group was watching developments in transfusion medicine as closely as the hemophiliac population. Like Hepatitis, hemophilia is not a new disease, with reports dating back as far as two thousand years. A gender-linked and hereditary condition, hemophilia is found in about one in every five thousand males, and is commonly transmitted from mother to son during pregnancy.⁵³ People with hemophilia lack a coagulation factor that is critical to the clotting of blood. As a result, they often suffer "prolonged bleeding from small cuts, internal hemorrhaging from minor accidents, and episodic bleeding in the knee, elbow, and hip."⁵⁴ For many it is the latter affliction that

⁵³ Hemophilia is passed on "in a skip-stop pattern: the female line carries it, yet only the male suffers from it. If a male hemophiliac marries and has children, all his sons will be normal, as well as his sons' and grandsons. But every one of his daughters will be a carrier of the sinister gene, and may therefore transmit the disease to one or more of her sons." (Quoted in *Hemophilia Today*, Canadian Hemophilia Society, Volume 29, No. 1, November 1993, p. 18.)

⁵⁴ Douglas Starr, *Blood*, op. cit., p. 46.

can prove the most debilitating, as many patients suffer “crippling pain in the joints as enzymes in the hemorrhaging blood corrode cartilage, bone, and nerve.”⁵⁵

The treatment of hemophilia was first improved with the arrival of safe, effective transfusions, and most dramatically, with the discovery in 1964 of cryoprecipitate by a young researcher at Stanford University. Until the 1950s, the only therapy available to hemophiliacs, the majority of whom lacked Factor VIII, was to receive transfusions of whole blood. The procedure, however, was considered risky because the large volumes of whole blood required to provide sufficient Factor VIII to control the bleeding, could harm a patient’s circulatory system and lead to heart failure. In the 1950s, the practice of transfusing patients with whole blood was replaced by infusions of plasma, the liquid part of blood that contains the necessary clotting factors. Although it had higher levels of clotting factor than whole blood, hemophiliacs still required large volumes of plasma to control serious bleeding, and, as a result, were condemned to making frequent hospital visits.

The discovery of cryoprecipitate, which was derived by thawing frozen plasma and extracting the Factor-rich crystals that had formed at the top, revolutionized the world of transfusion medicine, and transformed the treatment of hemophilia in the process. Not only did researchers discover that these small amounts of cryoprecipitate were far less costly than dozens of units of blood and easier to produce, they were much more effective in treating hemophilia. There were several problems, however, including the

⁵⁵ Douglas Starr, *Blood*, op. cit., p. 46.

impracticality of home care (the cryo had to be stored in a special freezer and carefully thawed), and the allergic reactions some patients experienced to the many proteins contained in the product.

The introduction in the late 1960s of freeze-dried factor concentrate – cryoprecipitate is fresh-frozen plasma – claimed to herald a new era in the treatment of hemophilia. The concentrates were more convenient than cryoprecipitate because hemophiliacs could store them at home in their refrigerators. Finally, hemophiliacs, many of whom felt isolated by their condition and castigated as feeble “sissies”, could presumably live normal lives: “It allowed hemophiliacs to work, attend school, travel, and participate in sports and other recreational activities... By 1980, the median life expectancy for severe hemophiliacs was near normal.”⁵⁶ This development in the treatment of hemophilia was not as positive as many had expected, however. The main problem stemmed from how the concentrate was manufactured. Because the process involved the pooling of thousands of units of fresh frozen plasma, there was a risk that one unit of infected plasma could contaminate the entire lot. Canadian hemophiliacs were particularly vulnerable in this regard, given their reliance on factor concentrate produced in the U.S. Almost half of the concentrate distributed in Canada was manufactured using the plasma of paid donors. Studies subsequently found higher levels of Hepatitis A and Hepatitis B infection in the blood of paid donors, including prisoners and low-income

⁵⁶ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 1, p. 166.

earners, than that obtained from volunteer donors.⁵⁷ The critique of the U.S. profit-driven blood industry reached a peak with the publication of Richard Titmuss's landmark study, *The Gift Relationship: From Human Blood to Social Policy*. In it the British sociologist compared the American and British systems, arguing that the latter's treatment of blood as a free community resource was far superior to the U.S. model:

... the commercialization of blood and donor relationships represses the expression of altruism, erodes the sense of community, lowers scientific standards, limits both personal and professional freedoms, sanctions the making of profits in hospitals and clinical laboratories, legalizes hostility between doctor and patient, subjects critical areas of medicine to the laws of the marketplace, places immense social costs on those least able to bear them – the poor, the sick and the inept – increases the danger of unethical behaviour in various sectors of medical science and practice, and results in situations in which proportionally more and more blood is supplied by the poor, the unskilled, the unemployed, Negroes, and other low income groups and categories of exploited human populations of high blood yielders. Redistribution in terms of blood and blood products from the poor to the rich appears to be one of the dominant effects of the American blood banking systems.⁵⁸

As Starr explains, the publication of *The Gift Relationship* coincided with a period in U.S. history during which Americans were asking tough questions about their role in the Vietnam War. The book's denunciation of the American approach to blood collection and distribution clearly struck a nerve in the country. And while government officials seemed to respond swiftly, promising that they would repair the problems and move toward a system of volunteer donors, the system was far more complex than they had

⁵⁷ See Richard Titmuss, *The Gift Relationship*, op. cit., Chapter 8.

⁵⁸ Richard Titmuss, *The Gift Relationship*, op. cit., pp. 245-246.

expected.

Evolving Knowledge of Hepatitis and AIDS

While a great deal of knowledge about Hepatitis was amassed during the first decade of the HIV/AIDS epidemic, the disease continued to elude the scientific and medical communities. Hepatitis was not a new disease, however, as epidemics of it had been traced back as far as the 18th century and possibly as early as the time of Hippocrates (4th century B.C.) There are documented reports of Hepatitis outbreaks as far back as 1883, when thousands of factory workers in Germany contracted it after being inoculated with small pox vaccine. One of the most serious outbreaks occurred in the period following World War II, when large quantities of pooled and dried serum had been used on the battlefield. The U.S. Army Medical Corps, for instance, found that a significant number of wounded soldiers who had received blood transfusions suffered from inflamed livers. In addition, they discovered that more than 30,000 American servicemen who had been vaccinated against yellow fever had contracted Hepatitis.

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 common to developing countries. Unlike the other strains, there are few recorded cases of the 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 the symptoms are often severe and long-lasting. While many “clear” the virus, for a time public health authorities became concerned with that sub section of individuals who had developed chronic hepatitis but remained symptom-free. Infection through blood transfusion became commonplace during the 1980s as many infected people donated blood, unaware that they carried the virus. Before a specific test for HIV was available, blood was tested for the presence of Hepatitis B, when 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.

This third strain was first reported in the medical literature in 1974. The following year, the National Institutes of Health in the U.S. confirmed that this new form of Hepatitis had contaminated the blood supply and that 7.5 per cent of heart surgery patients had contracted non-A, non-B hepatitis, twice the number who were infected with Hepatitis B. Like HBV, HCV can remain in the body for several years without appearing to cause infection. For this reason, the spread of Hepatitis C is often referred to in the popular media as the “silent epidemic”. A common treatment for Hepatitis C is interferon therapy, which in some cases helps patients to clear the virus. Recently, patients have been treated with a combination of interferon and ribavirin, an anti-viral drug.

Unlike Hepatitis, the history of AIDS is relatively short. The first cases were reported in the U.S. in 1978, followed a year later by the announcement in Canada of the first identified AIDS case in Windsor, Ontario. This “new” disease was identified initially as Gay-Related Immune Deficiency (GRID), much to the ire of gay rights organizations,

who feared that this would further stigmatize an already marginalized population. Having identified this new virus as a gay disease, it was only a short step to trying to find its 'Typhoid Mary'. It was not long before Gaetan Dugas, a gay flight attendant with Air Canada, became known as 'Patient Zero'.⁵⁹ The fact that Dugas travelled for a living, and that he was a self-professed "party animal" who regularly visited gay 'meccas' such as San Francisco and New York City, fuelled suggestions that he had infected dozens, if not hundreds, of gay men. There is still some dispute with regard to Dugas's causal role in bringing AIDS to North America, but it is widely believed that he did play a role. As the late Randy Shilts noted in one of the first, definitive accounts of AIDS in the U.S.:

"Whether Gaetan Dugas actually was the person who brought AIDS to North America remains a question of debate and is ultimately unanswerable. The fact that the first cases in both New York City and Los Angeles could be linked to Gaetan, who himself was one of the first half-dozen or so patients on the continent, gives weight to that theory."⁶⁰

But it was not long before researchers discovered that intravenous drug users in the New York City area were also coming down with pneumocystis carinii pneumonia (PCP), which was regarded as a common marker of HIV infection. Suddenly, the "gay" theory began to lose some credibility, as it became clear that this disease could also be transmitted through blood. By 1981, U.S. officials started investigating the first case of GRID in a heterosexual hemophiliac. Within six months, the U.S. Centers for Disease

⁵⁹ See Randy Shilts. 1987. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: St. Martin's Press.

⁶⁰ Randy Shilts. 1987. *And the Band Played On*, op. cit., p. 439.

Control reported a possible link between the blood products that such patients were using (Factor VIII concentrate) and this new, mystery disease. Armed with new information, U.S. officials agreed, in the summer of 1982, on a new name for the condition: Acquired Immunodeficiency Syndrome (AIDS).

By December 1982, Canadian officials realized also that this new blood-borne illness was not restricted to gay men. *Canada Diseases Weekly Report*, a publication of the federal government's Health and Welfare Canada, released a preliminary report showing that 70 per cent of hemophiliacs had compromised immune systems. Within months the first Canadian hemophiliac had died of AIDS. Despite the dire warnings from the U.S., where AIDS was fast becoming the leading killer of hemophiliacs, in early 1984 Health and Welfare Canada distributed 200,000 AIDS pamphlets saying the risk of contracting AIDS from blood was about one or two in one million.

A month later, Dr. Robert Gallo, of the U.S. National Institutes of Health, announced, amid much fanfare, that he and a team of researchers had identified the virus that causes AIDS. While there was some dispute regarding this claim – the Pasteur Institute in France had made a similar claim almost a year earlier – the news was greeted with giddy optimism in the U.S. One American government official gushed, "Today's discovery represents the triumph of science over a dreaded disease."⁶¹ Many soon realized, however, that isolating the virus was only a first step. By March of 1987, the

⁶¹ Quoted in André Picard. 1998 (first updated edition). *The Gift of Death: Confronting Canada's Tainted Blood Tragedy*. Toronto: HarperCollins Publishers, p. 66.

Food and Drug Administration announced that it had approved the use of the first drug to treat advanced cases of AIDS. The anti-viral drug, AZT, was not entirely new, however. In the 1960s, pharmaceutical giant Burroughs Wellcome first synthesized AZT as a potential cancer treatment, but the drug was soon shelved following concerns about its toxicity. Despite the doubts being raised about its potential side effects, all hopes were pinned on AIDS' "magic bullet."⁶² AZT remained the only approved anti-AIDS drug until 1990.

Testing for HIV, Hepatitis C in Canada: "We wait, they do nothing"

The 1980s was a period of intense activity in the scientific community, especially in relation to isolating HIV, the virus that is widely believed to cause AIDS. It also marked the beginning of government involvement in the AIDS domain. By the summer of 1982, eight cases of AIDS had been reported to the Health Protection Branch of the federal government. With the realization that three hemophiliacs in the U.S. were diagnosed with the same form of cancer that had been linked to a cluster of cases in homosexual men, the federal government struck a special committee in the fall of 1982 to study the risks of HIV transmission through blood. Almost two years later, the National Advisory Committee on AIDS was still reporting that the risk of contracting HIV from blood was extremely low. With much of the burgeoning discourse centered on the prevalence of HIV in homosexual men, the Canadian Red Cross Society (CRCS) decided

⁶² For an interesting discussion of the significance of AZT, see John Nguyet Erni. 1994. *Unstable Frontiers: Technomedicine and the Cultural Politics of "Curing" AIDS*. Minneapolis and London: University of Minnesota Press.

to launch a campaign urging members of high-risk groups (homosexuals with multiple partners, HIV positive people, Haitians⁶³, and intravenous drug users) to refrain from donating blood. In pamphlets and press releases, however, the CRCS adopted a less confrontational approach toward blood-donor collection, fearful that direct questioning of donors might expose the organization to human rights complaints from members of the high-risk groups.

Although Gallo officially isolated HIV in 1984, *The New England Journal of Medicine* had reported as early as 1983 that there was evidence that AIDS could be transmitted via blood from members of the so-called high-risk groups. By April of 1985, the first HIV-antibody test kit, which was developed in the U.S., was approved for sale in Canada. More than eight months of bureaucratic wrangling would pass, however, before Canadian blood donations would be screened for the presence of HIV.

Scientists also 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). Dr. Harvey Alter, of the U.S. National Institutes of Health, had 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 in Canada until 1990, but two “surrogate” (or substitute) tests had been available since 1974: one measured a liver enzyme while the other detected previous exposure to Hepatitis B. In 1986, when U.S. blood banks began using these surrogate

⁶³ Haitians were singled out because the country had high rates of infection among heterosexuals, especially young, “heterosexual” males who, because of economic necessity, took part in that country’s thriving gay sex trade with foreign tourists.

tests, the Canadian Red Cross and the federal government opted instead to study the tests' efficacy. During this time, it was estimated that in the U.S. about 100,000 people a year had contracted non-A, non-B hepatitis; Canadian estimates were roughly one-tenth of the American figure. Alter's advice fell on deaf ears in Canada, where the Red Cross urged caution and more evidence before implementing testing, just as it had done with respect to AIDS only years earlier. The U.S. began using surrogate testing in 1986, while Canada continued to insist that the costs of testing far outweighed the benefits.

Still, this as-yet-unnamed virus – identified for what it wasn't – paled in comparison with HIV, which was killing patients at an alarming rate. During this period, before the arrival of the life-saving drugs that have since prolonged the lives of people with AIDS, the road from HIV infection to full-blown AIDS was brutally short. And within that context many did not see Hepatitis C as a serious public health issue, including the blood system officials who testified before the Krever Inquiry. It seemed to belong to a second class of neglected diseases. Only recently has Hepatitis C begun to emerge as a public health concern affecting the health of all Canadians. The virus, for instance, has cut a swath through the injection-drug-using population of Vancouver's downtown East Side, where infection rates among injection drug users are as high as 88 per cent; in contrast, HIV infection rates are believed to be about 40 per cent.⁶⁴ Moreover, in some cases, patients have been found to be co-infected with Hepatitis C and HIV,

⁶⁴ Figures were taken from The Vancouver Injection Drug User Study (VIDUS) Update #2, September 1997, Vancouver, British Columbia.

which can frustrate treatment since the drugs used to combat HIV may worsen or counteract efforts to treat Hepatitis C. Bowing to pressure from Hepatitis C activists, the federal government announced in 1999 the creation of a research unit within Health Canada devoted solely to Hepatitis C research.

The Canadian Blood System

It would be an understatement to say that Canada's blood system is highly complex. Up until recently, it was composed of three main players: the Canadian Red Cross Society (CRCS), the Canadian Blood Agency (previously named the Canadian Blood Committee), and the Health Protection Branch of Health Canada. Since 1947, the CRCS has had a monopoly over the collection and distribution of whole blood in Canada. For more than a decade, it had operated the blood supply system without the involvement of federal or provincial governments. The CRCS simply collected blood from voluntary donors and provided it to hospitals and consumers free of charge. But with demand increasing for its services, the CRCS realized that it needed more financial support. Governments agreed, before long, to provide considerable public support for the CRCS's two programs, the blood transfusion service and blood donor recruitment. By the mid-

1970s, the provincial and federal governments collectively covered 100 per cent of the cost of the first program, and about 80 per cent of the second.⁶⁵

In the 1980s, the CRCS's role expanded further, with its move to the distribution of fractionated blood products. Reflecting nationalist sentiment that was growing in Canada vis-à-vis blood, the CRCS began a program to expand Canada's capacity to turn fresh-frozen plasma into concentrates through the process of fractionation. It soon became apparent, however, that the Canadian system still could not meet internally the demand for plasma and plasma derivatives, which justified CRCS's decision to continue to import plasma from the U.S. This would later prove deadly, as the plasma imported from the U.S. came from paid blood donors, some of whom were considered high risk for all manner of infection. Canada's voluntary blood collection system, it seemed, was anything but voluntary.

Up until 1991, the Canadian Blood Committee (CBC) administered the funding of the Canadian blood program on behalf of the provinces and territories. It was then replaced by a new body, the Canadian Blood Agency (CBA). Created as a "federal not-for-profit corporation with the power to enter contracts and borrow money,"⁶⁶ it was created to overcome some of the problems that had plagued the CBC. As Krever noted in his final report, the CBC had suffered from a lack of independence and had no corporate

⁶⁵ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 1, p. 47.

⁶⁶ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 1004.

existence of its own: "It could not enter into contracts with the Red Cross or other suppliers, borrow money, or make decisions about matters involving substantial amounts of money that would bind the governments it represented... As a result, major decisions required the approval of every major provincial and territorial government before they could be carried out."⁶⁷

Despite the promises and high hopes, Krever remarked that in some important respects the creation of a new blood agency did little to resolve the difficulties in the relationship between the two organizations. In fact, the lines of authority between the newly formed CBA and the CRCS remained blurred, despite the fact that the CBA had ultimate control over the CRCS budget. For instance, during the Inquiry hearings it was revealed that the CRCS had no intention to play by the Canadian Blood Agency's rules. Then Secretary-General of the Red Cross, Douglas Lindores was quoted as saying: "We [the Red Cross] will do the best we can to cooperate with the Canadian Blood Agency, but ... we do not consider ourselves bound by directives received from the Canadian Blood Agency."⁶⁸

At the Inquiry, witnesses also testified that the CBC approved the destruction of audiotapes and verbatim transcripts from meetings it held between 1982 and 1989. A subsequent investigation by Canada's Information Commissioner, John Grace, found that

⁶⁷ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 1004.

⁶⁸ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 1005.

the destruction of these records interfered with the public's right to know. The matter was then referred to the RCMP, which conducted a three-year investigation. The RCMP concluded that "certain elements required to support criminal charges against the committee or the employees of its secretariat are lacking."⁶⁹ Although the RCMP was able to confirm that the material had been destroyed, it was unable to determine "whether the destruction of these documents was done with any criminal intent."⁷⁰

Meanwhile, the regulatory authority over blood and blood products was vested in the third player, the federal government, through the Health Protection Branch of the Department of National Health and Welfare. In 1989, the Food and Drugs Act was amended to include blood and blood products. The Bureau of Biologics, which was part of the Health Protection Branch, regulated the sale and distribution of blood products. In particular, two divisions in the Bureau – the Blood Products Division and the Compliance Division – performed the regulatory function. The Blood Products Division was "responsible for reviewing new products submitted for approval, specifically blood products and drugs derived from blood. It also inspects blood centres, plasmapheresis⁷¹ centres, and manufacturers of blood products, and undertakes lot testing of blood

⁶⁹ Royal Canadian Mounted Police News Release, "No charges in destruction of Canadian Blood Committee Records," Feb. 26, 2001. Available at <http://www.rcmp-grc.gc.ca/html/nr-01-05.htm>

⁷⁰ Royal Canadian Mounted Police News Release, "No charges ...," Feb. 26, 2001.

⁷¹ Plasmapheresis is "a process in which only the donor's plasma is kept; the other blood components are injected back into the donor." Quoted in Picard, *The Gift of Death* (updated edition), op. cit., p. 277.

products.”⁷² The Compliance Division was “responsible for issuing licences and organizing inspection programs to ensure that manufacturers comply with acceptable standards.”⁷³

Systemic Problems in the Blood Supply

According to the Commission’s Final Report, not only was Canada’s blood system complex, it was extremely fragile, as well. The Report identified at least five systemic problems that contributed to the contamination of Canada’s blood supply in the 1980s: the dysfunctional relationship between the Red Cross and governments; delays in adopting preventive measures; failure to employ independent judgment; shortcomings of the operator of the system (the Red Cross); and the shortcomings of the regulator.

Regarding the first problem, there was no formal agreement or legislation pertaining to the “respective functions, authority, and accountability” of the parties involved in the supply of blood and blood products. This was especially pronounced in the relationship between the CRCS and the CBA. The CRCS, for one, questioned the authority of the CBA, which held the purse strings and hence the power to withdraw funding to the CRCS if it felt that the organization was being non-compliant. For its part, the CBA argued that its role was not limited to “financial stewardship”, but extended “to

⁷² *The Commission of Inquiry on the Blood System in Canada*, Interim Report, Ottawa: Minister of Supply and Services Canada, 1995, p. 7.

⁷³ *The Commission of Inquiry on the Blood System in Canada*, Interim Report, p. 7.

both direction and coordination of the blood system.”⁷⁴ But the authority of the CBA was never made clear. The CBA did not have a written contract with the CRCS, nor was there a formal contract to delegate authority from the provincial and territorial ministers of health. Given this absence, the CRCS did not accept the leadership of the CBA, nor did it believe it was bound by the directives issued by the CBA.

In addition, there was profound disagreement over the principles adopted by the CBA at a meeting of ministers of health in 1989. In particular, they sparred over the meaning of Principle 2, which encouraged national self-sufficiency in blood and plasma collections. The CRCS contended that this principle should be extended to include not only the collection of sufficient plasma for Canadian needs, but also the manufacture of fractionated products from that plasma in Canada. The CBA disagreed, maintaining that national self-sufficiency did not require a national processing and manufacturing capacity. Principles 4 and 6 also were of special importance. The former affirmed that the “safety of all blood components and plasma fractions should be paramount,” while the latter stressed cost-effectiveness and cost-efficiency. The CRCS questioned the wisdom of balancing costs against safety, since financial concerns could ultimately jeopardize the safety of the blood system.

The second systemic failure concerned the delay in adopting preventive measures that could have averted a national public health disaster. Krever noted that the principal actors in the blood supply system rejected a central tenet in the philosophy of public

⁷⁴ *The Commission of Inquiry on the Blood System in Canada*, Interim Report, p. 9.

health: "action to reduce risk should not await scientific certainty."⁷⁵ The Red Cross, he noted, failed to respond as vigorously or as promptly as it could have between 1983 and 1985 because "it did not fully accept that the risk of transfusion-associated AIDS existed until HIV had been discovered and had been shown to be the blood-borne pathogen that was causing AIDS."⁷⁶ Until the arrival of AIDS, it was well known that Hepatitis could be transmitted through blood transfusion. Although a test to screen for non-A, non-B Hepatitis did not exist until 1990, the U.S. chose in 1986 to introduce surrogate testing. While U.S. studies suggested that such testing "would probably reduce the rate of post-transfusion hepatitis significantly", Canadian officials wanted conclusive proof, which was not available at the time. In the absence of scientific proof, Canada chose to wait and study the efficacy of such tests. As Krever remarked, "public health has never clung to the principle that complete knowledge about a potential health hazard is a prerequisite for action."⁷⁷

The failure to employ preventive measures was also related to the manner in which officials estimated and disclosed the risk of transfusion- and infusion-associated AIDS as well as Hepatitis. Given the estimates that the risk of contracting AIDS from a transfusion was one or two in one million, it was perhaps not surprising that officials

⁷⁵ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 989.

⁷⁶ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 989.

⁷⁷ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 989.

were slow to respond. The Red Cross calculated this figure by dividing the number of transfused persons reported to have AIDS-like symptoms by the number of persons transfused. But, as Krever explained, the Red Cross ignored several factors, including the latency period associated with HIV infection during which infected persons do not exhibit any noticeable symptoms and the fact that new diseases are normally underreported. The true estimate for this period (1983) was about one in 10,000 per unit transfused, recognizing that most persons who are transfused received more than one unit. The same problems that prevented the Red Cross from accurately estimating the risk of transfusion-associated AIDS plagued the organization's response to the threat of infusion-associated AIDS, which refers to the infusion by hemophiliacs of factor concentrate that was made from large pools of plasma. It is now estimated that during the period when the Red Cross said infection was minimal, the true risk of exposure to HIV-contaminated lots of factor VIII concentrate was at least 65 per cent and, in some cases, 94 per cent.⁷⁸

The third problem was the failure to employ independent judgment. In the blood supply system, "a decision to reduce a risk can come from the manufacturer of a blood product, the operator of the system, or the regulator of the system."⁷⁹ In several instances, the failure to act independently resulted in needless suffering. For instance, when Connaught Laboratories notified the Bureau of Biologics and the Red Cross that it had

⁷⁸ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, pp. 991-2.

⁷⁹ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 994.

identified some Factor VIII concentrate that contained plasma from persons who had developed AIDS, the three organizations discussed the possibility of withdrawing the contaminated concentrates, but none took action to ensure that the concentrates were recalled.

Fourth, the operator of the blood system, the Red Cross, suffered from an internal structure that "was not conducive to sound and timely decision making."⁸⁰ For instance, its primary risk-reduction measure, asking donors from high-risk groups to refrain from donating blood, was poorly executed and failed to adequately educate the public. Part of the problem with introducing such a measure was the suggestion that the Red Cross, in isolating certain groups, was violating two of the principles of the International Red Cross, impartiality and neutrality.

The fifth problem concerned the Bureau of Biologics, the regulator of the blood supply system, which, among other things, lacked the resources needed to carry out its regulatory functions. For instance, it failed to carry out regular inspections of the Red Cross's plasmapheresis centres. In addition, Krever noted that the Bureau failed to act on important information provided by Connaught, the maker of Factor VIII concentrate. Connaught notified the bureau that between 1983 and 1984 some of the plasma that it used to make the concentrate came from the Irwin Memorial Blood Bank in San Francisco. It was known at the time that plasma from the California city carried a high

⁸⁰ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 994.

risk of contamination, so much so that even U.S. fractionators had stopped making factor concentrate from it.

The descriptive account of the blood system offered here is meant to provide the context within which to understand the blood activism that emerged in the time of the crisis. The conclusion will address some of the concrete changes made to the blood system as a result of the scandal, including the decision to strip the CRCS of many of its responsibilities, including that for the blood transfusion service.

Key Moments in the Canadian Scandal

In locating the starting point of the tainted-blood tragedy, it is possible to identify at least three important moments that are crucial for understanding the crisis and the subsequent emergence of blood activism: initial struggles for compensation (1987-1989); the Inquiry process (1993-1997); and the mobilization of people infected with Hepatitis C- tainted blood (1994-1999).

1987-1989: Initial Calls for Compensation

November 1987 marked a crucial date as it represented the first instance in which a request for compensation was made by the chairman of the Canadian Hemophilia Society's Task Force on AIDS. The call came on the heels of the release of what would later come to be known as the Archival Study, a damning report prepared for the Canadian Hemophilia Society which is widely considered the first serious, detailed examination of the tragedy. Three months later, the CHS put its request for compensation in writing to the Canadian Blood Committee, but the demand was ignored until the Royal

Society of Canada took up the case and urged the government to assist the recipients of tainted blood. Buoyed by these positive developments, the CHS stepped up its campaign by sending a formal document to the federal Minister of Health and Welfare, Jake Epp. The document urged the government "to respond swiftly and compassionately" by assisting infected hemophiliacs and their families:

One thousand Canadians with hemophilia have been infected with the human immunodeficiency virus (HIV) from the use of government approved medical treatment. Their lives and the lives of their families have been totally thrown into disarray even though most of them have not yet felt the full impact of this terrible virus. This is a horrendous medical catastrophe, a colossal failure of the country's blood system.⁸¹

The CHS requested a lump-sum payment of \$110,000 per person for all individuals infected by blood and blood products. It identified four ways in which the system had failed them:

There was no national blood policy, and on several occasions when products were at risk, there was no national agency willing to take emergency action;

There was substantial wastage of Factor VIII from Canadian plasma, resulting in increased dependence on American blood products during the critical years of HIV transmission;

There were delays in implementing measures to protect the Canadian blood supply against the transmission of HIV;

There were inadequate and incomplete efforts to recall potentially harmful products from distribution.⁸²

⁸¹ Canadian Hemophilia Society, "Hemophilia Catastrophe Relief: An Urgent Request to the Government of Canada," quoted in André Picard, *The Gift of Death* (updated edition), op. cit., p. 162.

⁸² Canadian Hemophilia Society, "Hemophilia Catastrophe Relief: An Urgent Request to the Government of Canada," op. cit., p. 163-4.

At this time the idea of a public inquiry was scarcely mentioned by the national office of the CHS, as it pushed for compensation in the hope that the parties could reach a deal in private. It was felt that this would allow the hemophilia community to keep hidden from public view any possible connection between AIDS and hemophilia. John Plater, a hemophilia activist from the Ontario chapter of the CHS, used the term "homophobia-phobia" to describe this fear.⁸³

In 1989, the federal government, which had rejected the idea of assistance for fear that it would imply wrongdoing, quietly acknowledged its role in contaminating the blood supply with HIV. (Hepatitis C was not mentioned.) Health Minister Perrin Beatty announced the terms of a carefully worded Extraordinary Assistance Plan (\$30,000 a year for four years) as compensation for inflicted harm. The decision came only six months after one of the largest gatherings of AIDS researchers in the world, the International Conference on AIDS, which was held in Montreal in June 1989. At the meeting, Prime Minister Brian Mulroney first spoke publicly about AIDS:

Having this illness neither diminishes people's humanity nor limits their rights. People are entitled to our respect as well as to our compassion. Shunning people with AIDS or attaching stigmas to the illness obscures the existence of AIDS when precisely the opposite is required... It is morally offensive, at the very least, to make persons with AIDS the outcasts of the twentieth century. It is also inhuman, the sort of blind ignorance which should make us thoroughly ashamed.⁸⁴

⁸³ Personal interview with John Plater, Toronto, August 31, 1999.

⁸⁴ Mulroney, quoted in André Picard, *The Gift of Death*, op. cit., p. 169.

However, not everyone at the conference was impressed with Mulroney's newfound concern for people with AIDS. As Mulroney spoke, a group of protesters from the radical AIDS action group, ACT UP, stood before the stage at which he was speaking with their backs turned to the speakers and their mouths gagged in a dramatic show of defiance. This new style of "in-your-face" activism, which had emerged in the 1970s during the height of the Vietnam War, was spreading to Canada. Local chapters of ACT UP had sprung up in various Canadian cities, including Montreal and Vancouver.

During the late 1980s, there was little discussion of the wisdom of offering only a four-year package to tainted-blood recipients infected with HIV. One suspects that was partly because it was presumed, given the limited scientific knowledge at the time, that the recipients would succumb to AIDS in a relatively short time, as other people with AIDS were doing. However, much to the surprise of the federal government, the majority of the recipients (655 out of a total of 976) were still alive four years later as the package was set to expire. And at that point, Janet Connors, then a little known wife of a Nova Scotia hemophiliac, began pressuring that province's health minister to pick up where the federal government package had left off. After several meetings with Janet and her husband Randy, Minister George Moody promised to try his best, but his appeals to his provincial and territorial counterparts, to reopen the compensation issue were unsuccessful. By April of 1992, Moody finally persuaded his province to go it alone. The Minister's decision, coupled with a preliminary report on tainted blood by the House of Commons Subcommittee on Health Issues, titled *Tragedy and Challenge: Canada's Blood System and HIV*, and mounting pressure from tainted-blood recipients, eventually

pushed the provinces and territories to reverse their original decision not to consider compensation. On September 15, 1993, a day before the Inquiry was to be formally announced, the details were made public of the Multi-Provincial-Territorial Assistance Program for people who acquired HIV through the blood system. Persons infected with HIV between 1978-1989 would receive a \$22,000 bonus for signing on to the plan, plus \$30,000 annually for life. Survivor benefits included \$20,000 per year for a spouse and \$4,000 per child for five years. But there was an important catch: the deadline to accept or reject the package was March 15, 1994; many speculated that this deadline was set to "force victims to decide if the program was adequate before there was a judgement issued in a civil suit and, more important, before Mr. Justice Horace Krever could make any recommendations."⁸⁵ In addition, the deal required that "victims" sign a waiver releasing the provinces, territories, the Canadian Red Cross Society, the Canadian Blood Agency, blood product manufacturers, hospitals, physicians, and their insurers of any liability. Against their better judgment, many chose to accept the deal since it meant short-term financial relief and the avoidance of lengthy, costly legal battles in court. As one victim testifying before the Inquiry said of the package: "I really question why it is called assistance when a seventeen-page waiver is required."⁸⁶

⁸⁵ André Picard, *The Gift of Death*, 1998, op. cit., p. 176.

⁸⁶ Testimony of Mr. and Mrs. Z at the *Commission of Inquiry on the Blood System in Canada*, Vol. 15A, Toronto, March 11, 1994. Quoted in Picard, *The Gift of Death*, 1995, op. cit., p. 236.

1993: Public Inquiry Ordered

Federal Health Minister Mary Collins ordered a public inquiry on Sept. 16, 1993.

The order-in-council that created the Inquiry appointed the commissioner

...to review and report on the mandate, organization, management, operations, financing and regulation of all activities of the blood system in Canada, including the events surrounding the contamination of the blood system in Canada in the early 1980s, by examining, without limiting the generality of the inquiry, the organization and effectiveness of past and current systems designed to supply blood and blood products in Canada; the roles, views, and ideas of relevant interest groups; and the structures and experiences of other countries, especially those with comparable federal systems.⁸⁷

The Inquiry began hearing testimony on February 14, 1994, Valentine's Day.

Although the House of Commons Sub Committee did officially call for its creation in May 1993, activists associated with the hemophilia community, in particular, stressed in interviews that they were instrumental, behind the scenes, in winning support for a public inquiry. Some of the activists noted that committee members essentially parroted activist demands made in private before the Committee: "We fed the committee members questions. We became specialists in feeding the information."⁸⁸

The Inquiry provided wide opportunities for citizen participation. Krever followed through on his publicly stated promise that anyone who was interested in testifying before

⁸⁷ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 1, p. 5.

⁸⁸ Personal interview with Durhane Wong-Rieger, former head of the Canadian Hemophilia Society, Ottawa, July 6, 1999.

the Inquiry would have the opportunity to do so. In addition, groups representing tainted-blood recipients also required legal representation if they were to take full advantage of the invitation to participate in the Inquiry. The newly formed Hepatitis C Society of Canada was granted intervener status at the Inquiry, but refused funding for legal counsel.

The Inquiry held 10 months of public hearings across the country during which 474 expert and lay witnesses presented testimony, some of which was highly charged and deeply emotional. The Inquiry's detailed, final report, which was released more than two years behind schedule, contained stinging criticism of many individuals charged with overseeing the safety of the blood system. In addition, and perhaps more important, Krever's unequivocal support for extending compensation to all people infected with tainted blood, regardless of the date of their infection, would help to fuel the compensation battles that later took shape over Hepatitis-C related infection. Specifically, Krever recommended that no-fault schemes be put in place "that compensate all blood-injured persons promptly and adequately, so that they do not suffer impoverishment or illness without treatment."⁸⁹

The Inquiry structure itself played a pivotal role in shaping the politics pursued by recipients of tainted blood. Specifically, I assert that the Inquiry suffered from an identity crisis of its own; it was unable to decide whether it was a "policy-oriented" inquiry concerned with public input or a "quasi-judicial" inquiry intent on uncovering the events that led to the tainted blood scandal. Indeed, the persistence with which Krever fought for

the right to name those individuals who were responsible for the decisions and non-decisions that occurred in the 1980s may have rightfully led some to conclude that he was more interested in laying blame or finding fault than in providing policy direction to the architects of a new blood supply system. Indeed, this claim was made by Douglas Lindores, the secretary general of the Canadian Red Cross during the Krever Inquiry. Lindores told an audience of policy specialists in 1997 that he was disappointed that the inquiry assumed the character of a criminal trial, adding that four factors may help to explain why this happened:

Diverse perspectives among the defendants. The defendants disagreed with each other on a number of important points. This heightened the adversarial character of the process, and made it look like each party was trying to blame the others, resulting in all parties looking guilty.

Intense media focus. Once individual tragedies came to light, the media spotlight focused on the inquiry, and the journalists involved became singularly focused on attributing blame. As a result, it became impossible to establish a constructive public dialogue on the future of the blood system. Complex issues were almost impossible to discuss in the extremely volatile public environment.

Complexity. Given the fact that many players within the blood system itself were unclear about its many divisions and layers of responsibility, the general public and media were unlikely to fully understand what went wrong and why. It was a situation ripe for the proliferation of inaccurate information.

Tension between federal and provincial governments. Throughout the inquiry's hearings, relations between the two levels of government were under strain. This made a constructive,

⁸⁹ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 3, p. 1045.

collaborative approach to the problem nearly impossible to achieve.⁹⁰

Lindores added that there was a disjuncture between accountability objectives and the investigative structures in place to achieve them. In particular, he argues that the Public Inquiries Act should be reviewed "to reflect recent experience and the modern reality of the six second media clip, both of which make it extremely difficult to sensibly discuss complex issues."⁹¹

The Inquiry was plagued by external strife, as well. First, Krever was under pressure from government to deliver his final report sooner rather than later; indeed, reports indicate that the Minister of Health at the time, David Dingwall, threatened to quash the Inquiry if it continued to stall delivery of its final report.⁹² Steadfast in his refusal to be bullied by government, Justice Krever issued his final report in November 1997, almost three years after its expected date of release. The three-volume report garnered praise from many organizations representing tainted blood recipients, some of which initially feared that the report would amount to nothing more than a "whitewash." As one activist recalled: "We felt at the time that Krever wasn't going to be tough

⁹⁰ Doug Lindores, quoted in The Exercise of Power Round Table, *In the Hot Seat: Commissions of Inquiry and Parliamentary Committees*, The Institute on Governance (Ottawa), Sept. 17, 1997, p. 3.

⁹¹ Doug Lindores, op. cit., p. 6. The suggestion that the Inquiries Act be reformed is not new, however. For earlier criticisms, see The Alberta Law Reform Institute, *Proposals for the Reform of the Public Inquiries Act*, Report No. 62, November 1992.

⁹² Former Federal Health Minister David Dingwall angrily dismissed this allegation in a personal interview as "absolute horseshit." (Personal interview, Ottawa, August 11, 1999)

enough. He kept calling it 'my' inquiry. We were quite afraid. We were truly astonished [when the Final Report was released]. It was as strong as we could have wished for."⁹³

Following the release of the report, the Canadian Hemophilia Society send a letter to the RCMP detailing what it viewed as four main areas of failure:

The decision not to introduce surrogate testing for the hepatitis C virus between 1986 and 1990. In his report, Judge Krever said that failure led to the infection of 28,600 Canadians, and that 85 percent of those cases were preventable.

Delays in introducing testing for HIV in the blood supply. A test was available on March 2, 1985, but universal testing was not in place until November 1 of that year. The report concluded that at least 133 people contracted the AIDS virus in that period.

Delays in the introduction of concentrates that were heat-treated. A decision was made in November 1984 to switch to the safer product, but it was not completed until July 1985. Judge Krever concluded that the inventory of unheated products was deliberately exhausted and, had blood system officials acted promptly, 'some of the hemophiliacs would have avoided being infected.'

Continued use of heat-treated products as late as 1987, after this method had been proved ineffective. After the belated switch to heat-treated concentrate, questions remained about the efficacy of heating methods to kill the virus; that, coupled, with the fact that manufacturers continued to use plasma that was not tested for the AIDS virus, led to the infection of a number of other hemophiliacs in 1986-1987, after the products were declared free of HIV.⁹⁴

⁹³ Personal interview with Durhane Wong-Rieger, Ottawa, July 6, 1999.

⁹⁴ Quoted in André Picard, *The Gift of Death*, 1998, op. cit., pp. 250-251.

1993-1999: The Mobilization of Tainted-Blood Recipients

Let's face it. The victims are a soccer ball right now. We're being kicked around by the feds and the provinces. It's like a boys' game. But this isn't a game. This is about people's lives.

- Jeremy Beaty, President, Hepatitis C Society of Canada⁹⁵

I used the term “blood activism” to describe the range of collective challenges that emerged in the wake of the scandal, including those from tainted-blood recipients infected with HIV/AIDS and those with Hepatitis C. This is not to suggest, however, that recipients were silent prior to the start of the Inquiry; in fact, as I discuss later, recipients played an important role in the first battle for compensation (1987-1989) and in pressing for an inquiry in the first place. It was during the Inquiry, and following it, however, that “blood activism” blossomed to include not only a select few group leaders attempting to broker deals behind closed doors, but a broader assortment of tainted-blood recipients. In particular, a group of individuals less accustomed to collective protest began to enter the fray.⁹⁶ Of this group of activists, Durhane Wong-Rieger of the Canadian Hemophilia Society said, “I think you’re talking about a different breed of people. These were not people who started out as activists. These are people who because of some accident to them were forced into this position. They were people, for the most part, who used to be

⁹⁵ Quoted in “Health ministers head for ‘showdown,’ *Ottawa Citizen*, Sept. 16, 1998.

⁹⁶ One term that was used to describe people such as Janet Connors was “accidental activist”. One should stress, however, that activists did not view what happened as an “accident.”

nice in life.”⁹⁷ Like their predecessors in the AIDS movement, some of the activists associated with tainted blood activism, especially those with Hepatitis C, had little knowledge of the complex medical issues related to blood and blood products. They recognized that if they were to become effective advocates, they had to become well versed in the language of medicine and science. Among this group of fledgling blood activists, only members of the tightly knit community of hemophiliacs could claim prior knowledge of some of these issues.

The organizations granted standing at the Krever Inquiry included: the Canadian Hemophilia Society, the Canadian AIDS Society, Canadian Hemophiliacs Infected with HIV, HIV-T Group (Blood Transfused), The Hepatitis C Group of Transfusion Recipients and Hemophiliacs, The Hepatitis C Society of Canada, and the Committee of HIV Affected and Transmitted. In addition, as stressed by social movement theorists, I include those persons not affiliated with any particular group or organization, but nonetheless political actors in their own right. For instance, many activists cited Nova Scotia’s Janet Conners, who tirelessly advocated on the provincial stage for spouses and children affected by and infected with tainted blood but refused to be aligned with an organization, as an inspiration.⁹⁸ What follows is a brief sketch of some of these organizations.

⁹⁷ Personal interview, Ottawa, July 1999. This was confirmed during interviews with some of these “accidental activists”, such as Nova Scotia’s Janet Conners, whose husband Randy became a national symbol of the devastation caused by the scandal. Another Hepatitis C activist, whose son contracted the virus during surgery, said in an interview: “I’m just a mom who got really angry.” (Personal interview with Leslie Gibbenhuck, Victoria, B.C., July 16, 1999)

⁹⁸ A chapter on the comparative politics of tainted blood in *Blood Feuds* credits Janet Conners and her husband Randy with single-handedly pushing the issue of compensation onto the national

The Canadian Hemophilia Society

Formed in 1953 by Frank Schnabel, dubbed by members of the community as "Mr. Hemophilia," the organization has expanded considerably from its modest beginnings. Its initial focus was on educating the hemophilia community and on encouraging governments and the medical community to provide the necessary infrastructure for hemophilia research. In what many considered a bold move at the time, Schnabel began to publicly criticize the Red Cross in the 1960s, urging that it be stripped of its monopoly over the blood business. He also issued repeated calls that governments begin to participate in the blood transfusion business in Canada, which would eventually lead to the announcement in 1973 that provincial and federal health ministers would set up a committee to oversee the blood program. In the 1970s, the group pressured governments to establish comprehensive-care clinics for hemophiliacs, similar to ones created in the U.S. This "one-stop shopping" approach would centralize the care and treatment of hemophilia in one physical space. By the early 1980s, the organization had succeeded, with the creation of at least one such centre in virtually every province.

Although it had been in existence almost 25 years at the time, the CHS was formally incorporated in 1977 as a voluntary service organization with the purpose of helping hemophiliacs in every way possible. Its objectives ranged from raising awareness to encouraging research to securing blood and blood products for hemophiliacs.

stage. See Norbert Gilmore and Margaret A. Somerville, "From Trust to Tragedy: HIV/AIDS and the Canadian Blood System," pp. 127-160, in *Blood Feuds*, op. cit.

Membership in the society is open to family members and friends of hemophiliacs. Its governing structure is fairly traditional, with an executive committee and a board of directors, the majority of whom are volunteers. In addition, it has a blood resources committee, which deals with issues of safety in blood products, and a medical and scientific advisory committee, which provides expert assistance and counsel on matters pertaining to the care of hemophiliacs. Members of the blood resources committee are mainly lay persons, while the latter committee is made up primarily of medical professionals.

By many accounts, 1987 marked a critical period in the radicalization of the hemophilia community. The realization that almost half of Canada's hemophiliacs were infected with HIV, combined with the death of Schnabel that same year, galvanized many in the community, and forced the CHS to abandon two of its main projects to focus on the issue of compensation. One of the main weapons in its arsenal was what later came to be known as the Archival Study, one of the first accounts of negligence in relation to tainted blood prepared by members of the group. Despite some initial reluctance from the organization's national office, the Ontario chapter of the CHS was among the first to call for a formal public inquiry.

Although the CHS was founded as an organization for hemophiliacs, it soon became clear during the Inquiry that it wished to speak for all recipients of tainted blood, including people who contracted Hepatitis C and HIV from transfusions. This provoked bitter infighting among members of the tainted-blood community, and resulted in the creation of new organizations to represent recipients of HIV-tainted transfusions and

persons with Hepatitis C. While some have criticized CHS leaders for trying to maintain a monopoly on blood issues, it is clear that for some time it was indeed the only national lay organization directly involved, through its seat on the advisory subcommittee of the Canadian Blood Committee, in the blood system.

The Canadian AIDS Society

The Canadian AIDS Society is a national umbrella organization representing more than 100 community based organizations throughout the country. Officially formed in 1988 following the first-ever meeting of AIDS community groups in Montreal, CAS remains the primary national voice for AIDS community organizations. Although it represents all people with HIV/AIDS in Canada, and it has made considerable inroads in dealing with minority communities, it remains, first and foremost, a gay-run organization. The organization was instrumental in pushing the federal government to create a National AIDS Strategy in 1990, and in rallying its member groups to ensure that the Strategy not be cancelled (as the federal government was hinting in 1996). The federal government eventually backed down, and renewed its commitment to fighting AIDS.

CAS's lawyer at the Inquiry, Douglas Elliott, stressed in an interview that CAS was initially reluctant to get involved in blood-related issues, fearing that it would be trespassing on CHS territory, but felt that its presence was necessary to ensure that the story of AIDS in the early 1980s not be portrayed solely by the CHS.⁹⁹ In addition, CAS

⁹⁹ Personal interview with Douglas Elliott, a lawyer representing the Canadian AIDS Society at the Inquiry, Toronto, Sept. 1, 1999.

was concerned about the “innocent victim” slant of other AIDS stakeholders, namely the hemophilia community. While relations between the CHS and the Canadian AIDS Society were previously “civil”, their sharp differences erupted in 1994 in a public battle over the notification of infected blood donors. Both groups fought the issue up the Ontario courts. CAS tried, albeit unsuccessfully, to prevent the Red Cross from providing to government health officials the names of all HIV-positive donors found while testing 175,000 blood samples that were collected before an AIDS test became available. CHS believed that the benefits of identifying the donors far superseded the question of whether consent had been obtained. The Ontario court ruled against the Canadian AIDS Society, arguing that HIV-positive donors did not have a privacy interest that was protected by the Canadian Charter of Rights and Freedoms.¹⁰⁰ As the former executive director of the CAS explained in an interview, the groups clashed over a fundamental philosophical issue, namely the proper role of the state. “They were saying ‘we’re innocent victims, we don’t deserve this.’ The whole compensation issue comes from their idea that the state should protect them. We have different expectations of what the state should do.”¹⁰¹

¹⁰⁰ Judge Carruthers argued that the Canadian AIDS Society did not satisfy the court that the Red Cross “fell within the concept of ‘government’ as defined in the Charter. See Ralf Jurgens, “Ontario Court Rules on Notification of Blood Donors,” *Canadian HIV/AIDS Policy and Law Newsletter*, Issue 1, Number 2.

