The Paradoxical Situation of Blood Donation in the Haitian-Quebec Community

Abstract

Blood donation involves precise regulations aiming to protect donors and recipients. At the beginning of the 1980's, thousands of Canadians were infected with HIV and Hepatitis C. To prevent the contamination of blood products, health authorities asked Haitians, among other groups, to voluntarily refrain from giving blood. Witness testimonies at the Royal Commission of Inquiry on the Blood System in Canada (Krever Commission) show how profoundly affected Haitians were by these events. Today, we know that it is preferable to use phenotyped blood from the same community as the donor in the case of certain diseases. Increasing blood donation from the Black community is believed to be the best way to find donors who will be compatible with patients suffering from sickle-cell disease. Blood supply agencies such as Héma-Québec are seeking to convince Haitians to give blood in greater numbers. However, this task represents a great challenge, since, less than one generation ago, authorities asked that Haitians voluntarily abstain from donating blood. This paradoxical situation inspired the present analysis. Through the conceptual lens of a constructivist approach to ethnicity, this case study draws on a number of sources. By retracing the history of this community and the major events that have affected it over the decades, we are brought to a better understanding of the perceptions and realities of the Haitian community in Montreal with regard to blood donation. Our analyses show that even if Haitian-Quebec leaders are positively disposed towards blood donation, our results also expose that past events of the 1980's have not been forgotten. Even if many are now willing to give blood to meet specific medical needs, for some, this could also contradict the usual universalist and altruistic message of blood donation. This case study highlights the importance of examining what happens at the relational boundary between minority and majority groups: after all, these events also contribute to redefining them.

Résumé

Le don de sang au Québec est encadré par des règles définies pour protéger les donneurs et ceux qui doivent subir une transfusion sanguine. Au début des années 1980, des milliers de Canadiens seront infectés par le VIH et l'Hépatite C. Pour prévenir la contamination des produits sanguins, les autorités sanitaires ont invité certains groupes, dont les Haïtiens, à s'abstenir volontairement de donner du sang. Les témoignages à la Commission d'enquête sur l'approvisionnement en sang au Canada (Commission Krever) ont montré à quel point les Haïtiens-Québécois en ont été affectés. Aujourd'hui, on sait qu'il est préférable d'utiliser le sang phénotypé qui provient de la même communauté que le donneur dans le cas de certaines maladies. Par exemple, l'augmentation de dons de sang de la communauté noire serait la meilleure façon de trouver des donneurs compatibles avec les patients atteints d'anémie falciforme. Convaincre les Haïtiens de donner du sang en plus grand nombre semble pourtant un véritable défi du fait qu'il y a à peine une génération, les autorités responsables ne voulaient pas de leur sang. C'est cette situation paradoxale qui a inspiré la présente analyse. À partir d'une approche constructiviste de l'ethnicité, cette étude de cas fait appel à de nombreuses sources afin de faire le point sur le rapport de la communauté haïtienne

du Québec au don de sang, en reprenant le fil de l'histoire de cette communauté. Même si les leaders de la communauté haïtienne québécoise sont maintenant plutôt favorables au don de sang et qu'Héma-Québec a fait de nombreux efforts pour recruter des donneurs au sein de cette communauté, nos analyses montrent que la mémoire des événements difficiles vécus dans les années 1980 n'a pas complètement été effacée. De plus, même si plusieurs peuvent être motivés à donner du sang pour répondre aux besoins médicaux de la communauté, pour certains, ceci peut aussi aller à l'encontre du message universaliste du don de sang. Cette étude de cas montre l'importance de s'intéresser aux événements qui affectent ce qui se passe à la frontière des relations entre minorités et majorité et contribuent ainsi à les redéfinir.

INTRODUCTION

Blood donation in Quebec involves voluntary, non-remunerated and anonymous donation governed by precise regulations aiming to protect both donors and recipients. Over the decades, exclusion criteria have changed with the discovery of new blood-borne diseases. At the turn of the 1980's, an estimated 2,000 Canadians were infected with HIV and another 30,000 with Hepatitis C, many of them hemophiliacs who were treated with contaminated blood products. In 1983, at the height of this major health crisis commonly referred to as the "contaminated blood affair", Canadian health authorities asked certain groups to voluntarily refrain from giving blood, more specifically persons at high risk of contracting AIDS.

The groups identified by health authorities in 1983 included homosexuals, heroin addicts, hemophiliacs and Haitians. They would later be known as the "4H" group. Haitians were included in this group because, in the United States, there had been reported cases of HIV-AIDS in recently immigrated Haitians, some of them having shown up at Florida's hospitals since 1981. The following year, the Centers for Disease Control (CDC) reported other confirmed cases in New York (Farmer 2006). Although the CDC had previously released data on AIDS in heterosexuals, "the article on Haitians constituted the first complete report focusing directly on persons outside the 'homosexual' category" (Farmer 2006, 211). Epidemiologists were unable to explain why Haitians seemed more afflicted with this new disease: "AIDS among Haitians was, in the words of many researchers, 'a complete mystery'" (Farmer 2006, 211). Notwithstanding this scientific uncertainty, American authorities decided to exclude Haitians from donating blood. Canadian health authorities based their decision on that of their American counterparts. They did not, however, take into account the size of the Haitian community within Quebec's Black population. Indeed, this group is proportionally more important in Quebec than it is in the United States and in the rest of Canada. In the mid-1980's, Haitians constituted half of Greater Montreal's Black population (Williams 1998 [1989]).

This event would greatly impact the relationship between the Haitian minority and the majority Quebec population that had, up until then, been relatively harmonious. One of its long-lasting consequences was to durably alienate Haitians from donating blood, even after the voluntary self-exclusion was lifted in 1988.

In the last few years, however, it has been confirmed that in order to treat certain diseases that necessitate numerous blood transfusions—such as sickle cell anemia—it is preferable to use phenotyped blood from the same community as the donor in order to reduce risks in line with allo-immunization (Duboz et al. 2012; Grossman et al. 2005; Price et al. 2009; Shaz and Hillyer 2010).¹ Phenotypic incompatibility can lead to the development of antibodies that, in turn, attack red cells in subsequent transfusions and lessen the treatment's efficacy.

