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Ouvrage recensé :

*The Drug Trial: Nancy Olivieri and the Science Scandal that Rocked the Hospital for Sick Children.*

par Brian Martin


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J. Prud’homme a fait un effort pour encadrer son histoire de ces deux professions dans un cadre d’analyse sociologique qui pourrait fournir des clés d’interprétation de leur cheminement et de leur statut actuel. Malheureusement, cette analyse reste superficielle et risque même de confondre, plutôt que d’éclairer, le lecteur non familier avec la sociologie des professions. L’auteur a peut-être voulu produire un livre moins académique, plus accessible, mais je pense que son ouvrage aurait gagné en profondeur s’il avait poussé l’analyse davantage.

Dans sa préface, le président de l’Ordre des orthophonistes et audiologistes du Québec se réjouit de la parution de cet ouvrage, mais s’empresse de critiquer le manque d’emphase sur les efforts « collectifs » qui ont favorisé l’émergence de ces professions, dont évidemment ceux de l’Ordre. Une autre « omission » concerne le rôle des groupes faisant la promotion des intérêts des usagers potentiels des services de ces professionnels. Ce second point m’apparait important, car sans la légitimité que confère la démonstration qu’une occupation répond à des besoins ressentis, il est quasi impossible d’obtenir la reconnaissance sociale et légale. Pour ma part, j’aurais souhaité que l’auteur traite des enjeux économiques du développement de ces deux professions, surtout dans un contexte de vieillissement démographique dans lequel une partie du marché de ces professions connaît une croissance importante. La question de la couverture de leurs services par les assurances privées ou publiques a probablement été un enjeu important qui aurait mérité quelques paragraphes.

Au plan de la forme, l’ouvrage aurait gagné d’un travail d’édition plus soigné (coquilles, syntaxe) et de l’ajout d’un index. Cela dit, voilà une contribution utile et intéressante tant pour les membres de ces professions qui pourront mieux prendre la mesure de l’évolution de leur métier que pour ceux qui cherchent à mieux comprendre comment se construit socialement l’organisation du travail dans le secteur de la santé.

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Disputes in science are invariably more complex than they appear on the surface. Talk to a whistleblower and you may be regaled with hours of “I did this, they did that,” accompanied by piles of documents, so
before long your head is reeling from the twists and turns. This applies to local disputes that involve only a few people; when cases receive media attention, another layer of complexity is added. In my experience with numerous disputes over the years, the protagonists span the full gamut of human types. A very few are paragons: truthful, hard-working, generous, polite, balanced and public-spirited. But others display common human traits such as anger, envy, ambition and spite. Complexities and human failings get in the way of simple narratives such as “fearless whistleblower challenges company” or “troublesome employee disrupts operations.” Observers often latch onto the narrative that makes most sense to them, sometimes taking their cue from media stories.

Nancy Olivieri, a doctor at the Hospital for Sick Children in Toronto, was the key figure in a long-running dispute over efficacy of drugs, treatment of patients and drug company funding and control, among other issues. To her supporters, she was a brave whistleblower; to her detractors, she was biased, vexatious and obstinate. Shuchman attempts to go beyond the polarised stereotypes in this saga. She provides a rich narrative, quite an accomplishment given the complexities involved, both in science and in plot. Furthermore, numerous legal threats and actions were issued from both sides in the dispute, making many sources reluctant to comment.

The scientific side to the story centres around thalassemia, an inherited blood disorder. Sufferers require frequent transfusions, with the side effect of accumulating dangerous levels of iron in the body. Drugs are needed to help get rid of the iron, but the standard drug, Desferal, requires long-duration injections that are extremely unpleasant. Olivieri studied an alternative drug, L1, developing an international reputation for her contributions. She obtained funding from Apotex, a large Canadian pharmaceutical company. But then – according to the dominant narrative – Olivieri discovered serious problems with L1, and Apotex threatened her with legal action should she speak out about them. She was eventually able to expose the dangers: a courageous whistleblower who, with the help of allies and the media, won against a greedy corporation.