¹⁰¹ Personal interview with Russell Armstrong, former Executive Director of the Canadian AIDS Society, May 28, 1997.

HIV-T Group (Blood Transfused)

Formed in Toronto in 1991 by Jerald Freise, whose wife Marlene was infected when she received a transfusion to treat her anemia, this organization focused its efforts on 'look-back' and 'trace-back' for transfusion recipients. Look-back involves identifying the recipients of blood components from donors who were HIV positive. The trace-back process involves identifying the donations that caused the HIV infection of recipients of blood components. Unlike hemophiliacs, who had been tested for HIV, transfusees had not been notified of whether they had received HIV-infected blood. One survey of the group's members found that only 5 of 41 people had been contacted as a result of a look back or trace back.¹⁰²

In one particularly gripping case recounted by Picard, a couple discovered that their newborn baby boy was injected with a small amount of blood when he was three weeks old "to put colour in his cheeks."¹⁰³ The family had never consented to the transfusion, which infected their child with HIV. It was later discovered that the blood had come from a gay man who had made more than 75 donations.

In 1992, founding members of the organization also testified before the House of Commons Subcommittee on Health Issues that conducted a preliminary examination of tainted blood. Members also testified before the Krever Inquiry, including Gabriel and

¹⁰² André Picard. 1995. *The Gift of Death*, op. cit., p.155-156.

¹⁰³ André Picard. 1995. *The Gift of Death*, op. cit., p. 236.

Lynn Kampf. Lynn, a nurse, found out only in 1993 that she had been infected more than a decade earlier during treatment for an ectopic pregnancy. "It was a real shocker for her," Kampf explained in an interview. "She had been working in the field for 10 years as a pediatric nurse."¹⁰⁴ To make matters worse, he said, once the diagnosis was confirmed, they discovered that help was not forthcoming. "We didn't even get a call from public health. You were left on your own to bob in the sea. It was a desert in terms of emotional support [until we joined the group]."¹⁰⁵

In 1994, the HIV-T Group raised the possibility that frozen blood samples might be contaminated with HIV, a move that led the City of Toronto Public Health Board to insist that the Red Cross test 150,000 samples. The testing identified 11 HIV-infected people. The HIV-T Group is best known, perhaps, for its criticism of Krever himself. Jerald Freise held a news conference at which he asked Krever to resign, citing possible conflict of interest stemming from Krever's previous work with the Royal Society of Canada. Kampf said he's "still not sure who Krever was really working for. He took some actions that were very promising. But he also shut down whole other avenues of investigation. He never called on a federal or provincial minister to testify, as the Walkerton Inquiry did."¹⁰⁶

¹⁰⁴ Personal interview with Gabriel Kampf, July 2001.

¹⁰⁵ Personal interview with Gabriel Kampf, July 2001.

¹⁰⁶ Personal interview with Gabriel Kampf, July 2001. Walkerton is the Ontario community where seven people died as a result of contaminated water.

Hepatitis C Society of Canada

People with Hepatitis C were the last group of tainted-blood recipients to organize politically. Founded by a small group in Toronto led by former sociology professor Alan Powell, the Hepatitis C Society of Canada began in 1994 under the banner of the Canadian Alliance of Transfused Hepatitis C Survivors. It changed its name to the Hepatitis C Survivors Society in 1995 before assuming its present name and expanded mandate shortly thereafter. While its first objective was to provide all manner of assistance to people with Hepatitis C and their families (whether infected through tainted blood or not), the organization soon became overwhelmed by the compensation issue. With a national office in Toronto, the organization has some 21 chapters throughout the country, although in recent years relations between the national organization and some of these chapters have been acrimonious. In fact, a previously active chapter in Victoria, B.C. recently severed ties with the organization, complaining publicly that the national office was providing little guidance and resources. In addition, two active members publicly resigned from the national office's Board in 1996, arguing that the organization had sold out those persons infected before 1986 and after 1990. The two members were particularly angered, not to mention puzzled, by the national office's desire to retain the legal counsel of Marlys Edwardh, who worked as commission co-counsel for the Krever Inquiry and who had previously worked on two public inquiries: the Royal Commission on Donald Marshall Jr. and the inquiry into the conduct of former industry minister Sinclair Stevens. In a letter to the Society, Edwardh indicated that she would not support

attempts to fight for fault-based compensation, which some members argued was the proper avenue to pursue.

Although informal networks of Hepatitis C recipients were beginning to develop by 1994, the media were slow to respond to the possibility that there was more to the tainted-blood scandal than HIV. One of the first reporters to take the Hepatitis C issue seriously was Brad Evenson, an *Ottawa Citizen* reporter who wrote a feature-length article in September 1993 on the “forgotten victims” of tainted blood.¹⁰⁷ It would take several months before other journalists responded to the story with investigations of their own. The Inquiry would prove to be a fortuitous arena for legitimizing the concerns of people with Hepatitis C. In particular, the testimony of Étienne Saumure, of Gatineau, Quebec, and the work of his tenacious lawyer, Pierre Lavigne, helped to put a sympathetic face on the plight of people with Hepatitis C. Saumure, one of eight sons, seven of whom had hemophilia, told the Inquiry a heartwrenching story of life as a hemophiliac with Hepatitis C. “I got rotten blood,” he said, “but I got the wrong disease.”¹⁰⁸ Saumure told the Inquiry how his once-successful roofing business collapsed, and how the cost of treatment for Hepatitis C placed his family on the brink of financial disaster. Saumure also pleaded with the Health Minister at the time, Diane Marleau, to show compassion to people with Hepatitis C. The Minister did not appear to take

¹⁰⁷ See Brad Evenson, “The forgotten ones: Focus on AIDS victims of blood transfusions ignores other sufferers,” *The Ottawa Citizen*, Sept. 17, 1993, p. A1.

¹⁰⁸ Quoted in Mark Kennedy, “Letter to the Red Cross: Tainted blood left a Halifax woman with hepatitis C and a legal fight against those in charge,” *The Ottawa Citizen*, Oct. 20, 1997, p. A3.

Hepatitis C seriously. In particular, she had made some flip comments in the House of Commons that angered people with Hepatitis C:

Mr. Pierre de Savoye (Portneuf): Mr. Speaker, my question is for the Minister of Health. The Krever commission has already been sitting for six months and will probably be sitting for a while yet. In the meantime, the life of some Canadians is in danger. Again, I ask the minister: What does she intend to do to warn those who are in good health?

Hon. Diane Marleau (Minister of Health): Mr. Speaker, I am very pleased to speak about people who enjoy good health. I do not think that they need to be told they are in good health. The hon. member's question is truly extraordinary, but I understand that he may have misspoken. Let me reassure you by saying that we take a real interest in this issue. However, as I said before in this House, it must be understood that medical treatments always involve some risks. Nothing is 100 per cent sure. It goes without saying that if people think they are suffering from side-effects, they should see a doctor. This is my opinion. In the meantime, we are interested in hearing what Mr. Justice Krever will have to say about these blood transfusions and their recipients...

Mr. Pierre de Savoye (Portneuf): Mr. Speaker, does the minister realize that some people will die while she just sits and waits for the findings of the Krever commission? Will the minister do something to save these people? After all, their life is in danger.

Hon. Diane Marleau (Minister of Health): Mr. Speaker, let us not get carried away! People have good reason to feel rather safe. If one have (sic) problems, one goes to see a doctor. We can get very good treatment in this country. Hepatitis C is not AIDS. Let us be reasonable, Mr. Speaker.¹⁰⁹

Gradually, the media began to take the issue seriously, and people with Hepatitis C began to take their place alongside other recipients of tainted blood. People with

¹⁰⁹ Hansard, debate in the House of Commons, May 26, 1994. Available electronically at: http://www.parl.gc.ca/english/hansard/previous/072_94-05-26/072OQ1E.html#4468 Marleau later apologized for these comments in a personal letter to Saumure.

Hepatitis C also received some support from the Canadian Hemophilia Society, with whom they would later clash. The former president of the CHS recalled that the mere mention of Hepatitis C surprised many in attendance at the Inquiry hearings:

At the time of the Inquiry, nobody knew about Hep C. It was a funny scenario. We all looked truly puzzled. I can remember sitting at the Inquiry and seeing a young Hep C guy from Quebec (Saumure). His brother had HIV and was getting compensation. He had Hep C, and he was getting nothing. I remember thinking, "What is Hep C doing here?" We were thinking HIV. I give Krever a lot of credit for giving him standing (at the Inquiry). That's how Hep C got into the inquiry.¹¹⁰

The CHS then began to search for information on the extent of Hepatitis C contamination. In late 1994, Wong-Rieger was in Edmonton when she received a Hepatitis C study conducted by the Red Cross that her group had requested through the federal Access to Information Act. "I started to read it and said, 'Oh my God!' It suddenly became clear that we had a second epidemic."¹¹¹ The CHS subsequently released the results of the study to selected media outlets, including *The Globe and Mail* and CBC Radio. The move incensed Krever, who later castigated the group publicly for trying to subvert the Inquiry process.

Fearing that Saumure's lawyer was attempting to steal the limelight and that the CHS was trying to subsume Hepatitis C recipients into an organization founded primarily for people with hemophilia, Hepatitis C recipients organized to form their own national support group. Within months, local chapters of the organization had been set up in major

¹¹⁰ Personal interview with Durhane Wong-Rieger, Ottawa, July 6, 1999.

¹¹¹ Personal interview with Durhane Wong-Rieger, Ottawa, July 6, 1999.

Canadian cities. While the group's leaders decried the Inquiry's refusal to grant it intervenor funding to cover the costs of legal counsel, recipients of Hepatitis C- tainted blood would soon become political actors in their own right, appearing in newspaper interviews and on television news broadcasts. Group members were permitted to cross-examine witnesses, present testimony, and otherwise exert themselves and their newfound identity on the political stage.

While advocates for people with Hepatitis C were working tirelessly behind the scenes to secure compensation for them, by the fall of 1996 activists began to stage noisy, albeit intermittent, protests to back their demands. Getting people with Hepatitis C to come out to protest, however, would prove difficult for at least three reasons. First, some patients were experiencing declining health, and could barely muster the energy to stage a noisy rally. Second, others feared coming out publicly and risk the stigma associated with this disease; many had tried to keep their condition hidden from family and friends. Third, many people with Hepatitis C were new to activism, unlike their counterparts in the AIDS movement who had cut their activist teeth in the gay rights movement.

One of the first Hepatitis C protests on Parliament Hill in October of that year barely caused a political ripple. By the summer of 1997, however, it seemed that their efforts might pay off when Health Minister Allan Rock announced for the first time that compensation might be extended to people with Hepatitis C. When word began to spread that Krever's long-awaited report might urge governments to compensate all tainted-blood recipients, Hepatitis C activists recognized it was time to step up their protests. As

expected by some and feared by others, Krever's final report called on governments to assist all recipients. By the beginning of 1998, federal and provincial health ministers met again to consider the Hepatitis C compensation issue. In what some saw as a minor breakthrough, the government announced in March of 1998 that it and the provinces and territories had agreed to a \$1.1 billion compensation plan, but that it would be restricted to recipients infected between 1986 and 1990. The decision to shut out recipients not infected during this time period launched the Hepatitis C community's most prolonged flurry of protest activity. Demonstrations were organized, media outlets contacted – activists had finally succeeded in focusing media attention on the fairness of compensation for some, but not for others. After some initial difficulty in rousing opposition political parties, activists were able to organize another protest on Parliament Hill, with representatives of all federal opposition parties in tow. Soon after, Hepatitis C activists, now secure in their belief that they had managed to win the support of opposition parties and of enough Liberal Party dissidents, called for a free vote in the House of Commons on the compensation package. Jean Chrétien rejected the call, and warned the party faithful that a vote against the limited package could have negative repercussions on them. One week later, the House of Commons rejected the Reform Party-led motion to extend compensation, 155 to 140. A tearful Carolyn Bennett, Liberal MP and former board member of the Hepatitis C Society, voted against the motion.

Conclusion

This chapter has elaborated some of the historical and cultural dimensions of blood as a means to contextualize the issues that would emerge to the fore in battles between activists and the state. It was followed by a more detailed consideration of the distinctive features of the Canadian blood system, and how they led to the contamination of the blood supply. Without a doubt, the strongest criticism of the blood system was the lack of a coherent, national blood supply operator. Finally, the last section highlighted three moments in the scandal that serve as guideposts in understanding the emergence of blood activism. Having laid out some of these details, it is now necessary to outline the theoretical framework that will be used to guide us through the case.

CHAPTER 3

Social Movement Theory as a Framework

This chapter explains and justifies the use of social movement theory as an appropriate lens through which to examine blood activism in general and Hepatitis C activism in particular. The blood movement was characterized by its diverse grouping of sophisticated advocacy organizations, grassroots activists, and tainted-blood recipients, many of whom had little or no experience with organized political activity. Within that context, the movement participants combined institutional, rule-conforming activity with more informal, non-institutional activity. In short, they worked with the system, playing by the institutional rules of the game, at the same time as they worked on the system from outside of those rules. And, as the intensity of the scandal grew, we witnessed an increasing reliance on non-institutionalized forms of political activity.

Social movement theory is appropriate for analyzing this process because it allows us to explore three important lines of inquiry that anchor this study: the role of the political opportunity structure; the formation of collective identity and agency; and the nature of political action/outcomes. Social movement theory is, of course, not the only framework within which to evaluate blood activism. This dissertation could have used an interest-group, or pluralist, approach to examine these issues, and the first part of this chapter will outline some of the shortcomings of this approach when it is applied to the case at hand. The chapter then discusses the concept of a social movement, and explains why the recipients of tainted blood should be regarded as a social movement. This is followed by a discussion of the two main strands of social movement theory, and why

aspects of each approach are central to this study. The next section discusses in greater theoretical detail the three elements just identified, and emphasizes that they are inextricably linked. In other words, it demonstrates that an elaboration of the political opportunity structure can help to 'explain' movement strategy, even though that structure is not static or immutable but may be altered or reconfigured as a result of both strategy and identity. Indeed, one of the strengths of the political opportunity structure approach is its recognition that while the POS may influence movement strategies and outcomes, collective action may also alter the POS. The latter is especially critical if we wish to look at the impact of specific opportunity structures on future movements. These relationships, in turn, are ultimately the focus for understanding movement outcomes.

The Shortcomings of an Interest Group Approach

Interest-group approaches are based on a pluralist view of society and political life. Pluralists believe that the political system is a dynamic container of activity in which groups spring up almost as quickly as others disappear. While pluralists accept that some changes may advance one interest at the expense of another, they argue that society naturally produces groups to champion an interest that may be disadvantaged by a recent change. The resulting equilibrium is the byproduct of healthy competition between established groups and newly emerging ones. Steven Lukes, among others, has criticized this approach as being "one dimensional" because it examines only actual, observable conflict.¹¹² It wrongly presumes, he says, that conflict must be observable to be

¹¹² See Steven Lukes. 1973. *Power: A Radical View*. London: Macmillan.

legitimate. What about interests that may not be openly articulated, or that may be difficult to observe? What about people who may be unaware of their interests? Robert Dahl, who symbolizes an empiricist-pluralist view, focuses on the study of actual, observable decision-making processes to determine how power is exercised.¹¹³ In studying decision-making, Dahl presumes that there is disagreement or conflict among two or more groups with respect to preferences that are consciously made and exhibited in actions, and that can be captured by observing people's behaviour. This view rests on the belief that interests are exhibited as policy preferences – so that a conflict of interests is little more than a conflict of preferences.

Some critics of pluralism have attempted to demonstrate that such a model of democracy can be anti-democratic because the so-called natural dynamism of any political system does not ensure the equal representation of all interests. According to this view, systems are not as politically penetrable as pluralists suggest, because their penetrability is compromised by the capacity of office holders to ignore policy options that are known to be disliked by political and economic elites, or to prevent such options, or issues, from ever reaching the public agenda.¹¹⁴ In this vein, critics such as Theodore

¹¹³ See Robert A. Dahl. 1961. *Who Governs?* New Haven: Conn.: Yale University Press.

¹¹⁴ Two influential critics of this one-dimensional approach offered by the pluralists are P. Bachrach and M. Baratz. See their classic articles, "Two Faces of Power," *American Political Science Review* 56 (1962) 4, 947-952, and "Decisions and Non Decisions: An Analytical Framework," *American Political Science Review* 57 (1963), 632-642. In the U.S., Theodore Lowi has been a vocal critic of the pluralist approach, especially in his *The End of Liberalism* (New York: Norton, 1979). E.E. Schattschneider's *The Semisovereign People* (Hinsdale, Ill.: Dryden Press, 1975), also stands out among the post-pluralist literature.

Lowi have argued that powerful interests in the U.S. have learned how to manipulate the democratic system. According to him, the American political system is no match for the “functionally oriented administrative units” within government, the growing specialization within the bureaucracy, and their “affiliates,” the increasingly powerful interest groups.¹¹⁵ This post-pluralist view focuses attention on the changing relations between groups and key government officials. Group politics is not seen as a dynamic arena in which opportunities to influence abound, but as a relatively closed system dominated by tightly knit alliances between key legislators, influential groups, and the leaders of government agencies. Group politics is therefore a vehicle for limiting, not expanding real political competition. Groups may do this by controlling what and who gets on the agenda, or by limiting the range of possible alternatives. In this process, organized interests are instrumental in defining issues and alternatives because they – unlike political parties or the media – often have a virtual monopoly on specialized knowledge. Schattschneider, for instance, identified four factors that help to explain why organized interests are successful in articulating some issues rather than others. First, not all interests in society are represented. Second, the groups who speak for them represent not all elements of specific interest communities. Third, the leaders of interest organization are often a part of the affluent class, and may steer debate or discussion on issues of concern to them personally. Fourth, in these types of systems, some groups enjoy greater influence than others because they can command substantial resources to a

¹¹⁵ Lowi, as discussed in A. Paul Pross. 1992. *Group Politics and Public Policy*. Toronto: Oxford University Press, p. 231.

given issue or cause.¹¹⁶ So, not surprisingly, the management of conflict is only a small part of politics.

In the Canadian literature on group politics, a number of factors – namely the structure of federalism, the media, and the particular policy field in which groups operate – are often summoned to explain the outcomes of pressure-group activity in the policy-making arena. Pross reserves the term “pressure groups” for so-called “formal” interest groups, although the precise meaning of “formal” is not always clear. Solidary groups and latent interests are also “interests” in the policy process, he notes, but their influence is less discernible.¹¹⁷ Generally, pressure groups are defined as “organizations whose members act together to influence public policy in order to protect their common interest.”¹¹⁸ Pross also distinguishes *institutional* from *issue-oriented* groups. Institutional groups, he argues, succeed mainly because of their organizational strength and the seemingly unlimited resources at their disposal. This allows them to acquire an extensive knowledge of those sectors of government that affect them and their clients. The “institutionalized interest emphasizes organizational goals above those of its individual members.”¹¹⁹ Coleman suggests that institutional groups, namely those representing

¹¹⁶ Schattschneider, as discussed in A. Paul Pross, *Group Politics and Public Policy*, op. cit., p. 233-235.

¹¹⁷ A. Paul Pross, *Group Politics and Public Policy*, op. cit., p. 6.

¹¹⁸ A. Paul Pross, “Pressure Groups: Talking Chameleons,” pp. 252-253. In Michael S. Whittington and Glen Williams (eds). 1995. *Canadian Politics in the 1990s*. Scarborough, Ont.: Nelson Canada..

¹¹⁹ A. Paul Pross, “Pressure Groups: Talking Chameleons,” op. cit., p. 260.

business interests, exert a disproportionate influence on policy outcomes.¹²⁰ The institutional approach to interest groups overstates the significance of structure to political action, while neglecting other important factors such as participants' perceptions of political activity, the influence of political culture, and identity formation as a precursor to action.

In Canada, post pluralist approaches to group politics are represented by the literature on policy communities. The term is meant to capture groupings of government agencies, pressure or interest groups, media representatives, and individuals who have an interest in a particular policy field and attempt to influence it. Most communities include two segments: the subgovernment and the attentive public. The subgovernment is the policy-making body in the field, the so-called 'inner circle' that can use its power to limit the participation of others in policy debate. The latter, which is loosely knit, has an ever-changing membership and thus a considerably weaker influence on policy. Pross suggests that the main strength of the attentive public is that it fosters the appearance of openness and citizen involvement in policy issues and, although it lacks the power of the subgovernment, it maintains a "perpetual policy review process."¹²¹ While members of the attentive public are not consulted regularly, they nonetheless can play an important role in policy development.

¹²⁰ See William D. Coleman. 1988. *Business and Politics: A Study of Collective Action*. Montreal: McGill-Queen's University Press.

¹²¹ A. Paul Pross, *Group Politics and Public Policy*, op. cit., p. 122.

Pross reminds us that the policy community should not be understood simply as being interested in making or remaking policy. Rather, the policy community can be used as a protective device, limiting rather than expanding opportunities for the general public to achieve policy changes. So long as the subgovernment can keep policy making at a technical level and out of the public eye, it may go about its business with little interference. But that is not always possible, as circumstances may force issues onto the agenda and bring a wider array of policy actors into the fray.

The model of policy making emphasized by advocates of the policy community approach fails to capture relations outside of the normal, structured government-interest group channels, and it appears to blur the division between state and civil society. The approach contends that "the world of state-society relations is richly varied and den[ies] that there is any advantage in working toward a single model."¹²² According to its advocates, policy communities – composed of government officials, media representatives, organized interests, even academics – vary according to the policy field in question. State actors, for instance, are said to exert tremendous influence over who is accorded access to the policy network, and hence control the policy agenda.

Interest-group approaches and to a certain extent, post-pluralist approaches such as the literature on policy communities, are thus burdened by four major shortcomings: interests are taken as given; legitimate or conventional action is valorized, as are

¹²² Michael M. Atkinson and William D. Coleman, "Policy Networks, Policy Communities, and the Problems of Governance," *Governance* 5, April 1992, p. 156.

institutionalized groups; activist legacies are ignored; and groups are assumed to be interested only in initiating policy change, not in influencing the behaviour of civil society.

Regarding the first criticism, the presumption that interests arise fully formed ignores the presence and creation of hitherto unestablished interests, especially those groups loosely defined in the literature as issue-oriented. I exclude here the objections of social movement theorists, who suggest that issues are of less importance than the identities created and maintained by different groupings of political actors. As Rosalind Brunt argues in the context of class consciousness, we need to step back to explain how actors become 'political':

No comrades spring class-conscious from the womb and metaphors that suggest they do indicate how the already-politicised forget the circumstances of their own politicisation and the extent to which these were both product and process of life-choices and contingencies.¹²³

Activists, like the identities they resist or to which they cling, are made, not born. One of the major objectives of this dissertation is to understand and explain the emergence of blood activism – why it took the form that it did, and how the movement changed to accommodate the needs of 'new' actors. Moreover, even if we accept that political actors indeed have "interests" – a suggestion even social movement scholars would readily accept – the literature is deficient in answering questions regarding the dynamics of group formation and/or group fragmentation. In order to explore these questions – the latter

¹²³ Rosalind Brunt, "The Politics of Identity," in Stuart Hall and Martin Jacques (Eds.). 1989. *New Times: The Changing Face of Politics in the 1990s*. London and New York: Verso, p. 152.

question being of special significance in the case of tainted-blood activism – we need to turn to social movement theory.

Regarding the second shortcoming, the interest group approach focuses its analytical lens squarely on legitimate or conventional action. The implicit assumption here is that radical or unconventional groups have little or no influence on the strategies of their tamer cousins. When looking at the environmental movement, for instance, it may be important to examine not only the structured relationships between environmental organizations in a policy community or policy network, but the impact of groups that may be interested in similar issues, but choose different strategies to make their voices heard. A social movement perspective allows for the possibility that marginal groups, while perhaps less successful in initiating policy change, may be instrumental in opening windows of opportunity for less radical groups to win important policy changes or to influence the policy process generally. Moreover, the line separating disruptive protest from institutionalized activity is not always clear.

Fainsod Katzenstein has made the important observation, based upon her study of activism in the Catholic Church and the military, that activism inside institutions may be just as disruptive as acts of defiance on the streets. The assumption regarding what are legitimate forms of protest also tends to suggest that such groups primarily target the state. But what do we make of protest that is not directed at the state, or of demands made by pressure groups that do not always involve direct or explicit policy outcomes or recommendations? Can pressure groups seek to influence policy indirectly, via the media, the courts, public opinion, or, as a last resort, through violence? As Pross has noted, “very

few pressure groups exist simply to influence government.”¹²⁴ The literature on policy communities seems to neglect this fundamental point. This is important since movements, while admittedly broader in scope, often include formal interest groups, some of which may have divergent aims.

There is an acknowledged bias in the interest group literature toward institutionalization. Uncritically, it is assumed that as groups acquire more resources and stronger organizational structures, they will necessarily become more conventional. This evidence, however, is far from conclusive. For instance, groups with few resources may nonetheless adopt conventional tactics. Similarly, groups with a wealth of resources may successfully resist the temptation to become conventional political players. And it is entirely possible for one branch of a movement to exhibit the features of a sophisticated advocacy organization, while another branch may rely instead on informal, unstructured networks of interaction.

The third criticism is that interest group approaches often fail to make important connections between groups and their forerunners. In failing to do so, they often overlook the possible influence of groups that may disappear from the political scene. From the perspective of interest group theory, groups that disband or fade away are no longer worthy of study. In my view, Pross incorrectly interprets the demise of an interest group as *a priori* evidence of the group's failure. A group's disappearance from the political stage, however, may not be as significant in understanding the policy environment in

¹²⁴ Pross, “Talking Chameleons,” *op. cit.*, p. 256.

which groups participate as Pross suggests. It is equally important to examine an interest group's demise from the perspective of its enduring influence on other groups that may form in its wake; a nuance captured in the social movement literature in its discussion of initiator and spin-off movements.¹²⁵ For instance, while several chapters of ACT UP, the AIDS Coalition to Unleash Power, have formed and disbanded in Canada, the United States, and parts of Europe, this does not suggest that ACT UP's brand of political action has altogether disappeared. Indeed, several individuals who began in ACT UP have carried this philosophy of direct political action to different organizations of which they are members, including, as we will discuss later, the Committee of Ten Thousand (COTT), a U.S. based group that represents hemophiliacs who contracted HIV through tainted blood, and the recently formed U.S. group, Hepatitis C Action and Advocacy Coalition (HAAC). In short, there is no logical connection between the demise of an interest group and the particular brand of activism to which its members were committed.

The fourth and final criticism, of policy change as the only legitimate end for groups, is that this overlooks the symbolic potential of group activity, including the creation of a collective identity, as well as the interplay of instrumental and symbolic goals. Moreover, if mentioned at all, this symbolic dimension of group activity is cast in terms of the devastating potential of an adherence to identity politics. The presumption is that identity politics valorizes difference, almost always at the expense of broader,

¹²⁵ See, among others, David S. Meyer and Suzanne Staggenborg. 1996. "Movements, Countermovements, and the Structure of Political Opportunity." *American Journal of Sociology*, Volume 101, No. 6, pp. 1628-1660.

communal goals. Wolin, for instance, conflates interest group politics with identity politics:

Interest politics dissolves the idea of the citizen as one for whom it is natural to join together with other citizens to act for purposes related to a general community and substitutes the idea of individuals who are grouped according to conflicting interests. The individual is not first and foremost a civic creature bound by pre-existing ties to those who share the same history, the same general association, and the same fate. He or she is instead a business executive, a teamster, a feminist, office worker, farmer or homosexual whose immediate identity naturally divides him or her from others. As a member of an interest group, the individual is given an essentially anticivic education. He is taught that the first duty is to support the self-interest of the group because politics is nothing but a struggle for advantage.¹²⁶

Therefore, I have chosen social movement theory, in particular elements of the theory that examine the interplay of structure and agency, because it recognizes that identities and interests are constructed and mutable, not given and fixed. In addition, the literature provides a rich discussion of the scope for different types of collective-actor influence. Moreover, it allows us to examine the impact of protest outside of its effect on policy outcomes. This is not to suggest that we abandon the study of policy outcomes; rather it is meant to focus our analytical lens on the different sources and influences on policy-making, including the role of collective-identity formation.

¹²⁶ Sheldon Wolin, "What Revolutionary Action Means Today," p. 244. In Chantal Mouffe (ed.). 1992. *Dimensions of Radical Democracy: Pluralism, Citizenship, Community*. London: Verso.

What's in a Name? Defining a Social Movement

Pinning down a solid definition of a social movement is an admittedly elusive task given the competing interpretations jockeying for position. For the purposes of this dissertation, della Porta and Diani's definition best captures the dynamic nature of movements. They define social movements as "*informal networks, based on shared beliefs and solidarity, which mobilize about conflictual issues, through the frequent use of various forms of protest.*"¹²⁷ In the next section, I will unpack the four components of this definition to make the case that blood activism should be viewed as a social movement. As noted in the introduction, a social movement should not be confused with a social movement organization (SMO), which is defined as a "complex, or formal, organization that identifies its goals with the preferences of a social movement or countermovement and attempts to implement those goals."¹²⁸ Social movements include social movement organizations as well as loose networks of activists connected to a movement's broad goals but perhaps not a part of a formal organizational structure. Social movements often rely on these networks, which they can mobilize at a moment's notice. Empirically, we cannot isolate a social movement in the same way that we can study a social movement organization. Indeed, Melucci notes that we must be careful not

¹²⁷ Donatella della Porta and Mario Diani. 1999. *Social Movements: An Introduction*. London: Blackwell Publishers Ltd., p. 16. Emphases added.

¹²⁸ McCarthy and Zald, quoted in Tarrow, *Power in Movement*, 1994, op. cit., p. 135.

to treat a collective phenomenon "...as a *unified empirical datum*, which, supposedly, can be perceived and interpreted by observers."¹²⁹ Melucci contends that this great "epistemological misunderstanding" is reproduced in conventional analyses of social movements. Such analyses tend toward a view of social movements as *the* unit of analysis, as opposed to social movement actors, treating action as though there are no actors:

Every empirical phenomenon offers us a cross section of a social structure, rather like a split in a rock reveals its inner composition and strata. Just as a photograph of a rock as a whole cannot be confused with the minerals and strata that compose it, so collective phenomena do not disclose their meaning to us if we only consider them in their totality.¹³⁰

Therefore, the study of social movements involves a careful understanding of the organizations that are part of the movement, the subjective interpretations of movement participants themselves, and the interactions between movement participants and authorities.

Della Porta and Diani's definition is one of many. Manuel Castells, in *The Power of Identity*, suggests that social movements are "purposive collective actions whose outcome, in victory as in defeat, transforms the values and institutions of society."¹³¹ This definition is problematic because the criteria used to judge a movement – actual effect on

¹²⁹ Melucci, quoted in Carol Mueller, "Conflict Network and the Origins of Women's Liberation," p. 235. In Enrique Larana, Hank Johnston, and Joseph R. Gusfield (Eds.). 1994. *New Social Movements: From Ideology to Identity*. Philadelphia: Temple University Press.

¹³⁰ Alberto Melucci, "A Strange Kind of Newness: What's 'New' in New Social Movements?" p. 106. In *New Social Movements: From Ideology to Identity*, op. cit.

¹³¹ Manuel Castells. 1997. *The Power of Identity*. London: Blackwell Publishers, p. 3.

societal institutions and values – are impossibly difficult to satisfy, especially within such a limited time frame. Simply put, values and institutions do not change overnight. While the dissertation suggests that blood activists did, ultimately, attempt to transform the relationship between the state and its citizens, especially as it relates to state responsibility for matters involving risk, it is premature to suggest that the movement was successful in doing so. For her part, Nelkin is unequivocal in her claim that Canada's tainted blood scandal shook the foundations of its voluntary blood collection system, which heretofore had been held in high public regard.¹³² Whether such a shift – from blood donation as the ultimate expression of humanitarianism to profound suspicion of all parties involved in conferring the “gift of life” – meets Castells's criteria, however, is open to debate. Castells exaggerates the extent to which the movements he discusses have transformed society, a deficiency most pronounced in his discussion of the women's movement's challenge to patriarchy. For instance, while acknowledging that it is indeed an unfinished project, Castells argues that the last quarter of the 20th century was witness to “a mass insurrection of women against their oppression throughout the world.”¹³³ Defining a movement by its outcomes, as Castells does, makes it virtually impossible to classify many movements, since outcomes are not always easily measured or, at the very

¹³² See Dorothy Nelkin, “Cultural Perspectives on Blood,” in *Blood Feuds*, op. cit.

¹³³ Manuel Castells, *The Power of Identity*, op. cit., p. 135. See especially, Chapter 4, “The End of Patriarchalism: Social Movements, Family, and Sexuality in the Modern Age,” pp. 135-242.

least, require a great deal of time to take hold. What do we make of movements stuck in this conceptual purgatory? Is every movement a movement in waiting?

Originally, Tarrow originally defined social movements as “collective challenges by people with common purposes and solidarity in sustained interaction with elites, opponents, and authorities.”¹³⁴ In the second edition of his popular book, *Power in Movement*, he revised the definition somewhat, referring to movements “as those sequences of contentious politics that are based on underlying social networks and resonant collective action frames, and which develop the capacity to maintain sustained challenges against powerful opponents.”¹³⁵ Neither of these definitions is able to capture what distinguishes social movements from interest groups, however. Moreover, Tarrow appears to assume that solidarity exists *a priori*, just as interest group theories do.

In a provocative article that tries to explode the conventional wisdom regarding the unique features of social movements as compared with interests, Paul Burstein goes as far as to suggest that the traditional distinction between the two is deeply flawed. The key distinction – that SMOs almost always operate at the margins with little or no direct link to the power holders in society, while interest groups enjoy relatively easy access – rests on a false dividing line. Instead, he counsels, the only useful distinction between non-governmental political organizations is a legal one. Political parties, which enjoy a special legal status as “political organizations that have a place on the ballot and a formal

¹³⁴ Sidney Tarrow, *Power in Movement*, 1994, op. cit., p. 4.

¹³⁵ Sidney Tarrow, *Power in Movement: Social Movements and Contentious Politics*. Cambridge, New York, and Melbourne: Cambridge University Press, 1998, p. 2.

role in organizing legislatures,"¹³⁶ occupy one end of the continuum, while 'interest organizations', the term he uses to group interest groups and social movement organizations, occupy the other end. His analysis leads him to reach different conclusions regarding the impact of political activity on public policy. First, he argues that interest organizations are constrained by the desire of elected officials to get re-elected. This desire means that politicians will need to respond, first and foremost, to the demands of their constituents. Only when the electorate's wishes are unclear or mildly felt, he argues, can the interest organizations in question have any chance of influencing public policy. Otherwise, politicians, being rational actors, will respond to the wishes of the majority, perhaps ignoring appeals by interest organizations. This does not suggest that political activity is futile. Conversely, interest organizations can affect policy if the electorate is not concerned with or cares little about the issue in question, and if the public's preferences are malleable or not etched in stone.

While Burstein's discussion is useful, especially in the context of understanding the important role of public opinion that is often neglected by social movement theorists, glossing over the differences between interest groups and social movement organizations makes difficult the task of understanding the different features that have a bearing on successful collective action. Burstein argues that the social movement organization's concern about winning "acceptance" is strikingly similar to the interest group's desire to

¹³⁶ Paul Burstein, "Social Movements and Public Policy," p. 9. In Marco Giugni, Doug McAdam, and Charles Tilly (eds.). 1999. *How Social Movements Matter*. Minneapolis: University of Minnesota Press.

win “access”. The two are not synonymous, however. An organization may secure access, but acceptance may still elude it. Conversely, a group may win tacit acceptance but lack any meaningful access.

Classifying Movements

Given the plethora of social movements that have made their presence felt in various local, national, and international contexts, it is useful to think of how we might classify them. And while there are a number of ways to do this, at least three approaches to classification are relevant to this study. First, McCarthy and Wolfson propose a distinction between *conflict* and *consensus* movements. Within the general social movement literature, they note, there is an acknowledged bias for conflict-oriented movements, which are “typically supported by minorities or slim majorities of populations and confront fundamental, organized opposition in attempting to bring about social change.”¹³⁷ Examples include the feminist, civil rights, and labour movements. Consensus movements, on the other hand, are defined as “those organized movements for change that find widespread support for their goals and little or no organized opposition from the population of a geographic community.”¹³⁸ Using lack of organized public

¹³⁷ John D. McCarthy and Mark Wolfson, “Consensus Movements, Conflict Movements, and the Cooptation of Civic and State Infrastructures,” p. 273. In Aldon Morris and Carol McClurg Mueller, eds., *Frontiers in Social Movement Theory*, op. cit.

¹³⁸ John D. McCarthy and Mark Wolfson, “Consensus Movements...,” op. cit., pp. 273-274.

opposition at the societal level as a key marker, one may characterize tainted-blood activism as an example of a consensus movement. Indeed, several polls suggested that a majority of the public supported efforts to gain compensation for tainted-blood recipients, and to create a safer blood system. One caveat is in order, however. Public support or sympathy is rarely fixed or permanent. Movements may begin as consensus movements, and later adopt the features associated with conflict movements. A movement that takes for granted the public support it enjoys may risk alienating its supporters if it chooses to adopt a more hard-line position. This is discussed in greater detail in a later section with respect to intra-movement tensions around the issue of compensation (for some versus all recipients) and the criminal prosecution of responsible officials. I will argue that the movement enjoyed greater support within its ranks as well as in the broader public arena when it chose to focus on compensation, but that it lost some of this support when it moved to consider the pursuit of criminal justice.

Second is Cohen's distinction between identity-oriented and strategy-oriented movements.¹³⁹ Identity-oriented movements have earned the troublesome label, new social movements (NSMs). As Offe argues, new social movements "relate to other political actors and opponents not in terms of negotiations, compromise, reform, improvement or gradual progress to be brought about by organizational pressures and tactics, but, rather, in terms of sharp antinomies such as yes/no, them/us, the desirable and

¹³⁹ See Jean L. Cohen. 1985. "Strategy or Identity: New Theoretical Paradigms and Contemporary Social Movements." *Social Research* 52, No. 4, pp. 663-716.

the tolerable, victory or defeat, now or never, etc.”¹⁴⁰ Initially, NSMs were presumed to be disinterested in the economy or the state, thus exhibiting ‘postmaterialist’ or ‘postacquisitive’ values. As Offe explains, postmaterialist values, which are found predominantly among members of the urban new middle class, focus “on participation, equality and the development of the self in its intellectual, esthetic and physical dimensions.”¹⁴¹ Recognizing that this might be too strict a conception, there is a growing recognition that the claims of new social movements are not simply symbolic or cultural. While many of these movements may be postmaterial in the sense they are not interested primarily in improving the income-distribution status of groups or individuals, “they are, at the same time, highly ‘materialist’ in the sense that they challenge the prevailing mode of production and the effects it has upon the physical and human substance of social life.”¹⁴²

NSM theory has been criticized for what it excludes (movements, especially those on the far right of the ideological spectrum, that do not fit the mould) and for what it obscures (identity politics). Calhoun argues that NSM theory often groups “relatively attractive” left-leaning movements, but ignores other contemporary movements, such as

¹⁴⁰ Claus Offe, “New Social Movements: Challenging the Boundaries of Institutional Politics,” *Social Research* 52, no. 4 (Winter 1985), p. 829.

¹⁴¹ Claus Offe, “The Separation of Form and Content in Liberal Democratic Politics,” *Studies in Political Economy* 3 (Spring 1980), p. 12.

¹⁴² Claus Offe, “The Separation of Form...” op. cit., p. 12.

the new religious right and fundamentalism.¹⁴³ Although Cohen makes this important distinction, in later work with Arato she stresses that contemporary social movements “are characterized by a dualistic politics of identity and influence, aimed at both civil society and the polity (or political society)...”¹⁴⁴ Koopmans refines this typology by adding a distinction between two types of identity-oriented movements: subcultural and countercultural movements. Subcultural movements, which include the gay and women’s movements, “are primarily directed at collective identities that are constituted and reproduced in within-group interaction.”¹⁴⁵ Countercultural movements, on the other hand, “derive their collective identity from conflicting and confrontational interaction with other groups.”¹⁴⁶ Kriesi et al, in their discussion of new social movements in Western Europe, adopt a typology that includes subcultural, countercultural and instrumental movements, the latter including the peace and ecology movements.

For the purposes of this dissertation, I propose to treat blood activism as a contemporary social movement characterized by a dual logic of instrumentality and identity. Activists were clearly concerned with influencing the political environment but they were interested also in defining themselves. Without such an articulation, it is not

¹⁴³ Craig Calhoun, “Social Theory and the Politics of Identity,” p. 22. In Craig Calhoun (ed.). 1994. *Social Theory and the Politics of Identity*, Oxford, UK and Cambridge, USA: Blackwell.

¹⁴⁴ Jean L. Cohen and Andrew Arato. 1994. *Civil Society and Political Theory*. Cambridge, Mass.: MIT Press, p. 504.

¹⁴⁵ Hanspeter Kriesi, Ruud Koopmans, Jan Willem Duyvendak, and Marco G. Giugni. 1995. *New Social Movements in Western Europe: A Comparative Analysis*. Minneapolis: University of Minnesota Press, p. 83.

¹⁴⁶ Kriesi, Koopmans, Duyvendak, and Giugni, op. cit., p. 83.

altogether clear that activists would have been successful in pressuring government to the degree that they did.

Why Blood Activism Constitutes a Contemporary Social Movement

Scholars of interest groups may be tempted to dismiss “blood activism” as yet another example of contemporary pressure group politics. And indeed at first blush one might assume that they would be correct in doing so. After all, “blood activists” pushed governments for financial compensation, attempting to reap positive rewards for their members, just as traditional interest groups seek to mobilize support for their respective constituencies. But this dissertation argues that while the battle for compensation became an important flashpoint in the struggles between activists and the state, this does not adequately explain the history of blood activism.

As noted earlier, della Porta and Diani identified four common characteristics of social movements: informal interaction networks, shared beliefs and solidarity, collective action focusing on conflicts, and the use of protest.¹⁴⁷ I now turn to a discussion of these four characteristics in making the case that we view blood activism as an example of a contemporary social movement that is characteristic of post-industrial society. First, blood activism was less organized around, and less constrained by, the role of formal organizations as its primary units. Individual members – many of whom clashed with or, at the very least, disagreed with group leaders and/or spokespersons – were an integral

¹⁴⁷ Della Porta and Diani, *op. cit.*, p. 14-15.

part of the advocacy networks that were developed to address blood-related concerns. Second, in spite of being represented by formal organizations, tainted-blood recipients activated strong, informal links across the country and with activists in other countries. They were aided, in part, by the explosion of Internet technology, which allowed individuals in far-flung communities to swap information on current medical developments. Third, movement actors are likely to engage in political or social conflicts, which seek to champion or oppose social change. By conflict della Porta and Diani are referring to

an oppositional relationship between actors who seek control of the same stake. In order for social conflict to occur, it is necessary, first, that this is defined as a shared field, with actors who perceive each other as different, but who, at the same time, are linked by reference to interests and values which both sides see as important, or as high stakes desired by two or more adversaries.¹⁴⁸

The “stake” in this case was blood. The conflicts concerned who was responsible for overseeing its supply, its safety, and who could be held accountable for the contamination of thousands of Canadians. Tainted blood activists locked horns with a number of adversaries, including government officials, not-for-profit organizations (the Canadian Red Cross), and the private sector (pharmaceutical companies). As part of the broader self-help movement, blood activists sought also to mobilize and empower “health consumers in situations of disempowerment and institutional conflict.”¹⁴⁹

¹⁴⁸ Della Porta and Diani, op. cit., p. 15.

¹⁴⁹ Mark A. Chesler, 1991. “Mobilizing Consumer Activism in Health Care: The Role of Self-Help Groups.” In *Research in Social Movements, Conflicts, and Change*, Vol. 13, p. 276. Chesler notes four specific features of the self-help movement: “First, they are part of a broader

Finally, actors use protest to articulate their demands. While the social movement literature tends to romanticize “unconventional” modes of protest, this does not imply that actors must engage in confrontational tactics to earn the moniker of social movement. Movements often adopt a mix of traditional tactics (lobbying) and unconventional means (demonstrations) to suit their needs. The tainted-blood movement then fulfills the four criteria laid out by della Porta and Diani, to varying degrees. They are perhaps weakest in the latter category, as conventional modes of protest were the exception, not the norm. This is not to say, however, that protest was nonexistent. Indeed, Hepatitis C activists, the last group of tainted-blood recipients to mobilize, made themselves heard and known by staging numerous demonstrations.

Paradigms Lost? Synthesizing Social Movement Theories

This dissertation draws from the two main approaches within social movement theory – NSM Theory and Resource Mobilization Theory (RMT) – to explain the emergence of blood activism. The identity (agency) and strategy (structure) paradigms, respectively, have been criticized for emphasizing one goal at the expense of the other.

social movement that seeks to create greater patient/consumer awareness and activism in health care. Second, they involve people dealing with major conflict and threat in their daily lives... Third, they work with their members to create a greater level of awareness of common grievances and interests, of confidence in their own actions and abilities, and of the possibility of acting together for change... Fourth, self-help groups often advocate for change in the medical care system: they articulate members' common concerns; target practices and practitioners that require alteration; open up lines of communication and collaboration often closed to individual consumers; and develop a power base with which to challenge resistant medical bureaucracies.” (pp. 299-300)

While each theory differs in key respects, my research will demonstrate that aspects of each theory can contribute toward a richer understanding of social movements in general and the blood movement in particular.¹⁵⁰

Blood activism cannot be understood solely through an NSM framework, as meaning construction was not the exclusive focus of blood activists. Although the movement created and asserted a collective identity, its orientation was not postmaterialist, as new social movements are often described. Conversely, resource mobilization theory is inadequate because it lacks the analytical tools to examine non-instrumental action. Following Lofland, my methodological approach seeks to emphasize causal variables over schools of thought, “answer improving” instead of “theory-bashing.”¹⁵¹ I should add, however, that attempts to merge these paradigms have come under criticism.¹⁵²

RMT is more state-centered in its approach, and hence, more akin to traditional approaches to interest-group lobbying that emphasize access to resources. Resource mobilization theorists assert that “social movement activities are not spontaneous and disorganized and that social movement participants are not irrational.”¹⁵³ This strategic

¹⁵⁰ Indeed, there is a growing current of social movement research that attempts to incorporate both paradigms. See, for instance, the edited volume by McAdam, McCarthy, and Zald, *Comparative Perspectives on Social Movements*, op. cit.

¹⁵¹ John Lofland, *Social Movement Organizations*, op. cit., p. 372.

¹⁵² Jean Cohen argues, for instance, that one cannot “simply add a consideration of solidarity, collective identity, consciousness, or ideology to the resource-mobilization perspective without bursting its framework.” (“Strategy or Identity...” op cit., p. 687)

approach to social movements was a response to previous theories of collective behaviour, many of which reduced political action to irrational outbursts of time and place. Emerging in the U.S. in the 1970s, RMT derived intellectual support from, among others, Mancur Olson's influential work, *The Logic of Collective Action*. Olson challenged the notion that groups, much like individuals, act in their self-interest. Indeed, Olson argued that the rational actor would pursue collective action only if the benefits of doing so outweigh the costs involved. The problem is that individuals may reap the rewards of collective action regardless of their involvement (the "free-rider" problem); they may consume the public good without contributing to it. Groups are forced to find ways in which to confer benefits (selective incentives or inducements) to individuals to encourage them not to free ride. This rational-choice approach to political action has been the source of considerable debate.¹⁵⁴

The concern with "mobilizing structures" – defined as "those collective vehicles, informal as well as formal, through which people mobilize and engage in collective

¹⁵³ Myra Mark Ferree, "The Political Context of Rationality: Rational Choice Theory and Resource Mobilization," p. 29. In Aldon D. Morris and Carol McClurg Mueller (Eds.), *Frontiers in Social Movement Theory*, op. cit. Game theorists have also tried to explain the dynamics of collective action using rational choice models. For instance, Dennis Chong treats mass protest movements as assurance games, "in which individual decisions to contribute are contingent on the aggregate level of participation." (Dennis Chong, "Coordinating Demands for Social Change," *Annals of the AAPS* 528, July 1993, p.126.)