People of sub-Saharan African descent constitute a population at higher risk of developing sickle-cell anemia.² As a result, increasing blood donation from Black communities is believed to be the best way to find donors who will be compatible with patients suffering from this disease. Given these circumstances, blood supply agencies such as Héma-Québec are seeking to convince members of certain communities, such as Haitians, to give blood in greater numbers. This objective is rendered more difficult by the fact that blood does not generally circulate between blood service providers unless there is an urgent need. It is therefore Héma-Québec's responsibility to provide blood products for its population, including specific phenotyped blood for some groups, such as Haitians.

After having been identified as a population that posed a risk of contaminating the blood supply, Haitian-Quebecers are now a targeted social group for recruiting new blood donors. It is this paradoxical situation that inspired the present case study. In the first part of this text, we explain our choice behind our case study approach (Ragin and Becker 1992). We then follow with a brief presentation of the constructivist approach to ethnicity, a particularly well-suited framework for this situation (Baxter and Jack 2008; Stake 1995; Yin 2009).

The presentation of our case study is divided into three parts. In the first part, we use official statistical data to sketch a brief portrait of the Haitian population in Quebec. We then retrace the history of the Haitian-Quebec community and follow its migratory waves, before moving on to a presentation of the main elements that have defined the Haitian community over the years, based on the work of historians, sociologists and anthropologists. These markers will allow us to understand the context in which minority Haitians and the majority Quebec population relations had developed prior to the contaminated blood affair.

In the second part, after a brief review of the question of blood donation among ethnic minorities, the literature produced as part of the Krever Commission will be used to underline what was at stake during the contaminated blood affair, from the Haitian point of view. Following the affair, the Royal Commission of Inquiry on the Blood System in Canada (1993-1997), more commonly referred to as the Krever Commission, was called to investigate the circumstances behind it. This commission's report is central to understanding the impact of excluding Haitian-Quebecers from donating blood on their community.

The third and last portion centers on an analysis of the perceptions and realities of the Haitian community in relation to blood donation today. This last section of the analysis sheds light on another major event: the discovery that blood from Black communities is potentially very useful for certain medical needs. This event contributes to an institutional shift with regards to potential Haitian donors. Three sources are used: 1) data from a qualitative study conducted in 2009-2010; 2) the findings of an audit report commissioned by Héma-Québec in 2009; and 3) statistical data provided by Héma-Québec on blood donation and Black communities, based on a database of blood donors (Progesa).³ We will conclude with a reflection on the hopes and challenges of recruiting blood donors from the Haitian community in Montreal.

HAITIAN-QUEBECERS' RELATIONSHIP WITH BLOOD DONATION: A CASE STUDY

"Case studies are analyses of persons, events, decisions, periods, projects, policies, institutions, or other systems that are studied holistically by one or more methods" (Thomas 2011, 513; also Simons 2009). Case studies enable the description of tangible cases that are "engaged in a perpetual dialogue with the environment, a dialogue of action and constraint" (Abbott 1992, 65). Yin (2009) argues that case studies are a suitable approach to examining questions with operational links needing to be traced over time. This research strategy is often used to investigate topics that aim to reflect upon improving public policy (Hamel 1998; Baxter and Jack 2008). It is hence appropriate to the study of the evolution of Haitian-Quebecers' relationship with blood donation over the last decades—even more so because we aim to reflect upon the favorable and unfavorable factors of recruiting members of this community as blood donors in order to meet new medical needs.

Researchers can decide whether to concentrate on a single case or on multiple cases. A "case" refers to a specific entity—a population, a local group, for example. According to Hamel (1998), if researchers are usually in the habit of defining their cases according to geographical borders or specific historical periods, Giddens proposes, through his analysis of modernity (1994), to situate them in reference to a "local interactionist context that is formed in time and in space and through which social relationships are experienced" (129, our translation). Our analysis related to a unique case: that of the Haitian minority in Quebec and its relationship with the

majority Quebec population. This case is both geographically and temporally localized. At first, we refer to past events (immigration waves from Haiti) but this serves to set the context in which the contaminated blood affair will later emerge in the early 1980's. Our analysis follows these significant events up to this day.

As Yin (2009) recalls, a case study is a comprehensive research strategy and not only a data collection method. It is through the integration of a theoretical framework that the analysis can go beyond a descriptive account of a unique case and venture into an exploratory approach aiming to generalize theoretical results. That is also why Thomas (2011) suggests differentiating the *subject* of study (the case) and the *object* that inscribes the case within its theoretical framework. If the chosen case is that of the Haitian community's relation with blood donation, then the main object is to understand how various events initiated by institutions that represent the majority population—Health Canada, the Red Cross, Héma-Québec—have influenced the relationship between minority Haitians and the majority population. This can be done by insisting on the paradoxical character of the messages sent by these institutions over the last decades and on the impact that this situation will have on Héma-Québec's capacity to recruit new blood donors from this particular community.

Baxter and Jack (2008) note that, on the theoretical front, many researchers choose to base their approach to the case on a constructivist paradigm.

Constructivists claim that truth is relative and that it is dependent on one's perspective. This paradigm 'recognizes the importance of the subjective human creation of meaning, but doesn't reject outright some notion of objectivity. Pluralism, not relativism, is stressed with focus on the circular dynamic tension of subject and object' (Miller and Crabtree 1999, 10). Constructivism is built upon the premise of a social construction of reality (Searle 1995). (Baxter and Jack 2008, 545)

As we will see in the next section, our analysis rests on a constructivist paradigm to ethnicity because it allows for a dynamic definition of the Haitian community main identity markers. We use markers to analyze the transformation of this community's relationship with blood donation and even if, in the last section, we refer to Héma-Québec's recent initiatives with the community, we are still mostly interested in the Haitian community's point of view. On a more general theoretical outlook, our case study aims to demonstrate the relevance of using the notion of "boundaries", proposed by Barth (1995), where minority and majority groups converge in a given society.

Abbott (1992) insists upon the importance of identifying the main events that will serve as the analysis' underlying theme. In accordance with those instructions, we've identified two major events that have an important role in this story: the voluntary self-exclusion of Haitians to blood donation in 1983 and the necessity of recruiting Black donors in the last few years. The method associated with case studies supposes that the researcher combines multiple information sources.