Shuchman aims to show there is much more to the story. To do this, she interviewed everyone possible and used documents to back up her findings. She has written the book as a continuous story, weaving the various strands together, mostly chronologically. Keeping track of the numerous personalities involved and the scientific, clinical and organisational zigzags would be a challenge for any author. Shuchman does an excellent job, though following it all requires concentration. As the book proceeds, the various strands of plot come together with quickening pace, almost like a novel.
Shuchman’s investigation reveals a side to the story that has not received so much public attention. She tells of how Olivieri bullied medical residents and patients, and how she began collaborations and then dumped her collaborators – without telling them – and proceeded with the work on her own. She tells how Olivieri’s story of being silenced by Apotex was a gloss on a more complex sequence: Olivieri had earlier been a prominent advocate of L1, and only turned fully against the drug after conflict with Apotex. Olivieri comes across as someone who was both charismatic yet difficult to work with, someone for whom others were either allies or enemies.

The story can be read in various ways: as the personal story of a scientific prima donna, as the inside story of the operations of a hierarchical, dysfunctional organisation (the Hospital for Sick Children) or as an exemplary story about scientific and medical ethics. Personally, I found it fascinating to notice the tactics used by the different players, including building alliances, publishing papers, using legal threats and actions, mounting attacks at a scientific conference, granting or denying funds or access to patients, appointing staff and using the media. A one-sided narrative would focus on Apotex’s use of its financial power to influence hospital and university administrators, countered by brilliant use of the media by Olivieri and her supporters. Shuchman tells also of attacks made by Olivieri, including allegations of misconduct and legal actions against colleagues and the media. Shuchman finishes the book with an account of what subsequently happened to the main players – the scientists – and to thalassemia patients. But she makes no attempt to sum up the lessons of the struggle or to assess the story in the light of research ethics, patient welfare or organisational reform. She does not introduce an explicit framework, such as any of those used by scientific controversy scholars, for understanding the events.

The book’s weaknesses lie mainly in what is not addressed. There are no comparisons with other controversies, and therefore no easy way to judge the significance of the issues. Shuchman does not say what issues or principles are most important. Access to drugs? Scientific independence from vested interests? Loyalty to patients? Free speech?

It is routine for whistleblowers to be smeared. Whistleblower groups often say that managers should examine the claims made, not the person who makes them. Shuchman does not offer sufficient justification for giving so much attention to Olivieri’s personal behaviour. Is Olivieri all that different from other whistleblowers, or from high-performing scientists generally? And what difference should it make that Olivieri is less than perfect? Shuchman gives no guidance. Likewise, Shuchman reports actions by Apotex, including shutting down drug trials and
threatening legal action, without much context. What is appropriate behaviour for drug companies? What should be done about behaviours judged inappropriate? Shuchman seldom enters this sort of territory. The result is an account that tells a lot about individuals and actions but sheds little light on bigger questions.

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Canadian studies of health care and health care workers are not rare, but Peter Twohig takes us behind the scenes, providing an insightful look at those whose work is integral to the modern health care system, but who are often out of sight and out of mind. In his study of laboratory workers in the Maritimes during the opening half of the twentieth century we learn not only about the people doing these jobs, and what they do, but we also acquire a broader picture of the rise of the modern hospital, the changing divisions of labour in health care, the rise of medical dominance, gender and work, and more. Twohig’s book is an interesting one that has many insights for scholars interested in a variety of fields, including health care, work, science, organizational analyses, gender, and Canadian (and Maritime) history.

Twohig begins by exploring the institutional context of the work, with a particular focus on the establishment of the Pathological Institute in Halifax and the Bureau of Laboratories in Saint John. He illustrates how the development of such laboratories was shaped by a myriad of concerns and trends including the public health movement, provincial governments’ public health initiatives, scientific advancement, concern over prevalent diseases, and developments in the medical profession. Other trends like the expansion of hospitals were also influential. Laboratories were first established to provide a number of public health services, for instance, to supply vaccines, and test water and milk, and also to conduct tests for medical doctors to facilitate their ability to diagnose and treat disease. Laboratories also came to be a location of medical training, and a key component of the modern hospital.

Unlike some studies of work, Twohig takes the time to describe precisely what laboratory workers did in this era. His discussion is insightful. For instance, Twohig shows how the work demanded skill,