¹⁵⁴ For a critique within social movement theory, see Frances Fox Piven and Richard A. Cloward, "Collective Protest: A Critique of Resource-Mobilization Theory." In Stanford A. Lyman (Ed.). 1995. *Social Movements: Critiques, Concepts, Case-studies*. New York: New York University Press. For an excellent critique of the rational-choice approach to political science, see Donald P. Green and Ian Shapiro. 1994. *Pathologies of Rational Choice Theory*. New Haven and London: Yale University Press.

action”¹⁵⁵ – has not been the exclusive domain of resource mobilization theorists.

Scholars working within the ‘political process model’ also focused their attention on the organizational dynamics of collective action, although they rejected the resource mobilization theorists’ conflation of social movements with formal organizations, or SMOs.¹⁵⁶ The RMT paradigm has come under intense criticism, especially from Europe.¹⁵⁷

If RMT responds to the “how” of social movement action (how movements amass and exploit resources), new social movement theory stresses the “why’. For NSM theorists, meaning displaces structure as the key explanatory variable. New Social Movement Theory defines movements in the broader context of sweeping value changes¹⁵⁸, and emphasizes goals such as identity and autonomy. Civil society, not the

¹⁵⁵ Doug McAdam, John McCarthy, and Mayer Zald, “Introduction” in McAdam, McCarthy and Zald (Eds.), *Comparative Perspectives on Social Movements*, op. cit., p. 3.

¹⁵⁶ Charles Tilly (1975-1978) is considered the father of the political-process model. Others who have followed in this tradition include Doug McAdam, who studied the critical role of local black institutions (namely churches and colleges) in the emergence of the civil rights movement in the U.S. See Doug McAdam. 1982. *Political Process and the Development of Black Insurgency, 1930-1970*. Chicago: University of Chicago Press.

¹⁵⁷ Margit Mayer isolates two factors to substantiate her claim that RMT is an ill-fitting paradigm for understanding European social movements: America’s “relatively open, fluid and decentralized political system”, which has prevented an antagonistic polarization between movements and the political establishment, and the “reintegration ... of insurgent, innovative reform movements in the course of American history into the dominant American ideology, utilitarian liberalism...” Margit Mayer, “Social Movement Research in the United States: A European Perspective,” p. 184. In Stanford A. Lyman (Ed.). *Social Movements: Critiques, Concepts, Case-studies*, op. cit.

¹⁵⁸ Ronald Inglehart’s pioneering work on postmaterialism has received widespread attention. See his *The Silent Revolution: Changing Values and Political Styles among Western Publics*, Princeton: Princeton University Press, 1977, and *Culture Shift in Advanced Industrial Society*, Princeton: Princeton University Press, 1990. Neil Nevitte has applied this model to the Canadian

state, is the main focal point. Of course, these strict categorizations do not explain fully the process of political protest. Identity and autonomy may be bound up with competition for resources; and, conversely, access to resources is often tied to larger political issues, such as autonomy. For NSM theorists, issues of collective identity are central to the creation of Social Movement Organizations. It is argued that social movement actors enter the political arena to defend, not their economic interests, but their collective identities.

Following Gamson, I use Melucci's notion of collective identity as it successfully bridges the gulf between identity oriented and strategically oriented paradigms.¹⁵⁹ Collective identity involves three dimensions: "first, formulating cognitive frameworks concerning the goals, means, and environment of action; second, activating relationships among the actors, who communicate, negotiate and make decisions; and third, making emotional investments, which enable individuals to recognize themselves in each other."¹⁶⁰ As Bartholomew and Mayer argue, however, this notion needs to be liberated from its cultural reductionism: "The construction of collective identity may not be

context in *The Decline of Deference: Canadian Value Change in Cross-National Perspective*. 1996. Peterborough, ON: Broadview Press.

¹⁵⁹ I should caution here that the notion of collective identity has come under criticism. Klandermans argues that there is "no such phenomenon as a stable collective identity which, once formed, governs collective action. Instead, I suggest that collective identities are transient phenomena. There is every reason to assume that the collective identity of movement participants changes over time as the life cycle of a movement evolves." (Bert Klandermans, "Transient Identities? Membership Patterns in the Dutch Peace Movement," p. 169. In *New Social Movements: From Ideology to Identity*, op. cit.

¹⁶⁰ Alberto Melucci. 1989. *Nomads of the Present: Social Movements and Individual Needs in Contemporary Society*. Philadelphia: Temple University Press, p. 35.

exclusively the outcome of processes in the sphere of symbolic codes, but may be shaped, also, by political struggle and the relationship between political and cultural dimensions of a movement."¹⁶¹ Contrary to Melucci's assertion "that political engagements with the state are not relevant to the construction of collective identity,"¹⁶² I follow Bartholomew and Mayer in asserting the importance of this endeavour. Specifically, I identify the state, and especially the Krever Inquiry, as a key variable in understanding the process of collective identity formation.

A main criticism of social movement theory is its tendency to overstate the identity claims of the social movement organizations' adherents, and to ignore the movement's context. Incorporating the concept of political opportunity structure, which accounts for, among other things, the interaction between SMOs, can help to rectify the latter criticism. Following several theorists, I assert that the two paradigms – NSM and RM theories – may actually complement one another, that each can make important contributions to the study at hand. As McClurg Mueller suggests, "one paradigm does not necessarily supersede the other, but rather affords a figure/ ground shift in what is considered problematic."¹⁶³ Similarly, Gamson and Meyer argue that we need to be "sensitive to the interaction between structure and agency, to the way in which both

¹⁶¹ Amy Bartholomew and Margit Mayer, "Nomads of the Present: Melucci's Contribution to 'New Social Movement' Theory," *Theory, Culture & Society*, Vol. 9 (1992), p. 152.

¹⁶² Amy Bartholomew and Margit Mayer, "Nomads of the Present..." p. 153.

¹⁶³ Carol McClurg Mueller, "Building Social Movement Theory." In *Frontiers in Social Movement Theory*, op. cit., p. 22.

opportunity and movement strategy influence each other.”¹⁶⁴ They cite Kitschelt’s study of anti-nuclear movements as an example of a structural approach that neglects the role of agency. Kitschelt treated the emergence of these movements “at a particular historical moment as a given, not his problem to explain.”¹⁶⁵ To the contrary, this study of blood activism takes as its “problem to explain” how a particular historical moment influenced the identity and strategies of the Hepatitis C movement. The next section focuses on the role of political opportunity structure. I deal with the issue of collective identity and agency in the section that follows.

Political Opportunity Structures: Mediating Between Structure and Agency

While Resource Mobilization Theory links successes and failures to resources internal to a movement (e.g.: the makeup of the organization, group leaders), the concept of “political opportunity structure” seeks to capture the impact of the external political environment on a movement’s capacity to mount a successful mobilization campaign. Although the concept has attracted considerable attention among movement scholars and comparativists in the U.S. and Europe, Canadian political scientists have largely ignored it.¹⁶⁶ Peter Eisinger laid the foundations of the political opportunity structure approach in

¹⁶⁴ Gamson and Meyer, “Framing Political Opportunity.” In *Comparative Perspectives on Social Movements*, op. cit., p. 278.

¹⁶⁵ Gamson and Meyer, “Framing Political Opportunity.” In *Comparative Perspectives on Social Movements*, op. cit., p. 278.

¹⁶⁶ Two notable Canadian exceptions are Jeffrey Ayres’ *Defying Conventional Wisdom: Political Movements and Popular Contention against North American Free Trade*, University of Toronto

a seminal 1973 article. Eisinger was interested primarily in how the structure of political opportunities helped to account for riot behaviour, but his conception of political opportunity structure as the "degree to which groups are likely to be able to gain access to power and to manipulate the political system," is not as far removed from current theorizing as one would think.¹⁶⁷ While definitions vary and there is increasing disagreement with respect to the variables that comprise such structures, Tarrow's conception is fairly well-regarded: "The concept of political opportunity emphasizes resources external to the group – unlike money or power – that can be taken advantage of by weak or disorganized challengers. Social movements form when ordinary citizens, sometimes encouraged by leaders, respond to changes in opportunities that lower the cost of collective action, reveal potential allies and show where elites and authorities are vulnerable."¹⁶⁸

Tarrow stresses, however, that we must be careful in using the term. To speak of a structure of political opportunity is, in some senses, a misnomer, since opportunities are always "situational" or context dependent. Nonetheless, he notes, the concept is useful because it helps us to understand how mobilization can move from those actors with

Press, 1998, and Miriam Smith's *Lesbian and Gay Rights in Canada: Social Movements and Equality Seeking*. 1999. Toronto: University of Toronto Press.

¹⁶⁷ See Peter Eisinger, "The Conditions of Protest Behaviour in American Cities," *American Political Science Review*, 1993, 67, pp. 11-28. It should be stressed that there is some disagreement regarding the origins of political opportunity structure theory. Tarrow (1998), for instance, credits social movement historian Charles Tilly with introducing and expanding upon the concept.

¹⁶⁸ Sidney Tarrow. 1994. *Power in Movement*, op. cit., p. 18.

deep-seated grievances and an abundance of resources to those with fewer grievances and less than adequate resources. A movement's early risers may open or take advantage of openings in political opportunity, which in effect carves out a new space for "late risers".

There are various ways to conceptualize political opportunity structure.

Researchers have focused on large-scale structures, on structures that are "proximate" to particular actors during a specific period of contention, on cross-sectional variations in opportunity, and on the impact on social movements of changes in political conflict and alliance.¹⁶⁹ Proximate opportunity structures are admittedly narrower in scope, focusing on how movement actors react to their immediate policy environment or to changes in their resources and capacities. Scholars who embrace this approach emphasize either "policy specific" or "group specific" opportunities. The first attempts to capture the impact of policy decisions and the greater institutional environment on collective action. "Group specific" opportunities, as the name implies, focuses on how changes affect certain groups positively or negatively. For instance, Tarrow cites the removal of restrictions on organizing workers as one example of a group specific opportunity.

The alternative, state-centred approach is interested in deriving conclusions that may be applicable beyond the confines of the subnational or group level. Within this approach, Tarrow identified two major strands: cross-sectional statism and dynamic statism. The first type examines how different state structures or institutional settings affect the strategies of movements. Kitschelt's work on the anti nuclear movements of

¹⁶⁹ Sidney Tarrow, "States and Opportunities: The Political Structuring of Social Movements," p. 42. In *Comparative Perspectives on Social Movements*, op. cit.

four European countries is an exemplar of this approach.¹⁷⁰ The second type does not take the state as given. Rather, it argues that states undergo changes that open or close windows of opportunity for collective actors. As Tarrow notes, this is perhaps the “boldest” of the four hypotheses regarding the political opportunity structure because its proponents argue that “*entire political systems undergo changes which modify the environment of social actors sufficiently to influence the initiation, forms, and outcomes of collective action.*”¹⁷¹

Given the conceptual diversity, it is worth reviewing some of the important features of political opportunity. Gamson and Meyer map the structure of political opportunity along two dimensions: cultural (society) versus institutional (the state) and stable versus weak.

¹⁷⁰ Herbert Kitschelt. 1986. “Political Opportunity Structures and Political Protest: Anti-Nuclear Movements in Four Democracies,” *British Journal of Political Science* 16, pp. 57-85.

¹⁷¹ Sidney Tarrow, “States and Opportunities: The Political Structuring of Social Movements,” p. 44. In *Comparative Perspectives on Social Movements*, op. cit. Italics in original.

Figure 3.1: Political Opportunity Structure: Some Variables

Source: Gamson and Meyer (1996)

STABLE		
Myths and narratives, values, cultural themes, belief systems, world views	Strong/weak state tradition	Strength of state institutions
		Strength and number of political parties
		Judicial and legislative capacity and independence
		Centralization of political institutions
		Strength of social cleavages
		Organization and political economy of mass media
		Patterns of linkage between interest groups and government
CULTURAL (society)		INSTITUTIONAL (the state)
Legitimacy		Economic and technological trends causing dislocations
Class consciousness		Strength of indigenous organizations
Climate, zeitgeist		Movement infrastructure
National mood	Mass media access	Shifts in political alliances
	Policy changes	Splits among elites
Issues cultures	Scope of conflict	Capacity for social control
Public discourse		Social control errors
Media frames		Elections
Ideas in good currency		
VOLATILE		

As this figure indicates, Gamson and Meyer locate elements such as belief systems and myths or narratives at the intersection of the cultural-stable areas, while other features such as elections and splits among elites are located at the intersection of the institutional-volatile areas. What may appear obvious from the matrix pictured above is the sheer complexity of political opportunity and the variables that comprise such structures. Indeed, many social movement scholars have criticized this tendency to lump all elements of the external environment under the broad category of political opportunity structure. As Banaszak demonstrates in her comparison of the American and Swiss suffrage movements, we must be careful about adopting some of the assumptions made by theorists of political opportunity. For instance, she notes that neither resource mobilization nor political opportunity structure theories can explain fully “the failure of the Swiss suffrage movement because they assume that movements with insufficient resources or political opportunities are either doomed to failure or (knowing that the conditions are unfavourable for success) will not make fruitless attempts at achieving their goals.”¹⁷² In the Swiss case, suffrage activists did not, as the theory suggests, try certain tactics and fail. Instead, they did not take advantage of a number of potentially useful tactics. Banaszak traces their failure to a general lack of information about the opportunities available to them, not to a lack of resources or opportunities. For this reason, Banaszak urges social movement scholars to look closely at the perceptions of movement participants as well as their social ties to other challenging groups to

¹⁷² Lee Ann Banaszak. 1996. *Why Movements Succeed or Fail: Opportunity, Culture, and the Struggle for Woman Suffrage*. Princeton: Princeton University Press, p. 216.

determine their effect on tactical decisions. In the case of the American suffrage movement, for instance, activists were successful in forging alliances with the abolition, temperance, and progressive movements, which greatly affected their success in securing the vote for women.

Moreover, Biskner points to two main problems with the concept when applied to actual cases:

First, some of its most important predictions become unfalsifiable: “openings” in the political context can always be found to account for the emergence (or other significant period in the development) of a movement, while it is nearly impossible to argue that an opening did *not* occur. Second, the POS framework does not allow clear predictions for which outcome (e.g., emergence or failure to emerge) should occur, because many important “openings” and “narrowings” of opportunities can generally be identified for any given case. The narrowing of opportunities should discourage movements, and thus should “cancel out” the openings. These two consequences occur even when the most concrete formulations of the POS concept are used.¹⁷³

Biskner’s first point is well-taken, but it seems to neglect the subjective dimensions of collective action. Opportunities, of course, do not exist as objective facts. The key factor here is the perceptions of movement participants. In some cases, they may respond to what they believe is an opening, and in the process, pry open the hitherto closed window of opportunity. This may explain why a certain degree of positive illusion is motivating and constructive for social movement adherents. Biskner’s second point

¹⁷³ Julie Biskner. 1999. “Opportunities and Challenges: Evaluating Changes in Political Opportunity Structures.” Paper delivered at the annual conference of the American Political Science Association, p. 1.

presumes a zero-sum game. The suggestion that the narrowing of opportunity should cancel out any openings presumes wrongly that the two are unable to coexist. Movements may benefit from an opening in one sphere, but encounter opposition in another. This does not, however, foreclose the possibility of successful collective action.

Jasper's critique of the political opportunity structure concept echoes some of Biskner's concerns. In particular, he notes that too often conceptions of the POS invoke a circularity of logic "in that whatever 'provides incentives' for collective action seems to be a political opportunity structure. When there is collective action, there must be a favourable opportunity structure."¹⁷⁴ Mindful of this danger that the concept "threatens to become an all-encompassing fudge factor for all the conditions and circumstances that form the context for collective action,"¹⁷⁵ Gamson and Meyer take great pains to "unpack" the concept and speculate about its general utility. And while there may be some dispute with regard to the elements they included in their matrix, their main conclusions are of greater importance. Gamson and Meyer emphasize that:

Relatively stable elements of opportunity are useful in comparing the incidence and success of movements in different settings. The volatile elements, however, are more useful in understanding the process of interaction between the opening and closing of political space and the strategic choice of movements. The volatile elements help us to understand movement outcomes as involving structures

¹⁷⁴ James M. Jasper. 1997. *The Art of Moral Protest: Culture, Biography, and Creativity in Social Movements*. Chicago and London: The University of Chicago Press, p. 35.

¹⁷⁵ Gamson and Meyer, "Framing Political Opportunity." In *Comparative Perspectives on Social Movements*, op. cit., p. 278.

which shape and channel activity while, in turn, movements act as agents that help to shape the political space in which they operate.¹⁷⁶

The concept of political opportunity structure would be of little interest were it not so dynamic or varied in its effects on opponents and challengers. According to Tarrow's original conception, opportunity structures can constrain or expand the field of collective action in four ways: they expand the group's own opportunities; they can expand opportunities for others; create opportunities for elites; and create opportunities for opponents.¹⁷⁷ The first refers to the ways in which movements create new opportunities and reach new publics through actions of their own. New forms of collective action may introduce the element of surprise, catching authorities off guard and scrambling to respond. From the perspective of our case, it is worth stressing the degree to which the forms of collective action remained somewhat stable, while at the same time causing substantial political ripples. Loud, in-your-face demonstrations were the exception, not the rule. In addition, it is unclear whether those demonstrations that did occur were spontaneously organized, or approved by the various groups representing recipients of tainted blood.

The second effect is the degree to which one movement's efforts may expand opportunities for others. Tarrow cites as an example the U.S. civil rights movement, "which placed new frames of meaning on the agenda, particularly the extension of the

¹⁷⁶ Gamson and Meyer, "Framing Political Opportunity." In *Comparative Perspectives on Social Movements*, op. cit., p. 289.

traditional notion of rights, that other groups could reshape around their own grievances."¹⁷⁸ One of the best examples of how movements create opportunities for opponents (or countermovements) occurred in the politically charged arena of abortion politics. The landmark *Roe v. Wade* ruling in favour of access to abortion by the United States Supreme Court in 1973, for instance, sparked a flurry of anti-abortion activity by the religious right.

The third, creating opportunities for elites, will be examined in greater detail in Chapter 5 in the light of the political jockeying that greeted news of limited compensation packages for Hepatitis C recipients. For instance, the normally fiscally conservative government of Ontario Premier Mike Harris surprised many by announcing that it would compensate those people with Hepatitis C who were shut out of the package announced in March 1998. This was all the more puzzling given that the Ontario government was part of the team that negotiated the federal-provincial-territorial settlement. The fourth, creating opportunities for opponents, is not relevant here, as the tainted-blood movement did not spark a 'countermovement' of opponents in the way that the feminist movement for reproductive choice awoke opposition from the religious right and anti-abortion forces.¹⁷⁹

¹⁷⁷ Sidney Tarrow, "States and Opportunities: The Political Structuring of Social Movements." In *Comparative Perspectives on Social Movements*, op. cit., p. 58-60.

¹⁷⁸ Tarrow, "States and Opportunities," op. cit., p. 59.

¹⁷⁹ See David S. Meyer and Suzanne Staggenborg. 1996. "Movements, Countermovements, and the Structure of Political Opportunity." *American Journal of Sociology*, Volume 101, No. 6, pp. 1628-1660.

Kitschelt's comparative study of anti-nuclear movements isolates three ways in which the POS "can further or restrain the capacity of social movements to engage in protest activity."¹⁸⁰ First, mobilization depends upon the movement's ability to amass resources (informational and financial). Second, social movement access is "governed" by institutional arrangements. Third, a social movement's opportunities are influenced by the actions of other social movements. Kitschelt tested two hypotheses. First, political opportunity structures condition the "range of likely protest activities." In open political systems, "assimilative" strategies prevail. By contrast, in relatively closed systems, movements adopt confrontational tactics. The second hypothesis suggests that the POS may "facilitate or impede" three types of movement impacts: procedural, substantive, and structural.¹⁸¹ Kitschelt found that in the case of nuclear energy these hypotheses best capture the impact of social movements. Surprisingly, he notes, the "magnitude of protest" had little impact on the willingness of governments to rethink controversial policies: "Rather it was shaped in certain pre-established ways by the channels and opportunities that political regimes offered to opponents to disseminate their message and disrupt established policies."¹⁸² I cite Kitschelt's study because I am interested in trying to understand whether the POS can help to explain why demands for compensation from government initially fell on deaf ears even though this eventually received almost

¹⁸⁰ Herbert Kitschelt. 1986. "Political Opportunity Structures and Political Protest: Anti-Nuclear Movements in Four Democracies," *British Journal of Political Science* 16, p. 61.

¹⁸¹ Herbert Kitschelt, "Political Opportunity Structures and Political Protest," op. cit., p. 66-67.

¹⁸² Herbert Kitschelt, "Political Opportunity Structures and Political Protest," op. cit., p. 84.

unanimous approval, even before Krever made his final recommendations. In this case, contrary to Kitschelt, the "magnitude of protest" may help to explain the willingness of government to rethink a given policy.

Given that the concept of political opportunity structure has the potential to be too general or all encompassing, it is necessary to identify those elements that are relevant to social movements in particular and collective actors in general. Tarrow identified at least five key components of the POS: the relative openness or closure of the institutionalized political system; the stability or instability of that broad set of elite alignments that typically undergird a polity; divided elites; the presence or absence of elite allies; (and) the state's capacity and propensity for repression.¹⁸³ As is evident, these are dynamic elements of political opportunity. For the purposes of the discussion to follow, I have amended Tarrow's list in order to identify three salient elements most relevant in the Canadian context: the broad institutional framework, the influence of political values and ideas, and the relationships between and among elites and allies, both within the state and without. I do not treat the relative openness of the political system as a discrete variable in my analysis as I see it as a product of the above three variables. As we will see later, each of these elements is linked.

¹⁸³ Adapted from the second edition of Tarrow's *Power in Movement: Social Movements and Contentious Politics*, op. cit., pp. 77-80. Tarrow's reconceptualization represents a recent addition to the literature, which previously identified four dimensions of political opportunity. See Doug McAdam, "Conceptual origins, current problems, future directions." In *Comparative Perspectives on Social Movements*, op. cit., p.27.

Kriesi argues that the extent to which a movement is dependent on political opportunities is a function of three factors: the movement's general orientation, the level of development of its organizational infrastructure, and the nature of the problem it is dealing with.¹⁸⁴ First, he argues that subcultural movements such as the gay rights movement are less responsive to changes in the POS than are countercultural or instrumental movements because they are concerned mainly with collective identity formation, which is constituted primarily within group interaction. Countercultural movements, on the other hand, are more susceptible to changes in the POS because their identities are fashioned in "conflictual interactions with authorities or third parties."¹⁸⁵ Instrumental movements seem to be the most affected, as they seek to "obtain specific collective goods or to prevent specific collective 'bads.'"¹⁸⁶ Second, Kriesi hypothesizes that movements with a stable organizational infrastructure are less likely to be affected by changes in the POS since they are less dependent on external support from allies than movements with fragile organizational structures. Third, movements with highly focused problems are more likely to depend on the POS, "especially when the problem itself is linked to specific political decisions."

¹⁸⁴ Hanspeter Kriesi, "The Political Opportunity Structure of New Social Movements: Its Impact on Their Mobilization," p. 192. In *The Politics of Social Protest*, op. cit.

¹⁸⁵ Hanspeter Kriesi, "The Political Opportunity Structure of New Social Movements: Its Impact on Their Mobilization," op. cit., p. 193.

¹⁸⁶ Hanspeter Kriesi, "The Political Opportunity Structure of New Social Movements: Its Impact on Their Mobilization," op. cit., p. 193.

Elements of Opportunity

Institutional Framework in the Canadian Context

The institutional framework encompasses the state's regulatory apparatuses and various political institutions. As Immergut points out, however, too often institutional approaches to public policy focus on institutions as independent variables, either as actors or structures.¹⁸⁷ Institutions are best conceived, in her view, as configurations: "By mediating political conflicts in distinctive ways, political institutions bring together different constellations of organized actors and change the ways in which they interact."¹⁸⁸ Moreover, the state is differentiated, which implies that some institutions are more important than others at given periods in time for particular movements. In this case, two aspects of the institutional framework are of critical importance: our tradition of public inquiries and federalism.

Public inquiries have been a distinguishing feature of the Canadian political process since the country's inception. Legally, federal commissions of inquiry are established by order in council of the federal cabinet under the Inquiries Act. The Act, which authorizes the establishment of inquiries into issues that fall under federal, constitutional jurisdictions, is divided into two parts. Part I outlines provisions for 'public inquiries' and defines them as inquiries "made into and concerning any matter connected

¹⁸⁷ See Ellen Immergut. 1992. *Health Politics: Interests and Institutions in Western Europe*. Cambridge, New York, Melbourne: Cambridge University Press, pp. 21-24.

with the good government of Canada or the conduct of any part of the public business thereof.”¹⁸⁹ Part II of the Act provides for “departmental investigations” which are mandated to investigate and provide an account of departmental activities, and the official conduct of department officials.

Essentially, the Act provides for two different types of inquiries: fact-finding inquiries into governmental or administrative misconduct that typically assume a formal “judicial” appearance; and policy-oriented commissions, which are concerned primarily with advancing public knowledge on broad socio-economic issues. While the concerns of the legal practitioner, like the rights of witnesses, inform the proceedings of fact-finding inquiries, social science research and public consultations are the focal points of policy-oriented commissions. Favoured by policy-makers and academics, policy-oriented commissions are viewed as “stepping-stones” in the policy process. According to Pross and Christie, the assumption underlying this interpretation of commissions of inquiry is that they “work systematically and objectively to determine both the public interest and the extent to which the people will permit the state to impose a particular interpretation of that interest.”¹⁹⁰

Salter rejects the dichotomy between “fact-finding inquiries” and “policy inquiries”, arguing that it does not take into account that inquiries often perform both

¹⁸⁸ Ellen Immergut, *Health Politics*, op. cit., p. 25.

¹⁸⁹ Law Reform Commission of Canada, p. 5.

¹⁹⁰ A. Paul Pross and Innis Christie, “Introduction,” p. 5. In Pross, Christie, and John A. Yogis (eds.). 1990. *Commissions of Inquiry*. Toronto, Calgary, Vancouver: Carswell.

functions. Instead, inquiries should be seen along a continuum according “to the degree to which fact-finding or achieving policy consensus is approved.”¹⁹¹ This is not to suggest that inquiries are anything but complex. Indeed, Salter argues that there are two fundamental contradictions of public inquiries. The first concerns their potential “to incorporate radical debate” but only “limited and pragmatic policy goals.”¹⁹² On the one hand, inquiries seem to have unprecedented opportunity to operate “without boundaries”. At the end of the day, however, an inquiry, which is mandated by and reports to government, might need to tone down this radicalism if it wishes its recommendations to be taken seriously by the government of the day. The second lies in the inquiry’s ambiguous relationship with the legal process. Inquiries are both “freed from the constraints of legal proceedings to conduct their investigations,” but they are also legal proceedings complete with a battery of lawyers.¹⁹³

Since 1868, over 500 inquiries have been appointed under Part I of the Inquiries Act, examining a broad range of issues, from allegations of governmental and administrative misconduct to the complex issues surrounding new reproductive technologies. The Krever Inquiry also was established under Part 1 of the Inquiries Act. Despite this historical legacy, inquiries have been the target of much criticism. The most

¹⁹¹ Liora Salter, “The Two Contradictions in Public Inquiries,” p. 176. In *Commissions of Inquiry*, op. cit.

¹⁹² Liora Salter, “The Two Contradictions in Public Inquiries,” p. 175. In *Commissions of Inquiry*, op. cit.

¹⁹³ Liora Salter, “The Two Contradictions in Public Inquiries,” p. 176. In *Commissions of Inquiry*, op. cit.

common complaint leveled against them by politicians and lay people alike has been their cost. This complaint is further compounded by the fact that governments are not legally or politically obligated to implement the recommendations put forward by the inquiry. This has led some to dismiss commissions of inquiry as legitimizing mechanisms aimed at achieving consensus on government policy.¹⁹⁴ Given the legacy of the Krever Inquiry and its impact on public opinion, such a dismissal would be premature. Instead, I argue that the Inquiry introduced policy norms or values into the discourse, against which government policy would ultimately be judged. It is worth remarking that, ironically, Krever's final recommendation regarding no-fault compensation was championed by political actors of various ideological stripes, including then-Reform Party Leader Preston Manning and Ontario Premier Mike Harris, who are chief proponents of aggressive deficit-cutting.¹⁹⁵

Building on Jenson's study of royal commissions, I advocate a more dynamic interpretation of inquiries, which recognizes them as important political spaces that are designed to ensure the participation of affected persons who do not normally have access to regular policy processes. Moreover, they create a fertile arena for the development and

¹⁹⁴ See Seymour V. Wilson, "The Role of Royal Commissions and Task Forces." In Bruce Doern and Peter Aucoin (eds.). *The Structures of Policy-Making in Canada*. Toronto: Macmillan; J.E. Hodgetts, "Should Canada Be De-Commissioned?" *Queen's Quarterly*, Vol. LXX, No.4 (Winter 1964), pp. 475-90; Bruce Doern, "The Role of Royal Commissions in the General Policy Process and in Federal-Provincial Relations," *Canadian Public Administration* 10 (1967), pp. 417-433.

¹⁹⁵ According to Durhane Wong-Rieger of the Canadian Hemophilia Society, her decision to publicly applaud Ontario Premier Mike Harris for agreeing to compensate people with Hepatitis

representation of contending views and stances on complex policy issues. By providing opportunities for public involvement in policy-making and relying on social science research, the public inquiry is a system of representation that generates and maintains ideas about policy issues.

To varying degrees, commissions of inquiry have given previously marginalized groups and individuals the opportunity to have their voices heard by decision-makers. As the on-going policy process becomes increasingly dominated by regularized consultation between state bureaucrats and institutionalized interest groups, groups or individuals with fewer resources will turn to other avenues for representation. Public inquiries, like royal commissions, have provided such avenues. As Aucoin explains, "...the requirement that commissions actively seek out the broadest range of interested and affected parties constitutes an essential condition for commissions providing policy analyses that contain added value to those done within the regular structures of government."¹⁹⁶ In this respect, the Krever Inquiry was instrumental in bringing to the fore the concerns of the "forgotten victims" of the tainted-blood scandal, namely people infected with Hepatitis C.

While often criticized, it should be emphasized that the recommendations put forth by various inquiries have been instrumental in influencing social attitudes on particular issues and in shaping identities. The representational and discursive capacity of

C so angered the federal government that she was effectively shut out of compensation talks with Federal Health Minister Allan Rock.

¹⁹⁶ Peter Aucoin, "Contributions of Commissions of Inquiry to Policy Analysis," p. 201. In *Commissions of Inquiry*, op. cit.

inquiries is best exemplified by the Mackenzie Valley Pipeline Inquiry, otherwise known as the Berger Inquiry.¹⁹⁷ Ultimately, public inquiries, when properly conducted, can become mechanisms for social change. They have expanded our vocabulary of politics, “and have added to the furniture that we now expect to find in Canada’s storefront of ideas.”¹⁹⁸

With regard to the second aspect, numerous studies in Canada have examined the impact of federalism on interest groups. Schultz analyzed the role of intergovernmental negotiations in the policy-making process, using a case study of the Canadian Transport Commission. His article tests two hypotheses: Morton Grodzins’ “multiple crack” hypothesis and Simeon’s hypothesis concerning the restricted access and limited effectiveness of interest groups. Briefly, the first hypothesis suggests that federal systems are valued by interest groups because the existence of two levels of government provides groups with “multiple access points” to pursue policy aims. Groups, it is argued, vacillate

¹⁹⁷ Established in 1974 to examine the social, economic, and environmental consequences of the construction of a gas pipeline in northern Canada, the Berger Inquiry adopted several practices to ensure the representation and involvement of all affected parties. First, the inquiry broke new ground by providing for the first time funds to a variety of environmental and aboriginal groups who lacked the resources to carry out their own research. The inquiry also set up both formal and community hearings. The formal hearings resembled a judicial process where expert witnesses were heard and cross-examined by lawyers. The community hearings, on the other hand, provided the forum for non-experts to voice their concerns over the construction of the pipeline. In establishing two different types of hearings, the inquiry sought to perform both its quasi-judicial function and representational function. As Berger explained, “We have tried in this way to have the best of the experience of both worlds, the world of everyday where most witnesses spend their lives, and the world of the professionals, the specialists, and the academics.” (Thomas Berger, “The Mackenzie Valley Pipeline Inquiry,” *Queen’s Quarterly*, Vol. 83, No. 1 (Spring, 1976), p. 32).

¹⁹⁸ Thomas Berger, Keynote Address, “Commissions of Inquiry: Praise or Reappraise?” Conference held at Queens’ University (Kingston, ON), Feb. 12, 1999.

between the two poles along the continuum (federal and provincial), depending upon the receptiveness of either branch of government. In addition, it is presumed that in some instances interest groups are capable of pitting one level of government against another in order to gain influence. In contrast, the second hypothesis challenges the first. A "crack", says Simeon, entails not only fissures but also opportunities for governments to ignore the demands of the groups. When issues enter the murky world of intergovernmental negotiations, interest-group influence may be "seriously undermined because they [the groups] are frozen out of the process."¹⁹⁹

In testing federalism as a powerful explanatory variable in determining policy outcomes, Schultz concludes that both hypotheses fail to adequately explain the course of events following the passage of the National Transportation Act in 1967. (Part III of the act, which would have turned over regulatory powers back to the federal government, was eventually scrapped.) The "multiple crack" hypothesis needs to be qualified, he says, because it fails to pay adequate attention to the perils of federalism vis-à-vis interest groups. The second hypothesis overlooks the important support function in intergovernmental negotiations. One of Schultz's most important conclusions concerns how the "multiple crack" hypothesis can work in reverse; that is, "the role of

¹⁹⁹ Richard Schultz, "Interest Groups and Intergovernmental Negotiations: Caught in the Vise of Federalism," in J. Peter Meekison, ed., *Canadian Federalism: Myth or Reality*, Toronto: Methuen, 1977, p. 376.

governmental actors in fostering or exacerbating the potential for internal conflict for the purpose of exploiting group division in the intergovernmental arena.”²⁰⁰

Cairns’ study attempts to reclaim the ground lost by excessively sociological considerations of political behaviour that overstate the importance of societies on government at the expense of the reverse phenomenon. This moves Cairns’ analysis beyond a mere discussion of federalism. For Cairns, government itself is the key political actor. “Federalism,” he explains, “at least in the Canadian case, is a function not of societies, but of the constitution, and more importantly of the governments that work the constitution.”²⁰¹ In making his case, however, Cairns makes some sweeping generalizations, including this statement: “The significant question, after all, is the survival of provincial governments, not of provincial societies, and it is not self-evident that the existence and support of the latter is necessary to the functioning and aggrandisement of the former.”²⁰² While it is certainly valid to suggest that provincial governments have the “capacity to mould their environment,” it does not follow, however, that they can do so without societal interference.

Our parliamentary system of government plays a crucial role not only in structuring the range of possible resolutions to complex policy issues, but also in how or whether dissident voices are heard. In particular, the role of party discipline cannot be

²⁰⁰ Schultz, op. cit., p. 382.

²⁰¹ Alan C. Cairns, “The Governments and Societies of Canadian Federalism,” *Canadian Journal of Political Science*, December 1977, p. 699.

²⁰² Cairns, op. cit., p. 699.

overestimated here, especially with respect to the 1998 vote on extending compensation to all people infected with Hepatitis C. Others have hypothesized that our Westminster model of government helps to explain the relative success of states in imposing losses on citizens and avoiding or deflecting blame for their actions. As Pal and Weaver explain in comparing our system with the U.S. separation-of-powers model, this might occur in several ways:

First, institutional arrangements may affect *who has power and influence* in the political system. Westminster systems, with their emphasis on collective cabinet responsibility and party discipline, tend to concentrate power in the hands of leaders of the governing party(ies) and offer fewer veto points to interest groups than the U.S. system. A second way ... is by affecting the *rules under which alternatives are compared and selected or rejected*. Westminster institutions are usually seen as giving the governing party or parties a substantial advantage over the U.S. system in determining which legislative alternatives are considered, and in what order. Third is the *capacity of opponents to access veto points* in the legislative process itself, and to punish the government in the next election. On both of these grounds, we would expect parliamentary type regimes to be more successful at loss imposition than presidential ones. Westminster institutions generally give governments better control over the legislative agenda, enforce party discipline, and through that discipline enable individual MPs to avoid blame by claiming that they simply were following party policy. Presidential systems have less agenda control, are more permeable to outside interests, and individual legislators cannot so easily avoid blame for loss imposition. Finally, political institutions may also affect the *objectives and strategies of policy makers and interest groups*. Institutions that make politicians appear individually accountable for policy decisions encourage blame avoidance strategies. In the Canadian parliamentary system, legislators can afford to impose painful policies, since voters know that they must follow their party whips and are therefore unlikely to blame them individually for their vote. In the U.S. Congress, on the other hand, blame-avoiding objectives by individual legislators are likely to be much more

prominent, and to play an important role in determining policy outcomes.²⁰³

These institutional differences can affect the government's capacity to impose losses. In a parliamentary system, they note, governments can restrict or deny access to interested groups or individuals. Since such systems allow governments to control the legislative agenda – including the ability to limit debate and force votes – it is theoretically possible for an incumbent government to impose losses swiftly, before opposition forces have had the opportunity to mobilize. Indeed, opposition member may decry such moves publicly, but in many instances, it is too little, too late. Pal and Weaver add, however, that parliamentary systems have disadvantages for imposing losses, as well. First, the concentration of power and accountability in the federal Cabinet makes it easier for disgruntled voters and/or interest groups who wish to punish the governing party or coalition to apportion blame. Moreover, the incumbent government must successfully duck a number of targets who have “blame-generating opportunities”, including the televised Question Period, during which the government is forced to respond to all manner of allegations, as well as independent bodies such as commissions, task forces, auditors, and commissioners. Therefore, despite the frequent suggestion that Westminster-style systems such as Canada's will be more effective overall at imposing losses than governments in the United States, Pal and Weaver maintain that “there are

²⁰³ Leslie Pal and R. Kent Weaver, “The Politics of Pain: Political Institutions and Loss Imposition in Canada and the United States,” presented at the Meeting of the Association for Canadian Studies in the United States, Pittsburgh, PA, Nov. 1999), p. 13. Emphases in original.

enough uncertainties and countervailing tendencies in anticipated institutional effects that a fuller investigation of specific cases is warranted.”²⁰⁴

Elites/Allies

The presence of shifting elite alignments is best characterized in liberal democracies by electoral instability. According to Tarrow, “The changing fortunes of government and opposition parties, especially when they are based on new coalitions, create uncertainty among supporters, encourage challengers to try to exercise marginal power and induce elites to compete for support from outside the polity.”²⁰⁵ While Canada has had a relatively stable government over the period of this study (with two consecutive Liberal governments elected in 1993 and 1997), nine different ministers have juggled the health portfolio since AIDS first became a public health issue in the early 1980s. Between 1993 and the present, Canada has had five health ministers.

²⁰⁴ Leslie Pal and R. Kent Weaver, “The Politics of Pain: Political Institutions and Loss Imposition in Canada and the United States,” p. 15.

²⁰⁵ Tarrow, *Power in Movement*, 1994, op. cit., p. 87.

Figure 3.2: Ministers of Health – Federal Government

MINISTER	TIME PERIOD
David Crombie	June 1979 – March 1980
Monique Begin	March 1980 - Sept. 1984
Jake Epp	Sept. 1984 – Jan 1989
Perrin Beatty	Jan. 1989 – April 1991
Benoît Bouchard	April 1991 – June 1993
Bernard Vaillancourt	June 18, 1993 – June 25, 1993
Mary Collins	June 1993 – Nov. 1993
Diane Marleau	Nov. 1993 – Jan. 1996
David Dingwall	Jan. 1996 – June 1997
Allan Rock	June 1997 – present

With reference to the absence or presence of influential allies, Tarrow notes that “challengers are encouraged to take collective action when they have allies who can act as friends in court, as guarantors against repression or as acceptable negotiators.”²⁰⁶ Among elite allies, Tarrow includes opposition parties, which in representative or democratic

²⁰⁶ Sidney Tarrow, *Power in Movement*, 1994, op. cit., p. 88.

systems are normally left wing in nature. In the next chapter, I lay out two types of elites/allies: the role of political parties, especially opposition parties such as the Reform Party, and the role of the media.

Political Values/Ideas

The influence of political values and ideas on social movements is often difficult to pinpoint, but its role should not be underestimated. As Jenson has argued, how and why certain values or ideas are legitimized may go a long way toward explaining movement successes/ failures. The universe of political discourse, Jenson contends, “comprises beliefs about the way politics should be conducted, the boundaries of political discussion, and the kinds of conflicts resolvable through political processes... (T)he universe filters and delineates political activity of all kinds.”²⁰⁷ Social movement theorists have captured this under the term “discursive opportunity structure,” which determines “which ideas are considered ‘sensible,’ which constructions of reality are seen as ‘realistic,’ and which claims are held as ‘legitimate’ within a certain polity at a specific time.”²⁰⁸

²⁰⁷ Jane Jenson, “Changing Discourses, Changing Agendas: Political Rights and Reproductive Policies in France,” p. 65. In Mary Fainsod Katzenstein and Carol McClurg Mueller (eds.). 1987. *The Women's Movements of the United States and Western Europe: Consciousness, Political Opportunity and Public Policy*. Philadelphia: Temple University Press. Recent work has examined the policy influence of ideas or ideologies, including Neil Bradford's *Commissioning Ideas: Canadian National Policy Innovation in Comparative Perspective*. 1998. Toronto: Oxford University Press.

²⁰⁸ Ruud Koopmans and Paul Statham, “Ethnic and Civic Conceptions of Nationhood and the Differential Success of the Extreme Right in Germany and Italy,” p. 228. In Marco Giugni, Doug McAdam, and Charles Tilly (Eds.). 1999. *How Social Movements Matter*. Minneapolis: University of Minnesota Press.

Although movements, especially the recent new social movements, are often regarded as the carriers of new values or ideas, movements also are influenced or shaped by pre-existing values.²⁰⁹ The next chapter discusses three such influences: the discourse of AIDS activism, the legal discourse, and the risk discourse. The role of AIDS activism is discussed in the context of the fundamental shifts it has produced in how we view people living with disease. In particular, AIDS activism has legitimized, perhaps even glorified, militant disease activism, and is an integral component of the 'policy legacy' inherited by blood activists. As one activist noted of groups such as ACT UP:

Their model of power is incredible. When they want something, they snap their fingers and it gets done. The government realizes that they cannot upset that group because they realize they're very vocal, they're very militant and they're united in their belief and they've been at it more than 13 years. We've just started this movement. We're just starting to follow that model. We know there's a lot of us out there. By sheer volume of numbers, we have the people to get nasty, to get in government's faces, to get in the doctor's faces, and get results. We're not afraid to stand up and say I have hepatitis C and I'm dying and I want the drugs for myself and everyone that's got it. A lot of people don't like confrontation and that's fine, but those people have no right to whine and complain that nothing's being done because they're not doing their part to help the cause.²¹⁰

It loomed large not only in the activist imagination, but in the government's as well. The legal discourse, with its emphasis on "winnable" cases, had a contradictory impact on blood activism. On the one hand, the spectre of long, protracted litigation may have

²⁰⁹ For instance, Miriam Smith traces the influence of the U.S. civil rights movement and its rights-based discourse on Canada's gay liberation movement. See Miriam Smith, "Political Activism, Litigation and Public Policy: The Charter Revolution and Lesbian and Gay Rights in Canada," *International Journal of Canadian Studies* 21, Spring 2000, pp. 81-109.

²¹⁰ Personal interview with Peter Madsen, Victoria, B.C., July 18, 1999.

pushed governments into acquiescing to movement demands. On the other, the focus on the legal avenues for compensation eclipsed movement efforts to mount effective challenges to the symbolic order. And, finally, the risk discourse, which is characteristic of post-industrial society, emphasizes, paradoxically, both the individual's role and responsibility in avoiding risk, and the state's role in minimizing its liability for risk-related injury. Was it reasonable to expect, for instance, that hemophiliacs would accept risk as an inherent consequence of their reliance on blood products?

Openness of the Political System as Function of Political Opportunity Structure

The relative openness of the political system is a crucial factor in understanding not only movement emergence, but also the strategies and successes of movements. According to della Porta and Diani, "a system has been considered more open the more political decisions are dispersed. The prevalent belief is that the greater the number of actors who share in political power (the greater the checks and balances) the greater the chance that social movements can gain access to the system."²¹¹ They divide the issue along three lines: territorial decentralization, functional separation of powers between the legislature, executive and the judiciary, and the overall amount of power resting in state hands. Theory suggests that the greater degree of autonomy and power afforded to peripheral bodies (provinces in a federal structure, for instance), the greater the likelihood of gaining access to the decision-making process. This dispersal of power, however, may

²¹¹ Della Porta and Diani, op. cit., p. 197.

not always work in the social movement's favour, because it increases the possibility of access for all political actors, including a movement's opponents.²¹² Similarly, the greater the degree of autonomy exercised by the legislature, the executive and the judiciary, "the more numerous will be the channels of access to the system."²¹³ Finally, on the concentration of state power, the authors suggest that the structure of political opportunity will be more open in "weak" states; that is, states in which "citizens maintain the possibility of intervening with the legislature and executive independently of mediation through political parties, interest groups, or bureaucrats."²¹⁴

In centralized (strong) states collective actors gravitate to the apex of power, whereas in decentralized states collective actors have a number of targets at their disposal. The result is that decentralized states have the greatest capacity to handle challenges from outside the polity because they invite participation and discussion, while strong states, which have a firm hold of effective policy instruments to effect policy changes, are more inclined to confront challengers, sometimes with the threat of violence. Tarrow recognizes, however, that state strength may be insufficient to explain the trajectory of contentious politics. In some cases, states, whether weak or strong (discarding for a moment the difficulty in assessing states' relative strength or weakness), may have "prevailing strategies" for dealing with challengers. State strategies may be

²¹² Della Porta and Diani, *op. cit.*, p. 200.

²¹³ Della Porta and Diani, *op. cit.*, p. 198.

²¹⁴ Della Porta and Diani, *op. cit.*, p. 199.

inclusive or exclusive. As the name suggests, *inclusive* strategies signal to challengers that the state is responsive to and willing to take account of their demands. *Exclusive* strategies, on the other hand, often shut out challengers from influencing policy. Nothing has been written about Canada in this regard, but according to Kriesi et al, weak states such as the United States and Italy have adopted inclusive and exclusive strategies, respectively, while strong states such as Sweden and France have adopted inclusive and exclusive strategies, respectively. In addition, as I will argue with respect to Canada, so-called weak or decentralized states may, paradoxically, be less open to challengers if power is concentrated in the political executive.²¹⁵ In other words, the system may be open to a wide array of challengers, but challengers' efforts may be minimized if there are few opportunities to influence the direction of policy.