Potential data sources may include, but are not limited to: documentation, archival records, interviews, physical artifacts, direct observations, and participant-observation.... In a case study, data from these multiple sources are then converged in the analysis process rather than handled individually. Each data source is one piece of the 'puzzle,' with each piece contributing to the researcher's understanding of the whole phenomenon. This convergence adds strength to the findings as the various strands of data are braided together to promote a greater understanding of the case. (Abbott 1992, 554)

Our research process led us to progressively integrate a number of different pieces to this "puzzle". Originally, we had access to both our own data from our 2009-2010 study with various ethnic communities (including Haitians) as well as Héma-Québec's audit with this community. We quickly realized that based on those, we were unable to examine this community's relationship with blood donation in the same manner as with other ethnic communities or simply by comparing our results with that of others on Black populations elsewhere. Consequently, the case study research strategy imposed itself as the best way to integrate past significant events—linked to the contaminated blood affair—and, at the same time, re-establish the analysis in a global context—with the evolution of the minority/majority relationship. Why was it necessary? First, the Haitian community was the only targeted ethnic community in the contaminated blood affair and until that event, in contrast with other Black communities elsewhere, it was relatively well integrated in Quebec. In order to produce a genuine case study and comply with its required elements, we have included new sources of information (archives, monographs, and statistical data).

A CONSTRUCTIVIST APPROACH TO STUDYING THE RELATIONSHIP BETWEEN QUEBEC HAITIANS AND BLOOD DONATION

As previously mentioned, our analysis is based on a constructivist approach to ethnicity (Martiniello 1995; Poutignat and Streiff-Fenart 1995). This approach, inherited from Weber (1971 [1921-1922]), highlights the importance of considering ethnic groups from a dynamic standpoint (Gallant 2008; Juteau 1999; Labelle 1994). Groups change over time with: the arrival of new immigrants; social, cultural and economic integration processes; and the passing of time and generations. From within, groups are defined in reference to a fluctuating assortment of 'markers' claimed by each group (Martiniello 1995; Poutignat and Streiff-Fénard 1995; Vatz-Laaroussi 2007), such as: the importance of a common name; behavioural traits; countries of origin; size of migratory waves; immigration statuses; shared memory of a prestigious past or, on the contrary, of domination and collective suffering; mother tongue and fluency in official languages; a certain territorial contiguity; the sharing of an economic niche; religious practices; community life; internal social dynamics; and affiliations and identity.

While some of the elements that bring about change in these groups come from within the group itself (internal), other elements of change are produced by the relationship with the majority group and with other ethnic groups (external). The dynamics are henceforth influenced by what happens at the boundary between groups (Barth 1995) and therefore also concern relationships of power and authority (Juteau 1999). Institutions that represent the majority play a part in defining ethnic groups, in addition to the attitudes of the majority population and other minority populations with regard to a specific group.

According to this theoretical perspective, the contaminated blood affair constitutes an event at the boundary of the relationship between the Haitian minority group and the majority Quebec population and it profoundly disrupted said relationship. In the last few years, Héma-Québec's recent initiatives to recruit new donors from this community to meet specific medical needs can also be seen as significant events impelled by an institution that represents the majority population. These actions can, in turn, modify the relationship between these two groups. But how does the Haitian community interpret these changes?

To start our analysis, we present a few elements that allow us to situate the statistical importance of the Haitian population in Quebec.

The Haitian population in Quebec

According to the 2011 National Household Survey,⁴ the Haitian population in Quebec, numbered at 119,185, constituted close to half of the province's Black population. Eighty-six percent of Haitians in Canada reside in the province of Quebec, and 94% of them live in Greater Montreal. After Italy, Haiti ranks as the second country of origin for immigrants in the Greater Montreal area. Twenty-five percent of Haitian immigrants settled in Quebec before 1981; 20% between 1981 and 1990; 21% between 1991 and 2000; and 34% between 2001 and 2011. In 2011, 57% of people of Haitian origin in Quebec were first generation immigrants, 38% were of the second generation, and 4% were third generation or more. Ninety-eight percent of Haitians speak French, which makes them one of the minorities with the highest French proficiency level in Quebec. Nevertheless, in the 2011 census, 41% of Haitians in the province declared that their native language was neither French nor English; we know that a good portion of Haitian immigrants speak Creole.

In order to follow the Haitian community's history and understand the impact of the contaminated blood affair had on it, it appears essential to very briefly present some of the salient points relating to its arrival and installation in Quebec. We will do so by referring to this community's main identity markers.

Three waves of immigration

The immigrant population originating from Haiti arrived in three waves (Icart 2006; Labelle et al. 2001). During the first wave (1960-1972), Haiti became the number one country of immigration in Quebec following two events: the take-off of the Quebec economy and the dictatorship of Duvalier (father), who reigned over Haiti starting in 1957, prompting the exile of thousands of professional workers. At the same time in Quebec, professionals were being sought for the new public system arising from the Quiet Revolution (Leblanc 1991). Hundreds of workers trained in Haiti thus came to Quebec, including doctors, nurses, teachers, technicians and other specialists. These individuals spoke French, were Catholic and educated, and possessed expertise that was in demand: they were the intellectual elite (Ledoyen 1992). As long as the public sector could welcome this new source of labour, Haitian immigrants were easily able to integrate into Quebec society. In 1971, Jean-Claude Duvalier took over from his father and repression struck anew, affecting farmers and factory workers (Leblanc 1991; Labelle et al. 2001). During this second wave of Haitian immigration, there was a need for non-specialized labour to replace the workers of Greek and Italian origin who were leaving the Quebec textile industry. Haitians took over this work. Younger than the preceding wave of immigrants, these individuals had little education and fewer qualifications; they mainly found demanding and poorly paid jobs. They arrived in the context of a slowdown in the Canadian economy in 1974, which was followed by the 1981 recession. Upon arrival, most spoke Creole rather than French. In the 1980s, the third wave was mostly composed of parents joining their families in Montreal, as well as a certain number of refugees, migrated from Haiti. These newcomers became part of a well-structured Haitian community, especially in the northeastern neighbourhoods of Montreal.

As Portes and Zhou (1993) suggest, the integration of immigrants is determined by three series of factors: government policies specifically addressed to them, the quality of their reception by civil society, and the dynamics specific to each community. We will now see that the Haitian-Quebec identity has defined itself, from within.

From the population of Haitian origin to the Haitian community

Icart (2006) talks about the "shining face" of the Haitian presence in Quebec and shows that, thanks to the know-how and skills of Haitian immigrants, from the 1980s, the province became one of the central hubs of scientific and literary production for the entire Haitian diaspora. Half of the immigrants who arrived at the turn of the 1970's set out to become teachers, and a number of Haitian doctors would gain renown in their fields: some of these doctors and other health professionals would, as seen earlier, would play a role in the contaminated blood affair and its subsequent consequences. Culture has created a bridge between Haitians and Quebecers. Haitians, especially those from the first wave of immigration, are French speakers and hence share the language of the majority.

