Infertile Women, Tall Girls, Short and Orphaned Children: The Socially Vulnerable Prey of Australian Medical Imperialists

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Lynette Dumble, Ph D, M Sc,
Senior Research Fellow, History and Philosophy of Science,
University of Melbourne,
Parkville, Victoria, 3052, AUSTRALIA.

Background: Medical imperialism is a criticism which in the past has been reserved for the paradigms behind the sterilization of Afro-Americans in the United States in the first half of the twentieth century, and the eugenic crimes against humanity in Adolf Hitler's World War II Germany. More recently the term has also been used to condemn the medicalized fertility regulation which is overwhelmingly inflicted on women in developing countries, the use of New Zealand and Indian women as commodities in cervical cancer experiments during the 1980s and 1990s respectively, the abandonment of African women in AIDS trials in the 1990s, and the political undertones which have made infertile women and third world countries the invisible and/or would-be victims of mad cow and Creutzfeldt-Jakob disease [CJD] imperialists in the 1990s.

Australian Medical Imperialism: Revelations in the 1990s indicate that Australian medicine has long been fraught with its own brand of imperialism; one which, in the main, has preyed on socially vulnerable women and children, and, which, despite stricter ethical guidelines, the medical fraternity still seeks to dismiss on the grounds of its self-ordained role to tell women what is best for them and their children.

In 1985, like similar programmes in most other parts of the world, the two decades-old government-sponsored Australian Pituitary Hormone Programme was abruptly halted when four young adults, one in the UK and three in the US, who had been exposed to human pituitary growth hormone [hGH] injections more than a decade earlier, suddenly died within months of each other from the brain illness referred to as CJD. A rare illness, affecting less than one per million in the majority of world regions, CJD was unheard of in humans before two German physicians, Creutzfeldt and Jakob, independently reported the initial sporadic cases in the 1920s. To this day, CJD has defied cure, but as the human pituitary affair demonstrates, is an it is illness which is not to be trifled with; outward warning symptoms only emerge after a years-long incubation period, during which time the agent of CJD has turned the brain into the sponge-like mass which led to the disease's original classification as a slow virus disorder. Death is almost certainly a welcomed escape from the myoclonic jerks of CJD which, while silently eating away at the brain over as many as four decades, robs its victim of all means of communication; sight, speech, hearing, the comprehension of native language, and the ability to write.

Doctor Knows Best: In the main, debate over pituitary hormone programs has centred around whether or not CJD was a foreseeable legacy for at least the final five years of the program. With the jury still out, the argument has served to distract attention from the medical deceit which kept the CJD news from those in jeopardy, namely the hormone recipients, once the CJD suspicion had been confirmed in 1985. In Australia, 1986 to 1990 efforts of government health authorities to inform pituitary hormone recipients of their CJD legacy were thwarted by medical arguments that government intervention would breach doctor-patient privacy, and at the same time, create undue patient anxiety. As a result, the majority of infertile women exposed to human pituitary gonadotrophin [hPG], and short-statured children exposed to human pituitary growth hormone, did not learn that they were at risk of a brain illness for which there was no known cure, and which could only be detected when symptoms emerged to confirm that a decade or more of latent infection had already devoured vital brain tissue, for a further seven years after the fact in 1992.

In 1993, under weight of public pressure, a government-commissioned independent inquiry commenced into the Australian Pituitary Hormone Program which it was then believed had placed the futures of 2,100-odd Australians in jeopardy. A year later, the inquiry returned a damning indictment of the manner in which the Commonwealth Serum Laboratories had collected and processed the hormones from the pituitary glands, together with strong criticism of the program's lawfulness, and the level of informed consent obtained from the hormone recipients.

Six years later, in 1997, public attention is drawn to two further chapters of Australian medical imperialism; one involving adolescent girls, who, in the 1960s and 70s, were subjected to the oestrogen hormone diethyl stilbestrol [DES] to stunt their height; and another involving orphaned children who, in the 1950s, were used as guinea pigs for vaccine experiments. Following front page publicity and editorial criticism in The Age on what are referred to as the "tall girl" and "orphan" affairs, the chairman of Australia's preeminent National Health and Medical Research Council, Richard Larkins, claimed that:
"the reputations of the Walter and Eliza Hall Institute of Medical Research and the Commonwealth Serum Laboratories, two Australian icons, have been *unfairly sullied*" [my emphases].