The flip side of openness is repression, which Tarrow and others treat as a distinctive element of the POS. In most analyses of the state's propensity and capacity for repression, the focus is on the official use of state-sanctioned physical force to quell dissent, and on the "police handling of protest events." According to della Porta, who has done some of the most comprehensive work on protest policing, we should view protest policing not as an independent dimension of the political opportunity structure, but rather as a barometer of the available POS, if only because "movement activists consider protest

²¹⁵ See Donald Savoie. 1999. *Governing from the Centre: The Concentration of Power in Canadian Politics*, Toronto: University of Toronto Press.

policing as one of the best and most 'visible' indicators of institutional attitudes to protest."²¹⁶

The Importance of International "Moments"

Up to now, we have been discussing elements of the domestic political opportunity structure that may be helpful in explaining movement dynamics. McAdam reminds us, however, that one should not overlook the international context of political opportunities, namely the "impact of *global* political and economic processes in structuring the *domestic* possibilities for collective action."²¹⁷ The structure of political opportunity, then, is not focused exclusively on state power at the national level, but must encompass the influence – on national as well as provincial governments – of international processes.²¹⁸ As noted in an earlier section on the international dimensions

²¹⁶ Donatella della Porta, "Social Movements and the State: Thoughts on the Policing of Protest," p. 64. In *Comparative Perspectives on Social Movements*, op. cit.

²¹⁷ Doug McAdam, "Conceptual origins, current problems, future directions," p. 34. In *Comparative Perspectives on Social Movements*, op. cit. (emphases in original). As one example, he cites research linking the success of the American civil rights movement to Cold War pressures between the U.S. and the Soviet Union.

²¹⁸ There is a wealth of literature on the influence of internationalization and globalization on public policy. Some Canadian examples include: Grace Skogstad, "Globalization and Public Policy: Situating Canadian Analyses," *Canadian Journal of Political Science*, December 2000, pp. 805-828; Keith Banting, George Hoberg and Richard Simeon, "Globalization, Fragmentation and the Social Contract." In Banting, Hoberg, and Simeon (eds.), *Degrees of Freedom*. Montreal: McGill-Queen's University Press, 1997; Bruce Doern, Leslie A. Pal, and Brian W. Tomlin, "The Internationalization of Canadian Public Policy." In Doern, Pal and Tomlin (eds.), *Border Crossings: The Internationalization of Canadian Public Policy*. Toronto: Oxford University Press, 1996, 1-26; and Steven Bernstein and Benjamin Cashore, "Globalization, Four Paths of Internationalization and Domestic Policy Change: The Case of Ecoforestry in British Columbia, Canada," *Canadian Journal of Political Science*, March 2000, pp. 67-99.

of blood activism, blood activism in Canada must be properly understood within a global context since international trends and events may also structure the domestic possibilities for successful collective action. For instance, many activists recalled an international event that signalled to them that a window of opportunity had suddenly opened: the high-profile conviction in 1993 of four French public health officials in connection with that country's blood scandal. "It was really a lucky break for us," according to one representative of the Canadian Hemophilia Society. "With that, we decided we could push all the issues on a fear of wrongdoing. Use the inquiry to call for compensation. Use the inquiry to call for safer products."²¹⁹ In addition, activists in Canada noted that they were buoyed by positive developments in Ireland, which introduced one of the most comprehensive compensation schemes for all recipients of tainted blood, including people with Hepatitis C. Of course movement participants are not alone in being affected by international events. The targets of movement activity – governments, Red Cross officials – may also be affected by such events, in the sense of feeling vulnerable and perhaps more open to dialogue or consideration of movement demands. Windows of opportunity, therefore, do not open by themselves; to expand the metaphor, they may be unlocked, which makes them easier to open.

²¹⁹ Personal interview with Durhane Wong-Rieger, Ottawa, July 6, 1999.

Agency and Collective Actors

Agency, as understood by Gamson, “refers to the belief that one can alter conditions or policies through collective action.”²²⁰ But the “belief” that one can effect change is insufficient from both a theoretical and an explanatory standpoint. Movement actors need to mobilize these beliefs into concrete action, and sometimes respond to changes in political opportunity that signal to them that they have the capacity to do so, as well. Although we have established that structural factors influence the beliefs of collective actors/movement participants vis-à-vis the possibility of change as well as their capacity to act, we must account also for the fact that actors do make choices in a given context. It is to the context within which these choices are made that we now turn. Agency, in this analysis, is composed of three aspects: collective identity, framing, and strategy.

Collective Identity

Movement actors construct an identity around which they mobilize other participants, and demonstrate their “we-ness” to potential challengers. Collective identity, according to Melucci, “is nothing less than a shared definition of the field of opportunities and constraints offered to collective action: ‘shared means constructed and negotiated through a repeated process of ‘activation’ of social relationships connecting

²²⁰ Klandermans, op. cit., p. 18.

through the actors.”²²¹ Collective identity formation is an all-encompassing process through which actors produce cognitive frameworks that enable them to survey their immediate environment and to assess the costs and benefits of their actions. Building and constructing a narrative is a critical component of collective identity formation:

In telling the story of our becoming – as an individual, a nation, a people – we establish who we are. Narratives may be employed strategically to strengthen a collective identity but they may also precede and make possible the development of a coherent community, or nation, or collective actor... They connect through narrative reversal the group under conditions of oppression and the group under conditions of liberation. Stories thus explain what is going in a way that makes an evolving identity part of the explanation.²²²

Polletta also stresses that subsuming narrative under the broader category of frame obscures some of the real differences between the two. One of the three main differences centers on how events are linked to outcomes in each one. As she notes, citing the work of Gamson, Snow and Benford, and Klandermans, what makes a frame successful “is clear specification not only of the injustice against which protest must be mounted but the agents and likely efficacy of the protest. People must be shown that deliberate action will have its intended effect.”²²³ Narrative, she says, works in a different way. It succeeds not only by virtue of what it conveys, but also by what it doesn’t convey:

²²¹ Alberto Melucci, “The Symbolic Challenge of Contemporary Movements,” *Social Research* 52, Winter 1985, p. 793.

²²² Francesca Polletta, “‘It was like a fever...’ Narrative and Identity in Social Protest,” *Social Problems*, Vol. 45, No. 2, May 1998, p. 141.

²²³ Francesca Polletta, “‘It was like a fever...’”, *op. cit.*, p. 141.

Individual intention is just one among the principles that may link events in a story. The question in a story is often just what the linkage is: are things happening because of chance or divine intervention, conscious intention, or subliminal drive? This is what grips us, what keeps us listening or reading. A story whose end was immediately apparent would be no story at all – would be the moral without the story.... Narrative necessitates our interpretive participation, requires that we struggle to fill in the gaps and resolve the ambiguities. We struggle because the story's end is consequential – not only as the outcome but as the moral of the events which precede it.²²⁴

Polletta suggests that more attention be paid to the role of narrative in movement decision-making processes, since stories are “lenses” through which movement actors assess the opportunities and obstacles, costs and benefits, successes and failure of collective action.

Framing

Framing involves “the conscious strategic efforts by groups of people to fashion shared understandings of the world and of themselves that legitimate and motivate collective action.”²²⁵ As Goffman wrote of framing, “There is a sense in which what is play for the golfer is work for the caddy.”²²⁶ Movements frame the problems/issues they seek to address, and the nature/ substance of their claims. Collective action frames “underscore and embellish the seriousness and injustice of a particular social condition or

²²⁴ Francesca Polletta, “‘It was like a fever...’, op. cit, p. 141.

²²⁵ Cited in McAdam et al. “Introduction,” p. 6. In *Comparative Perspectives on Social Movements*, op cit.

²²⁶ Erving Goffman, cited in Joseph Gusfield, “The Culture of Public Problems: Drinking-Driving and the Symbolic Order,” p. 202. In Allan M. Brandt and Paul Rozin (eds.) 1997. *Morality and Health*, New York and London: Routledge.

redefine as unjust and immoral what was previously seen as unfortunate but perhaps tolerable.”²²⁷ One of the main components of collective action frames is a “a sense of injustice.”²²⁸ It “arises from moral indignation related to grievances,” and involves issues of inequality. It may also refer to a feeling that authorities are not dealing adequately with a social problem. As Gamson notes:

The heat of moral judgment is intimately related to beliefs about what acts or conditions have caused people to suffer undeserved hardship or loss. The critical dimension is the abstractness of the target... When we see impersonal, abstract forces as responsible for our suffering, we are taught to accept what cannot be changed and make the best of it... At the other extreme, if one attributes undeserved suffering to malicious or selfish acts by clearly identifiable groups, the emotional component of an injustice frame will almost certainly be there.²²⁹

Strategy

Social movement literature often distinguishes movement goals and tactics from movement outcomes. Gamson, for instance, distinguishes two general types of movement goals: simple versus multiple, and displacing versus nondisplacing. Of the first type, Marx and McAdam employ the example of student protests against tuition hikes. The dilemma for the movement is choosing between a single issue (reduction of the tuition

²²⁷ Robert Benford, “An Insider’s Critique of the Social Movement Framing Perspective,” *Sociological Inquiry*, Vol. 67, No. 4, November 1997, p. 416.

²²⁸ Gamson, cited in Bert Klandermans. 1997. *The Social Psychology of Protest*. London: Blackwell Publishers, p. 17.

²²⁹ Gamson, quoted in della Porta and Diani, op. cit., p. 70.

hike) or addressing a wide range of student grievances. Each strategy has its strengths and weaknesses. A single-issue organization that successfully achieves its goal may face extinction, and may have difficulty in attracting a broad base of support than it would if it were addressing multiple issues. On the positive side, an organization pursuing a single issue can successfully stave off dissension and factionalism within its ranks. A multiple-issue approach is particularly useful in that it allows an organization that has achieved a particular goal to shift its energies to other goals, thus providing some degree of organizational longevity. Alternately, however, multiple-issue organizations may spread too thin the resources and energies of the SMO.²³⁰ In addition, this can lead to bitter infighting within the SMO. Gamson's often-cited study of the factors behind social movement success suggests that single-issue groups are more likely to be successful than SMOs addressing a range of goals.

Of the second type of goal, displacing versus nondisplacing, Gamson is referring to a movement's attitudes toward its opponent/opponents. Displacing goals, as the title suggests, seek to remove or replace the group's opponents. In the case of Hepatitis C activism, we might think of two opponents: the government in general and the body that oversees the collection and distribution of blood and blood products. As regards the government, movement activists were less adamant in their call for the government's resignation, although their efforts were aided in this regard by the federal opposition

²³⁰ Gary T. Marx and Douglas McAdam. 1994. *Collective Behaviour and Social Movements*, op. cit., p. 109.

political parties, which seized this issue as an opportunity to lambaste the federal government in general, and Health Minister Allan Rock in particular. The second main opponent, the Red Cross, was the target of displacement strategies by movement activists and in this regard, they succeeded, with the announcement of the overhaul of the Canadian Red Cross and its new institutional name, Canadian Blood Services. Whether the movement was instrumental in achieving this is unclear, given the fact that the Krever Inquiry also recommended that the blood agency be revamped.

A movement faces three types of decisions: institutionalized versus noninstitutionalized action, legal versus illegal, and nonviolent versus violent. A few words of caution are in order: these terms are not mutually exclusive; that is, movement actors might choose noninstitutional action, but eschew violence. Or, conversely, they may opt for a mix of institutionalized tactics and violence. According to Marx and McAdam, if the group chooses to advance its interests through the 'proper channels', it is *not* a social movement. Such an approach, however, freezes out the possibility that movements may opt to blend the institutional with the noninstitutional, as we witnessed in the case of tainted blood activism. The second choice, between legal and illegal means, is admittedly a difficult one for movements. On the one hand, law-breaking may help the movement by eliminating normative and symbolic controls as an effective response to the movement. Law breaking or rule breaking, if used wisely, can be strategically advantageous, since it not only demonstrates to their opponents that fear of arrest will not faze protesters, but also limits the options available to their opponents to control the group, providing, of course, movement activists are careful enough not to cross over from

rule breaking into outright violence. On the other hand, however, such a tactic may hurt the movement in the court of public opinion, by either reversing its previously favourable image in the media or by solidifying previously held negative views. The third choice, violence versus nonviolence, was discussed previously with respect to the AIDS movement. In that section, it was suggested that AIDS activists are careful in their use and support of violence, recognizing violence as a measure of last resort. Any movement that opts for violence must recognize the possible repercussions of such action, both internally and externally. Internally, the use of violence poses the real threat of litigation, which may place undue financial strain on the movement and its resources. Externally, violence may legitimate the use of state-sanctioned force in controlling the protesters. In the short history of the tainted blood movement, however, there are no recorded incidents of violence.

We can identify at least three types of tactics at the disposal of movement opponents. Movement opponents can appeal to: a) normative or symbolic tactics; b) material or political tactics; and c) physical control. Normative or symbolic tactics are often the movement opponent's "first line of defense." They constitute the "proper channels and the norms and symbolic controls" that prompt people to respect the rules of the game.²³¹ Material or political tactics can have both a positive and negative impact on a movement. Physical control is often a last resort of movement opponents, and is

²³¹ Gary T. Marx and Douglas McAdam, *Collective Behaviour and Social Movements*, op. cit., p. 110.

inherently risky for any opponent other than the state, which has the legitimate right to use force to maintain law and order.

As McCarthy *et al.* note, movement strategies, not to mention their success in implementing goals, are often dependent on their ability to win sustained media attention. The media are an especially important target for movements that lack the resources to influence policy makers directly. Since framing is not an end in itself, one must examine how a movement's attempt to frame an issue is translated onto the media landscape. As Gusfield notes, "mass media do more than monitor: They dramatize. They create vivid images, impute leadership, and heighten the sense of conflict between movements and the institutions of society."²³² According to Gamson and Meyer, social movement actors often exaggerate the frame of political opportunity, in an effort to encourage like-minded actors to get involved: "It is not merely a matter of seeing the glass as half-full or half-empty but seeing it as half-full when it is often 90 per cent empty."²³³

Gamson and Wolfsfeld argue that movements need the news media for three major purposes: mobilization, validation, and scope enlargement. While the media rely on social movements to provide "good copy," the authors argue that movements need the media far more than the media need them. As a result of this unequal power relationship, movements must "deal with a potential contradiction between gaining standing (in the

²³² Joseph R. Gusfield, "The Reflexivity of Social Movements: Collective Behaviour and Mass Society Theory Revisited," p. 71. In *New Social Movements: From Ideology to Identity*, op. cit.

²³³ William Gamson and David Meyer, "Framing Political Opportunity," p. 286. In *Comparative Perspectives on Social Movements*, op. cit., p. 286.

media) and getting their message across.”²³⁴ Sometimes, for instance, movement actors must resort to flashy or noisy tactics to attract attention. Getting in, however, is only half of the battle, since this affects how the movement actors are portrayed in the media: “... (T)he framing of the group may obscure any message it carries. Those who dress up in costume to be admitted to the media’s party will not be allowed to change before being photographed.”²³⁵

Of the six hypotheses regarding movement-media transaction identified by Gamson and Wolfsfeld, I deal with one that captures the influence of movement actors on media outcomes, namely: the notion that “the narrower the movement’s demands, the more likely it is to receive coverage that presents it sympathetically to a broader public.”²³⁶ Here I am concerned with how the Inquiry process itself narrowed and in some way shaped the type of media coverage. Did the Inquiry compartmentalize the issues in a manner that was more amenable to media explanation? Did it, so to speak, do the movement’s “dirty work”? In addition, I am interested in the relationship between the narrowing of movement demands and the attendant narrowing of the movement. The authors cite the environmental movement as an example of a broad movement that often focuses on smaller issues (e.g.: recycling) at the expense of the broader structural causes of environmental problems. This is not surprising, however. Movements often negotiate

²³⁴ William Gamson and Gadi Wolfsfeld, “Movements and Media as Interacting Systems,” *AAPSS*, 528, July 1993, p. 121.

²³⁵ Gamson and Wolfsfeld, “Movements and Media as Interacting Systems,” p. 122.

the delicate balancing act between the universal and the particular.²³⁷ In addition, I am interested in exploring the impact of media frames on media coverage of the scandal. Media frames, according to Gitlin, "are persistent patterns of cognition, interpretation, and presentation, of selection, emphasis, and exclusion, by which symbol handlers routinely organize discourse, whether verbal or visual."²³⁸

Outcomes of Protest

The social movement literature offers several ways to capture the outcomes of protest or collective action. Generally, however, it is recognized that outcomes are rarely attributable or explainable by reference to the structural features of the political system, nor to the agents themselves. Rather, outcomes are the result of actors' choices and the political context. Sometimes, actors' choices are constrained by the structure of political opportunity, while at other times the range of choices is conditioned by openings in the structure of political opportunity.

²³⁶ Gamson and Wolfsfeld, "Movements and Media as Interacting Systems," p. 123.

²³⁷ Habermas has criticized social movements for presumably struggling at both the universal and particular levels. For a critique of this view, see Jean Cohen's essay in Johanna Meehan (ed.). 1995. *Feminists Read Habermas: Gendering the Subject of Discourse*. New York and London: Routledge.

²³⁸ Todd Gitlin. 1980. *The Whole World is Watching: Mass Media in the Making and Unmaking of the New Left*. Berkeley, Los Angeles, London: University of California Press, p. 7.

Marx and McAdam divide movement outcomes into four main areas: new political or economic changes; specific legislation; changes in public opinion and behaviour; and the creation of new organizations and institutions.²³⁹ Alternatively, Rochon and Mazmanian evaluate the "success" of social movements along three tracks: policy change, process change, and value change. They argue, citing the examples of the nuclear freeze movement and the hazardous wastes movement, that movements can have a significant effect on policy outcomes by gaining access to the policy process, even if they do not win particular policy changes. The authors, for example, connect the failure and collapse of the nuclear freeze movement to its unsuccessful strategy to alter policy by passing a specific Congressional resolution. Although the resolution was finally passed, "it had no practical significance because it did not affect the actual conduct of superpower diplomacy."²⁴⁰ The second movement, on the other hand, realized that while important policy changes were necessary, "it was just as important to secure an opening of the policy process to greater public participation."²⁴¹ And while such closeness to the institutional reins of power is frowned upon by movement theorists and actors alike, mainly on the grounds that the movement may be coopted by the state, Rochon and Mazmanian argue that such suggestions fail to take account of the direct, positive impact of involvement in the policy process, especially as it relates to the development of

²³⁹ Gary T. Marx and Douglas McAdam, *Collective Behaviour and Social Movements*, op. cit., p. 109.

²⁴⁰ Thomas R Rochon and Daniel A. Mazmanian, "Social Movements and the Policy Process," *Annals of the AAPPS*, 528, July 1993, p. 87.

environment policy. Structural effects are seen as another type of impact, and capture the possibility that movements are not only subjects of structures, their actions may provoke changes in the structure of political opportunity itself, changes that will have affect future movements.

Incorporating some of these insights, I have chosen to think of outcomes in terms of their impact on *tainted-blood recipients*, on *policy*, and on the wider *political opportunity structure*. In the first category, I include the creation and legitimacy of a collective identity, the activation of networks, and the creation of services. In the second, I include the overhaul of the country's blood system, and the compensation victories for people with HIV and people with Hepatitis (both federal and provincial), and the failure to secure a federal compensation package for people infected before 1986 and after 1990. In the third category, I include changes in the policy process, social values, and institutions (Medicare). It should be stressed that my comments with respect to the latter are provisional and must reflect the fact that changes of this nature do not occur overnight. Chapter 6 provides a detailed analysis of outcomes using the three categories outlined above. Specifically, the attention paid to the impact of protest on tainted-blood recipients is intended to capture the fact that the goals of protest are not always external to the movement; engaging in collective action transforms the lives of participants, as well.

²⁴¹ Thomas R. Rochon and Daniel A. Mazmanian, p 84.

Conclusion

This chapter has laid out the intellectual terrain that will ground the analysis to follow. I began by explaining why social movement theory in general and the political opportunity structure approach (or political process model) in particular are ideal tools to explain the emergence of blood activism in Canada. Recognizing, however, that opportunities are not objective facts but subjectively interpreted by movement participants, I emphasized that it is necessary to unpack “political opportunity” and reflect on how opportunities are framed, by activists, through interaction with elites, allies and opponents. The next step is to lay out in greater detail the salient elements of the political opportunity structure that played a role in shaping the politics pursued by tainted-blood recipients.

CHAPTER 4

Elaborating the Structure of Political Opportunity Facing the Blood Movement

Political actors, be they newcomers or seasoned activists, face a multitude of challenges when choosing to pursue collective action. Do they work with their opponents to win change? Do they focus on securing a broad base of support or work to ensure that they have a committed, tightly-knit group of activists willing to press a given issue? Do they organize disruptive actions to get their message across? Tainted-blood recipients in general and people with Hepatitis C in particular, faced similar types of decisions, except for the important fact that many of them had little, if any, knowledge of the political system in which they found themselves. Most, if not all, of these recipients had little experience in dealing with the media. In some cases, such naiveté can work in the favour of political actors who might presume that change is possible with a lot of hard work. As one activist noted, "I was always taught that if something is wrong, then you should speak up. I just believed in my gut that we could make a change."²⁴²

As noted earlier, this dissertation explores how changes in the 'political opportunity structure' influenced the identities and strategies of those activists infected with and affected by tainted blood. Specifically, I am interested in how the POS influenced: a) the nature of political action pursued by recipients of tainted blood; b) the negotiation of the movement's collective identity; and; c) the concrete policy outcomes

and less tangible outcomes. In order to do this, it is necessary to discuss in greater detail those elements of the POS relevant to this study. They were: the institutional framework, elites and allies, and political values/ideas. The openness of the political system is treated here not as a discrete variable, but rather as a function of the three preceding elements. The link between openness and the political opportunity structure is more apparent in repressive states, in which opportunities for challengers may be non-existent. The following diagram illustrates the political context of mobilization, and the relationship between structure, agency, and outcomes.

²⁴² Personal interview with Janet Connors, Ottawa, August 11, 1999.

Figure 4.1: The Political Context of Movement Mobilization

The Institutional Framework

The Commission studying the tainted blood scandal is not dispensing justice, it is dispensing information...

- Editorial, The Globe and Mail²⁴³

The Krever Inquiry

Examining critical “moments” that alter the political opportunity structure often captures the impact of institutions on collective actors. The first, and, arguably, most important, element of the institutional framework was the existence of the Krever Inquiry

²⁴³ *The Globe and Mail*, Oct. 30, 1994, p. A18. In an editorial, the newspaper criticized Justice Krever, who had lashed out at the Canadian Hemophilia Society for leaking the damaging results of a study to the media. Of the leak, Krever reportedly said, “There was nothing to be gained, except some publicity.”

itself. Public inquiries are a unique feature of Canada's political opportunity structure. In this case, however, the Inquiry is not simply a structural determinant of movement outcomes, its creation itself also was a movement goal. This captures the elasticity of the POS concept, and underscores the fact that movement factors not only respond to changes in political opportunity, they may actually make or create opportunities. Media accounts of the scandal, for instance, ignored or downplayed the role movement actors played in the creation of the Inquiry itself, paying attention instead to the influence of elite actors (specifically, the members of the House of Commons Sub Committee who called for an Inquiry). When activist pressure is discussed, it is usually confined to a discussion of compensation, not to the role activists played in creating a political environment that might be responsive to activist pressure for compensation.

The Krever Inquiry had an official mandate to uncover the facts surrounding the blood scandal. Unofficially, however, it provided a public forum for the personal, painful narratives of individuals infected with tainted blood. Krever may have used somewhat sterile language to describe this role, referring to "the roles, views, and ideas of relevant interest groups," but in an interview he explained that the voices of those injured by the blood system were critical to the Inquiry process: "It seemed to me very obvious that to get a full understanding of this, we had to hear from the people affected."²⁴⁴ In addition, Krever said there was some suspicion about him, and there were fears that the Inquiry would amount to little more than a 'whitewash'.

²⁴⁴ Interview with Justice Horace Krever, Aug. 10, 2001.

The Commission's organizational and procedural arrangements reflected both its quasi-judicial and representational objectives. The Inquiry began with organizational hearings in November 1993 to determine which parties would be granted standing. In addition to the Red Cross, the Canadian Blood Agency, and federal and provincial governments, Krever granted standing to nine organizations representing recipients of tainted blood. The Commission then proceeded with its public hearings, which were divided into three main phases. The first phase, from February to December 1994, involved testimony from 315 witnesses across the country. Among the witnesses were people infected with tainted blood, representatives of AIDS-related and community organizations, employees of local Red Cross blood centres, and provincial government officials. Krever was not specific about what he intended to glean from victim testimony, except for noting that he made a commitment to hear from any tainted-blood victim "who wished to relate their experiences to me."²⁴⁵ During the second phase, from March to November 1995, the Commission turned to issues of broader national attention concerning the relationships between and among the key participants in the blood system. A total of 85 witnesses appeared before the Commission during this phase. Phase Three, between November and December 1995, consisted of roundtable discussions on issues affecting the current blood system. The last, unofficial phase of the Inquiry process, and perhaps the most controversial, involved the Commissioner's obligation, under Section

²⁴⁵ Horace Krever, *Commission of Inquiry on the Blood System in Canada*, Final Report, Volume 1, p. 7.

13 of the Inquiries Act, to notify any individual who might be cited in the report for misconduct. Krever identified a total of 95 individuals, corporations, and governments who might be singled out, and who had the right to appear before the inquiry to respond to the allegations. Before this final phase of hearings could begin, however, a number of individuals and institutions named by Krever, including the federal government that ordered the public inquiry, asked the Federal Court to quash the notices and prevent the Inquiry from including the findings in its final report. The government wanted its employees immune from any allegations of blame. According to Krever, the Privy Council Office, which oversees commissions of inquiry and should be divorced from politics, placed undue pressure on him and interfered with his independence as a commissioner.

After more than 18 months of legal wrangling, which took the case up to the Supreme Court of Canada, Krever was permitted to name responsible individuals. But, as Picard pointed out, the victory was bittersweet for tainted-blood recipients. In the time it took to settle the case, more than 300 recipients of tainted blood died, decreasing the financial burden on governments vis-à-vis compensation and/or possible lawsuits.

The Krever Inquiry was a major transformative institution (moment) that placed in sharp relief struggles over recognition and redistribution. According to Nancy Fraser, "the politics of recognition and the politics of redistribution appear to have mutually contradictory aims. Whereas the first tends to promote group differentiation, the second tends to undermine it. The two kinds of claims thus stand in tension with each other; they

can interfere with, or even work against, one another.”²⁴⁶ On the one hand, tainted-blood recipients wanted financial compensation (redistribution from the healthy to the sick), but they also demanded a public acknowledgment of what went wrong and recognition that they were victims of negligence and tragedy. Although it sought to address the redistributive questions that emerged, the Inquiry found itself ill-prepared to deal with the recognition end of the dilemma. While recognizing the importance of representation, and reserving space for recipients to recount their painful narratives, it did not, as Fraser would argue, transform group identities. Rather, it affirmed or encouraged group differentiation. For instance, the discourse that ensued surrounding the issue of compensation distinguished the deserving from the undeserving, and pitted hemophiliacs who contracted HIV against others who contracted Hepatitis C. The recipients of tainted blood, many of whom were previously united under the banner of the Canadian Hemophilia Society, eventually broke off from the group to form their own organization and to build their own identities.

As the Inquiry process unfolded, it became clear that there were sharp differences over who was entitled to be called a victim. Although activism began well before the Inquiry, it was only during the Inquiry that representational issues crystallized within the movement. As Kriesi points out, understanding the role of such moments or events is central to understanding ‘unsettled lives’. While settled lives “are usually governed by common sense – a set of assumptions that has become so unself-conscious as to seem a

²⁴⁶ Nancy Fraser, “From Redistribution to Recognition? Dilemmas of Justice in a ‘Post-Socialist’ Age,” *New Left Review*, No. 112, July/ August 1995, p. 75.

natural, transparent, undeniable part of the structure of the world," when "...daily life becomes disrupted in ways unpredicted by their accumulated knowledgeability, people will require new interpretations, which may be provided by ideologies, highly articulated self-conscious belief and ritual systems aspiring to offer a unified answer to problems of social action."²⁴⁷

While the news of tainted blood began to trickle through affected communities as early as the mid-1980s, not until the start of the Inquiry did the numerous fault lines begin to appear. The Inquiry raised important policy questions regarding who was accountable or responsible for the safety of Canada's blood supply, and addressed the issue of government liability for the failure of the system. While Canada launched one of the most extensive public inquiries on tainted blood in the world, it has lagged behind others on the issue of criminal charges. In France and Japan, for instance, senior health-care officials have been jailed for their roles in distributing contaminated blood and blood products. In Germany, pharmaceutical company executives were convicted.

The Inquiry process also provides a fertile ground upon which to examine issues of representation and/or identity, not to mention the intersection of recognition claims and redistribution claims. Justice Krever recognized the importance of representation when he expressly chose to include the voices of tainted-blood recipients in the Inquiry process.

²⁴⁷ Hanspeter Kriesi, "The Interdependence of Structure and Action: Some Reflections on the State of the Art," *International Social Movement Research*, Volume 1, *From Structure to Action*, edited by Bert Klandermans, Hanspeter Kriesi, and Sidney Tarrow. Greenwich, CT: JAI Press, 1988, p. 363.

As Krever's chief counsel, Marlys Edwardh, told a meeting, Krever's decision to extend standing to organizations representing these recipients was important "in changing the quality of the dialogue that existed from the moment the Commission got started."²⁴⁸ Approximately half of the 474 witnesses who testified during the 10 months reserved for testimony were injured by the blood system. This did not, however, resolve the struggles over the representation of the blood injured; it only reinforced the divisions, as the Inquiry became the site for conflicting claims of victimhood made by competing identities. The Canadian Hemophilia Society was one of the main social movement organizations galvanized into political action following the revelations of tainted blood in the mid-1980s. While the CHS was a dominant player in the hearings, it was not alone in representing tainted blood recipients. A total of seven groups, many of which severed ties with the CHS, were granted official standing at the hearings, not to mention the numerous other stakeholders, including provincial governments, the Red Cross, pharmaceutical firms, and AIDS-related SMOs.

The Inquiry serves as a key historical marker or moment to examine the process of identity formation, asking: How were hemophiliacs represented? How did they represent themselves? How did these representational strategies affect the identities of other groups, such as people with Hepatitis C, the so-called "forgotten victims"? For instance, the CHS was accused of trying, albeit unsuccessfully, to expand its fiefdom by subsuming

²⁴⁸ Marlys Edwardh, quoted in *Open Forum on the Implementation of Justice Krever's Recommendations: Where are we? And what still needs to be done?* Meeting of the National Blood Safety Council, Oct. 7-8, 1999, Toronto, p. 4. The document is available at: http://www.bloodsafety.gc.ca/docs/1999/min/10/m_1099_101-e.html.

the concerns of Hepatitis C sufferers under the hemophilia umbrella. I focus on identity formation in an attempt to challenge commonly held notions of hemophiliacs as occupying a fixed identity position. In particular, I was concerned with the gap between how the recipients of tainted blood viewed themselves individually and collectively, and how they were represented by their representatives and in media discourses. HIV-positive hemophiliacs have struggled to forge distinct identities and avenues for representation in an epidemic that remains linked to a gay-male identity. Moreover, this Inquiry was unique in that movement participants who became active during and after the Inquiry's deliberations clung to identities based, at least in part, on their health status and/or victimhood. Clinging to an identity based partly on one's health status poses myriad, practical problems that would-be participants must overcome if they are to engage in collective action. Collective action requires a great deal of energy, which may be difficult to muster when you are suffering from an illness such as Hepatitis C or HIV. Indeed, extreme fatigue is a common symptom experienced by Hepatitis C patients. The late Michael Callen, a longtime American AIDS activist, offers a useful characterization of the complex interplay between illness and activism:

My friends have their own theories about why I've survived. Some say it's because I have a sense of purpose — a reason to live — and that I'm passionately committed to life. They point to my political activism as Exhibit A. But I've often wondered if they're right. The problem is, my AIDS activism has been a double-edged sword. It has given me a reason to live, but it has also nearly killed me. On the one hand, feeling the first warning signs of yet another bout of bacterial pneumonia, I've said to myself, "I can't die yet; I have congressional testimony to give!" On the other hand, my schedule would probably kill a *healthy* person! The frenetic pace of my life has meant that I've been able to rationalize to myself that I mustn't

be all *that* sick because if I was, I couldn't keep so busy; but the sheer, physical wear and tear on my body, combined with the viciousness of political battles, makes me wonder whether my activism has been good or bad for my health.²⁴⁹

The identity of victim, of course, is not unique to people affected by the tainted-blood scandal. Indeed, an initial preoccupation of radical AIDS activists in North American was the tendency to explain the frightening incidence of AIDS as related directly to government neglect. For instance, ACT UP (the AIDS Coalition to Unleash Power) made much in its political sloganeering of former president Ronald Reagan's refusal to utter the word AIDS before well into the epidemic. The organization's main political slogan, "Silence=Death, was a direct attack on government inaction. Some of the AIDS movement's most radical voices even compared AIDS to government-sponsored genocide.

The effect of the Inquiry on victim mobilization cannot be overestimated. It not only provided an institutional arena within which movement actors could articulate their claims, it legitimized tainted blood as an important political issue. Moreover, the facts uncovered during the course of the Inquiry underscored for the blood injured the severity of the scandal.

²⁴⁹ Michael Callen. 1990. *Surviving AIDS*. New York: HarperCollins Publishers, p. 78.

Federalism

The structure of federalism in Canada means that the political system may appear: a) open at one level, but closed at another; b) open at both levels; and c) closed at both levels. Indeed, the literature on Canadian federalism is unsuitably vague in unpacking the distinctive dimensions of this structure in federal systems. This suggests that attention be paid to the interaction of federal and provincial powers in understanding the distinctively Canadian terrain of collective action vis-à-vis tainted blood. It is also critical to distinguish the impact of federalism on the scandal itself, from the impact it had on infected persons. With regard to the first, Trebilcock et al. point to federalism as one of the main reasons why the blood system failed Canadians. While both the *whole blood* sector and the *blood products* sectors appeared to be centralized on paper, in practice they were "decentralized and diffuse due to the practice of cooperative federalism and entanglement of provincial governments through their funding role."²⁵⁰ With regard to the second, it appears that decentralization, while expanding the movement organizations' access points, also complicated movement strategies. Apart from activists such as Nova Scotia's Janet Connors, who focused on pressing her provincial government, it became clear to other activists that they had to identify at least one enemy (the federal government) or run the risk of losing focus and/or momentum. Not surprisingly, perhaps, much of the action directed at provincial governments emanated from those activists

²⁵⁰ Michael Trebilcock, Robert Howse, and Ron Daniels, "Do Institutions Matter? A Comparative Pathology of the HIV-Infected Blood Tragedy," *Virginia Law Review*, Vol. 82, No. 8, August 1996, p. 1428.

living outside the apex of power in Ottawa, notably in British Columbia and Nova Scotia. The latter province, it should be reiterated, was the first to extend compensation to the spouses and children of persons infected with HIV-tainted blood, a move that prompted the other provinces and the federal government to stand up and take notice. Conners said in an interview that she was physically unable to travel to Ottawa to pressure the federal government, so she opted to fight the issue on her own turf.

Canada's structure of federalism also helped to explain much of the acrimony that ensued over extending compensation to Hepatitis C recipients. The major stumbling block to reaching a deal stemmed from the refusal of provinces to sign on to the package, a claim made repeatedly by senior federal government officials in interviews. One official explained the federal government's approach to reaching a compensation deal with the provinces: "We played hardball by saying to the provinces, 'if you don't get on board, you're going to get left in the dust. The federal government will go it alone and compensate.' The provinces, needless to say, didn't like hearing that because, whether viewed as federal arrogance or what have you, they saw it as being pawns in this game whereby they'd be painted as the bad guys if the feds came out and unilaterally compensated."²⁵¹

The complexity of intergovernmental relations was also brought home when Ontario stunned the rest of the country – and reportedly incensed Prime Minister Jean Chrétien – by offering to compensate those individuals left out of the compensation

²⁵¹ Personal interview with senior government official, February 2000.

package for people infected between 1986 and 1990; this despite the fact that all of the provinces and territories had agreed to the terms of the \$1.1 billion compensation plan announced in March 1998. It was somewhat puzzling that the Ontario government would choose to contradict the position it had agreed to support when it signed onto the package. In addition, in 1997 Ontario's Health Minister, Jim Wilson, angered many in the Hepatitis C community when he suggested that they should go to court if they want compensation. While some activists noted in interviews that Ontario Premier Mike Harris had an opportunity to "do the right thing", the fact that the federal government, in particular the Prime Minister, was at odds with Ontario in the past, suggests that the compensation package may have been a case of political opportunism, a chance for Harris to embarrass the Prime Minister.

As noted earlier, federalism also affected the internal workings of the organizations representing the blood injured. In particular, the Hepatitis C Society of Canada, the national body representing people with Hepatitis C, ran afoul of many members in local chapters throughout Canada, including a particularly acrimonious battle with a chapter in Victoria, B.C., which has since cut ties with the national organization to form its own group. While some local chapters targetted their respective provincial governments, none was as successful as Connors, who forced Nova Scotia's Minister of Health, George Moody, to break ranks with the other provinces and offer provincial compensation to people infected with HIV-tainted blood, including their spouses and children.

Elites/Allies

Political Parties

Not until the revelations concerning Hepatitis C did opposition parties on the national stage begin to take notice of the tainted-blood issue. The entry of the right-wing Reform Party in 1997 as the official opposition in Parliament was largely responsible for creating a political storm around the issue of Hepatitis C compensation. Blood activists recognized that they could capitalize on this opportunity to win support among this fledgling political party. Since opportunities are not unidirectional, however, the tainted-blood scandal represented an opportunity for the party to test its new-found political strength on the Parliament stage, as well. Of all the opposition parties vying for a chance to criticize the incumbent Liberal Party for its handling of the blood affair, the Reform Party was most active on the Hepatitis C file, in itself perhaps a surprising move given the party's attack on excessive government spending. The Party was conspicuously silent on how they could reconcile support for extended compensation with their loud support for fiscal prudence. But Grant Hill said in an interview that it wasn't difficult to see how the two issues – fiscal prudence and extending compensation – were linked. "That was very easy," he said. "It was going to cost more through the courts [not to offer compensation]. It was better to compensate [and avoid the risk of bigger costs in the long run]."²⁵² Hill also acknowledged that the Hepatitis C issue arrived at an important time in the life of the party. "The reason that it helped the party was that we were really identified on fiscal

²⁵² Interview with Grant Hill, Aug. 10, 2001.

issues, but not on compassionate issues.”²⁵³ A reporter who covered the scandal was more direct. “They were fighting the image of being heartless and penny-pinching. This was an opportunity for the Party to turn around this image and show that they had a conscience.”²⁵⁴

While each opposition party demonstrated its support for Hepatitis C recipients to varying degrees during the height of the controversy in the Spring of 1998 and joined recipients in a photo opportunity on Parliament Hill when the opportunity presented itself, the most vocal support came from Reform. Some of the Hepatitis C activists who were interviewed felt that the Reform Party was deeply committed to the issue; they were not, activists insisted, merely taking advantage of an opportunity to pounce on the Liberal government. Indeed, the Reform Party did use its allotted Opposition Day in the House of Commons in April 1998 to debate Hepatitis C compensation. This did not deter Prime Minister Chrétien from alluding to a poll that indicated the majority of Canadians felt that the Reform Party’s support for people with Hepatitis C was politically motivated. Regardless of the party’s motivations, ulterior motives or ideological leanings, Hepatitis C activists were content to work alongside the party to keep the compensation issue on the front burner.

The Hepatitis C issue also divided members of the incumbent Liberal Party, some of whom threatened in private to vote against their party on the issue. While this failed to

²⁵³ Interview with Grant Hill, Aug. 10, 2001.

²⁵⁴ Interview with Mark Kennedy, national health reporter, *The Ottawa Citizen*, Aug. 13, 2001.

materialize, there were several indications that Hepatitis C activists had successfully driven a wedge in the party itself, reportedly prompting Prime Minister Chrétien to take the unusual step of warning the party faithful that a vote in favour of extending compensation to all people with Hepatitis C would have negative repercussions on individual MPs. Grant Hill noted in an interview that several Liberal MPs told him in private that they supported the motion on extending compensation. The warning was serious enough to stifle any public dissent in the Liberal cabinet on the issue. One MP, Carolyn Bennett, who previously sat on the Board of Directors of the Hepatitis C Society of Canada, broke down in tears after voting against the compensation package.

The Media

What is interesting about the case of tainted-blood activism is whether “standing” in the media was granted by extra-media sources. Official standing at the Inquiry hearings, for instance, virtually guaranteed movement actors standing in the media, since much of the coverage of the scandal centered on the proceedings of the Krever Inquiry. The true test for Hepatitis C activists, however, came when they had to sustain media interest in the Hepatitis C story well after the Inquiry had completed its cross-Canada hearings at the end of 1995. Activists were partly aided by the legal troubles that befell Krever and the long delay (almost two years) between the end of the hearings and the release of the final report, the latter serving to keep the issue in the news. While they were able to seize on Krever’s recommendations that governments compensate all recipients of tainted blood, this strategy would not be without its problems. Most notably, the focus on compensation provoked bitter infighting within the Hepatitis C community, when it

became clear that some Hepatitis C recipients would not be eligible for government assistance. Moreover, some activists believed – and continue to insist – that the community should have focused its energy on building a case for criminal liability of individuals who had a hand in their infection, as activists, in tandem with the media, had so successfully accomplished in France.

Like their predecessors – hemophiliacs infected with HIV-tainted blood – Hepatitis C activists fought consistently to frame the tainted blood issue as a scandal, as the result of willful, calculated decisions by government and Red Cross officials. Federal and provincial governments, as well as blood system regulators, insisted that what took place was an unfortunate medical accident, but largely unavoidable, tragedy. Interestingly, while much of the evidence pointing to the French scandal was the result of dogged investigative journalism, the same cannot be said for the Canadian case. With the exception of an important article by Brad Evenson in *The Ottawa Citizen* in 1993²⁵⁵, a great deal of the media attention devoted to Canada's tainted blood saga was, instead, focused on the Inquiry and its aftermath, or consisted of reporting on allegations made by various activists. It is quite common, and indeed simplistic, to blame the media, however. After all, for movements attempting to influence the public and public policy, pointing the finger at the media helps to deflect attention away from them. If issues fail to arouse the requisite anger, a movement or group can target the media for failing to take the given

²⁵⁵ See Brad Evenson, "The forgotten ones: Focus on AIDS victims of blood transfusions ignores other sufferers," *The Ottawa Citizen*, Sept. 17, 1993, p. A1.

issue seriously. But are there instances in which the media should be held to account for its failure to educate, inform, and cajole the public?

Susan Moeller, in a provocative book on the politics of international media reporting, argues that the press are burdened by 'compassion fatigue,' "which acts as a prior restraint on the media. Editors and producers don't assign stories and correspondents don't cover events that they believe will not appeal to their readers and viewers."²⁵⁶ Her argument is sometimes unclear, however, with regard to the source of this fatigue – are the media actively choosing to forgo the coverage of certain events or are they responding to what they view as public "fatigue" with such reporting? But the effects of this are clear. Important international events, she argues, when the media choose to cover them, are reduced to formulaic, sensational, and image-driven coverage. In this cruel lottery, some crises take centre stage, only to disappear as soon as the tantalizing images do. Complex events, some of which cannot be reduced to quick sound bites, are given short shrift, or ignored altogether.

Moeller's thesis is instructive here because it underscores the importance of external factors that might help to explain why movement activists, especially those associated with Hepatitis C, had to struggle to get the media to take notice of the "second scandal". Indeed, the failure of the media to respond to the Hepatitis C scandal may be attributed partly to compassion fatigue. For the media, it seemed that the story of tainted blood ended with the news that almost 2,000 Canadians were infected with HIV-tainted

²⁵⁶ Susan D. Moeller. 1999. *Compassion Fatigue: How the Media Sell Disease, Famine, War and Death*. New York and London: Routledge, p. 2.

blood. Constructing a public case for revisiting the scandal seemed unnecessary. Mark Kennedy, a national health reporter for the *Ottawa Citizen*, said his editors were not particularly interested in the stories he was filing on Hepatitis C in the Fall of 1997 and the Winter of 1998. That is, until the government's announcement of limited compensation. Suddenly, Hep C was meriting front-page treatment in newspapers and was the lead item on TV and radio broadcasts. "Hep C became a big story because governments screwed up," Kennedy said. "It was politically dumb to create two classes of victims."²⁵⁷

Gregory Hamara, the director of communications for the Inquiry, took the media to task for its lack of entrepreneurial reporting and its reliance on the quick sound bites offered by witnesses at the Inquiry:

Yes, the plight of victims made for dramatic television. Yes, their individual stories moved the public. But it would be nice to think – and maybe here I'm being a bit idealistic – that had the media itself been more aggressive in its coverage in the early years of the AIDS epidemic – if the media had put forward the hard questions that demanded answers and commitment by governments – the kinds of questions they're asking the experts today – then maybe action could have been taken that might have resulted in a less devastating medical crisis.²⁵⁸

With little faith in the ability of journalists to uncover the facts, activists did some of the digging on their own. One activist, when recalling his dealings with the media, seemed to

²⁵⁷ Interview with Mark Kennedy, national health reporter, *Ottawa Citizen*, Aug. 13, 2001.

²⁵⁸ Gregory Hamara, "In Critical Condition? The Media Treatment of Canada's Blood Issue," an address to the Annual Law Luncheon of the Public Legal Education Society of Nova Scotia, April 12, 1995.

fancy himself a pseudo journalist, adding: "Did you see the article I put on the front page on the *Toronto Star* last week?" He was referring to an article in which he was quoted, not to an article he wrote. Another activist said of media interest in tainted blood: "The media didn't do the digging. We did the digging and fed it to them. We must have looked through 200 boxes. We were looking for anything regarding what the governments knew, what the pharmaceuticals knew. We were fishing."²⁵⁹

Eventually, the media woke up to the Hepatitis C scandal, but only after a concerted effort on the part of Hepatitis C activists. Blood activists were united in their desire to construct an identity that could counter the prevailing suggestion that they were victims of an unavoidable disaster, like flood victims or victims of Quebec's ice storm. And, with limited help from the media²⁶⁰, they consciously struggled and partly succeeded to move the blood scandal from a "disaster" frame to a "blame" frame. Hallahan and Steele, in their analysis of media coverage of HIV-tainted blood in *The Globe and Mail*, contend that while the Canadian Hemophilia Society played a key role in articulating this framing shift,

...(I)t is also clear that *The Globe and Mail* did not wait for critics to attack either the government or Red Cross for lapses in quality control over the blood supply. Evidence of the *blame* frame appears in *The Globe and Mail* well before the active efforts of the Hemophilia Society to create a public policy calling for the compensation of victims. Although the Red Cross was the target of

²⁵⁹ Personal interview with Durhane Wong-Rieger, July 6, 1999.

²⁶⁰ A handful of journalists who covered the tainted-blood scandal stands out: André Picard (*Globe and Mail*), Brad Evenson (*The Ottawa Citizen*), Mark Kennedy (*Ottawa Citizen*), Dennis Bueckert (*Canadian Press*); and Mike Hornbrook (CBC).

criticisms by sources early in the newspaper's coverage, the evidence from this study suggests that the newspaper and its correspondents – not outside claims-makers – were primarily responsible for the evolution of the *blame* frame during a period that preceded the hemophiliacs' efforts to seek government compensation."²⁶¹

Hallahan and Steele's findings contrast sharply with reporters' own observations that journalists were too slow to respond to the tainted-blood issue. *Globe and Mail* reporter André Picard, who has written by far the most of any Canadian journalist on tainted blood, remarked that journalists such as himself were "too trusting of the so-called experts; we all too often accept their views, however speculative or self-interested, as the unvarnished truth."²⁶² Just as they had accepted uncritically the suggestion that the risk of contracting HIV from blood was one in two million, the media accepted experts at their word when they assured the public that Hepatitis C was 'benign'. Despite the enormity of the tragedy, it should be emphasized that tainted blood did not warrant front-page news until late 1992. As Picard argues, "In an age when the media examine, in minute detail, everything from murder cases to the deliberately vague pronouncements of politicians, it is unbelievable that the infection of more than 2,000 Canadians with the deadly HIV virus and 60,000 more with the debilitating Hepatitis C virus went virtually unnoticed for almost a decade after the first victims started dying."²⁶³

²⁶¹ Debbie L. Steele and Kirk Hallahan. 1998. "Media Framing of the Canadian Tainted Blood Controversy, 1983-1993." Paper presented at the PRSA Educators Academy Research Conference, College Park, Maryland, p. 15.