For the earliest cohorts of immigrants, sharing an active Christian faith also contributed to creating links with the majority. In addition, according to Morin (1993), many Haitians voted yes in the referendum on Quebec independence in 1980. In this last author's view, the "romantic interlude between French-speaking rebels" (154) explains the Haitian fascination with the nationalist project (see also Williams 1998 [1989]). Moreover, Haitians "felt positively concerned by the passing of Bill 101" in 1977 (155), which instituted French as the official language in Quebec and restricted the rights of English-speaking communities.

According to Ledoyen (1992) and Labelle et al. (2001), Haitians primarily define themselves in relation to their native country, or the country of their ancestors, rather than a larger Black community. While 96% of the Haitian-Quebec community declares that it belongs to the Black community (Québec, MICC 2010), historical and cultural divisions have always existed between French- and Englishspeaking Blacks, who do not live in the same neighbourhoods. Quebec Haitians are concentrated in three north-east boroughs of Montréal while English-speaking Caribbeans reside in south-western boroughs of the city.

According to Labelle et al. (2001), language has been one of the greatest obstacles to establishing strong bonds within one same community. The adoption of Bill 101 was very poorly received among English-speaking Blacks. In Quebec, the latter find themselves in a similar situation to French-speaking Blacks in other Canadian provinces (Madibbo 2012). In Labelle's view, the promotion of a "Black identity," dear to the English-speaking Black community, was never unanimous within the Haitian community.

The Haitian community has had its own associations since the beginning of the 1970's. According to Potvin (1997), before 1986, the Haitian-Quebec community lived in hopes of a return to Haiti, and associations' activities were geared toward supporting families that had stayed in the country. Association leaders, originating from the first wave of immigration and from the Haitian lower bourgeoisie, were, up to then, scarcely aware of the problems that Haitians experienced with regard to economic integration in Quebec. According to Potvin (1997), a classist division separates the Haitian-Quebec waves of immigration and even generations. In the mid-1980's, community leaders "came to realize the existence of a gap standing between them, and especially the extent of racism in the lives of young people"

(Potvin 1997, 87-88). According to the ethnic diversity survey published in 2001 by Statistics Canada, 45% of Haitian-origin Canadians declared that they had been victims of discrimination or unfair treatment and most attributed this to their race or skin colour. More than 50% stated that they had experienced such treatment in jobrelated circumstances (Lindsay 2007).

This brief historic portrait shows that it is important to keep in mind distinctions between different waves of immigration from Haiti; these are also a reminder of the importance of class differences within this population. The first wave of immigration corresponds to those who integrated most successfully. The youths who arrived in the second wave and the second generation have lived through more obstacles and have been more strongly marked by discrimination. The question now arises: What do these observations have to do with the issue of blood donation?

It is mostly the first generation that has been affected by the contaminated blood affair but the memory of these events was transmitted to younger generations that had not had the reflex of developing blood donation practices because it did not exist in previous generations. In general, as previous studies have shown, ethnic communities and new immigrants already give proportionately less blood than the population's average. This is also the case with Black communities.

BLOOD DONATION AMONG ETHNIC MINORITIES

No existing studies have specifically examined the relationship between Haitians and blood donation in Western countries. Surveys conducted in the United States show that ethnic minorities,5 and especially African Americans, donate blood in proportionally fewer numbers (Glynn et al. 2006; Price et al. 2009; Murphy et al. 2009). Among Blacks, there has been a historical mistrust of the medical establishment (Boulware et al. 2002; Petersen 2002) and of biomedical research (Bussey-Jones et al. 2010), as well as a perception of discrimination and racism associated with the health system (Adegbembo et al. 2006; Murphy et al. 2009). Shaz et al. (2009) stated that Blacks were more preoccupied with the question of confidentiality than Whites. According to these authors, African Americans are more prone to give blood if they are certain that it will be used for transfusions within their own communities. Glynn et al. (2006) suggest that among Blacks, the main motivations for giving blood in the United States were social responsibility, receiving a request to give blood, and getting a health check. Schreiber et al. (2006), Hollingsworth and Wildman (2004), as well as Nguyen et al. (2008), agree that a higher than average number of Black donors complain about the way they are received at blood drives. Some authors have mentioned that those born overseas and new immigrants might not feel sufficiently integrated in their host countries to feel the need to participate in a 'citizen' activity of this type (Hollingworth and Wildman 2004).

In Australia, Polonsky et al. (2011a) conducted a survey using mixed methods (interviews and focus groups) with African immigrants. The informants seemed to have the impression that the white majority population would not want to receive their blood. According to the researchers, African immigrants appeared to be more interested in donating in contexts where they felt that they were part of a community and where they received recognition for their gesture. Giving blood may nevertheless not be a priority. Renzaho and Polonsky (2013) have found that medical mistrust was not significant for African migrants who had donated in Australia, but perceived discrimination, and more importantly personal discrimination adversely affected blood donation.

These authors have argued that the low donation rate among African migrant populations can be, in part, linked to different donation processes in the country of origin (Polonsky et al. 2011b). In most sub-Saharan African countries examined by Tagny et al. (2010), many have blood donation supply organizations based on family donation (replacement donation): in these countries' hospitals, they constitute over 75% of total donations. In Nigeria, Olaiya et al. (2004) found that only 7% of donations were voluntary, and that replacement donation-often for the donor's wife—was the norm. In Trinidad and Tobago, Charles et al. (2010) observed that a great majority of blood donors are replacement donors (93, 7%) which also coincide with Parmasad (2012) and Sampath et al.'s (2007) results regarding the high percentage of family donation in the same country. These last authors point out that low participation in blood drives can also be attributed to the population's lack of information, an argument put forth by Polonsky et al. (2011b) for African migrants in Australia. Replacement donation, which has historically been the blood donation system in Haiti, certainly plays a role in the practices of some Haitians in Quebec. For those Haitians, as we will present later in this article, if one is not called upon to offer some blood for an acquaintance or a member of one's family or for a justifiable cause, then one might be less prone to give blood voluntarily.