Other institutional and government spokespersons adopted a similar defence, denying any wrong doing, any breach of medical ethics, and any requirement for an inquiry to establish the entitlement of tall girls and orphans to compensation for harm which has beset them as a direct or indirect result of the medical experimentation.

In the mean time, it also came to light that, rather than the official 2,100 Australians at risk of human pituitary hormone-related CJD, the number was actually closer to between 2600 and 2700, since some 500 and 600 additional recipients, undoubtedly the overwhelming majority being infertile women, had been exposed to the hormones in the absence of government approval. This discrepancy was entirely related to women's infertility treatment because, unlike short-statured children whose years of biweekly and often daily growth hormone injections made it impossible for paediatricians to avoid the clerical red-tape which came with government sponsorship, the women's gonadotrophin injections usually lasted for less than six months. Consequently, there was frequently left-over gonadotrophin which infertility specialists could inject into new candidates without going through what they deemed to be a bureaucratic application process to certify new hormone supplies with the Department of Health. Initially, this frank medical arrogance simply undermined the controls set in place by the programme's sponsor, the federal government, but in the long-term, the Doctor Knows Best attitude has translated to government underestimates of the number of women at risk of CJD.

Saving Public Face or Public Health When Medicine Gets It Wrong: As the best known example of global medico-scientific imperialism, human pituitary hormone programs operated over three decades in an attempt to snare control of growth and fertility from nature [see review, Dumble, 1996]. In retrospect, nature had at least one obstacle in store which the tunnel vision of medical science eventually managed to visualize, but was still unable to overcome. Regrettably, when medical science confronted the reality of iatrogenic CJD, the damage control was geared to save public face, rather than to come clean and protect public health.

In brief, following experiments in the 1950s demonstrating that pituitary glands from human cadavers contained growth hormone and the fertility hormone known as gonadotrophin or follicle stimulating hormone, a government-sponsored clinical programme commenced in Australia in 1967 to conquer short-stature in children, and infertility chiefly, but not entirely, in women. Almost 20 years later, when the 1985 cluster of CJD deaths in human pituitary hormone recipients confirmed a suspicion that had been discussed throughout the 1970s, between 20 and 60 thousand recipients of hPG and hGH were estimated to be in similar jeopardy around the world.

Partly due to unique differences between iatrogenic and sporadic CJD, and partly due to medical design, the stage was set to invisibilize the CJD fate of the pituitary hormone recipients, most especially the infertile women exposed to hPG. Unlike sporadic CJD which tends to occur in the late fifth or sixth decade of life, iatrogenic human pituitary hormone-related CJD emerges at an earlier age, with, as examples, children treated with hGH contracting CJD, notably in France, before entering their teens, and the

mean age of five Australian women admitted to have suffered CJD from hPG being only 45 years when their neurologic symptoms emerged. Additionally, the prominent early features of dementia and electroencephalogram abnormalities in sporadic CJD are frequently absent from pituitary hormone-related CJD, and while sporadic CJD frequently has a chronic clinical phase persisting over years, iatrogenic CJD has a rapidly progressive course which generally brings death within months.

These differences between iatrogenic pituitary-hormone-related CJD and sporadic forms of the disease, together with the false prediction from health authorities and medical experts in Australia and elsewhere that CJD tragedies would be confined to hGH-treated children rather than hPG-treated women, has meant that some cases of pituitary hormone-related CJD have been belatedly recognized, or have passed unrecognized. Added to the ruse of doctor-patient privacy which served to keep CJD information secret from hormone recipients, this setting has virtually made it is impossible to estimate how many cases have escaped recognition altogether. To date, known examples of after-the-event CJD diagnosis include; a sixteen year old hGH-treated girl in the United States whose death in 1979 was attributed to pneumonia until a re-examination of her medical history and brain histology in 1986 confirmed that she had contracted CJD; an hPG-treated woman from South Australia, whose neurologic symptoms, and hPG treatment for infertility 12 years earlier, had taken place under the roof of the same institution, but whose psychiatric diagnosis persisted for two years before being corrected to CJD shortly before her death; a Western Australian hPG-treated woman who was misdiagnosed to be suffering from multiple sclerosis when her CJD manifested in 1988 subsequent to an infertility treatment in 1976. This woman's diagnosis was changed to read a degenerative/demyelinating illness before her death in 1989, but her CJD went unrecognised until 1993 when a government investigation into deaths amongst human pituitary hormone recipients recognised her CJD features and acknowledged that she had been another CJD victim of the program; and it has been widely speculated that the CJD in a Melbourne woman visiting the UK would almost certainly have escaped connection to her hPG infertility treatment had it not been for the coincidence that a member of the Oxford medical team had prior experience during his neurological training with a case of hPG-related CJD back in South Australia.