²⁶² André Picard. 1998. *The Gift of Death*, op. cit., p. 2.

²⁶³ André Picard. 1998. *The Gift of Death*, op. cit., p. 1.

Hallahan and Steele's analysis overstates the role of the media, and neglects the interactions between the media and activists, wrongly presuming that media interest in tainted blood was self-generated. One might assume that Hepatitis C activists would have benefited from the "framing" work of their predecessors (HIV-infected blood recipients), but incorporating Hepatitis C into this 'blame frame' was deeply problematic. Not only were the media slow to respond to the enormity of the second scandal, Hepatitis C activists struggled to counter the suggestion that blame could not be attached to the Hepatitis C issue because regulators and government officials could not have known better.

AIDS-infected hemophiliacs did some of the work of framing this as a scandal, but 'heppers' had to make the case that the blood scandal did not end with HIV infection. They successfully did this in a short period of time. A Vancouver man with Hepatitis C recalled his decision to go public with his story on a local cable program. "Doing the interview was a big step because I not only accepted it [the fact that I had Hepatitis C], I was going public. I felt my story needed to be told because I didn't want people to think that people with Hepatitis C are old, lying in hospitals. Here I am. I'm 32 years old. I look fit. I look healthy. I am your average person, your average home owner and yet I have got something that may possibly kill me."²⁶⁴ The television interview also allowed him to see the 'big picture' and step out of the victimhood trap:

I started turning my focus from feeling sorry for myself, to feeling sorry for other people who have it because I'm in a fortunate position and there are people much worse off than I am. They need

²⁶⁴ Personal interview with Peter Madsen, Victoria, B.C., July 16, 1999.

the help. I don't need the help right now. From that day on, my whole life changed, my whole perception changed toward how I was going to deal with this disease, how I was going to fight it tooth and nail to the end. And if I die in six months, I am going to make a lot of people's lives miserable as far as government, lawyers, politicians, whoever. If I can upset them, then I am doing what I am supposed to do. I am not going to go quietly. I am not going to lie down and allow it to happen. If I just bitch, complain, and argue, then I am just as ignorant as the people who stay silent are.²⁶⁵

To summarize, the media did play a key role in bringing to light the story of HIV-infected blood, but they were slow to respond to the revelations of Hepatitis C-tainted blood. Moreover, one cannot overestimate the role of the Inquiry in providing journalists with an ongoing narrative, replete with the dramatic Inquiry testimony of those injured by the blood system.

Values/ Ideas

I argue that three factors – the legacy of AIDS activism, the role of the legal community in emphasizing American-style litigation over symbolic pursuits, and the burgeoning risk discourse – influenced the “universe of political discourse” in which activists found themselves. The ‘universe of political discourse’ is a shorthand term to denote the boundaries of the political. It is the “terrain on which actors struggle for

²⁶⁵ Personal interview with Peter Madsen, Victoria, B.C., July 16, 1999.

representation... a space in which socially constructed identities emerge in discursive struggle."²⁶⁶

From HIV to Hepatitis C: The Policy Legacy of AIDS Discourse

The activism that emerged in the wake of the tainted blood scandal did not, of course, occur in a vacuum. Just as numerous social movements benefit from the trailblazing efforts of their predecessors – the civil rights movement in the U.S., for instance, fuelled the development of the feminist movement – the tainted blood movement in general and the Hepatitis C social movement organizations in particular owe a special debt to AIDS activism, which has left an indelible mark on many forms of disease-related activism.²⁶⁷ That is not to say, however, that blood activism was a mirror image of AIDS activism.

While ACT UP is one among many organizations dedicated to AIDS activism, it remains one of the most influential. Formed in New York City in 1987, it retains several

²⁶⁶ Jane Jenson, "Representations in Crisis: The Roots of Canada's Permeable Fordism," *The Canadian Journal of Political Science*, December 1990, XXIII: 4, p. 663.

²⁶⁷ AIDS activists have been credited with giving breast-cancer advocates a context within which to press their demands. As one breast-cancer activist told *The New York Times*: "They showed us how to get through to the Government ... They took on an archaic system and turned it around while we are quietly dying." (Quoted in Jane Gross, "Turning Disease Into Political Cause: First AIDS, and Now Breast Cancer." *The New York Times*, 7 January 1991. Susan Love, founder of the National Breast Cancer Coalition, said of the AIDS lobby's influence on breast cancer activism: "Women started to see with the AIDS movement that here was a group of people who took it (power) into their own hands, who said, 'We're going to yell and scream until you give us enough research money and we start to solve this disease.' Women with breast cancer are now saying, 'Hey, we can do that too.'" (Quoted in Claire Hoy, "The Politics of Breast Cancer," *Saturday Night*, (February 1995), p. 26.

chapters in major North American and European cities. Following ACT UP's bold presence at the International Conference on AIDS in Montreal in 1989, two Canadian chapters formed, in Montreal and Vancouver. Although they have since disbanded, the chapters were particularly active during the 1990s. Specifically, I argue that it has redefined disease-related activism in four key respects: 1) it has challenged medical and scientific authority; 2) it has disrupted the traditional modes of protest pursued by people living with illness/disease through its confrontational, in-your-face tactics; 3) it has challenged discursive constructions of patients and of disease/illness; and; 4) it has encouraged grassroots community organizing at the expense of reliance on state action.

First, it has posed a fundamental challenge to the hierarchical relationship between patient and doctor, and the previously unquestionable assumption that expertise rested solely in the hands of the scientific and medical communities. As one AIDS researcher noted, "The doctor isn't the same doctor as when I started in practice... The doctor in the past was somebody who made your decisions for you and held your hand; and ... you would just believe in him."²⁶⁸ AIDS activists became well versed in the medical jargon, amassing as much knowledge as they possibly could about the etiology of AIDS. Commenting on the group's presence at the 1989 International Conference on AIDS, at which ACT UP grabbed its first international headlines, one reporter wrote: "No other medical or scientific conference has seen anything quite like this well-informed consumer lobby. Researchers presenting data from drug trials found their results

²⁶⁸ Thomas Merigan, quoted in Steven Epstein. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley, Los Angeles, London: University of California Press, p. 346.

discussed by the guinea-pigs. Scientists describing new treatments found themselves questioned by people whose lives depend on the answers."²⁶⁹ At the 1996 AIDS conference in Vancouver, B.C., a group of activists symbolized this newfound deconstruction of medical jargon in their conference presentation, "An Assay is a Test," in which they, point by point, 'translated' a scientific report into language understandable by lay people. Their presentation was greeted with thunderous applause by a number of representatives of AIDS community organizations who were in attendance at the conference.

Second, AIDS activists have adopted a confrontational mode of protest that often secures the media spotlight, even though this has aroused some indignation from critics. Events in which members have chained themselves to the doors of corporate headquarters, have become grist for the mill: *Newsweek*, for instance, called AIDS activists "gangsters" as did the *U.S. News and World Report* John Leo. ACT UP, he said, is a "gangster group ... the No. 1 loose cannon of local politics, now powerful and feared."²⁷⁰ ACT UP has also staged dramatic 'die-ins', during which activists draw police-style chalk outlines around each other's 'dead' bodies. Its most popular symbol, Silence=Death, which was introduced to underscore the complacency and inaction of the U.S. government during the early years of the epidemic, is emblazoned beneath a pink triangle, the Nazi emblem once reserved for homosexuals. As Gamson explains, "ACT

²⁶⁹ "On the AIDS barricades," *The Economist*, 30 June 1990, p. 79.

UP takes a symbol used to mark people for death and reclaims it. They reclaim, in fact, control over defining a cause of death; the banner connects gay action to gay survival, on the one hand, and homophobia to death from AIDS, on the other."²⁷¹

Aronowitz views ACT UP "as the quintessential social movement for the era of postmodern politics."²⁷² For Aronowitz "postmodernity in our era of political rule consists ...of the indeterminacy of the relation between electoral outcomes and public policy."²⁷³ Despite its lack of official political power and its marginalized place in AIDS activism – many institutionalized or professional groups have distanced themselves from or condemned various ACT UP 'actions' – ACT UP has managed to score several political victories for people with AIDS, including a successful campaign forcing a pharmaceutical giant to lower the price of AZT, one of the first approved anti-AIDS drugs. Aronowitz traces the organization's success to "a partial breakdown of the legitimacy of the liberal state (where 'liberal' connotes not so much the dominance of political parties of modern social welfarism but a system where 'representation' is considered an adequate measure of legitimate power)."²⁷⁴ Gamson, however, resists the

²⁷⁰ John Leo, "When activism becomes gangsterism," *U.S. News and World Report*, February 5, 1990, p. 18.

²⁷¹ Josh Gamson, "Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement 'Newness'," *Social Problems*, Volume 35, No. 4, October 1990, p. 361.

²⁷² Stanley Aronowitz, "Against the Liberal State: ACT-UP and the Emergence of Postmodern Politics," p. 361. In Linda Nicholson and Steven Seidman (Eds.). 1995. *Social Postmodernism: Beyond Identity Politics*. UK: Cambridge University Press.

²⁷³ Stanley Aronowitz, "Against the Liberal State..." op. cit., p. 362.

²⁷⁴ Stanley Aronowitz, "Against the Liberal State..." op. cit., p. 360.

claim that ACT UP's brand of political action is postmodern. Borrowing from Foucault, Gamson suggests that ACT UP's enemy is not the state per se, but rather an enemy that is "invisible, disembodied, ubiquitous: it is the very process of normalization through labelling in which everyone except one's own community of the de-normalized (and its supporters) is involved."²⁷⁵

ACT UP embodies Melucci's assertions that "movements no longer operate as characters but as signs"²⁷⁶ As Melucci explains, "Movements operate as signs in the sense that they translate their action into symbolic challenges that upset the dominant cultural codes and reveal their irrationality and partiality by acting at the levels (of information and communication) at which the new forms of technocratic power also operate."²⁷⁷ ACT UP's actions on AIDS have demonstrated to society at large that a community can take hold of a punishing condition, and radically transform a community (the gay community) in the process. Using street theatre as their guide, ACT UP activists challenge the assumption that an HIV-positive diagnosis constitutes a death sentence. Indeed, almost paradoxically, AIDS activism becomes synonymous with life itself. A positive HIV diagnosis is not a sign of impending death, activists urge, but rather represents an opportunity to replace a negative construction with a positive, life-affirming one.

²⁷⁵ Josh Gamson, "Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement 'Newness'," op. cit., p. 357.

²⁷⁶ Alberto Melucci, "Social Movements and the Democratization of Everyday Life," in J. Keane (Ed.). 1988. *Civil Society and the State*. London: Verso, p. 249.

²⁷⁷ Alberto Melucci, "Social Movements and the Democratization of Everyday Life," op. cit, p. 249.

Third, much activist energy has been spent trying to resist the language commonly summoned to explain disease, and to repudiate the victim label. For instance, the AIDS community has long insisted on the use of the term "People with AIDS" (PWA) instead of "AIDS victim." As Navarre explains:

Of course there have always been patients who have challenged their illnesses and questioned medical authority, but never before had patients, as a group, affirmed their right to be exceptional. PWAs were saying no – no, we will not be characterized as victims; no, we will not be experimented upon without our complete understanding and approval; no, we will not be medicated without explanation; no, we will not go out with a whimper.²⁷⁸

Arthur Frank, writing on the history of illness, says that AIDS activists have altered our understanding of what it means to be ill. First, he says, they insisted on the term "person with AIDS", rather than "AIDS victim," which, despite its unpopularity in conventional academic texts, is still used frequently in the media. There is some controversy over the use of this term²⁷⁹, but we should acknowledge the importance of this language shift. Not only does it restore the dignity of people who are ill, it paves the way to an understanding of the "sick" person as an active, as opposed to passive, participant in his/her health. Frank also makes an important distinction between disease and illness, which was reinforced by the arrival of AIDS activism: "Illness is the

²⁷⁸ Max Navarre, "Fighting the Victim Label," p. 145. In Douglas Crimp (ed.). 1993. *AIDS: Cultural Analysis/Cultural Activism*. Cambridge: The MIT Press.

²⁷⁹ For an overview of the contested meanings of the language employed in the AIDS discourse, see, among others, Jan Zita Grover, "AIDS: Keywords" (pp. 17-30) in *AIDS: Cultural Analysis/Cultural Activism*, op. cit., and Judith Wilson Ross, "Ethics and the Language of AIDS" (pp. 39-48) in Christine Pierce and Donald VanDeVeer (eds.). 1988. *AIDS: Ethics and Public Policy*. Belmont, California: Wadsworth Publishing Company.

experience of living through the disease. If disease talk measures the body, illness talk tells of the fear and frustration of being inside a body that is breaking down. Illness begins where medicine leaves off, where I recognize that what is happening to my body is not some set of measures."²⁸⁰ At the very least, Frank appears to suggest, the experiences of PWAs have demonstrated to others with life-threatening diseases that it is safe to emerge from their imposed hiding, that they can resist the pain and stigma that often accompany illness: "To lose the sense of stigma, persons with cancer must come in from the margins and be visible ... Every attempt to hide cancer, every euphemism, every concealment, reconfirms that the stigma is real and deserved."²⁸¹

Fourth, AIDS activists such as those associated with ACT UP have become a model for effective grassroots organizing with little or no direct state involvement. It should be stressed, however, that ACT UP is in the minority in refusing state help. Most AIDS community-based organizations are indeed a mixture of both private and public support. They often retain some government-based funding, which is supplemented by aggressive fund-raising.²⁸² While it has been suggested that such a cozy relationship with government may sap their radical potential, Rayside and Lindquist caution against such

²⁸⁰ Arthur W Frank. 1991. *At the Will of the Body: Reflections on Illness*. Boston/New York/London: Houghton Mifflin Company, p. 13.

²⁸¹ Arthur Frank, *At the Will of the Body*, op. cit., p. 97.

²⁸² For instance, the AIDS Committee of Toronto, which has grown to become Canada's largest community-based, non-profit AIDS service organization, has an annual budget in upwards of \$2 million, almost two thirds of which emanates from private sources. The remaining one third comes from the federal, provincial, and municipal governments (Personal Communication, Charles Roy, AIDS Committee of Toronto)

an interpretation, which views state-community "partnerships" with provincial and/or federal government as a barrier to organizations' ability to remain strong, independent voices on behalf of people with AIDS. According to them, "the willingness of various governments to fund community groups has created rather than eliminated the room to generate radical criticisms of state policies."²⁸³ More radical organizations, such as AIDS ACTION NOW! in Toronto (which is similar to ACT UP in its militancy), would not be as effective as they have been were it not for the ability of other, state-funded organizations to provide the necessary services. For the most part, they suggest, community-based organizations have a healthy skepticism of government, much of which is attributed to their experiences in dealing with governments' half-hearted responses to AIDS in the early stages of the epidemic. Many community organizations recognize that the most effective approach to AIDS care/prevention involves a combination of both state-societal involvement, with organizations knowing best how to reach and target at-risk communities. This is not to suggest that a reliance on state sponsorship is devoid of problems. Indeed, Rayside and Lindquist worried about the normalization of AIDS policy into bureaucratic apparatuses, which may "lower the influence of community groups and re-instate traditional approaches to public health."²⁸⁴

To summarize, AIDS activism, and gay and lesbian rights activism before it, blazed a trail for tainted-blood activists, but it was a trail paved with uncertainty.

²⁸³ David Rayside and Evert Lindquist, "AIDS Activism and the State in Canada," *Studies in Political Economy* 39, Fall 1992, p. 69.

Hepatitis C activists, try as they might, have failed to arouse the type of anger that fuelled the AIDS movement. This may be partly explained by the perceived unity of the AIDS movement, which was formed by a group with a largely solidified gay identity, and, conversely, the lack of unity among the Hepatitis C community. It is not uncommon, for instance, to find at a typical meeting of a Hepatitis C support group, a mother whose child was infected during the course of surgery, a career intravenous drug user, and a senior citizen. Although the population of people living with AIDS has diversified with the rising rate of infection among heterosexual women and people of colour, many North American AIDS organizations are still staffed and run by gay men. Moreover, while some AIDS organizations have adopted a more inclusive agenda, they are aided perhaps by the existence of organizations dedicated to helping those diverse sub-populations, including women, minority women, Aboriginal people, Asian-Canadians, hemophiliacs, etc. The main hepatitis C organization that rose to prominence in the wake of the Krever Inquiry continues to struggle over how to best represent its equally diverse membership. In addition, however, the experience of AIDS, which spawned a number of organizations largely free from state control/support to look after the needs of people with AIDS, may have harmed the blood activists' demands for government compensation.

The Legal Discourse

The law 'matters' for social movements in terms of its "catalytic contributions to movement building" (lawyers have played a prominent role in the formation of the women's, civil rights, environmental, and animal rights movements), but also as a

²⁸⁴ David Rayside and Evert Lindquist, "AIDS Activism and the State in Canada," p. 71.

“source of leverage against recalcitrant opponents.”²⁸⁵ According to McCann, there are three ways in which movements can use litigation to strategically further their goals. First, movement actors and opponents alike indeed recognize that litigation “can impose (on opponents) substantial transaction costs in terms of both direct expenditures and long-term financial burdens.”²⁸⁶ In some cases, it is in the best interests of the opponent to essentially cut his/her losses, and avoid the exorbitant legal bills associated with protracted litigation. However calculated as it may appear, it may be argued that governments became receptive to compensation for people with Hepatitis C when it became apparent that the class-action lawsuits launched on behalf of Hepatitis C recipients infected between 1986 and 1990 might expose governments to even more significant financial losses. Interestingly, however, the strategy was not entirely successful, since governments appeared to be unfazed by a class-action lawsuit launched on behalf of persons infected before 1986 and after 1990.

Second, according to McCann, the movement’s powerful opponents often fear that they may lose decision-making autonomy to the courts if they insist on pursuing litigation. This, too, makes resolution or settlement far more attractive and politically prudent. The courts did demonstrate, perhaps indirectly, that they supported tainted blood recipients on a number of occasions. In the first high-profile case brought by a tainted-

²⁸⁵ Michael W. McCann, “How Does Law Matter for Social Movements?,” p. 90. In Bryant G. Garth and Austin Sarat (Eds.). 1998. *How Does Law Matter?* Evanston, Illinois: Northwestern University Press.

²⁸⁶ Michael W. McCann, “How Does Law Matter...,” p. 91.

blood victim, Rochelle Pittman was awarded more than \$500,000 in damages after it was revealed that her family doctor knew but never told her husband that he had received blood from an infected donor during the course of heart surgery. Although the judge in the case warned that the decision was “fact-specific” and should not be taken to apply broadly, tainted blood activists nonetheless applauded the decision.

Another important legal decision that succeeded in demonstrating to tainted blood recipients that, perhaps, justice was within reach, concerned the ability of Justice Krever to ‘name names’ in his final report. Several individuals and institutions – the Red Cross, pharmaceutical firms, and the federal government – tried to prevent Krever from doing so, but, as noted earlier, the courts ruled in his favour. Finally, says McCann, there is the danger of a symbolic loss for opponents in the court of public opinion: “Because citizens in our society are responsive to (legally sensible) rights claims, defiant groups often can mobilize legal norms, conventions, and demands to compel concessions even in the absence of clear judicial (or other official) support.”²⁸⁷ In other words, the power of legal discourse may influence not only movement opponents, but may strike a chord in the broader society, which may raise the risk of hard-line opposition from the movement’s foes.

McCann also addresses the oft-heard criticism that movements may be co-opted by the legal profession, and often lose their radical edge in the process. He suggests that it is premature to conclude that lawyers who become involved with social movements will

²⁸⁷ Michael W. McCann, “How Does Law Matter for Social Movements?” p. 91.

almost always overwhelm the movement, and pursue their own agendas. While there are indeed cases in which lawyers have pursued strategies independent of the movement in question and harmed the movement in the process²⁸⁸, there are several examples in which litigation has augmented the movement's potential for success. In addition, McCann notes, there is some evidence of "cause lawyering" (e.g.: the disabled rights movement), in which lawyers combine legal tactics with political tactics as part of a comprehensive strategy.

While it would be naïve to suggest that the lawyers representing tainted-blood recipients were motivated entirely by altruism, neither were all of the lawyers involved working from the sole perspective of financial gain. Douglas Elliott, for instance, who has worked in the field of AIDS law for several years, recalled in an interview that lawyers such as himself were earning far less money than the battery of lawyers hired by governments and the Red Cross:

You had to be doing it for more than money. The people [who were] representing the bad guys were getting a lot of money. We just eked out an existence. It was very disruptive to our practices. We sat four days a week at the Inquiry sometimes five.... It was like having two full time jobs. I lost a few clients as a result of my Inquiry work. The litigation has been very costly to pursue. The lawyers representing victims have gone years and years without being paid.²⁸⁹

²⁸⁸ One of the most compelling examples is discussed extensively by Jane Mansbridge, who argues that successful litigation before the Supreme Court sapped much of the energy of the women's movement's fight for an Equal Rights Amendment. (See Jane Mansbridge, *Why We Lost the ERA*, Chicago: University of Chicago Press, 1986.)

²⁸⁹ Personal interview with Douglas Elliott, a lawyer representing the Canadian AIDS Society, Toronto, Sept. 1, 1999.

Nonetheless, the announcement in the summer of 1999 that the estimated 50 lawyers who negotiated the settlement of class-action lawsuits launched on behalf of recipients in Ontario, British Columbia, and Quebec would share \$52.5 million provoked angry consternation within the Hepatitis C community. Moreover, it was revealed that the legal fees would be taken from the fund earmarked to compensate claimants. J.J. Camp, a Vancouver lawyer who oversaw the class-action suit for Hepatitis C claimants in British Columbia, defended his firm's portion of the fees (4.375 per cent of the total) to an audience of people with Hepatitis C. In fact, Camp added, what lawyers eventually settled for was considerably less than the percentage agreed to earlier, about 33.3 per cent:

"When I took on the class action in 1996, none of them [the people infected between 1986-1990] could find lawyers. We took the risk that we wouldn't recoup anything."²⁹⁰

Risk Discourse

Theorists as diverse as Ulrich Beck, Mary Douglas, and Anthony Giddens each have addressed the burgeoning discourse on risk, which is characteristic of late modernity. While their approaches differ, each is interested in how notions of risk have permeated society. In Beck's formulation of the "risk society," the critical difference between the risks of today and those connected with industrialization is the former's thoroughgoing power. The risks associated with modernity and the "afflictions they produce are no longer tied to their place of origin – the industrial plant. By their nature they endanger all forms of life on this planet. The normative bases of their calculation –

²⁹⁰ Lawyer J.J. Camp, speaking at HepFest 1999, Victoria, B.C., July 1999.

the concept of accident and insurance, medical precautions, and so on – do not fit the basis dimensions of these modern threats.”²⁹¹ For the purposes of our discussion, Beck’s reference to “social risk positions” is important to consider. As he notes, some people are more affected than others by the production and distribution of risks. The essential difference between risk positions and class positions, according to Beck, is that “in class positions being determines consciousness, while in risk positions, conversely, consciousness (knowledge) determines being.”²⁹² The difficulty arises in the process of amassing knowledge, which, in the class situation, is seemingly evident (the loss of a job, for instance): “No special cognitive means are required for this, no measuring procedures, no reflections on validity, and no consideration of tolerance thresholds. The affliction is clear and in that sense *independent* of knowledge.”²⁹³

In the case of risk situations, however, the risk itself often requires outside validation or articulation. The victimization of people who discover, for instance, that the food they eat may contain hazardous chemicals “is not *determinable* by their own cognitive means and potential experiences.”²⁹⁴ The danger may be invisible, hidden in a cup of tea; it is not tangible to the person assuming the potential risk. Paradoxically, the theorists of risk society suggest that we are both less capable of controlling our exposure

²⁹¹ Ulrich Beck. 1992. *Risk Society: Towards a New Modernity* (translated by Mark Ritter. London: Sage Publications, p. 22.

²⁹² Ulrich Beck, *Risk Society*, p. 53.

²⁹³ Ulrich Beck, *Risk Society*, p. 53.

²⁹⁴ Ulrich Beck, *Risk Society*, p. 53.

to risk, while at the same time the individualization of risk seems to suggest that we partake freely of risky activity. If we accept that the defining of risk is essentially a political act,"²⁹⁵ so too is the defining of a risk group. In the AIDS discourse, risk-group definition often goes hand in hand with the articulation of risk. AIDS activists have long decried the branding of homosexuals as members of a risk group. It is the act, not the person, they have argued, that defines the risk. Society constructs "others" – namely prostitutes, Haitians, and drug users – as risk groups deserving of condemnation, not support. Leiss and Chociolko frame the entire risk question within the ambit of responsibility. Indeed, as they note, the one lesson of their book is: "All of us in modern society have a direct and vital interest in the proper allocation of responsibility for risky activity."²⁹⁶ While concerned primarily with environmental risks and the firms which attempt to shirk their responsibilities, their failure to reflect on the context within which risky activity occurs assumes that isolating the supposed offenders is an end in itself.²⁹⁷

But, as Lyttkens notes, a discourse that presumes a simple connection between risk and responsibility fails to account for the relationship between risk and anxiety: "A risk can be marked not only because it is dangerous in itself but also because of its inability to satisfy basic needs for security, community of feeling and meaningfulness.

²⁹⁵ Kasperson, quoted in William Leiss and Christina Chociolko. 1994. *Risk and Responsibility*, Montreal and Kingston: McGill-Queen's University Press, p. 3.

²⁹⁶ William Leiss and Christina Chociolko, *Risk and Responsibility*, p. 5.

²⁹⁷ They refer to risky sexual activity only in passing as part of a host of other risk behaviours in which "the level of risk is far higher than what many people find acceptable for involuntary risks." (p. 56)

Some of those failings can be nearly impossible to fulfill; such is the case with man's anguish in the face of the enigmas of life and death."²⁹⁸ Nelkin and Gilman extend this argument, explaining that for many "locating blame for disease is in effect a strategy of control. If responsibility can be fixed, perhaps something – discipline, prudence, isolation – can be done."²⁹⁹

As illustrated, the discussion of risk in general is fraught with a host of problems. Risk is a catch-all phrase to describe activity that is deemed as potentially dangerous. It places the burden of responsibility on the backs of the defined risk-takers (members of so-called risk groups) to alter their behaviour for the sake of the common good. As Douglas notes, the meaning of the term "risk" has shifted from its old connection with technical calculations of probability. Economists, for instance, view humans as risk averse; rational actors make their choices according to the "hedonistic calculus." In current political usage, however, risk refers to danger, and high risk "means a lot of danger." Moreover, high risk refers not to the probability of pain or loss, but exclusively to negative outcomes.

The word has been pre-empted to mean bad risks. The promise of good things in contemporary political discourse is couched in other terms. The language of risk is reserved as a specialized lexical register for political talk about the undesirable outcomes. Risk is invoked for a modern-style riposte against abuse of power. The

²⁹⁸ Lyttkens, in Lennart Sjöberg (ed.). 1987. *Risk and Society: Studies of Risk Generation and Reactions to Risk*. London: Allen and Unwin, p. 128.

²⁹⁹ Dorothy Nelkin and Sander Gilman, "Placing Blame for Devastating Disease," *Social Research*, Vol. 55, No. 3 (Autumn 1988), p. 362.

charge of causing risk is a stick to beat authority, to make lazy bureaucrats sit up, to exact restitution for victims.³⁰⁰

Robert Castel, in a discussion borrowing heavily from Foucault, offers a counterpoint to Douglas's discussion of risk. He distinguishes the notion of risk from the previous notion of dangerousness, which was "formerly used to designate the privileged target of preventive medical strategies."³⁰¹ The shift from dangerousness to risk, he says, rests on the presumption of the disappearance of the subject:

The essential component of intervention no longer takes the form of the direct face-to-face relationship between the carer and the cared, the helper and the helped, the professional and the client. It comes instead to reside in the establishing of flows of population based on the collation of a range of abstract factors deemed liable to produce risk in general.³⁰²

The shift from dangerousness to risk effectively downloads responsibility from the state to individual citizens. That is, the state is not concerned with altering those factors which contribute to the spread of diseases such as AIDS – they are given – so much as with ensuring that these factors don't conspire to produce the negative result: reckless transmission of HIV. This "new mode of surveillance" purports to serve the public good in that it promises to produce a deterrent effect – it is presumed that those who know that they may be liable to criminal prosecution if they fail to act responsibly may think twice

³⁰⁰ Mary Douglas. 1992. *Risk and Blame: Essays in Cultural Theory*. London and New York: Routledge, pp. 24-25.

³⁰¹ Robert Castel, "From Dangerousness to Risk," p. 282. In Graham Burchell, Colin Gordon, and Peter Miller (Eds.). 1991. *The Foucault Effect: Studies in Governmentality*. Chicago: University of Chicago Press.

³⁰² Castel, "From Dangerousness to Risk," p. 281.

before placing others' lives "at risk." But, as critics of mandatory testing point out, if HIV transmission becomes a criminal offense, it will discourage many to be tested, since knowledge of an HIV diagnosis may expose persons to criminal prosecution.

According to Kinsman, the emphasis on risk and the apparent refusal of some infected persons to sacrifice their freedom of expression for the sake of public health "does not focus on the responsibilities of others in the same way – the mythical 'general population' (of public health and media discourses) – or on the responsibilities of governments, the medical profession, researchers, and drug companies. It constructs PWAs (People with AIDS) as the 'risk' and the 'problem'."³⁰³ This despite the fact, he notes, that the vast majority of HIV transmission occurs from people who have no knowledge they are HIV positive, or are ignorant of how it is transmitted.

When we examine Hepatitis C through the prism of risk, we can see how the risk discourse simultaneously downplays their health concerns, while magnifying their responsibility. In its written submission to the Krever Inquiry, 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. Joe Haché said when he found out

³⁰³ Gary Kinsman, "'Responsibility' as a strategy of governance: regulating people living with AIDS and lesbians and gay men in Ontario," *Economy and Society*, Vol. 25, No. 3 (August 1996), p. 395.

in 1991 that his son, Joey, had acquired Hepatitis C, he “didn’t think anything of it. We were always told not to worry about it.”³⁰⁴ The family had assumed that the symptoms their son was experiencing were related to his rare form of anemia, which prevents Joey’s body from producing red blood cells.

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, “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.”³⁰⁵ People with Hepatitis C found themselves in the unenviable position of being both *marked* by risk and *erased* as individuals whose health concerns were considered minor or non-life threatening.

The next chapter on collective identity discusses in greater detail how hemophiliacs figured in the risk discourse. Given their reliance upon blood or blood products, hemophiliacs have long been associated with risk. In his final report, Krever goes as far as to suggest that Canada was slow to respond to the dangers of HIV and Hepatitis C because infection was “widely accepted as an unfortunate but acceptable risk of blood transfusion and the use of blood products.” The discovery of infected blood moved this theoretical risk from being a frightening potential to a stark reality.

³⁰⁴ Personal interview with Joe Haché, Ottawa, Aug. 9, 2001. Joe’s son, Joey, cycled across the country for 67 days in the summer of 1998 to raise awareness of Hepatitis C.

³⁰⁵ Joyce M., quoted in Alan Powell, Hepatitis C Society of Canada, Submission to Mr. Justice Horace Krever and the Commission on the Blood System in Canada, July 31, 1996. p. 25.

Openness of/ Access to the Political System

Of course, openness is a contested and highly subjective term. What appears open to one political actor may appear closed to another. Paradoxically, openings also can shut down other opportunities or avenues of protest. The relative openness or closure of the political system is an important variable to consider here because it helps us to understand the factors that hamper or expand movement activity. As discussed earlier, one of the institutions – the Inquiry process itself – played a crucial role in solidifying an identity for tainted-blood recipients. Moreover, the willingness of Justice Horace Krever to hear from people with Hepatitis C and to give the Hepatitis C Society of Canada official standing at the Inquiry signalled to the “forgotten victims” that their struggles were worthy of some form of recognition. For the first-identified group of tainted-blood recipients (HIV-infected), however, the Inquiry was not an opportunity or opening that magically appeared. The Inquiry itself was an opening that activists themselves had a hand in opening.

Recognizing, of course, that opportunities are not objective facts and that the subjective interpretations of movement actors of opportunities are critical, it is still useful to conclude by reflecting on how a number of factors may have expanded or contracted the opportunities of movement participants. This task, however, is complicated by another reality: opportunities are not generalizable to all movement participants. That is, we need to distinguish the impact of opportunities on the two main groups of activists who constitute the blood movement: persons with HIV and those with Hepatitis C. There

is an important reason for doing so: tainted-blood recipients who contracted HIV became active politically years before the revelations concerning Hepatitis C, and, in a sense, are a part of the favourable political opportunity structure that paved the way for Hepatitis C activists to become politically active. With regard to HIV-infected persons, I argue that four factors expanded their opportunities (AIDS discourse, media interest, and the French scandal), and that one factor, homophobia, especially within the hemophilia community, initially contracted their opportunities. The Inquiry is both cause and effect, in that a goal of HIV-infected blood recipients was establishing an Inquiry in the first place. Once it was created, however, the Inquiry reinforced the fact that activists had indeed succeeding in exploiting other openings in the political system.

Figure 4.2: The Political Opportunity Structure: Contributing Factors

CONTRIBUTING FACTORS	HIV-INFECTED BLOOD RECIPIENTS	HEPATITIS C-INFECTED BLOOD RECIPIENTS
Krever Inquiry	Reinforced opening	Opening
Federalism	Opening	Narrowing
Political Parties		Opening
Media	Opening	
AIDS Discourse	Opening	Opening
Legal Discourse		Opening
Risk Discourse		Narrowing
French Scandal	Opening	
Homophobia	Narrowing	

Openings, Narrowings for HIV-infected Blood Recipients

As news begin to spread about the victims of HIV-infected blood, the profile of AIDS was increasing. By the mid to late 1980s, AIDS was generating a great deal of public controversy, not to mention government concern. In 1987, the prestigious Royal Society of Canada established four subcommittees to study AIDS. One of them, the legal-ethical committee, released a widely read report, *AIDS: A Perspective for Canadians*, in which one of the first formal recommendations of compensation was made. For better or for worse, AIDS had entered the public lexicon. Those infected with HIV through the

blood system, however shunned and stigmatized, did not have to explain the seriousness of the disease. It was assumed, given the paucity of effective drugs available on the market in the 1980s, that their days were numbered.

In 1989, Montreal hosted the Fifth International AIDS Conference, the largest gathering of AIDS specialists in the world. Aside from the regular paper-giving that is common to academic conferences, noisy demonstrations by AIDS protesters took place outside, some of which took direct aim at then Prime Minister Brian Mulroney. Less than six months after the conference and just weeks before the Christmas holidays, Federal Health Minister Perrin Beatty announced a compensation package for people with HIV-tainted blood. It appears that the government's timing of the announcement was intended to avoid the glare of media publicity. The government would have preferred to "play up" the announcement, according to one government official, but chose to respect the claimants' wishes that the news be kept low key.³⁰⁶

HIV-infected blood recipients were positively influenced by events outside of Canada, as well. As noted earlier, the conviction of four public health officials in France helped to cement among activists a belief that the Canadian scandal might result in similar charges being laid against politicians. The French story began to appear in the North America media in 1992, but for the most part, the anglophone media remained unaware of the story because, according to one journalist, few of them bothered to read

³⁰⁶ Interview with senior federal government official, February 2000.

French newspapers.³⁰⁷ By this time, *The Globe and Mail*'s André Picard, among others, began to pursue the story. One of the biggest challenges was putting a human face on such a complex story. Few of the infected individuals were comfortable with the prospect of having their stories told in the newspaper, but after some reluctance, a few began to tell their stories to Picard. It was not until the 1993 French conviction that "tainted blood" merited front-page news in the major news outlets. In May of that year, the House of Commons Sub-Committee on Health Issues had released its report, "Tragedy and Challenge," which hinted that there might be an inquiry. Soon after, Health Minister Benoît Bouchard, whom had earlier insisted that a full-scale inquiry was premature, made it official.

I earlier identified federalism as a factor in expanding opportunities. It should be stressed that on the whole, the division of powers between federal and provincial governments frustrated blood activists' attempts to press their claims. The compensation issue, for one, became mired in jurisdictional bickering between the provinces and the federal government. Provinces were steadfast in their refusal to support the extension of a federal assistance plan for HIV-infected blood recipients, which was set to expire at the end of 1993. They only relented and agreed to extend assistance followed a spirited campaign by Janet and Randy Conners, who persuaded Nova Scotia's Health Minister, George Moody, to help that province's recipients.

³⁰⁷ This was noted in an interview with André Picard, who said that he benefited tremendously from being posted in Montreal. One of the requirements of his job was to track events in French newspapers. (Personal interview, Aug. 17, 2000, Ottawa)

Secondly, homophobia prevented many tainted-blood recipients from speaking out publicly for fear of being 'outed'. This was especially pronounced within the hemophilia community, which had a high incidence of HIV. As noted earlier, hemophiliacs were especially vulnerable to this accusation because their condition prompted classmates to label them frail or effeminate.

Openings, Narrowings for Hepatitis C-infected Blood Recipients

With regard to Hepatitis C, I identify four openings: the AIDS discourse (and the saga of HIV-infected tainted blood), the Inquiry process, rival political parties, and the legal discourse. Regarding closings or narrowings of opportunity, I identify the parliamentary vote in 1998, federalism, the risk discourse, and, paradoxically, the compensation package offered to some blood recipients, as important variables.

The impact of the AIDS discourse was far-reaching but not uniform in its impact. It simultaneously opened a space for other recipients of tainted blood to articulate their concerns while serving as a reminder that the plight of people with Hepatitis C victims was not as tragic as that of those with HIV. On the whole, however, the saga of AIDS-tainted blood opened a window of opportunity for victims of iatrogenic illness. While the Inquiry solidified a place for the recipients of HIV-tainted blood, it played an even larger role in legitimizing Hepatitis C, and Hepatitis C activists, as worthy of public attention. Krever's decision to grant intervener funding to the newly formed Hepatitis C Society of Canada, allowed the group to play a formal role in the Inquiry. Group leaders nonetheless bemoaned Krever's refusal to extend funding to the group for legal counsel, which he had

extended to other intervenor groups. The entry of the Reform Party as the official opposition in May 1997 was a second factor. The Party was eager to make a splash on the parliamentary stage and saw Hepatitis C as a means to that end. In particular, the party's health critic, Dr. Grant Hill, followed the issues closely and grilled the government in the House of Commons.

Just as people infected with HIV had used the courts to press for government action, Hepatitis C recipients stepped up their fight by launching class-action suits in Ontario, Quebec, and British Columbia. Although activists later regretted their decisions to place their future in the hands of lawyers and openly criticized the fees collected by the lawyers, the prospect of a costly, protracted legal battle signalled to federal and provincial governments that a compensation package might be the best decision, politically and financially.

With respect to narrowings in opportunity, one would not expect to cite the announcement in March 1998 of the limited compensation package for people infected between 1986-1990. In fact, however, while it did spark a flurry of media attention, its main effect was to divide the already fragile Hepatitis C community. People who were eligible for compensation had to choose between solidarity with others who were left out of the package, or concern with their own situation. Many opted for the latter. The House of Commons vote on extending compensation, which came a month later, dealt a major blow to Hepatitis C activists. Media attention during the period leading up to the vote appeared to be unrelenting, suggesting that perhaps the Liberals would be unable to reign in their backbenchers, some of whom were threatening to vote for the motion to extend

compensation to all people with Hepatitis C. In the end, the Liberals defeated the Reform Party-led motion.

CHAPTER 5

Related by Blood: Unravelling Collective-Identity Formation

Jo-Anne Manser remembers the incident all too well. The Hepatitis C activist had just appeared on the nightly news criticizing the federal government for failing to compensate all people infected with Hepatitis C. A close friend, upon seeing her interviewed on TV, suddenly stopped coming over for her regular visit. “She did have the decency to tell me it was because of my Hepatitis C. And although I assured her that I could not transmit it to her, she wanted to be better safe than sorry... My son also had to endure terrible comments at school...”³⁰⁸ It suddenly struck Manser that, for better or for worse, Hepatitis C finally meant something in the public imagination. For years, activists like Manser had fought to create an identity for people with Hepatitis C – as a collectivity worthy of government and public attention, and as distinct from other recipients of tainted blood. They communicated via the Internet, swapping medical horror stories, catching up on the latest treatment news, all in an effort to build out of their devastation a vibrant, close-knit community.

Manser recalled that she initially bristled at suggestions she was an ‘activist’. Rather, she considered herself an advocate for people with Hepatitis C: “Activist for me conjured up visions of people throwing bombs. But I realized that it is a very short step from advocacy to activism. When you’re advocating for someone, you’re looking for resources to help people. When they don’t exist, then you have to invent them, or you

³⁰⁸ Interview with Jo-Anne Manser, Hepatitis C activist, Ottawa, March 19, 2000.

have to go to the people who have them (the resources). And then all of a sudden you're an activist."³⁰⁹ The incident, on one cold November morning, affirmed to her for the first time that activists had succeeded in creating a collective identity. The process began a few years earlier, when Hepatitis C activists staged their first protest, in front of the Ottawa offices of the Canadian Red Cross. At the time, a court challenge was under way to prevent Justice Horace Krever from "naming names" of responsible individuals and organizations in his yet-to-be released report. The activists wanted to press their claim that Krever should not be silenced. As Manser explained:

We didn't really know anything (at the time). All we knew was that they were trying to muzzle Krever. We had a couple of union people in the group. We got out our construction paper and wrote these signs, "Let Krever Speak," something that encapsulated what we wanted to say. We put out a press release. Our goal was not to harass the Red Cross employees. It was amazing, truly overwhelming. There was a whole pack of media there. People were there who didn't really understand. All we knew was that these big industry leaders were trying to shut up the judge who could shed light on something to do with Hepatitis C. So we did that and it was kind of exciting, the media turnout, the people who turned out. To take part in something like that and see a 30-second blip on the news, *it does something to people*, even if they don't truly understand the whole story themselves. It brought us together under a common bond... One thing about this disease is that you feel so isolated, so hopeless and helpless, that if you can get together and do something positive, and see some evidence that you have made some kind of difference, it does something to you. We had people out there with fevers popping Tylenol, people taking a break to sit in the shade, people on interferon therapy.³¹⁰

³⁰⁹ Interview with Jo-Anne Manser, Ottawa, March 19, 2000.

³¹⁰ Interview with Jo-Anne Manser, Ottawa, March 19, 2000. Emphasis added.

Two years later, in the weeks leading up to the House of Commons vote in March 1998 on extending Hepatitis C compensation to all infected persons, Hepatitis C activists stepped up their protest campaign. Ottawa activists planted crosses outside the lawn of Parliament Hill to underscore the deaths from Hepatitis C. As federal and provincial health ministers met behind closed doors to discuss compensation, three protesters stood outside the building, one with his hands covering his eyes, another with her hands covering her mouth, and another with his hands blocking his ears, to symbolize their frustration. That image was reproduced in newspapers across the country.

Meanwhile, in Victoria, B.C., a small group of activists took their rage to the steps of the provincial legislature. In a scene reminiscent of the political theatre staged by radical AIDS activists,³¹¹ Hepatitis C protesters made a mock coffin with one of their members laying inside, grasping a copy of the Canadian Bill of Rights. An activist dressed as the Grim Reaper stood behind the coffin. Hanging around his neck was a sign that read, "Tainted Blood – The Grim Reaper Calls," and "Bonjour, I'm collecting for the Liberals." In his best French accent, the Reaper intoned, "We must consider the pain and suffering of the people of Kosovo, we must consider the civil rights of the people of China and we must consider the civil rights of the people of Cuba." At this point, the 'corpse' sat up and interjected, "What about my pain and suffering?" What about my civil rights?" The Reaper replied, "Shaddup (sic). You're just a Canadian," before

³¹¹ One of the most dramatic examples of AIDS activism originated in New York City, where ACT UP protestors staged 'die-ins', during which protestors fall to the ground while other activists draw police-style, chalk outlines around their "dead" bodies.

pushing the 'corpse' back into the coffin.³¹² Events such as the one described above are crucial not only to mobilization but to the creation of a collective identity.

This chapter is concerned with elaborating some of the factors that facilitated the formation of this identity among tainted-blood recipients, as well as the internal and external obstacles that prevented this identity from fully solidifying. Not surprisingly, perhaps, the issue of identity and its representation is of constant, frustrating concern to movement activists. Indeed, a growing body of social movement literature is now devoted to the subject.³¹³ As Castells reminds us, there is little disagreement that all identities are constructed: "The real issue is how, from what, by whom, and for what."³¹⁴ I begin by outlining some of the theoretical points of convergence and divergence within the 'collective identity' school, addressing the critiques of identity politics, before proceeding to explore some of the forces that facilitated the formation of a collective identity among tainted-blood activists in general and that subset of Hepatitis C activists, in particular. I group these forces under three main headings: naming, blaming, and claiming.

³¹² This account draws from an article by Ron Thiel, "Rally," in *hepc.bull*, B.C.'s Hepatitis C News Bulletin, Issue no. 13, June 1999, p. 5, published by the Victoria chapter of the Hepatitis C Society of Canada.

³¹³ The burgeoning literature on new social movements is a case in point. See Claus Offe (1985), Alberto Melucci (1989), Hank Johnston, Enrique Larana and Joseph Gusfield (1994) and Craig Calhoun (1994), among others. For a critical review of the literature, see Nelson A. Pichardo, "New social movements: A Critical Review," *Annual Review of Sociology* 1997 (23), pp. 411-30.

³¹⁴ Manuel Castells, *The Information Age: Economy, Society, and Culture, Volume II, The Power of Identity*, London: Blackwell Publishers, 1997, p. 7.

While collective identity occupies a privileged place in the literature on NSMs and is often summoned to distinguish recent movements in Europe from those in the U.S., I argue that understanding and unravelling collective identity is crucial to understanding all social movements, not just those of the "new" variety. The American social movement literature, it should be stressed, does not neglect the role or existence of collective identity, but instead has been more influenced by the resource-mobilization approach, which is interested in elaborating the influence of organizational factors on movement mobilization and outcomes.

As Taylor and Whittier note, the approach favoured by 'new' social movement theorists wrongly tilts the balance in favour of culture, sapping social movements of much of their political significance: "... (I)t provides little understanding of how the injustices that are at the heart of most movements are translated into the everyday lives of collective actors."³¹⁵ Focusing on the role of meaning in the mobilization and maintenance of collective action is an attempt to address these concerns. Collective identity is one of the three crucial aspects of agency identified in Chapter 3. (The other two are framing and strategy choice.) In addition, this chapter suggests that current theorizing on collective identity often fails to capture fully the distinctive features of disease-related identities, for which it is not always easy to muster support. Framing a collective identity to which participants can relate is already an admittedly difficult task; trying to do so in the face of the stigmatizing meanings assigned to this identity, not to

³¹⁵ Verta Taylor and Nancy Whittier, "Collective Identity in Social Movement Communities: Lesbian Feminist Mobilization," p. 123. In *Frontiers in Social Movement Theory*, op.cit.

mention the sheer wear and tear of disease on a group's ability to mobilize, further complicates this challenge.