In their study on people of Comorian origin in Marseilles, France, Grassineau et al. (2007) observed, among other things, that in Comorian culture, blood is often associated with notions of family and kin—blood constitutes the basis for family identity. This genealogical conception of blood makes it therefore not "natural" to give blood to a stranger. Some Comorians also believe that their blood is more vigorous than others' blood and that it is preferable to keep it rather than give it away.

Although these studies' conclusions may be used to understand the relationship between Black communities and blood donation, we can understand that having specifically identified the Haitian community as an at-risk group for the transmission of AIDS put them in a unique position in comparison with other Black communities with regards to this question. In order to contextualize this issue, we will begin with a brief summary of the main questions raised during the contaminated blood affair.

The contaminated blood affair and the Haitian "voluntary self-exclusion"

The affair broke out at the beginning of the 1980's. As previously mentioned, four specific groups were asked by agencies not to give blood; among them were Haitians, the group easiest to identify publicly, owing to their combination of language and skin colour. The testimony of three representatives of the Haitian community presented before the Krever Commission in 1994 provide a good illustration of the issues involved (Commission Krever 1997).

In March 1983, after a special meeting of top executives, the Canadian Red Cross, without any consultation with representatives of the Haitian community, published a statement in which people with a high risk of contracting AIDS were asked not to give blood. This policy of voluntary self-exclusion came on the heels of an announcement of similar measures taken in the United States.⁶

The testimony given by representatives of the Haitian community before the Krever Commission underlined the fact that the Red Cross had no proof Haitians were at greater risk of being AIDS carriers than other groups. Dr. Victor Laroche, Haitian Minister of Health, condemned the attitude—prejudicial, in his view—of presenting the Haitian "people" as being a group at high risk of AIDS without an "irrefutable" scientific argument. Certain journalists similarly pointed out, for example, that AIDS is not hereditary and that it is therefore possible to question the scientific basis used by the Red Cross to establish a causal link between a national entity and a non-hereditary pathological state (David 1983). They also stated that medical history should have long since demonstrated the danger of associating possible epidemics with specific ethnic or religious groups (Leclerc 1983). To that effect, in 1988, doctors of Haitian origin would sign a statement of principles to request the adoption of the term "at-risk behaviours" rather than "at-risk groups" (Commission Krever 1997).

According to the witnesses' testimonies during the Commission, voluntarily giving blood to a blood bank was not a common practice in Haiti. In the summer of 1982, in Quebec, before the scandal erupted, only one Haitian donor, aside from members of the medical profession (doctors and nurses), turned out at the first and, at that time, the only blood drive organized in collaboration with the Haitian community. Moreover, the directive from the Red Cross addressed "recently immigrated Haitians." As emphasized in the testimonies, whether Haitian or not, new immigrants have their own concerns, such as finding jobs and a place to live, as well as dealing with problems of racism and discrimination. According to the witnesses who spoke during the Krever Commission, an entire population was singled out because of an extremely low risk; perhaps more damagingly, Haitian witnesses testified about

being symbolically linked with at-risk groups such as heroin users and homosexuals and strongly felt that they were being labeled and singled out, as we will later see, as having brought AIDS to Quebec.

In the months following the statement's publication, representatives of the Haitian community continued discussions with the Department of Health and the Red Cross to remove Haitians from the voluntary self-exclusion list. An agreement had indeed been reached to publish a statement to the effect that the Red Cross had never wanted to stigmatize the Haitian community and that there was no link between AIDS and the Haitian community. On July 22, 1983, before Haitians leaders could sign this agreement—after the Minister had already done so—the Red Cross published a second statement with essentially the same terms as in the first one: recently immigrated Haitians were still on the list of targeted groups. This led to a break in communication between both parties. The relative closeness of first wave Haitian origin doctors and nurses with Quebec's health care representatives in their everyday practice made this event more difficult to overcome; Haitians felt they should have been consulted prior to the first statement given their expertise in the health care sector and their previous relationship with decision-makers.

In the years following these events, the boycotting of blood drives was then encouraged by members of the Haitian community working in the health sector, for example during blood drives organized in nursing schools (Commission Krever 1997). In April 1985, in the United States, the CDC removed Haitians from the list of at-risk groups, without further comment (Farmer 2006). In 1990, the US Food and Drug Administration (FDA) still excluded Haitians from giving blood (those who immigrated to the country after 1977). However, after a major demonstration in New York, the FDA reversed its decision. In Canada, on the questionnaire used by the Canadian Red Cross in 1988, there remained an exclusion note for those who, since 1977, had lived in a region where AIDS cases were more frequent, but it did not explicitly mention Haiti. The note no longer appeared on the questionnaire in 1994.

Farmer (2006) notes the importance of taking into account the specific context of identifying the "4H" in the United States to understand why Haitians were included in this group, in the first place. In the United States, Haitians constitute a group that is discriminated against in three ways, "as black, foreign, and French and Creole-Speaking" (209).⁷ Haitians in the United States do not have the same visibility as other Black communities and in that particular context, their voice was not heard as much as that of the homosexuals'. The mere reproduction of an American directive by Canadian health authorities shows that they had not, at first, taken into account the very different status of the Haitian community in Quebec with respect to that in the United States. Hence, they had not considered the potential impact this directive would have on the privileged relationship between the Haitian community and Quebec society. As the witnesses appearing before the Krever Commission pointed out, it is difficult to find concrete proof of the effects of identifying Haitians as an at-risk group. Numerous anecdotes have been reported, but how can it be shown that Haitians were discriminated against for this specific reason in hiring processes, for example? Representatives of the community have instead highlighted the fact that an entire population was stigmatized and singled out for having "brought AIDS to Quebec":

The interpretation, for us, was that Haitians are AIDS carriers, they were contaminated people to be avoided. This was the popular interpretation, even if it wasn't ours. This is how it was perceived by the public. (Testimony of Dr. Alcindor, Krever Commission 1997)

In 1994, at the time the Krever Commission was being held, more than ten years had passed since the self-exclusion list was published. Had things improved? According to the documents submitted to the Commission, the climate of trust between doctors of Haitian origin and the community itself had improved and "Haitians [were] even ready to take part in scientific studies aimed at understanding the harmful effects of HIV in this community" (Krever Commission 1997, 40). A witness also observed that second-generation Haitians born in Quebec were socialized to blood donation, as were other Quebecers. But another witness doubted that the memory of events had disappeared within the community and noted that Haitians still felt poorly received at blood drives. Today, however, their blood is sought after. In spite of past events, how can this community be convinced to donate blood?

