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Clinical relationships tested by iatrogenicity: The case of haemophiliac patients faced with the epidemic of transfusional AIDS

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ABSTRACT

After being victims of a serious iatrogenous damage, what kind of relationship can patients rebuild with the world of medicine? In this article, I examine this question in terms of the contaminated blood affair in France. Using a qualitative study of haemophiliac patients and their families as a base, I looked at the changes in their modes of commitment to medicine, from the period preceding contamination with AIDS through blood transfusion, until the present day. It would seem that the experience of iatrogenous injustice was at the root of a major reconfiguration: all of the patients looked back over their trajectories, examined their relationship with the medical world and changed their positions, but without necessarily drawing the same conclusions or taking the same stances. This article looks at the change from relationships essentially based on cooperation to relationships that are more negotiated. It also shows the current diversity in forms of commitment: they are the fruit of critical work, carried out by patients and their families, which reassesses both the cognitive and moral bases of medical legitimacy. The analysis of the reconfiguration of the relationships that haemophiliac patients have had with the medical world in the aftermath of the contaminated blood affair is enlightening in two ways. First of all, the current medical world would appear to be deeply marked by health scandals and the victims have become prime actors. Secondly, the experience of iatrogenicity asks, with especial acuteness, the question of confidence that is at the core of any clinical relationship. It thus has a heuristic value of general scope.

Introduction

This article looks at the impact of issues of iatrogenous injury on the ways in which patients invest the world of medicine, based on the case of haemophiliac patients contaminated by the AIDS virus in France. At the beginning of the 1980s the epidemic spread to a great extent, particularly through transfusion. Haemophiliac patients were among the first victims. Haemophilia is a serious and hereditary illness caused by a deficiency in coagulation. More than half of those suffering from the severe form of the pathology and requiring regular recourse to blood therapies were infected by the HIV virus before the end of 1985 (i.e. approximately 1350). This became a national scandal when journalist Anne-Marie Casteret published documents showing that the French national centre for blood transfusion (CNTS) had knowingly distributed batches of contaminated blood products. When this article was published (*Evénement du jeudi* of the 25th April 1991), it aroused considerable public indigation (Casteret, 1992). Why had the haemophiliac patients – well known by medical services – not been informed of the dangers of blood products? Why had public authorities, haemophilia and transfusion doctors and even the French Haemophiliacs Association systematically ignored or minimised the risks, despite the increasing number of warnings in the public arena? A series of investigations and court cases took place in a context of intense media mobilisation. The

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first case led to the conviction of high-level personnel within public health institutions. The second case, in 1999, prosecuted three former ministers, including the prime minister. The secretary of state for health was found guilty, whereas the two others were acquitted. A final investigation led to 30 people being charged: civil servants from health administrations, personnel from ministries and transfusion doctors. Among the latter, the personal responsibility of ten haemophilia doctors was called into question with regard to the contamination of their patients. After years of investigation and toing-and-froing between various jurisdictions, this final case ended with all charges being dismissed. From a legal point of view the affair was officially closed in 2003, but until then it had caused an unprecedented crisis, and haemophilia medicine was changed forever. Health institutions went through a series of reforms which were built around the principle of health safety. More generally, the crisis also affected political institutions. The trial of the ministers had required a constitutional reform and it was the first time that the acts of members of the government could be judged, thus introducing accountability for politicians. Macrosocial changes have been studied (in particular, Steffen, 1999, 2001); however, this is far less true of the local work produced by the actors who were the most directly affected. It is important to return to the matter in order to understand how changes in the public arena have interacted with the reconfiguration of individual experiences.

Methods

This study is based on research on the world of haemophilia and the ordeal of the contaminated blood affair, looking at the changes over the last 40 years and examining the experiences of the different actors involved with haemophilia. This article focuses on the experiences of patients and the families. It is mainly based on data gathered during 57 biographical interviews (of an average of 3 h) of adult patients (38) or their families (19). Included in the study were HIV-negative (15/38) and HIV-positive (23/38) haemophiliac patients, parents of children who were contaminated (13/18) or not (5/18) – 6 of whom had lost at least one son through AIDS – and the wife of one patient who had been infected, and who had in turn contaminated her through sexual contact. The study included not only victims who had taken legal action (17/37 people who were contaminated or parents of contaminated children), but also those who had not turned to the courts, either because they had not been infected by the virus (20) or because they preferred not to prosecute (20). Haemophilia not being a socially discriminating pathology, those who were recruited had differing levels of education and social condition. They came from all over France, with regions having very different rates of contamination. I worked on the basis of “recruiting circles” (French Haemophiliacs Association, legal files, specialist doctors, etc.) and then, from these different circles, by “snow-ball” techniques, asking interviewees to put me in touch with other people they knew. This was vital, in order to include people who had broken away from the medical and associative aspects of the world of haemophilia.

The interviews took the form of life narratives. At first, people gave chronological accounts (sometimes jumping back and forth and giving concentric micronarratives) of their lives as haemophiliac patients, spontaneously choosing the episodes they deemed to be of most importance. I then asked them to come back to certain aspects, either because they had not mentioned them, or because they seemed to require closer attention. Finally, I asked them to tell me which moments had marked them the most. The contamination and the ensuing affair were almost systematically mentioned as major events at the root of the most important changes in therapeutic relations and, more generally, in their relationships with the world of medicine. Despite the intensity of the crisis following the contaminations, no third party came forward to referee the tense face-off between doctors and patients. More often than not, reassessment of clinical commitment was performed on the basis of individual introspection and retrospection by the latter, with exchanges being the exception rather than the rule – which made biographical interviews even more valuable. I will not specifically analyse the work of justification that the victims used to put their cause forward in the public arena: these aspects (amongst others) will be used when needed, when they allow us to grasp the origins of the current stance taken by patients and their families with regard to medicine. In this article I first show that research on patient–doctor relationships and on victims has remained relatively watertight, and that nowadays we lack works which help us understand the impact of injuries relating to medical activity. I then analyse the specific case of haemophilia and the contaminated blood affair. I examine the model of cooperation which structured patient–doctor relations prior to the scandal and how the latter demonstrated its limits. I then look at the new basis of commitment to medicine. Finally, I examine how patients and their families redeveloped contrasting relationships with the medical world, in terms of their critical reflection in the aftermath of the iatrogenous contamination. There are four major orientations on the current map for haemophiliac patients and their families, relating to their conceptions of medicine and to their degree of proximity to or distance from it (Fig. 1).

A sociology of patients reworked by a sociology of victims

Few works have looked at patients’ relationships with the medical world after experiencing an iatrogenous injury. Many works have examined patients, on the one hand, and victims on the other, without analysing the meeting point of these two specific dynamics. The patient–doctor relationship has been a topic of investigation, ever since the first works in the field of the sociology of medicine, and research has revealed sensitive historical changes. They show the increasingly common model of an “active patient” (Barbot, 2006), who demands the right to assess, or even manage, the work done by professionals.

There are three major successive sociological approaches. In the middle of the 20th century the sociology of medicine focused on medical professions (Parsons, 1951) and portrayed the sufferer as an “object of care” in the