Theories of Collective Identity

As Friedman and McAdam argue, for a social movement organization collective identity "is a shorthand designation announcing a status – a set of attitudes, commitments and rules for behaviour – that those who assume the identity can be expected to subscribe to."³¹⁶ In addition, they note, collective identities bind individuals to others, they connect us to people with common causes and concerns. These benefits identities confer on its members function as "selective incentives" that help movement organizations to motivate individuals to pursue collective action. This does not, however, make collective identity politically relevant. According to Klandermans, "collectively defined grievances that produce a 'we' feeling and causal attributions that denote a 'they' which is held responsible for the collective grievances are needed for transforming routine ingroup-outgroup dynamics into political conflict."³¹⁷

Collective identity, to recall Melucci's definition, refers to "the field of opportunities and constraints offered to collective action."³¹⁸ Following Gamson, I use

³¹⁶ Debra Friedman and Doug McAdam, "Collective Identity and Activism: Networks, Choices, and the Life of a Movement," p. 157. In *Frontiers in Social Movement Theory*, op. cit.

³¹⁷ Bert Klandermans, *The Social Psychology of Protest*, op. cit., p. 41.

³¹⁸ Alberto Melucci, "The Symbolic Challenge of Contemporary Movements," *Social Research* 52 (Winter 1985), p. 793.

Melucci's notion of collective identity as it successfully bridges the gulf between what Cohen has called the 'identity oriented' and 'strategically oriented' paradigms.³¹⁹ We cannot, as it were, understand movement goals and tactics without some reference to the complex social relationships between actors, nor can we fully grasp the importance of collective identity processes without attention to how these identities translate into successful or unsuccessful strategies. As Bartholomew and Mayer argue, however, this notion needs to be liberated from its cultural reductionism: "The construction of collective identity may not be exclusively the outcome of processes in the sphere of symbolic codes, but may be shaped, also, by political struggle and the relationship between political and cultural dimensions of a movement."³²⁰

This chapter seeks to capture the influence of identity on movement strategy, and how identity itself – its construction, its renegotiation, and its strength or fragility – is linked to the political opportunity structure in which movement actors find themselves. This is not to suggest, of course, that the political opportunity structure fully determines movement identity, strategy, and outcomes, since, as we noted earlier, movement participants must be cognitively aware of the structure, its opportunities and constraints,

³¹⁹ I should caution here that the notion of collective identity is not without its critics. Klandermans argues that there is "no such phenomenon as a stable collective identity which, once formed, governs collective action. Instead, I suggest that collective identities are transient phenomena. There is every reason to assume that the collective identity of movement participants changes over time as the life cycle of a movement evolves." (Bert Klandermans, "Transient Identities? Membership Patterns in the Dutch Peace Movement," p. 169. In *New Social Movements: From Ideology to Identity*, op. cit.

³²⁰ Amy Bartholomew and Margit Mayer, "Nomads of the Present: Melucci's Contribution to 'New Social Movement' Theory," *Theory, Culture & Society*, Vol. 9 (1992), p. 152.

if they are to act. As della Porta and Diani explain, however, variables of a strictly political nature can influence actors' self-perceptions. Citing Lowi, they note that the process of collective identity "can be explained by reference to a reformulated version of the well-known argument that forms of policy-making direct forms of political action, not vice versa. Social actors, in fact, tend to recognize themselves in certain characteristics, but not in others, in a way which is coherent with particular policy networks or the issues which inspire certain public policies."³²¹ For example, Asian-American identity, they note, cannot be explained by sole reference to the independent actions of social actors themselves. Rather, one must look to areas such as immigration policy and the government's treatment of minority groups, which gloss over differences within the Asian community and produce identities and interests that neglect or overlook the real differences among members of the Asian community. In the case of tainted blood, the decision to compensate only some of the people who contracted Hepatitis C through tainted blood, is viewed as one of the main political variables that weakened collective identity. This is not to say, however, that Hepatitis C activists were fully united under a common banner before the decision to limit compensation was made. Rather, the governments' strategy, to offer assistance to recipients infected between 1986 and 1990, compounded internal problems that were already present.

Movements then, contrary to Melucci, do not operate merely as 'signs', nor are they unconcerned with the "production and distribution of material goods and

³²¹ Della Porta and Diani, *op. cit.*, p. 96.

resources.³²² According to him, movements “are instead concerned mainly with information – in both the narrow sense of demand for factual information about, say, the siting of a nuclear plant, and in the broader sense of struggles over public resources, as in the challenge of the women’s movement to sexist advertising.”³²³ Melucci is indeed correct to suggest that information is an important resource for movements, especially when considering the efforts that were made to suppress any potentially damaging information related to the scandal. In the case of tainted blood, activists spent a great deal of energy amassing information through government access-to-information requests and the like. But blood activists were not interested in information for information’s sake. Instead, this was connected to broader goals, such as substantiating their demands for compensation and for the criminal prosecution of responsible individuals.

Forms of Collective Identity

In an attempt to understand the benefits collective identity confers on its members, Castells distinguishes three forms of identity building:

Legitimizing identity: introduced by the dominant institutions of society to extend and rationalize their domination vis-à-vis social actors.

Resistance identity: generated by those actors that are in positions/conditions devalued and/or stigmatized by the logic of domination, thus building trenches of resistance and survival on the basis of principles different from, or opposed to, those permeating

³²² Alberto Melucci, *Nomads of the Present*, op. cit., p. 205.

³²³ Alberto Melucci, *Nomads of the Present*, op. cit., p. 205.

the institutions of society, as Calhoun proposes when explaining the emergence of identity politics.

Project identity: when social actors, on the basis of whichever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformations of overall social structure.³²⁴

The first type of identity-building leads to the creation of a civil society, which, in turn, reproduces “the identity that rationalizes the sources of structural domination.”³²⁵ The second, which may be the most important type in Castells’s view, generates the formation of ‘defensive’ communes or communities. The lesbian separatist movement and religious fundamentalism are examples of this trend, which Castells terms “the exclusion of the excluders by the excluded.”³²⁶ The third type produces subjects, “the collective social actor through which individuals reach holistic meaning in their experience.”³²⁷ It is difficult to say with any degree of certainty where we can situate blood activists within this typology, since the identity they succeeded in creating seems to retain elements of all three. In the first place, one may argue that the identity is legitimizing in the sense that it has generated “a series of structured and organized social actors, which reproduce, albeit in a sometimes conflictive manner, the identity that

³²⁴ Manuel Castells, *The Power of Identity*, op. cit., p. 7.

³²⁵ Manuel Castells, *The Power of Identity*, op. cit., p. 8. Castells is using the Gramscian concept of civil society, not the typically positive meaning employed by mainstream scholars of civil society studies. Civil society is noted for its double character, “which makes it a privileged terrain of political change by making it possible to seize the state without launching a direct, violent assault.” (Castells, p. 9)

³²⁶ Manuel Castells, *The Power of Identity*, op. cit., p. 9.

³²⁷ Manuel Castells, *The Power of Identity*, op. cit., p. 10.

rationalizes the sources of structural domination.” In the second, one may argue that the identity is rooted in resistance. That is, some tainted-blood recipients have withdrawn from mainstream political life to form their own communities of support. Indeed, one witnesses some version of this in parts of British Columbia, where activists have severed ties with their national organization. This type of defensive identity is seemingly borne of the extreme cynicism vis-à-vis government felt by recipients of tainted blood. In the third instance, project identity, social actors use their newfound identity to advocate for sweeping changes in our overall social structure. Of the three, this is by far the most ambitious.

It is critical to recognize that when speaking about collective identity, we are not simply referring to the active identity formation of a movement, but to pre-existing identities, as well. Tilly provides a useful illustration of this in his discussion of “embedded” and “detached” identities. Embedded identities are so named because they are located in the everyday lives of citizens. Examples include the common cleavages that animate politics, such as race, gender, ethnicity, and class. As Tilly explains: “Although they usually operate on a small scale, when under attack by power holders and enemies embedded identities such as religious affiliation and ethnicity can become the basis of fierce, extensive contention.”³²⁸ Two noteworthy examples are the breakup of the Soviet Union and the Protestant Reformation. Detached identities, by contrast, rarely govern

³²⁸ Charles Tilly, “From Interactions to Outcomes in Social Movements,” p. 264. In *How Social Movements Matter*, op. cit.

social relations. Examples include associational memberships and legal categories such as “minority”, tribe” or “disabled persons.” The degree to which identities are embedded or detached matters, according to Tilly, because they affect “the quantity of widely available knowledge they can draw upon, the density of underpinning social ties, the strength of conflicting commitments, the ease of emulation from one setting to another, and therefore the effectiveness of different organizing strategies.”³²⁹

Elaborating the process of collective identity is helpful not only in attempting to explain movement formation, but movement strategy and possible fragmentation, as well. While resource mobilization theorists tend to trace a movement’s failure to a lack of resources, whether human or financial, perhaps we should be looking to collective identity as the possible ‘phantom’ variable or source of explanation. This is not to suggest that we dispense with the task of examining the strategies and resources used by the blood activist movement. Rather, we need to connect this question to a broader consideration of how identity informs movement strategy and outcomes, since each victory or loss, in turn, is crucial to movement actors’ self perceptions as well as outside perceptions of the movement. A movement still smarting from a key defeat is unlikely to be viewed as a force to be reckoned with, nor is it likely to recover from the sheer humiliation of a particular loss.

The account of collective-identity formation offered here departs from traditional accounts that are common to social movement scholarship. Typically, for instance,

³²⁹ Charles Tilly, “From Interactions to Outcomes in Social Movements,” p. 265. In *How Social Movements Matter*, op. cit.

movements that have successfully forged a collective identity are presumed to face the added problem of trying to control its consumption. In such analyses collective identity assumes the properties of a public good, in the sense that all can consume it without contributing to its production (Olson's free-rider problem). Friedman and McAdam point to several examples of social movements for which this problem is most apparent. For instance, many women who were influenced by the feminist movement have embraced a feminist identity, but "the identification carried with it no obligation to join a feminist organization or to participate in forms of collective action intended to realize equal rights for women."³³⁰

The main problem with this formulation and the perspective of collective identity as a public good is its implicit assumption that the collective identity being forged is almost always a positive one. This may be correct in the case of the feminist and student radical labels discussed by McAdam and Friedman, but not so if we examine collective-identity formation among tainted-blood recipients. Indeed, the opposite is true. Activists faced an uphill battle in forging a collective identity because members were reluctant to reveal their HIV or Hepatitis C status for fear of ostracism from their respective communities. From the moment recipients organized politically, they were confronted

³³⁰ Debra Friedman and Doug McAdam, "Collective Identity and Activism: Networks, Choices, and the Life of a Social Movement," pp. 166-167. In *Frontiers in Social Movement Theory*, op. cit.

with trying to manage what Goffman has termed a “spoiled identity.”³³¹ To be infected with tainted blood implies that the person is him/herself tainted in some way, leaving aside for the moment the type of infection, Hepatitis C or HIV, and the nature of infection (injection drug use, unprotected sexual activity, transfusion, or the use of blood products in the case of hemophiliacs). Much has been written about the myths that fuelled AIDS hysteria³³², many of which were based on fears of the unknown. People with Hepatitis C noted in interviews that they too were discriminated against by friends and family alike, many of whom treated them as social outcasts or pariahs. The stigma that had so insidiously attached itself to people with AIDS in the early stages of the epidemic, when experts were unsure whether it was safe even to kiss a person with HIV, spread also to people with Hepatitis C. As one Hepatitis C activist explained in an interview, “I went through my dentist dropping me as a patient, my food tray being left in the hall of the hospital. I had to reassure my son’s teachers. All of a sudden it was like I had become the Hep C lady.”³³³

All of this is not to suggest, however, that the free-rider problem was not present. Indeed, this negative identity, with which movement activists were confronted, helped to produce a free-rider problem of sorts. Many tainted-blood recipients who were infected

³³¹ See Erving Goffman. 1963. *Stigma: Notes on the Management of Spoiled Identity*, Eaglewood Cliffs, NJ: Prentice Hall.

³³² These fears were not unwarranted. In the late 1980s, for instance, the citizens of Arcadia, Florida set fire to the house of the Ray family, whose three hemophiliac children had HIV.

³³³ Personal interview with Jo-Anne Manser, Hepatitis C activist, March 19, 2000, Ottawa.

during the 'magic' time period for which the government was willing to offer assistance stepped forward to accept compensation, but they distanced themselves from the broader community of blood activists, fearing that any association with the community might expose them to pain and stigma. It seemed that they were content to 'free-ride' off the backs of those activists who worked tirelessly to press the compensation issue even though some of these same activists knew they would be ineligible for compensation. Stigma, then, affects not only the individual who must suffer its effects, but has very real consequences for movement actors. The literature on collective identity, especially within social movement scholarship, assumes that identity is always a positive attribute, and neglects the possibility that movements may be faced with the arduous task of trying to reverse or alter the negative identities inscribed upon them. In all of the various instances of stigma identified by Goffman, the same sociological features can be found.

An individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated. We and those who do not depart negatively from the particular expectations at issue I shall call the normals... By definition, of course, we believe the person with a stigma is not quite human.³³⁴

Friedman and McAdam explain movement recruitment problems as a direct outcome of movement success in forging a powerful collective identity: movements that are successful in demonstrating to those in power that there is greater constituency

³³⁴ Erving Goffman, "The Stigmatized Self," from *Stigma: Notes on the Management of Spoiled Identity*. In Charles Lemert and Ann Branaman (Eds.). 1997 *The Goffman Reader*. Malden, Massachusetts, and Oxford, UK: Blackwell Publishers, p. 73.

support for a given course of action may discourage new, sympathetic individuals from getting involved. The message this sends to these individuals is that the movement itself is doing an adequate job without their help.

Paradoxes of Identity

Of course, the process of identity formation, while crucial to understanding movement emergence and outcomes, is also problematic. Della Porta and Diani identify three paradoxes of identity that may frustrate attempts to locate the proper role of identity in studies of collective action. The first relates to the “simultaneously static and dynamic nature of social identification.”³³⁵ As they note, “reference to identity evokes the continuity and the solidity of allegiances over time. On the other, one cannot ignore the fact that identity is open to constant redefinitions... As a result, in spite of their relative stability, even feelings of identification can be – and in fact are – subject to recurring modifications.”³³⁶ The second paradox refers to the contradictory nature of multiple identities. Individuals, of course, belong to and identify with different collectivities. New lines of identification may clash with or ideologically oppose previous ones, such as is the case with feminist- and class-based identities. The third paradox relates to the role of identity in rational accounts of collective action. As they note, when “the definition of identity comes into contact with components relating to the emotions or to values, its

³³⁵ Della Porta and Diani, *op. cit.*, p. 86.

³³⁶ Della Porta and Diani, *op. cit.*, p. 86.

relationship with models of rational action, concerned with calculation of costs and benefits, can seem extremely weak.”³³⁷

The general conclusion one can draw from the previous discussion is that the process of collective identity formation is almost always a “work in progress.” Movements seeking to build a coherent or cohesive identity must confront this reality and adopt strategies that simultaneously solidify their identity, but destabilize it as well. The last thing movement actors desire is to be pigeonholed. Following Butler, I would assert then that those identities that continue to swirl around illness need to be articulated and re-articulated as a response to the political forces that attempt to silence them. As she argued, “So what I’m calling for is not the surpassing of particularity, but rather a double movement: the insistence on identity and the subjection of identity-terms to a contestation in which the exclusionary procedures by which those identity-terms are produced are called into question. This seems to me to be the necessary and contingent place of identity within a radical democratic culture.”³³⁸

In other words, blood activists needed to both affirm and reject the identity they had a hand in fashioning. On the one hand, they expended a great deal of energy in convincing the public, the media, and government that Hepatitis C was a serious medical condition, but at the same time, they had to reject the “sick role” if they were to be effective politically. They had to demonstrate simultaneously that Hepatitis C was making

³³⁷ Della Porta and Diani, op. cit., p. 86.

³³⁸ Judith Butler, in “Discussion,” *October* 61, “The Identity in Question: A Special Issue,” (Summer 1992), p. 108.

them sick, in order to counter suggestions that theirs was not a serious disease, without implicitly suggesting that they were so weak as not to be taken seriously as a political force. It is instructive here to recall Parsons's notion of illness, which emphasized that health and illness are individual states of the mind and body. As Gerhardt points out, Parsons rejected the idea that illness could reside in collectivities. Parsons was attempting to demonstrate that a society or whole races could not be sick, but that does not deter him from characterizing illness, from a strict sociological perspective, as an aspect of deviant behaviour:

Illness, in so far as it is motivated, is a form of deviant behaviour, and, as such, may be subjected to a standard sociological analysis of deviance. Compared with other types of non-conformist behaviour, sickness characteristically entails passive withdrawal from normal activities and responsibilities. As such, it should be distinguished from active rebellion against the normal social expectations, and from the types of deviance characterized by compulsive conformity. For it is an escape from the pressures of ordinary life.³³⁹

Lupton explains that Parsons's sick-role model rests on the false assumption that the patient is not blamed for his or her illness. According to Parsons's model, once the "sick" person seeks help from a physician, he or she is no longer regarded as deviant. However, she argues, "deviance is not abrogated by entering the sick role."³⁴⁰ Parsons's other litmus test is that after seeking medical help, the ill are expected to follow their doctor's directions, investing their faith and trust in the expertise of the physician. The

³³⁹ Talcott Parsons and Renée Fox, quoted in Uta Gerhardt. 1989. *Ideas about Illness: An Intellectual and Political History of Medical Sociology*. London: Macmillan Education Ltd., p. 9.

short history of Hepatitis C activism, however, illustrates that people with Hepatitis C, like their predecessors in the AIDS movement, are not content to crumble under an omniscient medical authority. As Singer notes, patient activism has produced an important resistance to the isolation imposed by illness and by the institution of the Hospital, the latter being "a form of power to which subjugated bodies give their informed consent, because they have no other choice."³⁴¹ The Hospital, she says, should be understood in all of its metaphorical manifestations. It is not so much a physical place, but rather a process exercised by a number of institutions in which the interrogated subject comes to expect intrusions upon his or her privacy.

While the experience of AIDS activism has demonstrated that illness can be effective as an identifier when the group in question contains some semblance of an identity and a fertile political terrain upon which to articulate its demands, constructing an identity around illness is more problematic when a group lacks some of these essential building blocks. This difficulty is especially pronounced for those who belong to less-cohesive social groups, such as IV drug-users, and remain the target of societal condemnation for their apparent role in the spread of AIDS. Their struggles are no less real, only more difficult to resolve, as they are entangled in a complex web of oppression, from within and without.

³⁴⁰ Deborah Lupton. 1994. *Medicine as Culture: Illness, Disease and the Body in Western Societies*. London, Thousand Oaks, New Delhi: Sage Publications, p. 89.

³⁴¹ Linda Singer. 1993. *Erotic Welfare: Sexual Theory and Politics in the Age of Epidemic*. London: Routledge, p. 103.

Schneider and Ingram have argued, for instance, that governments often engage in the social construction of 'target populations.' Groups, they note, with a less-than-favourable public image often find themselves shut out of the policy-making process altogether, while those with a more positive image seem to enjoy a greater chance of gaining access.³⁴² The connection between intravenous drug use and Hepatitis C is one that Hepatitis C activists have struggled to combat since they emerged on the political stage. Hepatitis C activists railed against suggestions by prominent researchers that intravenous drug use and promiscuous sex were more to blame than tainted blood for infecting thousands of Canadians with Hepatitis C. They were reacting, in part, to the Krever Inquiry testimony of Saya Feinman, a hepatitis researcher at a Toronto Hospital. He reported on a survey of 352 donors in Toronto who tested positive for HCV, 23.9 per cent of whom admitted to using intravenous drugs, while 17.6 per cent acknowledged that they had been promiscuous. Only 15 per cent of the donors surveyed had received blood. Activists charged that the Canadian Red Cross, in conjunction with the Canadian Liver Foundation, embarked on a calculated "trash the victims" campaign to stereotype all people with Hepatitis C as 'druggies'.³⁴³ Activists were also incensed by remarks made by Prime Minister Chretien in 1998. Asked about his reaction to Ontario's decision to compensate all people who contracted Hepatitis C through the blood system, Chretien

³⁴² See Anne Schneider and Helen Ingram. 1993. "Social Construction of Target Populations: Implications for Politics and Policy," *American Political Science Review*, 87, pp. 334-347.

³⁴³ This charge is levelled by the Hepatitis C Society of Canada's Alan Powell in the organization's submission to the Inquiry, July 1996, op. cit.

said, "The Krever commission indicated that from '86 to '90 we had the responsibility. From there, when there is no responsibility, where do you start and where do you finish? Do you deal with those who have it through blood tranfusion? What about those who have used needles...?"³⁴⁴ At the same time, however, the main Hepatitis C organization, the Hepatitis C Society of Canada, recognizes that it represents all persons with Hepatitis C, not only those who contracted it through tainted blood. Given the wide incidence of Hepatitis C among Canada's drug injecting population – as much as 88 per cent on Vancouver's East Side – activists have had to tread this line carefully.

What's Wrong with "We": Critiques of Identity Politics

It is quite common to encounter excessively critical dismissals of the importance of "identity politics". As Pichardo notes in a thoughtful review of the NSM literature, "whether the politics of identity represents a liberation or stagnation of modern politics is a point of contention. The liberation of joining the personal with the political may represent a radical challenge to state domination, but it may also result in an 'anti-politics of identity' – an apolitical withdrawal from politics."³⁴⁵ Within the Marxist Left, for instance, critiques of identity politics abound, much of them centering on the dangers

³⁴⁴ Mark Kennedy, "Reform demands apology from PM for hep-c remarks," *Calgary Herald*, May 26, 1998, p. A11.

³⁴⁵ Nelson A. Pichardo, "New Social Movements: A Critical Review," *Annual Review of Sociology* 1997, 23, p. 414.

associated with political strategies that attempt to displace class as the fundamental political category for organizing mass resistance. Representative of this view, Jenny Bourne claims: "Identity politics is in. Exploitation is out (it is extrinsically determinist). Oppression is in (it is intrinsically personal). What is to be done is replaced by who am I."³⁴⁶ As Dobrowolsky notes in a study of feminist constitutional activism in Canada, however, critiques of identity politics fail to recognize that "collective identities are integral to the concept of representation."³⁴⁷ Moreover, she argues, citing Phelan, these critiques often fail to realize that perhaps "it is not so much that identity politics is fragmenting or divisive, but that 'it is the failure to acknowledge and respond to the inequalities and injustices that mark some identities that is divisive.'"³⁴⁸

In a discussion of the links between personal and collective identity, William Connolly suggests that marginalized or stigmatized groups should not adhere to identity politics because it places them in double jeopardy.³⁴⁹ First, he says, the collective identifications inscribed on you impinge on your freedom to define yourself. Second, any attempt by a member of such a group to reverse or shift these terms of identification is almost futile, given the fact that you will be viewed, almost assuredly, by these

³⁴⁶ Quoted in Liz Bondi, "Locating Identity Politics," p. 87. In Michael Keith and Steve Pile, eds., *Place and the Politics of Identity*. London/New York: Routledge.

³⁴⁷ Alexandra Dobrowolsky, "Of 'Special Interest': Interest, Identity and Feminist Constitutional Activism in Canada," *Canadian Journal of Political Science* XXXI: 4, December 1998, p. 712.

³⁴⁸ Alexandra Dobrowolsky, "Of 'Special Interest'", op. cit., note 20, p. 713.

³⁴⁹ William E. Connolly. 1991. *Identity/Difference: Democratic Negotiations of Political Paradox*. Ithaca and London: Cornell University Press.

categorizations which have been applied to you. Hence, Connolly states: "Here the politics of collective identity sustains the negative definitions it bestows by insisting that the categories up for political contestation be applied to those contesting them."³⁵⁰

Connolly understands that there is a drive to present and defend a true identity, one that will always stand in fierce opposition to other identities attempting to forge ahead. These other identities need not be in direct competition with the powerful identity; their presence alone is enough to warrant serious concern, as they illustrate the failure of the powerful identity to subsume them. "A powerful identity," he says, "will strive to constitute a range of differences as *intrinsically* evil, irrational, abnormal, mad, sick, primitive, monstrous, dangerous, or anarchical — as other. It does so in order to secure itself as intrinsically good, coherent, complete or rational and in order to protect itself from the other that would unravel its self-certainty and capacity for collective mobilization if it established its legitimacy."³⁵¹

With the mainstream liberal paradigm, the critique of identity politics dovetails with critiques of interest group politics. Identity, in such formulations, is almost synonymous with "interests", narrowly defined. Just as critiques of interest-group politics point to their negative impact on democracy, identity politics is almost always seen as antithetical to a strong, vibrant democracy. Identity groups (eg: blacks, gays and lesbians) are criticized for being too demanding, for wanting special favours, just as interest groups

³⁵⁰ William E. Connolly. 1991. *Identity\Difference*, op. cit., p. 200.

³⁵¹ William E. Connolly. 1991. *Identity\Difference*, op. cit., p. 65-66.

are painted as selfish, self-interested political actors with little or no regard for others. Indeed, Wolin appears to conflate identity politics with interest politics, although he doesn't specify the precise meaning of the former. "Interest politics," he says, "dissolves the idea of the citizen as one for whom it is natural to join together with other citizens to act for purposes related to a general community and substitutes the idea of individuals who are grouped according to conflicting interests..."³⁵² Interest groups are said to have the resources, financial and human, to facilitate exchange and dialogue with policy-makers. Social movements, it should be stressed, do not necessarily enjoy such privileges. In the case of tainted blood, while many members of the Hepatitis C Society of Canada and the Canadian Hemophilia Society participated in state-sponsored political activity (the Inquiry process itself) and their leaders negotiated with government officials, their organizations scarcely resembled traditional interest groups. The Canadian Hemophilia Society could best be described as the consumer voice for people with hemophilia, while the Hepatitis C Society was, and still is, a fledgling organization still seeking out ways to best represent its members. The Hepatitis C Society's representational tasks are complicated by the heterogeneous nature of group membership. Many of its members, for instance, are former or current injection drug users.³⁵³ In addition, some of the groups' activities indicate that they are just beginning to cut their activist teeth, unlike the

³⁵² Sheldon Wolin, "What Revolutionary Action Means Today," p. 244. In *Dimensions of Radical Democracy*, op. cit.

³⁵³ The Hepatitis C Society of Canada does not collect data on the background of actual members.

professional, well-funded lobbyists who dot the Canadian political landscape.³⁵⁴ The CHS, on the other hand, has a rich history from which to draw – it has been in existence since 1953 – not to mention a relatively unified membership.

Critiques of interest groups and identity politics fail to acknowledge the important, positive role group-formation plays in the construction of identities. As Mansbridge argues, citizens need to oscillate between these protected enclaves where they can “explore their ideas in an environment of mutual encouragement,” and the broader political world if they are to “test” those ideas effectively:

Interest groups, political parties, and social movements... provide different forms of protected enclaves in which members legitimately consider in their deliberations not only what is good for the whole polity but what is good for themselves individually... The present reigning hostility to ‘identity politics’ does not recognize the value to democracy of deliberative enclaves in which the relatively like-minded can consult easily with one another.³⁵⁵

The HepFest described earlier in the introductory chapter presented an opportunity for people with Hepatitis C to form “protected enclaves”, in which they could consult with one another, jostle with one another, on different strategies for achieving their goals, in a mutually supportive environment. Although the event was open to friends and family of people with Hepatitis C, it was mainly an opportunity for people with Hepatitis C to

³⁵⁴ For instance, Justice Krever castigated the Canadian Hemophilia Society for “leaking” a study suggesting that up to 12,000 people may have needlessly contracted Hepatitis C from transfusions that could have been screened.

³⁵⁵ Jane Mansbridge, “Using Power/Fighting Power: The Polity,” p. 57. In Seyla Benhabib (Ed.). 1996. *Democracy and Difference: Contesting the Boundaries of the Political*. Princeton, NJ: Princeton University Press.

join together in a friendly environment in which they could cement an identity, and possibly overcome the tensions between people infected with tainted blood and others who were infected through intravenous drug use.

Collective Identity in Motion: The Politics of Naming, Blaming, and Claiming³⁵⁶

While questions of representation are multifaceted, in this study they are grouped along three lines: a) the representation of members by their leaders; b) the representation of organizations to other organizations; and c) outside representation (public identity). Each is critical in developing an understanding of identity formation because groups trying to fashion an identity face a distinctive set of challenges. Although they rarely speak with one voice, the constraints of democratic politics mean that groups often require strong leaders who can advocate on their behalf. Social movement organizations may also fall victim to internal tensions between organizations, which has implications for how organizations represent themselves to the outside world (public identity).

Regarding the first, representation by leaders, it is interesting to note that Durhane Wong-Rieger, the head of the CHS at the time, is not a hemophiliac herself, nor is she the relative of one. An expert in conflict resolution who teaches at the University of Windsor, she was hired as a consultant in 1990 to help the CHS board, which was being torn apart by the stress of dealing with the crisis. According to one account, she became president of

³⁵⁶ The subtitle is adapted from William L.F. Felstiner, Richard L. Abel, and Austin Sarat, "The Emergence and Transformation of Disputes: Naming, Blaming, Claiming," *Law and Society Review*, 15 (1980-81), pp. 631-653.

the group “because, in large part, she was not aligned with any faction as different members in the group pushed for their issue – AIDS, Hepatitis C, or hemophilia – to take precedence.”³⁵⁷ Other accounts of her brand of politics are less charitable: “She’s a megalomaniac,” said one unnamed source. “She never met an issue she didn’t want to hijack.”³⁵⁸

During its first 35 years of existence, according to Picard, the CHS “rarely behaved like a consumer group. Its primary focus was education.”³⁵⁹ It “politely lobbied” for awareness of hemophilia and for improvements in medical care, but rarely denounced medical or government officials: “With no history of activism, and few resources in terms of money or scientific personnel, the CHS was at best a tame advocate.”³⁶⁰ The sobering reality of the frightening rise in the number of infected hemophiliacs would, however, propel the CHS into the political arena. Its initial foray into politics focused on securing financial compensation for recipients of tainted blood.

Representatives of the Hepatitis C Society of Canada also faced challenges from within the organization. Two Board members publicly resigned from the Board, complaining that the organization had ‘sold out’ those persons who were infected before 1986. In addition, there is no love loss between the national office of the Hepatitis C

³⁵⁷ “The Canadian Hemophilia Society: Profiles of caring,” in *We’re all related by blood*, an advertising supplement to *The Globe and Mail*, November 22, 1997.

³⁵⁸ Jenefer Curtis, “Blood Money,” *Chatelaine* December 1998, p. 62.

³⁵⁹ André Picard. 1995. *The Gift of Death*, op. cit., p. 161.

³⁶⁰ André Picard. 1995. *The Gift of Death*, op. cit., p. 162.

Society and some of its local chapters. Members of a local British Columbia chapter, for instance, noted in interviews that the compensation issue, while important, dominated the energies of the national office, at the expense of other issues, namely education and research. They argued that the national office provided little in the way of direction to their member organizations. One member of the Victoria group said the national office is out of touch with their membership: "The national office's database only keeps a record of who has paid their dues. My database tells me if you have taken herbs, what kind, what stage your liver disease is at, which dentists will treat people with HCV."³⁶¹

Interorganizational politics were also part of the struggle for representation. For instance, bitter political infighting ensued between the CHS and the Canadian AIDS Society. While relations between both organizations were previously "civil", their sharp differences took shape in the public battle over the issue of notification of possible recipients of tainted blood. Both groups fought the issue up to the Ontario courts. The case involved the testing of 175,000 blood samples collected in 1984-1985 for a study on Hepatitis B, before HIV testing was instituted in Canada. After pressure from, among others, the CHS, the Red Cross began in early 1994 to test the samples for HIV. The Canadian AIDS Society argued that health officials had no right to inform HIV-positive blood donors because the donors never consented to an AIDS test. Douglas Elliott, the lawyer who represented CAS in the case, explained the group's reasoning: "The next time you give a urine sample to your insurance company, are they going to test you for AIDS

³⁶¹ Personal interview with David Mazoff, July 10, 1999, Victoria, B.C.

without your consent? The next time you donate blood for a study on cholesterol, is someone going to come around later and test your blood for AIDS?"³⁶² The Executive Director of the CAS explained in an interview that the groups clashed over more fundamental philosophical issues, as well, namely regarding the role of the state. "They were saying 'we're innocent victims, we don't deserve this,'" Russell Armstrong said. "The whole compensation issue comes from their idea that the state should protect them. We have different expectations of what the state should do."³⁶³ Rather than allow bureaucrats to make important decisions regarding the lives of people with HIV/AIDS, Armstrong said that AIDS organizations have struggled to take ownership of the disease.³⁶⁴ The issue of the splintering of the group (divisions among members) was so crucial that the CHS sought the help of Wong-Rieger to smooth over differences. "She wanted to speak for us, to lump us in with the rest of the victims," one member of the Hepatitis C Society said in an interview. "But we rejected her efforts."³⁶⁵

Finally, outside representation (public identity) is crucial given the volume of media coverage afforded the Inquiry. According to Johnston et. al., public identity

³⁶² Quoted in Jane Coutts, "Don't name blood donors with HIV, group warns," *The Globe and Mail*, October 1994.

³⁶³ Personal interview with Russell Armstrong, former Executive Director of the Canadian AIDS Society, May 28, 1997.

³⁶⁴ One should be careful, however, not to overestimate this claim. AIDS organizations, after all, fought aggressively in 1996 to ensure the renewal of the National AIDS Strategy, the federal government's major AIDS initiative.

³⁶⁵ Personal interview with Alan Powell, founding member of the Hepatitis C Society of Canada, August 31, 1999, Toronto.

captures "the influences that the external public have on the way social movement adherents think about themselves."³⁶⁶ This is important in the context of recipients of tainted blood in that their representatives waded into an AIDS discourse that delineates innocent and guilty "victims". For instance, hemophiliacs have been cast as the quintessential "innocent victims", the unwitting victims of a "normal" lifestyle. This contrasts sharply with homosexuals or IV drug users, who have been blamed for pursuing an "unhealthy" lifestyle.³⁶⁷ This is only half of the story, however. Hemophiliacs also suffer the stigma that is commonly felt by other people with AIDS. In one famous case, Indian teenager Ryan White was taunted by his community when residents learned that he was HIV-positive. His attempts to enter the Indiana school system were met with boycotts by his schoolmates' parents, many of whom feared their children might be exposed to infection. White eventually became a national icon and the public, heterosexual face of AIDS. Congress eventually passed a law in 1990, the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act³⁶⁸, in his name.

³⁶⁶ Hank Johnston, Enrique Larana, and Joseph R. Gusfield, "Identities, Grievances, and New Social Movements," p. 18. In *New Social Movements: From Ideology to Identity*, op. cit.

³⁶⁷ Interestingly, in an attempt to discredit the compensation claims made by blood recipients, it was suggested that some Hepatitis C patients contracted the disease through morally proscribed behaviour such as intravenous drug use and promiscuous sex, a move that incensed the Hepatitis C Society of Canada. Indeed, as noted in Chapter 2, the rates of Hepatitis C and HIV infection among the drug-using population of Vancouver's East Side are high.

³⁶⁸ Although named for a hemophiliac, the CARE Act funds the delivery of a wide range of AIDS services at the local and state levels. For a discussion of the history of the Act, see Patricia D. Siplon, "Washington's Response to the AIDS Epidemic: The Ryan White Care Act," *Policy Studies Journal*, Vol. 27, No. 4, 1999, pp. 796-808, and Elinor Burkett. 1995. *The Gravest Show on Earth: America in the Age of AIDS*. New York: Picador.

Goldstein asserts that even “innocent victims” such as White must endure the wrath of fearmongers, thereby dispelling any notion that there are good and bad ways to contract HIV. Of the medical response to his condition, White said: “They [The doctors] marked my folders ... They marked ‘fag’.”³⁶⁹ In an apparent slip, one newspaper report even identified White as a “homophiliac,” conflating homosexual and hemophiliac.³⁷⁰ Activists associated with the hemophilia movement agreed that homophobic attitudes among hemophiliacs – they were fearful of a possible connection between homosexuality and hemophilia – prevented the CHS from responding swiftly and publicly to the threat of AIDS within the hemophilia community.

The question of public identity is crucial in determining how and why opportunities were seized or not. Since an opportunity does not emerge as an objective fact, but is, rather, subjectively interpreted, how movement actors see themselves reflected in the media is important in shaping not only collective action but also the form it takes. Indeed, social movement literature has begun to pay attention to the media’s role in the construction of framing processes, since much of the energy of political actors is often reserved for developing strategies to garner favourable media coverage. The testimony at the Inquiry, I argue, provided easily digestible sound bites, and helped activists to secure the media spotlight.

³⁶⁹ Richard Goldstein, “A Death in the Family,” *The Village Voice*, April 24, 1990, p. 15.

³⁷⁰ Sander Gilman, “AIDS and Syphilis: The Iconography of Disease,” p. 105. In Douglas Crimp (ed), *AIDS: Cultural Analysis/Cultural Activism*, op. cit.

In order to solidify an identity that would be taken seriously by others, blood activists engaged in the politics of naming, blaming, and claiming. With respect to Hepatitis C, I group activist concerns along three main tracks: fostering awareness of the devastating potential of Hepatitis C (naming), the pursuit of criminal sanctions against those individuals and organizations responsible for the needless contamination of the blood supply (blaming); and the fight for financial compensation (claiming). Each of these pursuits – naming, blaming, and claiming – is inextricably linked, since activists soon realized that their success in pursuing the first (naming) would greatly affect their ability to successfully pursue the second and third (blaming and claiming). Those organizations representing persons infected with HIV-infected blood, as will be discussed, experienced different challenges with respect to the first process (naming).

The Politics of Naming

A great deal of activist energy is spent trying to resist the language commonly summoned to explain individuals or groups. As Jenson notes in her discussion of nationalist movements in Canada, one goal of such movements, like other social movements, “is to resist ‘outside naming’ and to be ‘self-naming.’”³⁷¹ For instance, she notes, Canada’s indigenous peoples have chosen to deploy the term “Aboriginal” as a deliberate “rejection of the names imposed by the colonizers.”³⁷² The term Aboriginal

³⁷¹ Jane Jenson, “What’s in a Name? Nationalist Movements and Public Discourse,” p. 107. In Hank Johnston and Bert Klandermans (Eds.). 1995. *Social Movements and Culture*. London: UCL Press.

³⁷² Jenson, “What’s in a Name,” p. 112.

Peoples includes those who belong to the Indian, Inuit, and Métis Nations. Thus, "an act of representing a community by name has real, material consequences; it is not simply a struggle over words."³⁷³ In the AIDS discourse, a similar process took place. AIDS organizations long insisted on the use of the term "People with AIDS" (PWA) instead of "AIDS victim." For instance, the manifesto of the National Association of People with AIDS in the U.S., known as the Denver Principles, opened with this statement regarding naming: "We condemn attempts to label us as 'victims,' which implies defeat, and we are only occasionally 'patients,' which implies passivity, helplessness, and dependence upon the care of others. We are 'people with AIDS.'"³⁷⁴ This change has been recognized by several media outlets. It is important to stress, however, that although AIDS activists decry the use of the term "victim", their political activity consistently portrays people with AIDS as victims, of societal prejudice, of government foot-dragging, of pharmaceutical "profiteering." Gran Fury, the artists' collective that produced several memorable brochures and fliers for ACT UP, deliberately tackles the enemies of AIDS, from religious figures to medical and scientific officials to the media. One poster, emblazoned with the words "We die, they do nothing," clearly marked people with AIDS as victims. Next to the word "they" were the names of prominent politicians, the Food and Drug Administration, the National Institutes of Health, the national media, and

³⁷³ Jenson, "What's in a Name," p. 108

³⁷⁴ "Founding Statement of People With AIDS/ARC (The Denver Principles), cited in Max Navarre, "The PWA Coalition Portfolio," p. 148. In Douglas Crimp (Ed.), *AIDS: Cultural Analysis/ Cultural Activism*, op. cit.

minority leaders.³⁷⁵ The venerable *New York Times*, renamed the New York “Crimes”, was the target of protests over its failure to devote much attention to AIDS, and for its editorial claims that AIDS cases were on the decrease, and thus did not require undue media attention. Representatives for people with hemophilia and Hepatitis C, on the other hand, have been less reluctant (some might argue more inclined) to summon the victim label in describing their situation.

Before they could construct an identity for themselves as people with Hepatitis C, activists first had to give voice to this ‘new’ disease. As Rosenberg argues, “in our culture a disease does not exist as a social phenomenon until we agree that it does – until it is named.”³⁷⁶ Unlike the recipients of tainted blood who contracted HIV and later developed AIDS and who were able to “benefit” from media and lay constructions of HIV/AIDS as epidemic, people infected with Hepatitis C-tainted blood were not afforded such a luxury. For the most part, blood activists needed to position Hepatitis C as another disease worthy of attention from governments, the media, and the public at large. Whatever the difficulties associated with media constructions of AIDS – the predominant association with homosexuality, and the stigma this brought – one thing was certain: AIDS was a potent symbol, an “epidemic of signification.”³⁷⁷ From the moment Hepatitis C was

³⁷⁵ See Douglas Crimp and Adam Rolston, *AIDS Demographics*, Seattle: Bay Press, 1990.

³⁷⁶ Charles Rosenberg, “Framing Disease: Illness, Society, and History, p. 306. In Charles Rosenberg. 1992. *Explaining Epidemics and Other Studies in the History of Medicine*. Cambridge, New York and Victoria: Cambridge University Press.

uttered at the Krever Inquiry, it was forced to struggle in the shadow of AIDS, that omnipresent and deadly threat burned in the public's memory.

This first pursuit, naming, was indeed a tricky one for activists. On the one hand, they had to build a strong case for taking Hepatitis C as both a newly emerging but serious public-health issue. For instance, movement actors spoke in interviews of their often frustrating attempts to enlist the support of public health officials, a challenge made difficult by the reluctance of public health units to be identified with the militant activists who had begun to appear on the nightly news and in newspaper stories. It seemed that their strategy to gain media attention was a double-edged sword: on the one hand, each successive news story made easier the task of 'pitching' another story, fulfilling their goal of raising public awareness; on the other hand, however, the media attention also complicated efforts to generate sympathy among and support from public health authorities, mainly because the attention painted people with Hepatitis C as angry, rabble-rousers. In addition, movement activists had to carefully balance their attempts to play the "newness" card with respect to this disease against the claim that Hepatitis C was not new at all, that Hepatitis C was a proverbial "time bomb" that many chose not to detonate. This was an especially sensitive issue since it could potentially contradict their claim that government and regulatory body officials, as well as members of the scientific and medical communities, knew enough about the dangers of Hepatitis C but chose to do

³⁷⁷ This term is borrowed from Paula Treichler, "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification," pp. 31-70. In Douglas Crimp (ed.). *AIDS: Cultural Analysis/Cultural Activism*, op. cit.

nothing. One should recall that blood system officials stressed in their Inquiry testimony that little was known about Hepatitis C at the time, arguing that it was reasonable to forgo surrogate testing for a disease that didn't even have a name until 1989.

As witness after witness testified at the Inquiry, patients were constantly confronted with the suggestion that any symptoms they were experiencing were only "in their heads." One patient told the Inquiry: "It took me 18 months of doctors to try and find out exactly what was wrong – it was hormones, it was post-partum depression, it was psychiatrists. Basically, it was all in my head, until I did find a doctor who decided to run a gamut of tests on me, and came back with Hepatitis C as a verdict. It was very difficult. My marriage suffered greatly in the 18 months preceding my diagnosis."³⁷⁸

People infected with HIV through tainted blood did not experience similar problems with respect to naming for several reasons, which is not to suggest, however, that their experience was less difficult. First, the earliest community to be struck by HIV-infected tainted blood was the hemophiliac community, which had a long-established organization dedicated to looking after their needs (the Canadian Hemophilia Society). Unlike people with Hepatitis C, who had to struggle to define their needs as well an organization to look after those needs, hemophiliacs had a relatively strong community infrastructure from which to draw. Their unique struggles helped to cement a lasting bond and inspired strong feelings of kinship. It was not uncommon, for instance, for

³⁷⁸ Lisa Holtz, Inquiry Transcript, Volume 35, April 22, 1994, pp. 7052-7054, quoted in Alan Powell, Hepatitis C Society of Canada, Submission to Mr. Justice Horace Krever and the Commission on the Blood System in Canada.

hemophiliacs (overwhelmingly male) to refer to each other as blood brothers. Second, within the hemophilia community there was a strong reluctance to associate hemophilia with AIDS, given the long-held connection of AIDS with homosexuality. Hemophiliacs, it was reasoned, were already subject to prejudice and schoolyard taunts from classmates who viewed them as sissies because they had special medical needs. The message was clear: it was difficult enough to live life as a hemophiliac, but it would be unbearably difficult to live life as a hemophiliac with HIV, or a hemophiliac suspected of being HIV-positive. Worse still, efforts to raise awareness of hemophilia and encourage people to be candid about their condition would be thwarted by a strong public connection between hemophilia and AIDS. This fear was strong enough to keep HIV-positive hemophiliacs in what Cindy Patton has called the 'clot closet'.³⁷⁹

David Kirp, in a study of hemophilia activism in the United States, provides an interesting comparative account of the mobilization of hemophiliacs and homosexuals in the face of AIDS. Both gay men and hemophiliacs, whom he terms the "odd couple of AIDS," have been regarded as less than normal, the first group as a result of "deviant behaviour" and the latter by their association with tainted blood. Although they followed different trajectories, both groups responded to AIDS "by internalizing the shame of their circumstance, living closeted lives, concealing or camouflaging the significance of their

³⁷⁹ This term is cited in Michael Davidson, "Strange Blood: Hemophobia and the Unexplored Boundaries of Queer Nation." In Timothy B. Powell (ed.). 1999. *Beyond the Binary: Reconstructing Cultural Identity in a Multicultural Context*. New Brunswick, N.J.: Rutgers University Press.

condition.”³⁸⁰ Liberation arrived for both groups during the late 1960s, but in different forms. For hemophiliacs, it came in the form of Factor VIII concentrate, which allowed hemophiliacs to self-administer the clotting factor at home and avoid frequent visits to the hospital to be treated for minor bleeds. For hemophiliacs, then, the key to liberation came in the form of a medical ‘magic bullet’, which would allow them to live their lives as normally as possible. According to Kirp, reiterating a claim made in the context of Canada, American hemophiliacs “implicitly trusted their caregivers, the physicians, and the pharmaceutical establishment, which had brought normality within reach.”³⁸¹ The seeds of liberation for gay men, conversely, were sown in the form of a political event (the Stonewall riots in New York) during which they demonstrated a show of defiance against the police. Unlike hemophiliacs, who viewed normality as a medical construct, gays recognized that the very category “normal” needed to be deconstructed. It soon became apparent that if they were going to reverse the predominant construction of homosexuals as deviant, nothing less than collective action would be required. And, more important, they would have to focus their energies on attacking the very institutions that reinforced this prejudice. This realization would eventually work its way onto the agenda of AIDS activists, who sought to underscore the “criminal” negligence of governments

³⁸⁰ David Kirp, “The Politics of Blood: Hemophilia Activism in the AIDS Crisis,” p. 297. In Eric Feldman and Ronald Bayer (eds.), *Blood Feuds*, op. cit.

³⁸¹ David Kirp, “The Politics of Blood: Hemophilia Activism in the AIDS Crisis,” p. 298. In *Blood Feuds*, op. cit. Similar suggestions have been made about Canadian hemophiliacs’ relationship of trust with the medical and scientific communities, which is supported by the fact that doctors and scientists occupied prominent positions in the Canadian Hemophilia Society.

who did little or nothing to stem the spread of AIDS because of its association with homosexuality. This legacy of distrust of government to do its job would help to spawn the creation of self-sufficient, arm's length, community-based organizations, something that hemophiliacs, who saw in the medical community allies instead of enemies, severely lacked.³⁸²

Davidson takes the AIDS community (and the larger "queer community") to task for failing to include HIV-positive hemophiliacs within the borders of a "Queer nation."