PERCEPTIONS OF BLOOD DONATION TODAY

How do people of Haitian origin in Quebec perceive blood donation today? Between March 2009 and May 2010, our research team conducted a study to better understand the perceptions of ethnocultural communities in Montreal with regard to blood donation. Eighty-three interviews, each 1.5 to 3 hours in length, were conducted with partners of Héma-Québec from communities that organize blood drives; with representatives of ethnocultural associations not associated with this cause; with Héma-Québec representatives; and with blood donors from various communities. Among the thirty-one donors interviewed, of which ten were from Black communities, four were of Haitian origin. Among the forty-six organizational representatives of the Haitian community. Two of the Haitian representatives were also blood donors.⁸

To complete our analysis, we have also used the results of an audit report with Haitian opinion leaders in August 2009 (commissioned by Héma-Québec), as well

as four information sessions to better understand the community's relationship with blood donation which were also used to discuss sickle-cell anemia. These information sessions reached almost 400 persons from the Haitian community. Twelve individuals were also interviewed by phone: these interviews lasted 40 minutes on average. After these sessions, a report was produced and then passed on to us. We start by presenting the results of our own study.

Our interviews from the Blood donation among Quebec's ethnocultural communities study

Interviews confirm the idea that voluntary blood donation to a blood bank is not part of the culture of immigrants of Haitian origin:

First, in Haiti, giving blood wasn't a part of our culture. People do it, they say, people sell their blood This same person arrives in Canada. Do you think they'll want to give blood automatically, just like that? There is work to be done. (Man, 45 years old, born in Haiti, blood drive partner)

To give blood, people really have to be integrated because it's not the kind of thing that Haitians did back home. (Man, 53 years old, born in Haiti, blood drive partner)

Blood donors of Haitian origin nevertheless do not define themselves as regular donors, and appear to be more motivated by solidarity and even a certain sense of obligation toward close acquaintances—a type of motivation they share with donors from other Black communities:

We would prefer to give blood to a family member. I, too, seriously, if I could give knowing that I was directly giving to a family member, to save their life, it would be better If, for example, it was possible that for each blood donation, a replacement donation had to be made, now that would be the *perfect* solution. (Man, 53 years old, born in Haiti, blood drive partner)

Our informants all mentioned that they knew people in the community who refuse to donate blood because of events related to the contaminated blood affair.

When I arrived here in the 1980s, there was the AIDS affair and people were saying that this was something that came from Haitians, that they were the main carriers of AIDS. Then they realized that was wrong, but people were very angry. From then on, they lost interest They haven't forgotten what happened and today still, they hesitate to give blood Each time, it's important to remember that when you give blood, you aren't giving it to the Red Cross, you're giving it to community members. (Man, 53 years old, born in Haiti, blood drive partner)

The other major problem we have in the Haitian community is that in the 1980s, we were

officially singled out by the Red Cross. People haven't forgotten. Those who will never give will use this as an argument. And don't think that I'm just talking about people in general. This is also true for doctors or nurses. (Man, 45 years old, born in Haiti, blood drive partner)

While the memory of these events seems to be well alive, the interviewees stated that they were confident that new generations would be less affected and that they would, eventually, be favourable to giving blood.

It will eventually fade away because the people who feel they were hurt are aging But the problem is that, because parents speak to young people Some think this will end up being forgotten, and young people are also less hesitant to give blood because they're more educated. (Man, 45 years old, born in Haiti, blood drive partner)

The whole issue of participation in Quebec society, that's an issue as well in the Black community. [...] Because they don't access services for them, let alone go to an organization to give blood. [...] I think that [pause] a combination of racism and a combination of a resistance to integrate. You could talk about the chicken or the egg, right. Which comes first? [laughs]. After a while, when you face racism, experience racism, I think people from older generations pass on this idea of, I guess. [...] People just sort of keep away from public agencies because it's like they don't like me, it's not for me. And I think it's detrimental to the community in general. So, when it comes to things like giving blood, talking about Hema-Quebec, people don't, in general. They don't go because they don't trust the system. [...] People they don't go to Quebec agencies in general, they would rather avoid, in different areas, in different topics; it's a recurring issue that Blacks don't go for whatever reason. (Man, 32 years old, born in Jamaica, religious leader)

Young Haitians cannot, however, count on models of donors from their own communities, precisely as a result of the events of the 1980s that affected their parents' generation.

Our interviews reveal that mistrust in the medical establishment can be shaped by negative personal experiences and/or historical events. The latter was mostly mentioned by English-speaking Caribbean informants who indicated a long history of medical mistreatment towards Blacks as one of the reasons behind their relative lack of confidence in public health institutions. This view was far less common with our Haitian informants, who instead, were more concerned about feeling not welcomed at blood drives or sometimes even greeted with suspicion. Haitians, along with other Black informants in our study, mentioned the idea that the blood of Blacks was not welcome, that it would be discarded:

They say in my community that a blood donation made by a Black person is not taken into consideration by Héma-Québec and will therefore be discarded. (Man, 53 years old, born in Haiti, blood drive partner) I always had the impression that my blood would be rejected one way or another, for one reason or another. I can't remember if I was ever told that the blood of certain communities was refused . . . I always had the impression that my blood might be stored somewhere without being used. But that's a belief, who knows where it comes from . . . in my community . . . I think there's some mistrust, just like I've had. Our blood might be collected, but it'll be put aside and kept apart from the blood of Quebecers. (Man, 39 years old, born in Haiti, emigrated in Canada from 1981, regular donor)

People think that even if the blood is collected, it ends up being discarded. . . I was surprised, I mean, it's not only what a cab driver might think, but also a teacher or a doctor. (Man, 45 years old, born in Haiti, blood drive partner)

It is worth keeping in mind that for various medical reasons, quite a number of people cannot give blood. In the case of Black community members, the main cause is insufficient iron levels among women, or a recent trip to a country where cases of malaria are detected. Many authors, including Schreiber et al. (2006, also Shaz and Hillyer 2010), have found that deferral can bring about some level of frustration from those who attempt to donate but are refused. This can also be exacerbated on community blood drives where one is expected to give blood in front of his or her peers but is unable to do so. In France, a study with Comorians in Marseilles illustrate how pervasive this pressure can become, as some Comorian donors go to the extent of giving blood even if they know their blood will later be discarded because they do not want to be deferred in front of their peers (Grassineau et al. 2007).