Although the entire concept of blood-transfusion-related CJD was frankly dismissed by public health authorities, by 1987, official US and New Zealand hGH, though not hPG, recipients, had been advised not to donate blood and organs. It took until 1992 for Australian and British blood banks and transplant programmes to follow suit, with the result that these communities were exposed to the risk of secondary CJD transmission for five years longer than their American and New Zealand counterparts.

The Tall Girl and Orphan Episodes: The imperialist characteristics of the Australian Pituitary Hormone experience also dominate the medical efforts to stunt the growth of adolescent girls, and prevent childhood infections in orphaned children. None at the time of being at the receiving end of the various hormones or trial vaccine were suffering from any illness. Rather, like the social vulnerability of short stature or infertility in pituitary hormone recipients, the above average height in adolescent girls, and the parentless situation of orphans, was exploited by medical imperialists to apply a medical cure for what amounted to variance from the social norm. Similarly, the attitude adopted by the endocrinologists and pediatricians responsible for the DES experiments when the reproductive cancer downside of DES became known in the 1970s, was the same "keep it quiet" approach of the pituitary hormone operators. Back in 1981, Norman Wettenhall, a leading figure in the growth stunting program, described the hormone treatment as a "reasonable course of action under careful supervision". Yet, within the same 1981 discourse where he admits to personally stunting the height of 270 girls and 14 boys between the years of 1959 and 1979, Wettenhall admits that the growth effect of the oestrogens, on which his DES imperialism had been totally dependent for 20 years, was still only partially evaluated. Listed, too, were "other effects" of the oestrogens; menstrual irregularities like "break through" bleeding [for which Wettenhall's cure was "just simple reassurance"], increased vaginal secretion, pigmentation of breast nipples, nausea, an increase in fat tissue [which according to Wettenhall "may please some girls, but in others a reduced calorie intake becomes necessary, and some girls may have real difficulty in losing weight while on oestrogen therapy"], ovarian cysts, breast swelling and tenderness, and superficial venous thrombosis. By this time, Wettenhall had carried out limited follow up studies, but, perhaps due to his flawed statistical design, had failed to note that there was a 10% lower fertility rate in DES-treated girls compared with a group who were untreated.

In the end, the silence of medical imperialists serves to rub salt into the wounds of their prey. The tall girls describe their journey since discovering what had happened to them as a one of anger and grief, but they also affirm that the journey is one of sharing and determination to trace the roots of the pain they have internalized over years within their bodies and minds. Like the pituitary hormone recipients, and the guardians of orphans, the parents of above average height adolescents were told by medical experts that it was safe to stunt their daughter's growth with hormones. In the absence of frank medical advice, guardians were unable to judge whether their consent on behalf of their daughters was informed or otherwise. Rather, in an era where medical science summoned unconditional faith, and downsides rarely entered the equation, little thought was given to whether their entrusted children were being subjected to medical experimentation. Rather, it was assumed that medical interventions were nothing less than true and trustworthy.

To date, little is known about the side effects of the vaccine experiments, but the tall girls have discovered that they share a vast array of reproductive health problems; infertility, miscarriage, ovarian cysts, endometriosis, fibroids, breast cancer, and rare cancers of the lower reproductive system. They also share a long list of additional health problems which coincide with those experienced by both females and males exposed to DES in utero; lowered immunity, chronic fatigue syndrome, skeletal and muscle disorders, obesity and depression. Also in common with daughters and sons of women treated with DES during pregnancy to prevent miscarriage, the tall girls are duly concerned about the delayed effects of DES, particularly the risk of reproductive cancer to themselves and their own children.

Lamentably, the dismissal of the tall girls and orphan affairs by a medical consortium, including Richard Larkins, chairman of the National Health and Medical Research Council, Suzanne Corey, director of the Walter and Eliza Hall Institute of Medical Research, Wettenhall, and various representatives of the state and federal health departments, illustrates that health authorities have failed to learn from the human pituitary hormone tragedy. For the socially vulnerable who were exploited in growth stunting and vaccine experiments, this augers badly for their prospects of a meaningful apology. Equally, like hPG and hGH recipients before them, the DES-treated tall girls and vaccine-treated orphans face a tough battle in the court room if they are to win adequate compensation for the dire impact of medical imperialism on their past, present and future.

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