As he notes,

If the concept of queer was mobilized to call into question the identitarian character of post-Stonewall sexual politics, then its more radical implications would be accommodation of a wider matrix of constituencies than those usually defined by "gay" and "lesbian". If so, these constituencies might include figures usually (but not exclusively) defined as heterosexual.³⁸³

While hemophiliacs played a pivotal role in "securing an image around which legislation, research, and public policy could be made without having to engage issues of homosexuality and homophobia,"³⁸⁴ they were marginalized from the dominant, gay-dominated AIDS discourse. Initially, Canadian and American organizations for

³⁸² Relations between people with hemophilia and medical staff were not always pleasant, however. Janet Conners explained in an interview that hemophilia clinic staff warned her husband, Randy, that if he did not behave responsibly (e.g., avoid alcohol), he could be denied important treatment. "They [the nurses and staff at the hemophilia clinics] thought that these patients were somehow their boys. There was always a constant threat hanging over their heads that if they weren't good little boys, they were going to lose their home care. The hemophilia nurse said if Randy was drinking too much, he was going to lose his home care." (Interview with Janet Conners, Aug. 11, 1999)

³⁸³ Michael Davidson, "Strange Blood:..." op. cit., p. 55.

³⁸⁴ Michael Davidson, "Strange Blood..." op. cit., p. 51.

hemophiliacs resisted being associated with gay organizations. Rather, it is meant to underscore the problematic relationship between hemophiliacs and the larger queer community, for whom hemophiliacs represented a “conflation of an essentialist discourse of blood and a constructivist discourse of feminized masculinity.”³⁸⁵ ‘Hemophobia’ is the term Davidson uses to describe the merging of these two discourses of blood and sexuality.

The Politics of Blaming

Two factors coalesced to rouse blood activists to anger and to amplify their “injustice frame.” First, one of the main culprits (the Red Cross) was associated with altruism. Prior to the news of the scandal, the Canadian Red Cross was one of the country’s most venerated institutions.³⁸⁶ The Red Cross had stood as a powerful reminder of the kindness and generosity of strangers to those in need. As one observer noted in an interview, “the Red Cross was like Santa Claus. And it was like trying to prove that Santa Claus was a pedophile.”³⁸⁷

³⁸⁵ Michael Davidson, “Strange Blood...” op. cit., p. 55.

³⁸⁶ Historian John F. Hutchinson recalls, in a book examining the historical roots of the International Red Cross Movement, “the enduring legacy of his childhood experience ... was an implicit belief that the Red Cross was beyond criticism. It was as unthinkable to make negative comments about the Red Cross as it was to desecrate the graves of fallen soldiers.” (p. 1) See Hutchinson’s *Champions of Charity: War and the Rise of the Red Cross*. Boulder, Colorado and Oxford, UK: Westview Press, 1996.

³⁸⁷ Interview with Dawna Ring, a Halifax lawyer who represented Janet Connors at the Krever Inquiry, Aug. 8, 2001.

Ironically, the organization's positive image initially helped blood activists to establish a frame of injustice because it seemed almost unconscionable that a non-profit organization that was created to look after others would instead play a key role in harming them. For instance, in one particularly fiery exchange at the Inquiry between Krever and Douglas Lindores of the Canadian Red Cross, the Commissioner asked pointedly why the organization had failed to apologize to Canadians infected through the blood system. When asked during a radio phone-in show, Lindores had said that the Red Cross was waiting for "Krever to do his work" before it could make any decision regarding issuing a public apology:

THE COMMISSIONER: ... Now, quite frankly I do not think that is the reason why the Red Cross has not apologized, the fact that I am conducting this Inquiry. And I am going to put to you what I think is the reason and you can tell me how wrong I am, if I am wrong. The reason why the Red Cross has not apologized is because it was contractually bound by a contract called a "policy of insurance" not to make any admission of liability. And the concern is that an apology might be construed as an admission of liability which would lose the Red Cross the coverage and protection of an insurance policy. Am I wrong?

LINDORES: It is a complicated question, sir, and I wish I had a simple answer for you.

THE COMMISSIONER: I think it is a simple question, Mr. Lindores.

LINDORES: In terms of the statement that I made and the answer on the telephone I would stand by that statement. With respect to your question, it is my understanding that that is also the situation.

THE COMMISSIONER: Now, I am not clear about that answer. That is the situation, you mean the fact that you are contractually bound not to make an admission. Is that what you mean when you said, "that is the situation"?

LINDORES: Yes, that is I believe the situation, yes.

THE COMMISSIONER: Well, is that not the reason the Red Cross has not apologized? Is it because I am conducting an inquiry that you cannot apologize?

LINDORES: ...As the Chief Executive Officer of an organization I have a variety of very complicated responsibilities. And one of them is to defend my organization and my staff and be loyal to them until such time as negligence or some other act requiring apology is in fact proven.

THE COMMISSIONER: I did not understand that. Your position that there is no need for a humanitarian organization to apologize for what happened as a result of the use of its product unless there is a legal finding of negligence? Is that what you are saying?

LINDORES: No, sir, this is an extremely ... emotionally charged environment in which we are all trying to continue to supply this country with a steady and dependable supply of blood products. There are many different factors which enter into the consideration of such a request, not the least of which that you abandoned staff, who in my view, conducted themselves with full credit, during an extraordinarily difficult period and sell them out in order to achieve some short term public relations gain. That is just one of the issues. I have said, unfortunately it is a complicated issue, and it does not lend itself very easily to yes and no answers.

THE COMMISSIONER: Well, I will not pursue this, but I confess I have great difficulty in understanding how an apology from the organization is the selling out and the abandonment of staff. But I do not think I will get any more enlightenment from continuing the discussion. But I confess that is the one thing that I fail to understand in this discussion.³⁸⁸

The state, however, in distinguishing the deserving from the undeserving, helped to problematize the frame of injustice, and complicated movement strategies to build a commonality of grievances. Marking some people with Hepatitis C as victims of

³⁸⁸ Testimony, *Commission of Inquiry on the Blood System in Canada*, Nov. 23, 1995, Vol. 217, pp. 45535-45542.

government neglect, for failing to implement testing when it was widely available, but shutting out others who were infected when testing was presumably not available, reinforced and lent credence to the suggestion that one could reasonably separate people with Hepatitis C into two camps. For some of the Hepatitis C activists interviewed, this marked a turning point. Even among those who qualified under the limited compensation plan, there was a deep sense that the movement had been successfully torn apart.

Secondly, injustices that are linked to large-scale accidents serve as powerful mobilizers, contrary to the claims of resource mobilization theorists that grievances are irrelevant to movement mobilization. In the case of “suddenly imposed grievances”, to use the term coined by Walsh in connection with the nuclear reactor accident at Three Mile Island, “not only are the grievances clear, in addition, relatively straightforward causal attributions can be made, and most importantly the events impose a collective identity upon those affected; everyone is a victim of the same accident.”³⁸⁹ Although the tainted-blood scandal affected only a small proportion of the population, activists stressed in the media that they were simply the unlucky ones who happened to need a transfusion or relied on blood products. It could have just as easily been someone else.

Tainted-blood activists realized that if they were to portray their membership as indeed authentic victims of a gross injustice, it was critical to set their sights on a clearly defined list of enemies. Activists thus centered their attention on three main sets of adversaries: the role of governments (both federal and provincial); the role of the

³⁸⁹ Bert Klandermans, *The Social Psychology of Protest*, op. cit., p. 40.

Canadian Red Cross; and, to a lesser extent than in the U.S., the international blood-banking industry. Blood activists reserved much of their finger-pointing for the federal government and the Canadian Red Cross. Private interests have been less the focus of attention, although activists have, as of late, begun implicating pharmaceutical firms in the scandal. The Inquiry singled out Connaught Pharmaceuticals, Bayer, and Miles Canada in its report.

A blaming strategy is also critical for what it obscures, in this case the suggestion that all of those persons who contracted HIV and or Hepatitis C through means other than tainted blood are somehow to blame for their condition. In other words, blaming strategies may define a list of external as well as internal enemies. The internal enemies were, by implicit suggestion, those high-risk persons who donated infected blood, whether knowingly or unknowingly. Not surprisingly, it was a small step from blaming the government to blaming the blood donors, be they homosexuals, drug users, or other at-risk groups, who, it was suggested, were supposed to know better. In Montreal, for instance, members of the Haitian population were subjected to discrimination after the Red Cross urged them not to donate blood for fear of contamination. At the Krever inquiry, the head of a Haitian nurses' association testified that the singling out of Haitians by the Red Cross dealt a devastating blow to the community: "Haitians taking a bus were told: 'I don't want to sit next to you, you have rotten blood, you have AIDS' ... The

message that trickled down to the public was that Haitians were to be avoided like the plague.”³⁹⁰

The blaming strategy did gain some momentum when the Royal Canadian Mounted Police announced immediately after the release of the Inquiry’s final report in November 1997 that it would investigate whether there was ample evidence to lay criminal charges against government and Red Cross officials. To date, however, the RCMP has yet to comment publicly on the issue.³⁹¹ Tainted-blood recipients are left to wonder whether the pursuit of criminal justice will materialize to the levels experienced in France and Switzerland, where public officials have been held criminally liable for their respective roles in the tainted blood tragedies.

The Politics of Claiming

The issues surrounding compensation for receiving HIV-tainted blood went largely unnoticed in the popular press, in contrast to the very public battles which would ensue over Hepatitis C compensation. And, for the most part, those infected with HIV-tainted blood were quite content to keep it that way. Conversely, the politics surrounding Hepatitis C compensation were not as clear-cut as members would have hoped. While their predecessors – those infected with HIV through tainted blood – were able to win compensation for all recipients of HIV-tainted blood regardless of the date of infection,

³⁹⁰ André Picard, “Labelling of Haitians as blood-donor risks called devastating.” *The Globe and Mail*, 27 September 1994, A6.

people with Hepatitis would not be so fortunate. Recognizing that a limited deal would be viewed by some as, at best, a hollow victory and worse, a colossal defeat, Hepatitis C activists commented in interviews that they had no choice but to pursue an “all-or-nothing” strategy: any scheme that shut out some recipients would be seen as unacceptable, not to mention morally reprehensible. With the help of information released at the Inquiry, and supplemented by their own amateur sleuthing, activists worked tirelessly to uncover evidence to substantiate their claim that the cut-off period was an arbitrary one. ALT testing, they would argue, was available much earlier. In West Germany, for instance, the test, which measures the likelihood of liver dysfunction, was instituted as early as 1968. Some of the Hepatitis C activists would later clash with their lawyers, some of whom believed that the 1986-1990 window was the most legally convincing, not to mention, “winnable” avenue to pursue.

The compensation issue reached its peak during the spring of 1998 following the announcement on March 27 of a limited compensation package offered by the federal, provincial and territorial governments. Whether this announcement caught activists off guard remains contested. Senior government officials insist that they gave the respective organizations “the heads up” on the deal at least two to three weeks prior to the announcement. One government official, who spoke to the issue on condition of anonymity, even suggested that Hepatitis C representatives said privately that the limited

³⁹¹ The RCMP created a web site more than a year ago, but it provides relatively little information regarding the ongoing investigation.

deal might be acceptable to their membership. Judging from the fury greeted by this announcement, however, nothing could be further from the truth.

What made the issue of Hepatitis C so contentious, as far as possible government compensation was concerned, was the presumed lack of scientific knowledge of the disease³⁹², not to mention the sheer variation in the number of people possibly eligible for compensation. (The initial number of people infected with Hepatitis C was estimated at 60,000, compared with about 2,000 infected with HIV.) Until 1989, Hepatitis C was known only by what it was not (non-A, non-B Hepatitis). Much of the debate centered on the wisdom of compensating a group of people whom, it was argued, were not faced with a disease as life-threatening as AIDS. In an ironic turn of events, however, thanks to the development of “drug cocktails” some of the same people infected with HIV in the 1980s are living longer, productive lives than people infected with Hepatitis C, heretofore regarded as a less-serious, non-life threatening disease.

In the one-month period between March 27 (when the announcement was made) and April 28 (the House of Commons vote on extending compensation), several hundred articles on the subject appeared in newspaper articles across the country.³⁹³ The Hepatitis C story led national television newscasts and dominated radio call-in programs. Suddenly,

³⁹² One senior government bureaucrat, who spoke on condition of anonymity, noted in an interview that studies commissioned by the government even called into question the validity of the symptoms – such as extreme fatigue – experienced by people with Hepatitis C. The bureaucrat also added that the bulk of tainted-blood recipients were interested primarily in money, not in seeing that Hepatitis C be taken seriously by government as a public health issue.

³⁹³ A survey of media coverage of Hepatitis C in 1998 alone found 937 items. These included articles from metropolitan daily newspapers, as well as television reports.

it seemed as though the story would never go away. Prime Minister Jean Chrétien, who was visiting Cuba during the time, was summoned back to Ottawa to ensure that the party faithful voted with their government on this issue. Allan Rock, the Minister of Health, became the media's favorite whipping boy. Words like 'embattled,' 'beleaguered' and 'under fire' became almost cliché ways in which to describe the minister. On the day reserved for discussion of Hepatitis C in the House of Commons, Rock appeared indignant in his belief that the deal he was instrumental in striking with the provinces and the territories was the best solution to a dilemma with possibly far-reaching, negative implications for the Canadian health-care system. Commenting on the problems inherent in extending compensation to all, Rock said:

Mr. Speaker, I have listened to today's debate with great interest but one striking feature of the debate in the House today is that among those who have spoken in favour of this resolution, not one hon. member has confronted the true question at issue. The true question is whether governments should make cash payments to those who are harmed through no fault of anyone but because of risk inherent in the medical system...

It seems the opposition parties have failed to confront that real question. They paper over that question because it is very tough. It is a very difficult question to answer. Ministers of health of this country came to grips with it some weeks ago and we concluded that we had a position on when governments should pay cash payments to those who are injured through no fault of anyone but because of risk inherent in the medical system.

The easy course, naturally, would be simply to pay those who are making a claim upon the government. Ministers of Health are custodians of Canada's health care system and we have a larger responsibility, a responsibility to show leadership on these tough questions and confront them directly, no matter how difficult they may be...

The moral high ground does not rest with those who urge that easy course. The true moral high ground is with those on this side of the House with the courage to stand and say we will take the tough decision on the difficult question we face. The true moral high ground rests with those in the government who will stand in their places next Tuesday and vote against this motion not because we are callous, not because we lack compassion, but because we are responsible for a public health care system that cannot and will not continue if we take the course the opposition urges.

I encourage all members of the House to consider the implications of this difficult and wrenching dilemma but to confront the real question that lies beneath it. Can we sustain our public health care system if we make cash payments to all those who are harmed by the health care system, regardless of fault, merely because of the risk inherent in the process?

Infection with hepatitis C through the blood system was just such an inherent risk before January 1986. As a result I say we should conduct research, we should do whatever we can to prevent such injury in the future, we should accept responsibility for the period when we should have acted, but I oppose this motion because it is not the proper policy.³⁹⁴

Reform Party Health Critic Grant Hill, the medical doctor who spearheaded his party's campaign to extend compensation, tried to refute the rationales upon which the government decision was based. According to Hill, the first rationale – the 1986-1990 timeframe – was “an arbitrary legal phoney (sic) dividing point... It is very evident that the regulators messed up; Judge Krever said so plainly and clearly. The special new test

³⁹⁴ *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998. Available electronically at: http://www.parl.gc.ca/36/1/parlbus/chambus/house/debates/091_1998-04-23/HAN091-E.htm#LINK115

the government said was unavailable before 1986 was developed in 1958. I have practised medicine in this country and I have used that test for much of my medical career.”³⁹⁵

The second rationale, that extending compensation to all people infected with Hepatitis C through the blood system would set a dangerous legal precedent, is wildly exaggerated. “The health minister went on to say that other medical misadventures like breast implants or obstetrical tragedies would be under the same cloak if we were to compensate all victims of Hepatitis C. That is wrong. As I said before, I have practised medicine. I had medical malpractice insurance. If I made a medical mistake, I would personally be sued for that mistake... If a manufacturer were to make faulty medical devices, it would be sued.”³⁹⁶

The third rationale (since all governments agreed to the deal, it must be right) neglects the fact that all governments – federal, provincial, and territorial – are implicated in this tragedy. “Krever has said that the provinces as well as the federal government are responsible. The federal government takes the brunt of this responsibility sadly, but just because 13 people rob a bank, does that mean robbing a bank is right?”³⁹⁷

Soon after the federal government released the terms of the limited compensation deal, Ontario Premier Mike Harris broke ranks and announced that his government would

³⁹⁵ *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998.

³⁹⁶ *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998.

³⁹⁷ *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998. Extending the analogy, CTV reporter Craig Oliver commented on the relationship between the federal government and the provinces vis-à-vis tainted blood, noting: “If Ottawa was robbing the bank, the provinces were driving the getaway car.”

agree to compensate those Hepatitis C patients shut out of the package. Condemned by the Liberal government as a calculated political move, the decision nonetheless pleased some activists.

In the following summer of 1999, federal, provincial, and territorial governments and counsel for Hepatitis C recipients filed a proposed settlement agreement with the courts for final approval. As it sought to settle class-action lawsuits launched in Ontario, British Columbia, and Quebec, the courts in these provinces had to approve the deal. It was later revealed that class-action lawyers across Canada who negotiated the compensation deal for those infected between 1986-1990 would earn \$52.5 million for their efforts. Members of the Hepatitis C Society of Canada held a news conference at which they criticized the move.

In the fall of 1999, people with Hepatitis C who were shut out of the \$1.1 billion deal took their fight to Washington, D.C., arguing that Canada knowingly accepted prison plasma from Arkansas and Louisiana in the early 1980s, and was aware of the fact that the plasma was likely contaminated with Hepatitis C and/or HIV. The lawsuit named a Toronto pharmaceutical company (Connaught Laboratories Ltd.) that manufactured blood products until 1987, a blood broker that bought plasma from the U.S., and the Bureau of Biologics of Health Canada, which monitored the safety of the blood supply. Others implicated include then-governor of Arkansas, Bill Clinton, who allegedly had links to a U.S. firm that collected the prison blood, and federal Finance Minister Paul Martin, who

during the 1980s sat on the Board of Directors of Canada Development Corp., of which Connaught was a subsidiary.³⁹⁸

Finally, in April 2000, as activists had feared, the courts in the three provinces approved the deal, which clearly spelled out that the governments, in settling the action, “do not admit any liability or wrongdoing on their part.” The settlement funds are to be distributed based upon severity of illness, from Level 1 (a fixed \$10,000 plus reimbursement of some medical-related expenses) to Level 6 (up to \$225,000 for persons with advanced stage liver disease attributed to HCV infection).

Conclusion

As this chapter has attempted to demonstrate, constructing a collective identity is a messy, often incomplete, process. The issue of collective identity/representation was of constant, if not frustrating, concern to movement activists. While Justice Krever recognized the importance of representation when he chose to include the voices of people infected and affected by tainted blood in the Inquiry process, this did not resolve the struggles over representation; it only reinforced the divisions, as the Inquiry became the site for conflicting claims made by competing organizations representing the blood injured. While the Canadian Hemophilia Society was a dominant player in the hearings, it was not alone in representing tainted-blood recipients. A total of nine groups, many of which broke off from the CHS, were granted official standing at the hearings, not to

³⁹⁸ Mark MacKinnon, “Martin on hot seat for missing documents,” *The Globe and Mail*, April 6, 2000, p. A6.

mention the numerous other stakeholders, including provincial governments, the Red Cross, pharmaceutical firms, and AIDS organizations.

Blood activists in general were unable to coalesce around a single, all-encompassing identity because of several internal and external factors. Internally, people with Hepatitis C faced intra-organizational tension between persons infected via tainted blood and others infected through intravenous drug use.³⁹⁹ One activist noted in an interview that it is wrong to separate the infected into these camps, since IV drug users were also infected, albeit indirectly, with tainted blood. Moreover, presuming that IV drug users are somehow to blame for their infection neglects the fact that risk-taking among this population may not be a choice, but rather shaped by complex socio-economic factors, including poverty and sexual abuse. Secondly, there was an uneasy relationship between people infected with HIV through tainted blood and other HIV-infected people; it was viewed that the former were 'innocent victims' of government negligence, and therefore worthy of greater compassion than people infected with HIV through other means. Thirdly, the sheer diversity of persons lumped under the victim label made it difficult to present a unified voice for tainted blood recipients.

Externally, if this challenge wasn't daunting enough, recipients were further divided according to their suspected time of infection. As noted earlier, the federal government compensation package was extended only to those individuals who could

³⁹⁹ Illingworth has taken this argument one step further, suggesting that the state's decision to outlaw drug use forces IV drug users "to perform these activities in ways that ultimately endanger their lives." Illingworth employs the term "forced" here to amplify her contention that

prove they were infected after Jan. 1, 1986, and before July 1, 1990, during which time the government acknowledges responsibility for failing to test for HIV and Hepatitis C. This package shut out those persons who were infected before 1986 as well as those who suspected but could not prove that they were infected during the designated time period. In contrast, it is worth noting that the Extraordinary Assistance Plan offered in 1989 by the federal government to people infected with HIV-tainted blood compensated all, regardless of the presumed date of infection. Some of those who received compensation were infected with tainted blood during the late 1970s and early 1980s, when a test for HIV was not available.

the activities performed by IV drug-users are only deemed illegal by the state. Quoted in Patricia Illingworth. 1990. *AIDS and the Good Society*. New York and London: Routledge, p. 82.

CHAPTER 6

Explaining Movement Strategy and Outcomes: What Happened Here?

Movement Strategies

Once a movement has defined a set of goals it wishes to pursue, it must follow through with the appropriate strategy or strategies to effect these goals. Does it target government officials directly? Does it try to enlist the support of the media to reach the intended audience? Or does it focus its efforts on changing public attitudes? In addition, a movement must keep in mind that any decisions it chooses to make vis-à-vis strategy may affect, positively or negatively, its ability to draw more members into the movement fold. A disruptive strategy may not only harm the movement in the court of public opinion, it may compromise efforts to expand its numbers. Movements that rely primarily on disruptive strategies (e.g.: demonstrations, acts of civil disobedience) to force issues onto the media or government agenda must always calculate, to the best of their abilities, the relative costs and benefits of these tactics. As Rochon notes, an ideal movement strategy, to be effective, must be aimed at multiple targets. It must be “*convincing* with respect to political authorities, *legitimate* with respect to potential supporters, *rewarding* with respect to those already active in the movement, and *novel* in the eyes of the mass media. These are not entirely compatible demands.”⁴⁰⁰

⁴⁰⁰ Rochon, quoted in della Porta and Diani, op. cit, p. 181. Emphases added.

But the strategies of movement actors themselves are not simply the product of individual participants' thoughts, beliefs, or attitudes. They are influenced by a constellation of factors, including the movement's collective identity and the greater political environment (political opportunity structure).⁴⁰¹ And the latter, of course, may play a pivotal role in shaping the collective identity of the movement in question. For instance, movements that lack a coherent or widely recognized collective identity must devote considerable energy to laying the necessary groundwork to have their demands heard in the first place. Before movement participants can make demands on the state, the carriers of those demands need to solidify their position as legitimate political actors deserving of the government's ear.

In addition, research has suggested that a movement's strategies may depend upon its organizational features. Movements, it is argued, that lack a rich supply of political and financial resources may have to resort to "outsider strategies" if they are to win the hearts and minds of policy makers and the broader public.⁴⁰² In order to do this, movements need to mobilize third parties – the media, and the mass public – in order to pry open a window of opportunity in the governmental arena. Conversely, movement with greater resources can afford to focus their energies on traditional methods such as

⁴⁰¹ Kitschelt's study of anti-nuclear protest in four countries is one of the strongest defenses of the role of the political opportunity structure in influencing movement strategies. See Herbert Kitschelt, "Political Opportunity Structures and Political Protest: Anti-Nuclear Movements in Four Democracies," op. cit.

⁴⁰² John D. McCarthy, Jackie Smith and Mayer N. Zald, "Accessing public, media, electoral and government agendas," p. 291. In *Comparative Perspectives on Social Movements*, op. cit.

lobbying or litigation. This is not to suggest, however, that the categories are mutually exclusive. A movement may adopt "outsider" strategies as a means to gain access to the courts or to lobbying. Since strategies are context dependent, what may work in one arena may be unsuccessful in another. In turn, whether movement actors choose to confront their opponents in a highly charged arena will depend upon their perceptions of the receptivity of opponents. It is not, therefore, correct to assume that demonstrations and other public displays of protest exhaust the range of possibilities available to a movement.

In the following section, I will argue that blood activists adopted a blend of outsider and insider strategies. They capitalized on the "opportunity" to participate in a formal, state-sanctioned public inquiry, but recognizing that opportunities can be "fickle friends", supplemented this periodically with instances of disruptive protest. The decision to leak to the media the results of a damning study on Hepatitis C during the course of the Inquiry is one important example of this.

McCarthy, Smith and Zald distinguish four specific agendas movements need to influence: the media agenda, the public agenda, the governmental agenda, and the electoral agenda. The media agenda refers to the collection of issues that receive attention in the mass media; the public agenda is the set of issues that gain currency in mass and narrower publics; the governmental agenda is the set of issues that gain the attention of the governmental arena; and the electoral arena is defined as the set of issues that receive the attention of candidates who are running for public office.⁴⁰³ Within each arena, there

⁴⁰³ John D. McCarthy, Jackie Smith and Mayer N. Zald, "Accessing public, media, electoral and government agendas," p. 293. In *Comparative Perspectives on Social Movements*, op. cit.

are available strategies. For instance, movements wishing to influence the media agenda may choose indirect means (demonstrations, acts of civil disobedience) or direct means (media appearances, advertisements). The authors note, however, that movements, due to their generally resource-poor nature, have fewer tactics at their disposal than organized, resource-rich interest groups. While they do not deny the fact that issues are malleable and subject to framing and reframing and that the "rhetorical quality" of frames is crucial to their success, McCarthy et al. argue that the competitive logic of the agenda-setting environment limits the capacities of movements to develop "strategic frame dissemination repertoires, or tactical combinations aimed at communicating their frames to various audiences and agenda gatekeepers."⁴⁰⁴ As a result, the agenda-setting process may be more difficult to influence than scholars of framing suggest.

In the case of tainted blood activism, the ability to influence agendas was varied. Tainted-blood activists generally adopted one or more of the following tactics: public protest or demonstrations; pressure on key government officials; pressure on opposition parties. The Krever Inquiry is distinctive in the sense of a being both a part of an overall strategy but also a goal in and of itself. After some initial trepidation, activists became convinced that the establishment of an Inquiry would help them to pursue a case for compensation, and for criminal prosecution of responsible individuals and/or institutions.

Those persons who acquired HIV 'profited' from the legacy of AIDS activism that preceded them, during which a generation of activists made a convincing case that people

with AIDS were a worthy constituency, not to mention a potentially potent political force. AIDS activists, some of them radical, managed to get on the government and public agenda via the media. AIDS activism opened the policy process to consider how policies directly affect the lives of people with AIDS. The existence of activist groups who steered clear of any involvement with government and institutionalized AIDS service organizations provided the necessary balance to ensure that neither government nor the more traditional AIDS groups lost sight of the radical voices operating at the fringes.

On the other hand, tainted-blood recipients who acquired Hepatitis C, while initially benefitting from the attention tainted blood garnered in the media had only marginal success in positioning Hepatitis C patients as a distinctive social group with a common identity. The issue of tainted blood was part and parcel of the mainstreaming of AIDS, that is the shift from AIDS as being identified with a marginalized population (gay men) to being a matter of concern for heterosexuals as a result of the infection of hemophiliacs.

Getting on the media agenda was initially challenging for blood activists because tainted-blood recipients, especially those infected with HIV, were reluctant to come forward. In addition, people with Hepatitis C had a more difficult time getting on the media agenda because it was presumed that the story of tainted blood had already been told. The Hepatitis C story did not fit easily into the "newshole", which is restricted by the reality of limited space (in newspapers) or limited airtime (on radio and television).

⁴⁰⁴ John D. McCarthy, Jackie Smith and Mayer N. Zald, "Accessing public, media, electoral and government agendas," p. 310. In *Comparative Perspectives on Social Movements*, op. cit.

Coverage of tainted blood in Canada centred primarily on the Krever Inquiry, which provided a daily catalogue of riveting testimony from 'ordinary' Canadians. Their stories, however, were anything but ordinary.

Compared with the media and public agendas, the governmental and electoral agendas are fairly difficult to penetrate. McCarthy et al. explain that this is due to the fact that the "gatekeepers of these agendas are scarcer and more restricted by their official obligations."⁴⁰⁵ It is theoretically easier for movements to affect the electoral agenda than the governmental agenda, because, despite political parties' promises to the contrary, there are no guarantees that issues raised during elections will ever see the light of day once a party enters political office. Add to this the fact the general skepticism that elections are little more than personality contests, during which a party's stand on a particular issue is less significant than how the party leader "performs" in public or in the media.

Components of Movement Strategy

Tilly identified four factors that influence movement strategy: worthiness, unity, numbers, and commitment. Social movements, he says, consist of "a sustained challenge to power holders in the name of a population living under the jurisdiction of those power holders by repeated public displays" of these factors.⁴⁰⁶ Since strength is calculated as a

⁴⁰⁵ John D. McCarthy, Jackie Smith and Mayer N. Zald, "Accessing public, media, electoral and government agendas," p. 298. In *Comparative Perspectives on Social Movements*, op. cit.

⁴⁰⁶ Charles Tilly, "From Interactions to Outcomes in Social Movements," p. 257. In *How Social Movements Matter*, op. cit.

product of these factors, not as a sum, Tilly argues that when any one of these values is zero, strength is zero, as well. Movement participants do not need to score high in each area, however, since a high value in one area can make up for a low value in another.

Tilly provides a rough sketch of each factor:

Worthiness: sobriety, propriety of dress, incorporation of priests and other dignitaries, endorsement of moral authorities, evidence of previous undeserved suffering.

Unity: uniforms, marching or dancing in unison, chanting of slogans, singing, cheering, linking of arms, wearing or bearing of common symbols, direct affirmation of a common program or identity

Numbers: filling of public space, presentation of petitions, representation of multiple units (e.g., neighborhood associations), direct claims of numerical support by means of polls, membership inscriptions, and financial contributions.

Commitment: persistence in costly or risky activity, declarations of readiness to persevere, resistance to attack.⁴⁰⁷

The first factor is critical in understanding the emergence of Hepatitis C activism, since people with Hepatitis C had to demonstrate their worthiness simultaneously as both distinct from people infected with AIDS and as a part of the broader community of tainted-blood recipients. In other words, they needed to illustrate that Hepatitis C was both different from AIDS, but also similar and no less deleterious to a person's health. The AIDS movement, for instance, was able to construct a compelling narrative around government neglect (some of the more militant voices invoked the genocide metaphor⁴⁰⁸

⁴⁰⁷ Charles Tilly, "From Interactions to Outcomes in Social Movements," op. cit., p. 261.

⁴⁰⁸ For an interesting discussion of the use of the genocide metaphor in two competing movements, see Arlene Stein, "Whose Memories? Whose Victimhood? Contests for the

to illustrate the government's response to AIDS), and made a convincing case that governments failed to respond to AIDS because they deemed the gay community, in particular, to be a disposable population. However crude this explanation may appear, it gained wide currency, and gave the AIDS movement much of its rhetorical, not to mention dramaturgical, force. Not surprisingly, then, the federal government's decision in December 1989 to provide an Extraordinary Assistance Plan to people infected with HIV through tainted blood attracted little controversy, both within government circles, the media and in the larger population. The use of the word "extraordinary" underscored the government's insistence that the package not be misconstrued as compensation, which entails legal liability. The Plan also included a waiver preventing legal action against the government. Only when it was discovered that the four-year assistance plan was close to expiring – and its recipients had surpassed life expectancy estimates for people with AIDS – did a discussion begin regarding how to extend it. Eventually, the provinces, which heretofore had resisted getting involved, agreed to do their part. It was suggested in several interviews that the federal government never expected these individuals to live as long as they did, given the knowledge at the time (1989) of the accelerated death caused by AIDS.

People with Hepatitis C also struggled to demonstrate their worthiness based on what they insisted was a meaningless time frame foisted upon them by lawyers who were interested in reaching a settlement with the government. Suddenly, following the decision

to compensate only those infected between January 1, 1986 and July 1, 1990, anyone who was infected with Hepatitis C-tainted blood outside of this time-frame could no longer claim to be an "authentic" victim, at least in the eyes of government.

Activists were particularly vulnerable on the "unity" issue. While there were indeed cracks in the movement from its initial foray into political activity, this became increasingly evident in the debate over compensation, which divided recipients according to their suspected time of infection. Many movement participants felt that their national organization had sold them out. This had devastating results for the movement, but positive results vis-à-vis government: it demonstrated to government that people with Hepatitis C did not speak with one voice, and movement leaders were forced to prove that they indeed spoke on behalf of all people with Hepatitis C, a claim made increasingly difficult by the presence of whistleblowers in the movement itself, who decried their national office's handling of the compensation debate. In particular, movement dissidents questioned the national office's decision to hire Marlys Edwardh, commission co-counsel for the Krever Inquiry, to represent them, despite the fact that she had indicated in a letter that she would not be party to discussions of fault-based compensation. This incident would eventually lead to the high-profile resignations from the Hepatitis C Society of Canada of two key members, Jo-Anne Manser of Ottawa and Leslie Gibbenhuck, of Penticton, B.C.

Regarding the third, numbers, Hepatitis C activists faced considerable hurdles, not the least of which was the reluctance of many infected individuals to come forward

publicly for fear of being ostracized from their respective communities. The fear of "coming out" was even more pronounced within the community of those with HIV-infected blood, many of whom feared that such an admission could fuel suggestions that they were gay. Hepatitis C activists had to walk a fine line between presenting to both the public and the government that there is indeed strength in numbers while avoiding the suggestion that their numbers were so large as to make the issue of financial compensation to all a dangerously costly endeavour. Indeed, this strategy proved particularly tricky when the government released new figures on the number of persons potentially infected with Hepatitis C-tainted blood, figures the activists strenuously insisted were inflated to bolster the governments' position that extending compensation might bankrupt the government. During a heated debate in the House of Commons in 1998, Health Minister Allan Rock suggested that compensating all people with Hepatitis C might open the floodgates: "[N]ext month or next year there will be others who come forward with claims equally as compassionate, with demands equally as desirable, equally as emotional and they too will want money. Where will it end? It will end with governments paying out cash compensation regardless of fault to all who have an emotional claim and will end with a country unable to afford or sustain its health care system."⁴⁰⁹ Only later did the federal government acknowledge that their figures were mistakenly calculated, with the true figure being much smaller (by about two thirds) than

⁴⁰⁹ *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998.

the initial government estimates. This new information did not, however, prompt the federal government to revisit the issue of who would be compensated.

Regarding the fourth, blood activists demonstrated commitment, but this was hampered by the fact that many movement participants experienced varying levels of ill health, which profoundly affected their ability to engage in sustained protest activity with elites and authorities. It was not uncommon, therefore, to see uneven levels of political activity by activists, some of whom retreated for short periods of time to attend to their pressing health needs, letting others pick up the slack. This interrupted participation especially wreaked havoc in provinces with smaller, tightly knit organizations, and fewer committed activists. For instance, when one particularly strident activist swore off political activity due to declining health, the Ottawa chapter of the Hepatitis C Society all but ceased to exist. Several activists who were interviewed lamented their inability to attract large numbers to participate in demonstrations. Despite this, however, one activist noted that she tried to capitalize on the threat of mass protest, which government wanted to avoid at all costs. To this end, she spoke of using "back room" and "front room" strategies: "My answer (to government negotiators) always was, 'you can deal with them (the demonstrators outside) or you can deal with me.' We can sit here and deal at the table and hopefully we will come up with a rational solution or you can go out and deal with them. And the more outrageous people became out there, the easier it was for us to say, 'deal with us.' It made a great deal of sense."⁴¹⁰

⁴¹⁰ Personal interview with Durhane Wong-Rieger, July 6, 1999, Ottawa.

Defining and Achieving Outcomes

It is common to frame a discussion of outcomes in the language of success or failure. Success, however, is a slippery concept. Is it an all-or-nothing category? Is it correct or misleading to speak of limited success, such as the case with Hepatitis C compensation for some, but not for others? Are short-term victories more important than having a longer-lasting impact on a new series of challenging groups? Whose perceptions of success matter more: group leaders, rank-and-file members, or policy makers? Moreover, one might note that it is absurd to talk of success when dealing with the contamination of thousands of Canadians with HIV and Hepatitis C. How, one might argue, can we rightly speak of success in the light of the devastation visited upon recipients of tainted blood? Is it best when discussing outcomes to reflect on perceptions of success and failure among movement participants, since there may be divergent interpretations of success and failure within a movement? In this case, people with Hepatitis C may interpret the outcomes differently than those with HIV.

Before proceeding, it should be stressed that to speak of outcomes does not necessarily imply that we can always determine who can claim proper credit for a given outcome. Tilly nicely illustrates the problem of defining outcomes as one of three overlapping circles, each of which represents one set of variables: all movement claims, all effects of movements' actions, and all effects of outside events and actions.

Figure 6.1: Identifying Social Movement Outcomes

Source: Tilly (1998)

A = Effects of movement action that bear directly on movement claims

B = Joint effects of movement action and outside influences that bear directly on movement claims

C = Effects of outside influences (but not movement actions) that bear directly on movement claims

D = Joint effects of movement actions and outside influences that don't bear on movement claims

The "problem" to which Tilly is referring is the fact that "A" is not the only possible explanation of movement outcome. That is, "the commonsense meaning of social movement outcome" as one of cause and effect – movement actions either fulfill or fail to

fulfill movement claims – does not exhaust the range of possibilities. Outcomes, for instance, may be the result of both movement actions and outside influences (intersection B), they may be the product of external events and actions that are favourable to or satisfy movement claims (intersection C), or the product of movement actions and outside influences, which do not bear directly on movement claims (unintended consequences). Tilly's schema is intended to capture some of these "unanticipated effects" of social movement action that are often missing from traditional accounts of social movement outcomes. As he argues, sometimes "movements have their largest effects not through advancement of their programs but through these other outcomes – transformation of participants' lives, co-optation of leaders, or even renewed repression."⁴¹¹ If we fail to look beyond the fact of whether outcomes match movement leaders' stated goals, says Tilly, we may miss some of these important byproducts of collective action. It is critical, then, to focus on movement interactions and dynamics, as a means to overcome some of the methodological problems associated with identifying outcomes or consequences.⁴¹²

⁴¹¹ Charles Tilly, "From Interactions to Outcomes in Social Movements," *op. cit.*, p. 268.

⁴¹² As Giugni notes in the case of the environmental movement, "if we do not first shed light on the interactions between Greenpeace activists, political elites and institutions, public opinion, and Shell's leaders, we will find it difficult to attribute the company's decision to destroy the Brent Spar oil rig to the environmentalists' outraged call for a boycott. After all, without interaction, there are simply no outcomes or consequences." Quoted in Marco G. Giugni, "Was it Worth the Effort? The Outcomes and Consequences of Social Movements." *Annual Review of Sociology* 1998, p. 389.

Types of Outcomes

In his widely cited work, Gamson suggests that we view success as a set of outcomes that fall into two major categories: "one concerned with the fate of the challenging group as an organization and one with the distribution of new advantages to the group's beneficiary."⁴¹³ In the first category, the guiding question centers on the *acceptance* of the group by its opponents as a valid representative for a legitimate set of interests. In the second, we are concerned with any *new advantages* conferred on the group's beneficiary during and after its challenging period. Combining these two categories, Gamson devises four possible outcomes: full response, cooptation, preemption and collapse. The full response and collapse categories are relatively straightforward; the first denotes the achievement of both acceptance and new advantages, while the latter indicates the absence of neither. Cooptation refers to the existence of acceptance, but without new advantages, and preemption implies the opposite, new advantages but no acceptance.

Gamson identified four main indicators of acceptance: consultation, negotiation, formal recognition, and inclusion. The first involves a degree of initiative on the opponent's part to invite group representatives to address an issue of importance to the group. The key here is the initiative of the opponent; consultation does not derive if an opponent, for instance, acquiesces to a group's demand to be heard. The second, while

similar to the first, is concerned with the willingness of opponents to negotiate, on a regular basis, with the challenging group. The outcome of the negotiation is less important here than the implicit suggestion that the opponent views the group as an authentic spokesperson for a constituency. A minimal acceptance relationship exists if one of these indicators is present.

The issue of acceptance in the case of blood activism is complicated by a number of factors, not the least of which is the competition between and antagonism among the various groups. Acceptance of the group by its opponents as legitimate representatives is critical, but so is acceptance by the constituency the group represents. The latter should not be taken as given, which Gamson's account seems to suggest. Although the Canadian Hemophilia Society was seen as an authentic spokesperson for hemophiliacs in general as well as hemophiliacs infected with HIV, the newly formed Hepatitis C Society of Canada fell victim to bitter infighting and was accused of selling out its membership. This is interesting in the light of the fact that the group formed in response to the refusal of people with Hepatitis C to be represented by the Canadian Hemophilia Society in the first place. Internally, the Hepatitis C Society was forced to deal with a rapidly expanding membership, which included not only recipients of tainted blood but intravenous drug users who contracted the virus through injection drug use. The suggestion that the majority of people with Hepatitis C contracted the virus in the latter manner, which was

⁴¹³ William Gamson, *The Strategy of Social Protest*, Homewood, Illinois: The Dorsey Press, 1975, p. 28.

reported in the media and in expert testimony before the Inquiry, fuelled arguments among Hepatitis C activists that they were the victims of a smear campaign.

While Gamson's work has been influential, several scholars have refined his conceptual framework to stress some of the variables left out of his analysis, which linked internal factors such as resources to group success. Rochon and Mazmanian added a third type of impact, changes in social values. "By changing social values," the authors argue, "movements expand the range of ideas about what is possible."⁴¹⁴ This has an effect on politics, they add, because it redraws the boundaries of the political. The other two adopted by Rochon and Mazmanian, policy change and policy-process change, resemble Gamson's new advantages and acceptance, respectively. According to Rochon and Mazmanian, movements that wish to gain legal or behavioural change must press for change on all three dimensions.⁴¹⁵ Kitschelt and Burstein include structural effects as another type of impact. The focus on structural effects captures the possibility that movements are not only subjects of structures, their actions may provoke changes in the structure of political opportunity itself, changes that will have affect future movements. They redraw the boundaries of the political. Movements may be said to have their greatest impact on future challengers when they are able to effect such changes, whether negative or positive.

⁴¹⁴ Thomas R Rochon and Daniel A. Mazmanian, "Social Movements and the Policy Process," *Annals of the AAPPS*, 528, July 1993, p. 77.

⁴¹⁵ The authors cite as an example of a "Pyrrhic victory", the Temperance Movement's success "in passing the Eighteenth Movement without diminishing the alcohol consumption of Americans." (Rochon and Mazmanian, p. 77).

How Outcomes Occur

Adapting Gamson's approach to capture the "political process occurring between the initial challenge and potential substantive political changes," Burstein argues that success should be viewed as the political system's responsiveness to the demands of a social movement organization. It occurs in five stages:

Access responsiveness, the willingness of the target to hear the concerns of the movement organization (similar to Gamson's acceptance);

Agenda responsiveness, the target's willingness to put the movement's demands on the political agenda;

Policy responsiveness, the target's adoption of new policies (particularly legislation) congruent with the manifest demands of protest groups (which Gamson would consider a new advantage);

Output responsiveness, the target's effective implementation of its new policies; and

Impact responsiveness, the degree to which the actions of the political system succeed in alleviating the grievances of the protest group.⁴¹⁶

One of the stumbling blocks in Burstein's analysis, to which he devotes little attention, is the extent to which one can gauge public sentiment or attitudes on a given issue, not to mention the fact that molding public opinion is not the exclusive domain of interest organizations. Politicians, too, engage in efforts to shape and read public opinion, sometimes in concert with interest organizations, but sometimes in opposition to these

groups. In this case, for instance, the federal government responded, albeit indirectly perhaps, to a poll that indicated overwhelming support for extending compensation to all people infected with Hepatitis C through tainted blood by releasing somewhat inflated estimates of the number of people infected with Hepatitis C through tainted blood. One senior government official recalled in a personal interview that the government had no choice but to respect the numbers tabulated by the Laboratory Centers for Disease Control (an epidemiological branch of Health Canada), despite the insistence by the organizations representing tainted-blood recipients that the true numbers were much lower than those forecast. The implicit message in releasing the figures was to suggest that extending compensation to all people with Hepatitis C would be much costlier than initially anticipated. Unfortunately, no polls were conducted to gauge the impact of this announcement on citizens' attitudes vis-a-vis compensation.

In this case, for instance, the federal government responded, albeit indirectly perhaps, to a poll that indicated overwhelming support for extending compensation to all people infected with Hepatitis C through tainted blood by releasing somewhat inflated estimates of the number of people infected with Hepatitis C through tainted blood. One senior government official recalled in a personal interview that the government had no choice but to respect the numbers tabulated by the Laboratory Centers for Disease Control (an epidemiological branch of Health Canada), despite the insistence by victims' organizations that the true numbers were much lower than those forecast. The implicit

⁴¹⁶ Paul Burstein, Rachel L. Einwohner, and Jocelyn A. Hollander, "The Success of Political Movements: A Bargaining Perspective," p. 283. In *The Politics of Social Protest*, op. cit.

message in releasing the figures was to suggest that extending compensation to all people with Hepatitis C would be much costlier than initially anticipated. Unfortunately, no polls were conducted to gauge the impact of this announcement on citizens' attitudes vis-a-vis compensation.

Incorporating some of these insights, I have chosen to think of outcomes in terms of their impact on *tainted-blood recipients*, on *policy*, and on the wider *political opportunity structure*. In the first category, I include the creation and legitimacy of a collective identity for recipients of tainted blood, the activation of networks, and the creation of services. In the second, I include the overhaul of the country's blood system, and the compensation victories for people with HIV and people with Hepatitis (both federal and provincial), and the failure to secure a federal compensation package for people infected before 1986 and after 1990. In the third category, I include changes in the policy process, social values, and institutions (Medicare). It should be stressed that my comments with respect to the latter are provisional and must reflect the fact that changes of this nature do not happen overnight.

Impact on Tainted-Blood Recipients

If one examines tangible outcomes in other countries in which there was evidence of HIV and/or Hepatitis C contamination, Canada's response to the issue is stellar by comparison. As noted, HIV-infected blood recipients, the smaller of the two groups, received federal compensation in 1989 and, when these funds expired, another package of provincial and territorial assistance. With regard to Hepatitis C, the federal and provincial governments, after steadfastly refusing to consider the issue, relented and offered help to

persons infected between 1986-1990. In the United States, for instance, the government was slow to offer compensation to recipients of HIV-infected blood; people with Hepatitis C victims have not received any restitution. The efforts by American blood activists to win compensation were effectively limited by an "insuperable barrier" in the legal system. Blood shield laws in 47 U.S. states "carve out an exemption to the principle of strict liability that prevailed in tort law for injuries resulting from defective products."⁴¹⁷ It was reasoned in the 1950s, when these laws were adopted, that the provision of blood to a patient did not constitute a sale, but a service, which was central to a hospital's mission of caring. The Congress finally authorized the funds necessary to compensate the estimated 7,000 recipients infected with HIV in 2001, almost two years after the Ricky Ray Hemophilia Relief Fund Act was first passed by Congress. Each victim is expected to receive a one-time payment of \$125,000. By comparison, Canada made its first formal offer of assistance more than a decade ago, in 1989.