Interviews from Héma-Québec's commissioned audit and information sessions

The consultation and information sessions organized by Héma-Québec with the Haitian community were aimed to better understand the community's relationship with blood donation and to discuss sickle-cell anemia. The results from these consultations complete our own study's results. Respondents of the telephone survey stated that in Haiti, blood donation takes the form of replacement donation blood or family donation. Also, interviews conducted in this survey revealed that the occurrence of sickle-cell anemia is little known within the community. Traditionally, Haitians rarely speak of their health problems and they are more preoccupied by other problems: "In the community, public health issues that concern people are, in order: HIV (and sexually transmitted diseases [STDs]), violence among young people, poverty and then, very far behind, sickle-cell anemia" (Interview excerpt, Héma-Québec 2009, 15). Sickle-cell anemia can also be perceived as a "shameful" disease, and is not that easily talked about openly. Haitian leaders who took part in this survey confirmed that the contaminated blood affair has left a mark on the collective memory of their community:

People were very cooperative and went to give blood before the 4H campaign. They haven't been interested in giving blood since. They haven't forgotten what happened. People don't dare donate because as soon as their backs are turned, they think their blood will be discarded. (Interview excerpt, Héma-Québec 2009, 23)

They do, however, recognize that some community members are open to the cause, on certain conditions:

In the community, certain people are open to blood donation, especially educated people or the financially well off. Others hesitate because of the stigma of the 1980s, so they boycott blood donation. I would be prepared to encourage people I know to give blood on the condition that the situation first be cleared up. People need to be approached and reassured that they won't go through what happened back in the day. (Interview excerpt, Héma-Québec 2009, 25)

All are confident that young adults may constitute a more promising target when it comes to finding new blood donors among Haitians.

The wide majority of these young people were born here and are influenced by their social circles in Quebec, which justifies a Quebec-style information campaign ... on the condition that young people are approached where they are. They can be found in festive settings rather than community organizations. They ... use IPods, cell phones and Facebook. (Interview excerpt, Héma-Québec 2009, 33)

Addressing the medical needs brought on by the occurrence of sickle-cell anemia within the community in order to convince members of the Haitian community to give blood is fairly well perceived, but raises some concerns:

There should be no objection, if it is clearly explained that sick people need frequent transfusions and that eventually they need blood with the same characteristics as their own. (Interview excerpt, Héma-Québec 2009, 37)

Be careful not to recreate historical barriers. We've forgiven, but we don't want to create negativity for the 18-35 year old people who are open to blood donation. (Interview excerpt, Héma-Québec 2009, 49)

The leaders also expressed their reluctance about identifying donors by racial profiling in order to trace phenotyped blood by ethnic background:

This goes against the basic antiracist cliché that we all have the same blood. A good scientific, official, international explanation would be needed. Otherwise, I'm reluctant, I couldn't support this measure and I wouldn't defend it. This touches a sensitive nerve because we're trying to get away from the ghettoization of Blacks. Maybe Héma-Québec should find another way than asking for ethnic identification A campaign cannot be First, it will be important to seriously explain things so people don't get offended. They need to be told that it won't be used against them, that it is not intended to stigmatize them. People are already reluctant to donate blood and there's uphill work to be done with a portion of the community. (Interview excerpt, Héma-Québec 2009, 38).

The leaders suggested broadening the debate, for example, by showing that other groups are just as affected by specific diseases. They also proposed a number of avenues for improving recruitment, for instance using various channels to disseminate the message, namely ethnic media, churches, professional associations, and social networks on the web. They further recalled the importance of creating a network of allies from the community and suggested recruiting spokespersons among Haitian doctors, athletes and priests. However, they also said that, "For sickle-cell anemia, it would be important to use affected people as spokespersons-not stars, but real people from everyday life" (Interview excerpt, Héma-Québec 2009, 32). The various festive events in the life of the community are also good opportunities for organizing blood drives. The leaders reiterated the importance of adapting the level of language to all social strata as well as preparing messages in Creole in order to reach a greater number of Haitians. Other studies, such as Grassineau et al.'s (2007) with people of Comorian origin in Marseilles, also indicate that the involvement of community leaders is essential in the diffusion of the blood donation cause, as they can also dispel "any ambiguity about religious or cultural objections to blood donations" (406). In this sense, their involvement can also appease any reluctance or doubts regarding the seemingly paradoxical situation of blood's universality coupled with the uniqueness of phenotyped blood that can be found in many communities. Although case studies, such as the Haitian community in Montreal and the Comorian case in Marseilles are not easily transposable because of their sociocultural complexities and distinctive environments, some suggestions, such as involving leaders and even cultural intermediaries in the blood donation cause can be seen as transferable knowledge if they are adapted to local context.

Héma-Québec's initiatives within the Haitian community

Since Fall 2009, Héma-Québec has launched various initiatives to stimulate donor recruitment in Black communities, among other things by inviting the *Association d'anémie falciforme du Québec* to take part in its awareness campaign. According to Héma-Québec's Office for donor recruitment and marketing, there have been 53 outreach activities since the beginning of 2011, including: information booths, targeted presentations, group discussions, participation and sponsoring of community and cultural events, radio interviews, etc. Since 2009, there have been 27 blood drives

organized within the Haitian community in which a total of 3,168 people gave blood. Thanks to the information on ethnic origin that is now provided on the questionnaire filled out by donors,⁹ we learn that 53% of those that chose to check the "Black" category are new donors. Data provided by Héma-Québec between December 5th, 2010 and December 4th, 2011, showed that a mere 25% of Black donors gave a second time during that timeframe. We know, however, that donors can give again after a 56-day waiting period in between donations. Hence, there is a need to question the capacity to maintain their interest for the cause after the first donation, especially when this donation is made following a direct request by a community member afflicted by sickle-cell anemia.

DISCUSSION AND CONCLUSION

What can be learned from this presentation of the Haitian community, including its arrival, its integration into a host society, and the events that have affected its perception of blood donation?

The social and economic integration of Haitians in the first wave of immigration was especially smooth. This could be a factor favourable to a practice of civic involvement, such as blood donation, especially since many of these immigrants worked in the health sector and were sensitive to the need. However, it is also the earliest Haitian immigrants who were affected by the events relating to the contaminated blood affair. The informants we interviewed and who have been in Quebec for several decades, as well as those who testified before the Krever Commission reiterate just how vivid these events are in the community's collective memory.

Haitians in the second wave of immigration have experienced other types of difficulties in line with discrimination and racism. The youths of this wave of immigration have experienced more difficulties, in particular those who speak Creole rather than French. Our study's informants mentioned the importance of disseminating information on blood donation in Creole, as well as taking into account the diverse level of schooling found among targeted groups. The various immigration waves have led several of the cited authors to recall the importance of the different socioeconomic realities within the Haitian community. This is a significant element to take into consideration when choosing the groups that will collaborate with the organization of blood drives or when deciding upon respected and recognized spokespersons within this diverse community.

According to the 2011 census, a fewer than average number of Haitians held university degrees or more (16%, compared to the Quebec average of 19%). The unemployment rate was 13% in comparison with the Quebec average of 7% (NHS 2011). Average incomes were lower than that of the Quebec population. Could the less favourable socio-economic profile of the Haitian community be a curb to the recruitment of new blood donors? In studies on blood donors at large, results are contradictory: while certain studies confirm, for example, that education levels and higher incomes are favourable to regular donation (Ownby et al. 1999; Piliavin and Callero 1991), others find no difference (Germain et al. 2007; Healy 2000). Yet, the integration problems, especially in the case of recent immigrants, may suggest that blood donation is not a priority for people who have other preoccupations in their everyday lives.

All informants seemed to count on younger individuals to become involved in the cause of donating blood. Young people are generally recruited in the context of blood drives in universities and colleges. According to various surveys conducted with members of the Haitian community between 1980 and 2009,¹⁰ Haitian students have a high failure rate, both with respect to other minorities and to the majority. Regardless of their native language, Haitians also appear to have the most difficulty completing their college studies compared to other groups. It would thus be necessary to consider recruiting them elsewhere. The informants consulted by Héma-Québec have offered avenues in this regard.

Can social marketers use the prevalence of sickle-cell anemia to promote blood donation? The motivations reported in the surveys demonstrate that the need for transfusions among close acquaintances is certainly a strong incentive. Blood supply agencies must nonetheless be attentive to the risks associated with putting too much emphasis on the specific characteristics of blood from Black communities, as the quotes presented earlier have shown. To over-emphasize the fact that donated blood will primarily be used for the Black community is to contradict the usual universalist and altruistic message of blood donation.

This article has mentioned similar results with other studies regarding immigrant populations or minority communities such as in the United States with African Americans, in Australia with African immigrants and in France with Comorians in Marseilles, namely that: they proportionally give less blood than the majority society; they are sensitive to perceived discrimination or inadequate welcoming at blood drives which can translate into the belief that their blood will be refused or that they as blood donors are not welcomed; they have a preference for giving blood to someone within their community (African Americans) or by participating in the blood donation cause as part of a community (African immigrants in Australia). Although these cases share some similarities with the Haitian-Quebec case presented in this study, our constructivist approach to ethnicity based on internal and external identity markers reminds us to be vigilant as to generalizing or transposing results from one case study to another. Indeed, the distinctiveness of these sociocultural markers, of context, and of relationships of power and authority between minority and majority groups allude to the complexities and idiosyncrasies of each case study. No other situation can really be compared with that of Haitian-Quebecers in terms of their relation with blood donation. First, they were asked to refrain from donating blood and now, they are actively recruited to give blood in order to fulfill increasing medical needs—Haitians have known a uniquely paradoxical situation.

Despite everything, Haitian-Quebec leaders are favourable to increasing their community's participation in blood donation. They have proposed concrete actions to achieve this goal. Here, the use of the "boundary" notion as set forth by Barth (1995) is relevant: we can say that these actions attest to the desire for a more porous boundary between Haitians and Quebecers. By choosing spokespersons and using Haitian media, Héma-Québec *crosses* the boundary and enters into the Haitian community. Jointly organizing blood drives, for its part, are a way to enable a certain *abolition* of this boundary. By taking into account the view of Haitian leaders so as to improve their reception in blood drives and relationships with deferred donors, or by promoting greater ethnic diversity among Héma-Québec employees, the Haitian community can *in turn cross the boundary into the Héma-Québec territory*.

NOTES

1. Affected individuals can also be found in Mediterranean communities of the Middle East, although in much smaller numbers (Bailey 2000).

2. It is a genetic disease inherited from two parents who are carriers of a mutant gene that produces a malformation in red blood cells and gives rise to a number of complications. According to the Sainte-Justine University Hospital in Montreal, 1/4300 people in Quebec is afflicted by it and without early detection, it claims the lives of 15%-20% of children who suffer from the disease before the age of 10.

3. Since 2009, those who fill out the blood donor questionnaire are invited to indicate their ethnic belonging. The proposed categories are: White, Black, Latin-American, Arab, Asian, Indian from Asia and Native. The information gathered between December 5th, 2010 and December 4th, 2011 was compiled.

4. When available, we offer data from the 2011 National Household survey.

5. In this article, we refer to ethnic minorities or ethnocultural communities as those who might not primarily identify or are not seen as being part of the "majority" culture in a given country and who, in part or in whole, adhere to different ethnicity markers as people from the "majority" culture—they can either be born in the country of reference or overseas. Immigrants or migrants will refer to those born overseas.

6. The first cases of HIV-AIDS were identified in November 1981 in the Haitian-origin population in the United States. Epidemiologists from the CDC were perplexed, since no Haitians had declared that were homosexual. On March 4th, 1983, the CDC made its first reference to the 4H and Haitians thus became an at-risk group (Farmer 2006).

7. Locher (1984) would use a similar expression to talk about Anglophone West Indians in Quebec, a "triple minority", for racial (black/white), demographic (minority/majority) and linguistic (English/French) reasons.

8. Detailed methodology is described in the following paper: Tran, Nathalie YL, Charbonneau, Johanne, Valderrama-Benitez, Valeria. 2013. Blood donation practices, motivations and beliefs in Montreal's Black communities: The modern gift under a new light. *Ethnicity & Health* 18.6: 508-529.

9. Answering this question is optional; the donor is not obligated to provide a response.

10. Labelle et al. 1983 and 2001; Laperrière 1998; Ledoyen 1992; McAndrew et al. 2006, 2008 and 2009; Morin 1993; Potvin 1997; Tchoryk-Pelletier 1989.

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