Beyond these material benefits or advantages, one should not underestimate the impact the scandal has had on the blood injured. These outcomes, while perhaps less obvious, are no less important than the important policy outcomes to which analysts normally refer when discussing the impact of protest events. First, they were able to form a collective identity around their suffering, an identity that helped them to make sense of their illness. In the case of Hepatitis C, this coming together was critical, as a general lack of information was what led many to despair. Finding reliable information, and getting

⁴¹⁷ Ronald Bayer, "AIDS and Blood in America: Science, Politics, and the Making of an Iatrogenic Catastrophe," p. 34. In Eric A. Feldman and Ronald Bayer (eds.), *Blood Feuds*, op. cit.

others to take seriously Hepatitis C prompted patients to take charge of the disease. They struck informal and formal networks of interaction to exchange information and to provide support. The experiences of tainted-blood activists also signal the need to pay closer attention to how disease is becoming an important political cleavage. While AIDS activists emerged on the political stage well before the revelations of tainted blood, the scandal has unleashed a new group of disease activists which has begun to press the public, the media, and government to take seriously Hepatitis C as an emerging public health concern. The decision of Health Canada in 1999 to create a new Hepatitis C Division as part of Health Canada suggests that the government has indeed heeded the message. This was part of the government's new philosophy with respect to Hepatitis C, "care not cash." Nonetheless, it is hoped that this initiative, which has earmarked millions of dollars to the Canadian Institutes of Health Research to devote to Hepatitis C-related areas of study, will improve the lives of people living with Hepatitis C.

One can only speculate about how AIDS has transformed the hemophilia community, which was forced to address its own internal, ingrained homophobia and its previous relationship of trust with the medical community. One hemophiliac who was infected with both HIV and Hepatitis C noted in an interview that he witnessed this when he was hospitalized for complications from his HIV infection. He recalled an incident when a nurse approached him to say, "you're a hemophiliac. Why didn't you tell us? We would have treated you better [than a gay man with AIDS]"⁴¹⁸

⁴¹⁸ Interview with James Kreppner, March 2001, Toronto.

When we look at outcomes for the two main challenging groups, the Canadian Hemophilia Society and the Hepatitis C Society of Canada, we see a different picture. Using Gamson's terminology, the Hepatitis C Society of Canada gained 'new advantages', but acceptance has been elusive. It won the ability to participate in the Krever Inquiry, but this acceptance was mixed, as it was the only group denied funding for legal counsel. Leaders of the group were included in negotiations over compensation, but not without pressure. In addition, the Hepatitis C Society is not accepted internally as the representative of people with Hepatitis C. Former members have accused of it being a group in name only, run from a national office based in Toronto with little or no direct influence from member chapters. Internally, it had to deal with an expanding membership, which included not only those infected through the blood system, but IV drug users, as well. The Canadian Hemophilia Society gained both acceptance and new advantages. Internally, the CHS has had its share of strife, but it has managed to accommodate this by allowing local chapters to chart their own course. As a result, Ontario has one of the most militant chapters of the organization in the country.

Impact on Policy

There is some reluctance to consider changes in policy when discussing social movement outcomes, as it is argued that such a focus tends to blur the distinction between movements and interest groups. There is, however, ample reason to do so, since movements often creatively combine instrumental and expressive goals. The gay rights movement may be concerned, for instance, with winning acceptance for the gay lifestyle,

but that does not preclude actions to pressure policy makers to alter legislation that discriminates against gays and lesbians.

Profound changes have occurred at the level of policy, including the compensation settlements reached for HIV and Hepatitis C, the dismantling of the Canadian Red Cross Society and the announcement in September 1998 that it would be replaced by a newly formed organization, Canadian Blood Services. Power is now centralized in the new agency, which is responsible for overseeing the collection, recruitment, testing, processing, and distribution of blood and blood products. At its first public meeting in January 1999, representatives of the new national blood agency stressed that openness, accountability and communicating with the public would be priorities for Canadian Blood Services as it attempts to restore public confidence in the blood system. But the new agency has already come under fire. The president of the Canadian Hemophilia Society criticized the agency for failing to notify hemophiliacs months earlier that Health Canada had temporarily suspended the distribution of blood products from the U.S. after a donor had died of the human equivalent of "mad cow disease."⁴¹⁹

Impact on Political Opportunity Structure

Movements also seek broader changes that may transform the political opportunity structure for future, perhaps unrelated challengers. Burstein cites the example of the U.S. civil rights movement's successful campaign to eliminate literacy tests for blacks, which had effectively blocked them from voting. The important spin off of this

⁴¹⁹ Anne McIlroy, "New blood tests further protect against hep C, AIDS infections," *The Globe and Mail*, January 20, 1999, p. A2

was that it opened the door for less educated whites as well as blacks to vote. Tainted blood activism, one could argue, may have an unanticipated effect on the future victims of the risk society.

Here I include changes in public opinion and social values, changes in the policy process, and the creation of new institutions and organizations. As regards changes in public opinion and values, one must recall that Hepatitis C was virtually absent from the media and public vocabulary prior to both the Krever Inquiry and the creation of organizations designed to represent people with Hepatitis C. Hepatitis A and B – the two most popular strains of Hepatitis – had garnered some attention, mainly within the scientific literature, but little treatment in the popular media. Hepatitis B, however, had been a cause for concern among members of the gay community, among which rates of infection were abnormally high. Researchers later became interested in a possible relationship between previous exposure to Hepatitis B and the likelihood of contracting HIV.

With regard to changes in social values, the scandal and the wave of activism that it unleashed have reinforced the need to consider the role of governments and voluntary organizations such as the Red Cross in minimizing exposure to risk. Tainted blood activism may have an unanticipated effect on the future victims of the risk society. Already, one can detect interesting parallels between the blood scandal and the Walkerton tainted-water tragedy, the victims of which have begun to press the Ontario government for compensation. States will continue to grapple with how to best protect citizens from

undue risk, but they must learn to do so in a climate of increasing hostility and distrust. Events such as the tainted-blood tragedy and others have contributed to this new climate of unease. As Powell and Leiss argue, a 'risk information vacuum' is primarily responsible for the social amplification of risk:

At the core of all risk issues there are problematic aspects – lack of timely information, uncertainties in the risk estimates, lack of trust, lack of credibility, complexity in the scientific descriptions, and so forth – which breed apprehensiveness, suspicion, and concern over personal safety among the public. In a risk information vacuum, this latent apprehensiveness, suspicion, and concern feeds upon itself and, in the absence of the dampening effect that good risk communication practices might supply, may be amplified to the point where credible and pertinent information might make no difference in the formation of popular opinion.⁴²⁰

Leiss has argued that part of the problem is that governments often confuse the twin tasks of risk management and risk *issue* management as if they were one and the same. Risk management is relatively straightforward, involving scientific assessments of the probable harms that might result from certain substances or activities. Risk issues are messier, conditioned and shaped by a constellation of groups attempting to steer government policy in a given direction. The outcome of risk issues or controversies, according to Leiss, may have little to do with any "objective" or probabilistic assessment of the risk factors involved. Although governments must do both – they must manage risks *and* risk issues or controversies – they appear less able to do the latter. Leiss attributes this to the difficulties that governments encounter "in integrating multiple

⁴²⁰ Douglas Powell and William Leiss. 1997. *Mad Cows and Mother's Milk: The Perils of Poor Risk Communication*. Montreal and Kingston: McGill-Queen's University Press, p. 214.

decision inputs of qualitatively different sorts into a coherent framework within and across issue types.”⁴²¹

As regards changes in the policy process, Rochon and Mazmanian argue, citing the examples of the nuclear freeze movement and the hazardous waste movement, that movements can have a significant effect on policy outcomes by gaining access to the policy process, even if they do not win particular policy decisions. The authors, for example, connect the failure and collapse of the nuclear freeze movement to its unsuccessful strategy to alter policy by passing a specific Congressional resolution. Although the resolution was finally passed, “it had no practical significance because it did not affect the actual conduct of superpower diplomacy.”⁴²² The second movement, on the other hand, realized that while important policy changes were necessary, “it was just as important to secure an opening of the policy process to greater public participation.”⁴²³ And while such closeness to the institutional reins of power is frowned upon by movement theorists and actors alike, mainly on the grounds that the movement may be coopted by the state, Rochon and Mazmanian argue that such suggestions fail to take

⁴²¹ William Leiss, “The Public Controversy over Genetically Modified Foods,” *ISUMA: Canadian Journal of Policy Research*, Vol. 1, No. 2, Autumn 2000, p. 81.

⁴²² Thomas R Rochon and Daniel A. Mazmanian, “Social Movements and the Policy Process,” *op. cit.*, p. 87.

⁴²³ Thomas R. Rochon and Daniel A. Mazmanian, “Social Movements and the Policy Process,” *op. cit.*, 84.

account of the direct, positive impact of involvement in the policy process, especially as it relates to the development of environment policy.⁴²⁴

Finally, the blood scandal has seen the creation of new organizations and institutions. For one, the scandal gave birth to the Hepatitis C Society of Canada, and transformed the Canadian Hemophilia Society from its role as a tame consumer advocate to a more outspoken critic. In addition, thanks to the actions of the Inquiry and activist agitation, the blood system was completely revamped in September 1998. In addition, following criticisms that the government needed to step up its research into Hepatitis C, Health Minister Allan Rock announced in 1999 the formation of a new research branch of Health Canada devoted solely to Hepatitis C research, a move that was criticized by some activists as too little, too late. Providing money to 'victims' will not ease their suffering, Rock told the media. Devoting government funds to research into effective treatments will.

And while it would be premature to pay sole credit to the movement for all of these important changes (the Krever Inquiry was an important catalyst), one needs to recall that the contents of the Krever Inquiry became important points of articulation for movement actors. Although the report is widely available and key excerpts were published in major Canadian newspapers, activists saw the need to digest the report and publicize some of its main points. In the Inquiry report, some activists found a script they could follow or from which they could liberally borrow. Interestingly, however, activists

were initially worried that the Inquiry report would amount to nothing more than a whitewash, a fear that justified continued independent pressure in the face of continued delays in the release of the report. In fact, the legal challenges that delayed the release of the report proved fortuitous for activists, who used the opportunity to weigh in on the issue in the media, and demand that Krever be permitted to make potential findings of misconduct against responsible individuals, institutions, and corporations. What those parties who tried to prevent Krever from naming names didn't realize was the impact this would have on keeping the story alive in the media. And, despite their skepticism about its contents, activists were instrumental in lending legitimacy to the report, which, not surprisingly, was greeted with a lukewarm response by the government.

It also has been suggested that the scandal and its aftermath may alter one of the country's most coveted institutions: our public health care system. As Picard notes, it has "expanded the definition of Medicare in the twenty first century" to account for those instances "when treatment does more harm than good."

By strongly endorsing a public health model, one that emphasizes prevention and that compensates people in those rare instances when treatment does more harm than good, he [Krever] is expanding the boundaries of medicare so that it becomes more just. Implicit in his recommendations is the idea that state-funded healthcare in Canada does not start with a visit to a doctor's office and end with a discharge from the hospital; it begins with informing the public about all manner of health issues and caring for them not only when

⁴²⁴ Rochon and Mazmanian evaluate the "success" of social movements along three tracks: policy change, process change, and value change. The first two, Giugni notes, are close to Gamson's original formulation, while value change is a new addition.

things go right, but when they go wrong; healthcare, literally, from cradle to grave.⁴²⁵

Movement Strategies, Outcomes in Comparative Context: The Cases of France, the U.S. and Japan

Blood activism, of course, is not unique to Canada; it is international in scope, a fact that is reflected in the 'advocacy networks' that like-minded activists have developed.⁴²⁶ Varying degrees of activism have emerged in those countries that have witnessed blood scandals, including France, Germany, Switzerland, Japan, the United States, Ireland, the Netherlands, Italy, and New Zealand.⁴²⁷

One should not underestimate the severity and impact of Canada's scandal. One comparative study, for instance, singles out Canada as one of only three countries (France and Japan being the other two) that "experienced the most prolonged and bitter public debate about wrongdoing in connection with contaminated blood and blood products."⁴²⁸ In classifying Canada's tainted-blood scandal along a continuum of high-, moderate- and low-intensity, Marmor, Dillon and Scher argue that Canada's was an instance of high-

⁴²⁵ André Picard, *The Gift of Death* (updated edition), op. cit., p. 255.

⁴²⁶ For instance, hemophilia activists in Canada have collaborated with American activists in bringing to light the tangled story of prisoner-donated blood and its role in the Canadian blood scandal, which implicates, among others, Finance Minister Paul Martin.

⁴²⁷ See the chapters in the edited volume, *Blood Feuds*, op. cit.

⁴²⁸ Theodore R. Marmor, Patricia A. Dillon, and Stephen Scher, "The Comparative Politics of Tainted Blood: From Hesitancy to Scandal," p. 354. In *Blood Feuds*, op. cit.

intensity scandal. They base their findings on a set of predictors, which, to varying degrees, were present in the three countries identified, including: “a unified group of hemophiliacs with a political identity, a compelling narrative appealing to the larger population, a paternalistic political culture, and a centralized decision-making regime.”⁴²⁹

Although Marmor et al. do not reflect specifically on the Hepatitis C issue, I argue that the added plight of these “forgotten victims” only strengthens the aforementioned argument regarding the severity and/or intensity of Canada’s scandal.

Interestingly, however, blood activism in many of these countries was confined to underscoring the plight of people who contracted HIV through tainted blood, even though it is widely known that many recipients of blood and blood products were infected with Hepatitis C. An exhaustive examination of the unique features of blood activism in these countries is beyond the scope of this dissertation. Instead, I highlight three countries – France, the United States, and Japan – where blood activism took an interesting turn. France and the United States occupy extreme positions: France reserved some of the harshest punishment for government officials and blood regulators, while the U.S. is one of the only industrialized countries to have failed to finalize a compensation deal for infected persons, a fact made all the more baffling given its strong activist tradition. Japan occupies a middle ground.

In France, the media played an especially critical role in rousing groups to action. A 1991 magazine article by journalist Anne-Marie Casteret, in particular, included

⁴²⁹ Theodore R. Marmor, Patricia A. Dillon, and Stephen Scher, “The Comparative Politics of Tainted Blood,” *op. cit.*, p. 354-355.

startling revelations from the minutes of a meeting at the country's National Blood Transfusion Centre. During the meeting, one official revealed that distribution of non-heat treated blood products to hemophiliacs would continue until all the stocks were depleted or until the law forbade it. Officials also knew that almost all of the factor concentrate was contaminated with HIV, but chose to withhold that information from France's hemophilia association and the Ministry of Health. As a result, almost half of France's 2,500 hemophiliacs were infected with HIV-tainted blood. According to Steffen, the Casteret story sparked a "vehement press campaign," a no-holds-barred press war for the latest salacious tidbit of information. Suddenly, says Steffen, "newspapers started their own investigations and, day by day, the public, astounded and avid for further revelations, discovered new documents stamped 'confidential.'"⁴³⁰ The French media became embroiled in turf wars between the established medical press, which framed the issue in terms of medical mistakes, and a new crop of aggressive, largely ambitious journalists who were more interested in pointing fingers, and, in the process, advancing their own careers. As Steffen suggests:

The press grasped the opportunity to modify its relations with politicians, the medical profession, and the legal world – three areas in which the French press had relatively little autonomy. The affair provided an opportunity for young journalists to assert themselves in a highly competitive professional sphere, as medical journalism shifted from the hands of doctors to those of journalists wanting to

⁴³⁰ Monika Steffen, "The Nation's Blood: Medicine, Justice, and the State in France," p. 112. In *Blood Feuds*, op. cit.

specialize in medical issues. The blood affair also encouraged investigative journalism, a relatively undeveloped field in France.⁴³¹

Whatever their motives, however, the French media were successful, despite the luxury of a public inquiry, in drawing public and government attention to the plight of tainted-blood victims.

In the U.S., one of the most militant organizations to emerge in the wake of the its blood scandal was the Committee of Ten Thousand, which broke off from the National Hemophilia Foundation, arguing that the NHF's cozy relationship with government and the pharmaceutical industry was part of the problem, not the solution. As far as Hepatitis C is concerned, a new group, Hepatitis C Action and Advocacy Network (HAAC), formed recently in the U.S. Tearing a page from the radical, direct-action AIDS activist group, ACT UP, HAAC has become a vocal opponent of the pharmaceutical industry, specifically its pricing of treatment drugs for Hepatitis C. HAAC bills itself as "a national, grassroots, all-volunteer group of individuals committed to non-violent direct action to end the Hepatitis C crisis."⁴³² (ACT UP bills itself is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis."⁴³³ HAAC launched a campaign in 1999 against Schering-Plough Pharmaceuticals, the makers of Intron-A, one of the three brands of alpha-interferon approved to treat HCV

⁴³¹ Monika Steffen, "The Nation's Blood: Medicine, Justice, and the State in France," p. 112. In *Blood Feuds*, op. cit.

⁴³² Taken from "Health Care Community Alert: Consensus Statement to Schering-Plough Pharmaceuticals, Rebetrone Development and Marketing Practices," no date, downloaded from heplace.com.

⁴³³ Taken from ACT UP contact sheet, 24 April 1995.

infection. In June, the company was granted FDA approval to market ribavirin, an oral anti-viral, to be used in combination with alpha-interferon in the treatment of Hepatitis C. Results of the combination therapy have been positive, with as much as half of the patients who are using the combination for six months to a year showing a good response. Until June of 1998, the first treatment prescribed for HCV was alpha-interferon, a drug that is injected subcutaneously three times a week for six months to a year. Alpha-interferon causes serious side effects in most people, including severe depression and flu-like symptoms. Only 15 to 20 per cent of people who go through alpha-interferon monotherapy for a year reduce the Hepatitis C virus to undetectable levels. This leaves the majority of people left to endure an arduous treatment for little good effect. And of the few who do respond, relapse is common. The only saving grace for these patients is that alpha-interferon treatment may slow down liver disease progression even if the amount of HCV isn't significantly reduced.

The group demanded that the company cease its unprecedented "bundling" of the anti-viral, ribavirin, with its brand of interferon (Intron-A) under the name Rebetrone. In an unprecedented move, Schering-Plough secured the exclusive right to market ribavirin only in a package with their brand of alpha-interferon (Intron-A). "Never in the history of drug development, approval or marketing has bundling like this been forced on any patient population," HAAC contends. The bundling of the drugs makes it impossible for patients to purchase ribavirin separately to be used in combination with other available and less costly interferon. For example, while Glaxo Wellcome manufacturers Combivir,

which combines two of that company's anti-HIV drugs, AZT and 3TC, in one pill, each of these drugs is also available individually, allowing people with HIV to pick and choose the most useful combination treatment for them. HAAC contends that the bundling of ribavirin with Intron-A prevents doctors from the legal and common practice of prescribing off-label. Some patients respond better and/or experience fewer adverse reactions to one interferon over the others. Bundling limits the physician's ability to making dosing adjustments of both the ribavirin and the interferon. In addition, there is some indication that the different formulations of interferon vary in efficacy. HAAC argues that Allowing Schering-Plough to get away with this bundling strategy "sets a disastrous precedent for the pharmaceutical industry, the consequences of which could go far beyond those now being faced by people with Hepatitis C."⁴³⁴ The wholesale cost for six months of Rebetrone treatment is \$8,600. The wholesale cost for six months of Intron-A alone is \$2,500. This means that the wholesale cost for six months of ribavirin, if you could get it alone, is an astounding \$6,100. Ribavirin is available in Mexico and Western Europe; however, because Schering-Plough does not own the rights to the drug there, the price is at least 265% lower than in the United States.

Canadian advocates for Hepatitis C differ markedly from their American counterparts in terms of their seeming reluctance to embrace the aforementioned U.S. groups' brand of in-your-face activism. Yet some Canadian activists have begun forging links with the U.S. based group. Marmor, Dillon, and Sherr explain that these divisions

⁴³⁴ "Health Care Community Alert: Consensus Statement to Schering-Plough Pharmaceuticals, Rebetrone Development and Marketing Practices," no date, downloaded from hepplace.com.

within the hemophilia community – between the radical voices of activists associated with COTT and the more mainstream National Hemophilia Foundation – “prevented the development of a more powerful and unified public movement.”⁴³⁵

In Japan, groups representing hemophiliacs became important players in a relatively short time. According to one account, “the Japanese story is a clear example of the role that interest groups played in the shaping of blood scandals.” Unlike tainted-blood recipients in other countries, Japanese hemophiliacs were also successful in expanding their coalition to include student supporters and other non-hemophiliacs. In addition, Feldman notes that hemophilia organizations were able to exploit the absence of gay organizations in the AIDS-policy making arena, and have an impact on the 1987 AIDS Prevention Law passed by the Japanese Diet. The blood injured won compensation as well as apologies from government officials and pharmaceutical companies. The president of Green Cross, Japan’s largest pharmaceutical company, “even got down on his hands and knees, and bowed so deeply that his forehead touched the floor. It was the defining moment of the conflict; a display of physical and psychological vulnerability...”⁴³⁶

⁴³⁵ Theodore A. Marmor, Patricia A. Dillon, and Stephen Scher, “The Comparative Politics of Contaminated Blood,” p. 361. In *Blood Feuds*, op. cit.

⁴³⁶ Eric Feldman, “HIV and Blood in Japan: Transforming Private Conflict into Public Scandal,” p.81. In *Blood Feuds*, op. cit.

Conclusion

Canada's tainted-blood scandal is distinctive in that it consisted of two separate but related scandals: HIV and Hepatitis C. Although thousands of people in other countries were infected with HIV and Hepatitis C through tainted blood, Canada's scandal politicized two groups, one with a rich social history and another group of relative newcomers united by little more than a little-known medical condition. An answer to why outcomes and strategies differed in Canada in comparison with other countries must begin, I argue, by paying attention to those distinctive features of Canada's political opportunity structure. In emphasizing the structural determinants of movement success and failure, we should not, however, underestimate the impact of the subjective nature of terms such as "opportunities," "successes," and "failures." Moreover, opportunities may provide the grounds for choosing to pursue collective action (discouraging or encouraging challengers), but they do not solely determine action or outcomes.

CHAPTER 7

Conclusion

This research has addressed both the nature of victim mobilization and the outcomes of protest within a social movement framework. Social movement literature, not of course without its flaws, successfully combines an interest in how movements and/or movement organizations form, with a concentration on movement strategies aimed at securing positive outcomes. The concept of “political opportunity structure” that undergirded this dissertation injected a structural component into the analysis, while the focus of New Social Movement theorists on collective identity helped to shed light on those issues that transcend resource attainment. Indeed, one of the main assumptions that grounded this analysis was that in order to reach a sophisticated understanding of social movement activism, one needs to pay attention to this complex interplay between structure and agency. Focusing solely on the process of collective identity formation as an end in and of itself, or on the structural determinants of collective action, leaves the analyst with an unnecessarily incomplete picture of the dynamic process of contentious politics.

Specifically, I examined how aspects of the ‘political opportunity structure’ influenced: a) the strategies adopted by political actors; b) the negotiation of a collective identity; and c) the policy outcomes. One of the objectives of this research was to demonstrate that events or “moments” can play a pivotal role in transforming the political opportunity structure in which social movement actors find themselves, by extension transforming the social movement itself. One of these moments, the Krever Inquiry,

helped to open a window of opportunity for activists: it not only legitimized tainted blood as an important political issue worthy of media and public attention, but gave shape to the fledgling movement of tainted blood recipients. These activists, it should be stressed, were politically active before the Inquiry and, in fact, are partly responsible for the establishment of the Inquiry. But the Inquiry itself lent further legitimacy to the plight of the blood injured, especially those infected with Hepatitis C. These moments, however, are not unidirectional in their impact; they also signal to opponents a movement's weak points. State actors recognized that there were indeed cracks in the movement, between individuals infected with HIV and those infected with Hepatitis C. And, within the ranks of Hepatitis C activists, there were divisions over whether to accept a compensation package that recognized only those infected during an isolated time period.

This study has attempted to refine three aspects of social movement theory. First, I elaborated the nature of collective identity formation, demonstrating that this process is contested, even among movement adherents, and that this contestation had important implications for the movement and its attempts to affect public policy. Second, although the concept of political opportunity structure requires greater refinement, I demonstrated that it allows the analyst to bridge concerns with structure, on the one hand, and agency, on the other. In particular, the notion of framing is a useful bridge that focuses our attention on how movement participants interpret, respond to, and create opportunities in the political and social environment. Movement actors may, in the short term, take the political environment as given, but that does not preclude the possibility of change in the long term. For instance, Hepatitis C activists recognized that party discipline, a staple of

Canada's parliamentary system, was strong enough to ensure that the incumbent Liberal Party would quash an attempt to extend compensation to all people with Hepatitis C. Recognition of this, however, did not deter activists from pressing for change, notably in the provincial realm. In other words, they accepted as "given" that certain features of the political system resist change, but found alternate routes to achieving their goals.

Third, I argued that the assumption of the growing institutionalization of movements over time, which dominates interest group as well as resource mobilization theories, fails to account for the possibility that actors who participate in state-sanctioned activity may disrupt convention just as effectively as demonstrators chanting in the streets. The assumption that once admitted, you must play by the rules of the game, is not borne out when we examine blood activism. A leader of a social movement organization may agree to meet with government officials in one instance, but stand outside Parliament Hill on another day with duct tape covering her mouth to dramatize the plight of victims who feel their voices are being silenced. Although instances of dramatic protest of the sort described in the social movement literature were few and far between, activists nonetheless adopted various tactics to dramatize their plight. They staged demonstrations, petitioned and lobbied government and opposition politicians, and told their stories to the Inquiry and to the media. The latter was crucial, because it demonstrated to the greater public and to others who were reluctant to speak out, that there was nothing shameful about being the recipient of tainted blood.

I argued also that it is naive to suggest, for instance, that social movement organizations are indistinguishable from traditional interest groups since some actions of

SMOs departed from the model of “normal” interest group behaviour. Whether SMOs start off as interest groups or retain some of the features of interest groups should not be misconstrued as evidence that they fail to meet the criteria used to define social movement organizations. Just as the existence of Green Parties in Europe does not preclude the existence of the environmental movement, neither should we view the institutionalized nature of some social movement organizations as incontrovertible evidence of movement deradicalization. Social movements are, by their very nature, heterogeneous agglomerations of groups with different tactics, philosophies, and resources.

The tainted-blood movement, for one, was composed of seasoned AIDS activists, traditional consumer groups (the Canadian Hemophilia Society), and fledgling organizations (the Hepatitis C Society of Canada), as well as individual activists who retained tenuous or no affiliation with formal organizations. What sustained movement activists and fuelled movement activity was a loose, sometimes informal network of affiliation bolstered by the presence of the Internet, which allowed individuals in far-flung communities to forge common bonds across time and space. The movement rarely spoke with one voice (movements rarely do), nor did it exhibit a single, cohesive identity. Its strength, rather, was forged in its diversity: a group of committed activists working on the frontlines, organizing demonstrations, petitioning government, and another group of activists engaged in formal, institutionalized interaction with elites and authorities. Just as other movements require radical activists to work alongside lobby groups, the tainted-blood movement benefited from this mix of traditional lobbyists and frontline protesters.

That being said, the balance was tilted toward more conventional forms of political activity.

While several theoretical perspectives provide a window into the world of group-state interaction, the framework adopted here lended itself well to outlining the process through which groups and/ or movement organizations form in the first place. As we noted, this is especially important in the context of tainted blood, since the Inquiry gave birth to one group (the Hepatitis C Society of Canada) and radically transformed another (the Canadian Hemophilia Society). Finally, lumping in the organizations representing persons infected with tainted blood with traditional lobby groups overlooks the crucial differences between interest groups with a healthy supply of resources and those that operate with less-than-adequate resources. Moreover, the implicit assumption that flows from this point – organizations that are funded by the state are less likely to be critical of government – is seriously challenged, if not refuted, by the experience of the Canadian Hemophilia Society, which was harshly critical of government.

Review of Findings

While tainted-blood activists were successful in winning compensation and in reforming Canada's blood system, they were not entirely successful. This was partly due to the fact that blood activism was initially grounded in an AIDS narrative, which began to unfold in the mid-1980s. Recasting the narrative to include people with Hepatitis C

proved to be a difficult task for several reasons. First, people with Hepatitis C did not represent a unified political group with a legacy of activism from which to draw. AIDS activism had grown from the seeds planted by the gay and lesbian movement and could draw from the rich and diverse experiences of this movement. Action on AIDS was seen as a precursor to the physical survival of the gay community, just as gay activism before it was connected with the cultural survival of the gay community. Second, the tendency to pit disease against disease would complicate efforts to lodge Hepatitis C within the AIDS-focused tainted blood narrative. The sheer, frightening potential of HIV provided a compelling narrative that Hepatitis C, while for some of its patients equally devastating, was unable to muster. Unlike HIV, which moved from its almost certain association with death to a more chronic condition, Hepatitis C began and continues to be seen as an unfortunate medical condition that is, for the most part, non life-threatening.

Implications for Policy

I identify four major findings of this research that have a bearing on public policy. First, this case demonstrates that the discipline of public policy needs to pay closer attention to the increasing influence of social movements in the policy process. While tainted-blood recipients were a difficult constituency to mobilize, this research explained how blood activists did so “successfully” and in a short time frame, securing not only compensation victories but contributing to the overhaul of our country’s blood system. Second, this research has sought to expand our understanding of public inquiries as sites for contestation over meaning. As Jenson has argued, commissions of inquiry are not

merely sounding boards for “interests”, they actively shape interests and identities.⁴³⁷ The Krever Inquiry represented an important vantage point from which to assess social movement activism and outcomes. As an institutionalized political space, it provided a forum for social movement organizations to perform the types of activist rituals necessary to bring attention to issues that may not be deemed political. The fact that the movement used conventional as opposed to unconventional tactics to secure the attention of citizens and policy makers reinforces the idea that the line separating disruptive from non-disruptive protest is blurred at the best of times. Loud, in-your-face demonstrations of the sort romanticized by an earlier generation of social movement scholars fail to capture the multiple expressions of group solidarity that typify social movements.⁴³⁸

The participation of blood recipients in a formal Inquiry also muted any confrontational collective action that might have ensued had they been barred from participating in the Inquiry. Movements sometimes capitalize, in the court of public opinion at least, from being shut out of the policy-making process. In this case, the question is whether direct, confrontational tactics would have garnered a different outcome, or whether blood activists would have fared better or worse had they refused to engage with the state. Interestingly, some of the Hepatitis C activists who were interviewed said that they should have learned something from their predecessors, namely radical AIDS activists who have engaged in unconventional modes of protest (e.g., die-

⁴³⁷ Jane Jenson, “Commissioning Ideas,” op. cit., p. 45.

⁴³⁸ See Mary Fainsod Katzenstein. 1998. *Faithful and Fearless*, op. cit.

ins) with largely positive results. Indeed, some suggested that the model of AIDS activism adopted by radical, direct-action groups such as ACT UP may be worth emulating. This is an ambitious prospect, however, that can be achieved only if people with Hepatitis C strengthen the bonds that unite them, as AIDS activists did so effectively beginning in the late 1980s. In addition, it will require that Hepatitis C activists work diligently to demonstrate the urgency of this silent public health threat.

Third, this research has raised larger, indeed troubling, questions regarding the boundaries of state responsibility in matters involving risk. The 'risk society' highlights the vulnerability of all to imminent threat, but the production and distribution of risks affect some more so than others. In the context of tainted blood, people with hemophilia were at greater risk than the general population, given their reliance on blood products. The implications of this research extend far beyond the specifics of tainted blood, however. The number of groups that have claimed compensation for governmental neglect or wrongdoing is growing: Aboriginal people who were forced to live in residential schools; Japanese Canadians interned during the Second World War; the Dionne quintuplets; the Duplessis orphans; and victims of thalidomide. Governments are increasingly being called upon to compensate individuals or groups for inflicted harms, and are forced to choose whom they can or should compensate given rapidly shrinking budgets. The cold, fiscal reality that neoliberal governments claim they are powerless to resist provided a ready justification for inaction with respect to testing for Hepatitis C, and resulted in the needless infection of thousands of Canadians. At the time, Red Cross

officials opted for more research, arguing that the \$2 million price tag for the study was minuscule compared with the \$20 million that would be required to fund testing.

The fact that Mike Harris's government initially balked at settling compensation claims made on behalf of Walkerton victims, when just a year earlier the Premier was urging the federal government to 'do the right thing' vis-à-vis people with Hepatitis C, indicates that compensation issues are inherently political. Moreover, the settlement of compensation claims made against government may have little to do with the veracity of the claims being made on behalf of claimants. For instance, in a classic instance of political posturing, the Ontario government decided to compensate people with Hepatitis C who had been shut out of the \$1.1 billion deal negotiated by the federal, provincial, and territorial governments. People with Hepatitis C in Ontario benefited directly from the political infighting between Harris and the Prime Minister.

Fourth, this research underscores the need to expand our understanding of "policy outcomes", which is too instrumental a term to capture the nuanced effects of collective action. While blood recipients were "successful" in securing compensation – a 'textbook' outcome– they also pursued outcomes that do not fit easily in the standard definition of outcomes. For instance, they succeeded in creating a collective identity for tainted-blood recipients, and forced us to rethink notions of what "sick" people can and cannot do. Outcomes, then, are not simply changes in policies, but changes in perceptions, acceptance, and opportunities that are subjectively interpreted.

Possible Avenues for Research

While political opportunity structures are context-specific, social movement scholars, political scientists and public policy analysts have begun to pay greater attention to the similarities across countries and to the comparative dimensions of protest and politics. The approach adopted here lends itself well to further work in which we can compare the outcomes of 'blood' protest in states with similar or widely variant political opportunity structures. As the literature suggests, this would necessitate a shift from studying "proximate" opportunity structures to cross-sectional studies of opportunity structures in various countries. Indeed what can we learn from the interactions of elites and opponents in societies with different histories? Surely, one is not looking for sweeping generalizations, but rather the kinds of results or insights that may provoke further questions. In the case of blood activism, one is bewildered by the fact that the U.S. blood scandal was unable to arouse the type of anger and activism that we witnessed in Canada, especially given the rich, American tradition of activism, from civil rights to gay rights to feminism. Part of the answer may lie in the fact that Canadian blood authorities were slower to respond to the threat of contaminated blood than their American counterparts. But this is probably only half an answer. The other half may be answered by a comparative exploration of the POS in Canada and the U.S. As noted in Chapter 6, the inability of U.S. tainted-blood recipients to secure compensation may be due to the existence of "blood shield laws" that protect the blood system from legal action. There

remains a potential, yet untapped, to study “blood activism” across countries, much in the way that Trebilcock et. al attempted to do with respect to the institutional features of blood politics.⁴³⁹ Their study, however, was conspicuously silent on the dynamic process of collective action by recipients of tainted blood.

This study also suggests that health policy researchers and analysts begin to pay closer attention to the influence of culture and politics on definitions of disease. In particular, political scientists might begin to examine how states define and respond to disease, and in the impact this may have on patients attempting to articulate their own responses and to make sense of their suffering. In the case of tainted blood, the fact that governments played a role not only in defining Hepatitis C but also directly or indirectly contributed to the infection of thousands of Canadians, no doubt makes this task all the more pressing.

The Future of Blood Activism

This case has demonstrated how a group of people, from all walks of life, some of whom were united only by a little-known medical condition, shaped a collective identity, which became the basis for political action. The fact that they were able to do this in the face of deteriorating health is a testament to their tenacity and to their dogged insistence that the issue receive the attention it merits. Many of the Hepatitis C activists interviewed

⁴³⁹ See Michael Trebilcock, Robert Howse, and Ron Daniels. “Do Institutions Matter? A Comparative Pathology of the HIV-Infected Blood Tragedy,” *op. cit.*

for this study – especially those persons not speaking officially as group leaders – felt that their failure to secure compensation for all people with Hepatitis C points to abject failure, while others argued that given the enormous odds stacked against them, it is a wonder they were able to secure the limited compensation package they did. For some, the compensation package remains a most obvious political outcome of an otherwise discouraging process. Focusing, however, on the obvious, neglects some of the intangible outcomes of blood activism that were explored in Chapter 6.

The blood scandal has no doubt had an important impact on its ‘victims’. The history of Hepatitis C activism, for instance, continues to unfold to the present. The Hepatitis C Society of Canada, which was created less than six years ago, is in the process of organizational change. Board members have resigned or have been fired, as have employees. Jeremy Beaty, the high-profile president of the Society during the compensation battles, stepped down in 1999 after almost four years at the helm. In February 2000, the Society released a strategic plan, which it hopes will provide an “operational direction” for the organization. The organization says it needs to “move further into our community, further into mainstream institutions which do not adequately serve the needs of our community, while actively involving those who are living with and affected by Hep C.”⁴⁴⁰ Today, the Hepatitis C community is further divided by the creation of a new national organization, HepCan, which is competing directly with the Hepatitis C Society. HepCan was registered in the summer of 2000 as an alternative

organization that purports to have 'direct' links with the community. To date, it retains a loose organizational structure, with member groups free to articulate their own viewpoints.

Whether blood activists in fact succeeded in satisfying all of their demands still remains an open question. One fact, however, remains unassailable. Recipients of Hepatitis C-tainted blood and, to a lesser degree HIV-infected blood recipients, politicized an issue that had barely received any notice, and managed to get governments and citizens alike to stand up and take notice. The price that those injured by the blood system have paid, however, for their political action, both personal and financial, are inestimable.

⁴⁴⁰ Hepatitis C Society of Canada, Strategic Plan, February 2000, (<http://www.hepatitiscsociety.com>)

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Key Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ACT UP	AIDS Coalition to Unleash Power
BOB	Bureau of Biologics
CAS	Canadian AIDS Society
CBA	Canadian Blood Agency
CBC	Canadian Blood Committee
CHS	Canadian Hemophilia Society
COTT	Committee of Ten Thousand
CRCS	Canadian Red Cross Society
EAP	Extraordinary Assistance Plan
HCV	Hepatitis C Virus
HeCSC	Hepatitis C Society of Canada (HeCSC)
HIV	Human Immunodeficiency Virus
NSM	New Social Movements
RMT	Resource Mobilization Theory
POS	Political Opportunity Structure
SMT	Social Movement Theory

Research Participants (arranged alphabetically)

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Joe Haché	Hepatitis C activist, father of Joey Haché, an Ottawa teenager who cycled across Canada to raise awareness of Hepatitis C
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André Juneau	Former Assistant Deputy Minister, Department of Health, Government of Canada (1993-1998)
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*** In addition, two government officials requested anonymity**

Appendix: Chronology of Compensation Debacle

Sept. 1988	Recipients of HIV-infected tainted blood make their first formal requests for compensation.
Dec. 14, 1989	The federal government announces its carefully-worded Extraordinary Assistance Plan, which provides \$120,000 over four years to each hemophiliac or transfusion recipient infected with HIV through the blood system. The decision sparks little internal debate within government and media circles, perhaps not surprising given the holiday season.
Oct. 1990	A report commissioned by the Ministers of Health says Canada should institute a no-fault insurance system for all victims of 'medical misadventure'.
March 1993	Ontario court begins to hear case filed by Rochelle Pittman, whose husband contracted HIV during the course of heart surgery. During the trial, it was revealed that the family doctor knew but never told Mr. Pittman that he had received blood from an infected donor. Rochelle Pittman only found out she was positive after her husband's death.
April 1993	With the federal plan one year away from expiring, tainted-blood recipients begin to urge the provinces to compensate.
April 1993	In a bold move, the Nova Scotia government breaks ranks with the provinces and decides to compensate recipients of HIV-tainted blood, offering them \$30,000 annually for life. Nova Scotia AIDS activists Randy and Janet Connors are credited with persuading Health Minister George Moody to go it alone.
Sept. 15, 1993	The 11 remaining provinces and territories follow suit, announcing a \$30,000-a-year compensation package.
Oct. 1993	Government announces a formal public inquiry to examine the circumstances surrounding the tainted-blood tragedy.
Nov. 22, 1993	Ottawa lawyer Pierre Lavigne, representing a group of little-known Hepatitis C patients, is granted standing at the opening of the Commission of Inquiry on the Blood System in Canada.

- March 14, 1994** Ontario court rules in favour of Pittman, and awards her more than \$500,000 in damages. Madam Justice Lang warned that the decision was "fact-specific" and should not be taken to apply broadly. Nonetheless, tainted-blood activists laud the decision.
- March 15, 1994** Deadline for tainted-blood recipients to accept provincial compensation package. In return for compensation, they must waive the right to sue the Red Cross and federal and provincial governments. Most recipients accept the plan, feeling they have little choice. Many, however, decry the timing of the deadline, only one day after the Pittman judgment, which lawyers had to scramble to digest, and well before the release of the Krever inquiry report.
- Oct. 1994** The Canadian Hemophilia Society leaks the results of a 1992 study suggesting that as many as 12,000 people may have needlessly contracted Hepatitis C as a result of a Red Cross decision to forego testing. Justice Krever lashed out at the Society for leaking the study, which was obtained through federal access-to-information legislation, to the media before presenting it to him at the Inquiry.
- May 1994** Newly formed Hepatitis C Survivors' Society is granted standing at the Inquiry, but the organization decries the Commission's refusal to grant it intervener funding.
- May 26, 1994** Federal Health Minister Diane Marleau angers many in the tainted-blood community by scoffing at calls for Hepatitis C compensation.
- Sept. 10, 1996** Federal and provincial health ministers meet to discuss issue of Hepatitis C compensation.
- Sept. 19, 1996** The first class-action lawsuit on behalf of people with Hepatitis C is launched in British Columbia.
- Oct. 10, 1996** Ontario Health Minister Jim Wilson tells people with Hepatitis C that their only recourse is to sue, which touches off a flurry of protest activity.
- Oct. 11, 1996** Hepatitis C activists stage a hastily assembled protest on Parliament Hill; they are virtually ignored by MPs.

- July 24, 1997** **Health Minister Allan Rock announces for the first time that compensation may be extended to people with Hepatitis C.**
- July 25, 1997** **Ontario follows the lead of British Columbia in launching class-action suit on behalf of people with Hepatitis C.**
- Nov. 17, 1997** **Federal Health Minister Allan Rock promises people with Hepatitis C that their claims will be dealt with humanely.**
- Nov. 27, 1997** **Justice Horace Krever releases long-awaited final report on the scandal. In the three-volume report, Krever urges governments to compensate all tainted-blood recipients. "Compensating some needy suffers and not others," he writes, "cannot be justified."**
- Dec. 2, 1997** **Quebec becomes the first province to formally support extending compensation to all recipients of Hepatitis C-tainted blood.**
- Feb. 4, 1998** **A poll by Angus Reid suggests that 87 per cent of Canadians support the idea of extending compensation to all people who contracted Hepatitis C through the blood system.**
- Feb. 17, 1998**
the **Federal and provincial health ministers meet again to consider the Hepatitis C compensation issue.**
- March 10, 1998** **Ontario lawyers launch another class-action suit, this time on behalf of people with Hepatitis C infected prior to 1986 and after 1990.**
- March 27, 1998** **Government announces \$1.1 billion compensation plan, restricted to people infected with Hepatitis C between 1986 and 1990. Details of the plans have yet to be ironed out.**
- April 3, 1998** **Angered by the limited package, Hepatitis C activists stage protest on Parliament Hill; Reform Party vows to push the issue.**
- April 7, 1998** **Former federal Health Minister Monique Begin breaks her silence, and suggests in an interview that the Liberal government should compensate all people with Hepatitis C. Begin served as health minister from 1977 to 1984 – the period during which the blood supply was first contaminated with HIV and Hepatitis C.**

- April 20, 1998** **Hepatitis C activists stage another protest; support grows among the other federal political parties, led by the Reform Party.**
- April 22, 1998** **Prime Minister Chrétien rejects a call for a free vote in the House of Commons, ordering that a vote on compensation should be viewed as a vote of confidence in the government.**
- April 28, 1998** **In a dramatic vote, the House of Commons rejects the Reform Party-led motion on extending compensation, 155-140. Liberal MP Carolyn Bennett, a former board member of the Hepatitis C Society of Canada, votes against the motion.**
- May 1, 1998** **The federal government is angered by the about-face of the Quebec, Ontario, and B.C. governments, each of which had initially supported the limited deal, but broke ranks to throw their support behind an extended package.**
- May 4, 1998** **Much to the ire of the federal government, Ontario Premier Mike Harris promises to compensate all people with Hepatitis C who were shut out of the package.**
- May 5, 1998** **Compensation deal is reopened.**
- Dec. 1998** **Class-action lawyers leak the details of the \$1.1 billion aid package, which would compensate those infected between 1986-1990 on a sliding scale, with the most money going to the sickest. The package also covers people who were "secondarily infected" with HIV.**
- Feb. 24, 1999** **A group of tainted-blood recipients announces in Washington, D.C., plans to file a \$660-million class-action lawsuit against the U.S. government, the states of Arkansas and Louisiana, and the Food and Drug Administration, in connection with the "unlawful and willful collection and distribution of contaminated blood and plasma from prisons in the U.S." Among those implicated by their accusation are then-governor of Arkansas, Bill Clinton, and current finance minister Paul Martin. The suit alleges that while the FDA suspended the use of prison plasma to manufacture blood products in 1982, it allowed this plasma to be exported to Canada.**
- May 1999** **Thieves break into the offices of the Quebec chapter of the Canadian Hemophilia Society, stealing a computer, three telephones, and documents related to the blood scandal. On the**

same day, an Arkansas prosthetics clinic owned by Michael Galster is firebombed. Galster is the author of *Blood Trail*, a fictional account of how the prison-plasma program worked. Mike McCarthy, a hemophilia activist who appeared as the lead plaintiff months earlier in Washington, tells the media that he is convinced that the two crimes are linked.

- June 1999 Federal, provincial, and territorial governments and counsel for people with Hepatitis C file a proposed settlement agreement with the courts for final approval. As it seeks to settle class-action lawsuits in Ontario, British Columbia, and Quebec, the deal must be approved by the courts in these provinces.
- July 1999 News is leaked that class-action lawyers across Canada who negotiated the compensation deal for those infected between 1986-1990 will earn as much as \$52.5 million for their efforts. The Hepatitis C Society of Canada holds a news conference at which they criticize the move.
- July 1999 The Quebec government passes an order-in-council in the National Assembly, offering a one-time cash payment of \$10,000 to people who contracted Hepatitis C before 1986 and after 1990, the period not covered by the \$1.1 billion package. Quebec recipients lash out at the payment, arguing that Premier Lucien Bouchard reneged on his commitment to first consult those most affected.
- Aug. 1999 Court hearings begin on settlement of class-action suits in Quebec, Ontario, and British Columbia.
- Aug. 2000 Hepatitis C recipients who were infected between 1986 and 1990 approve a plan from the Canadian Red Cross Society that awards them \$79 million in assistance. The deal was critical in ensuring that the Red Cross avoid bankruptcy as well as many lawsuits that had been launched against it by tainted-blood recipients. The deal, which was brokered by former Ontario Premier Bob Rae, was justified by its supporters on the suggestion that forcing the Society into bankruptcy would hurt others throughout the world who benefit from the humanitarian efforts of the Society.
- Nov. 2000 The British Columbia government agreed to provide \$6.5 million to settle a class-auction suit launched on behalf of Hepatitis C

recipients infected before 1986 and after 1990. The deal works out to about \$5,000 for each person involved in the class action.

Jan. 2001

The Manitoba government announced a provincial compensation plan for Hepatitis C recipients shut out of the federal-provincial package of which Manitoba was a part. Recipients will receive a one-time payment of \$10,000. In addition, the province agreed to cover the cost of Rebetron, a drug treatment for Hepatitis C, at a cost of \$19,000 per patient per year.

June 26, 2001

An Ontario judge approved a Canadian Red Cross assistance plan to Hepatitis C recipients who were shut out of the federal-provincial package. Justice Warren Winkler, who had rejected a Red Cross offer in February, said the revised settlement was "fair, reasonable, and in the best interests of the class as a whole."