



***Experimentation on a Canadian  
Aboriginal population:  
Investigating historical, unethical  
research***

*Miriam Shuchman M.D.*

*Faculty of Medicine (Psychiatry), University of Toronto  
and  
Research Ethics Consult Service,  
Buffalo Clinical & Translational Research Center  
University at Buffalo/State Univ. of New York*

# Historical unethical research: investigations & concerns

- Investigating nutrition research in Aboriginal communities in the 1940's and 1950's
  - Vitamin research in Northern Manitoba & in Residential Schools in 4 provinces (Work by Ian Mosby and David Napier)
- Investigating other research in the 1940's and 1950's
  - Vaccine research in Aboriginal babies in Saskatchewan, 1930's-1940's (Work by Maureen Lux)
  - Syphilis study in Alabama (Tuskegee), 1930's-1970's (Work by James H. Jones & Susan Reverby)
- Concerns about specific cases of unethical historical research
  - Was the research immoral at the time it was conducted?

# Historical unethical research: what can we learn?

- How and when was the unethical historical research exposed?
- Could it happen today?
- What is the role of federal commissions?
  - Truth & Reconciliation Commission
  - Presidential Commission for the Study of Bioethical Issues



# Northern Manitoba survey: 1941-42

- Team assembled to work in 5 Cree communities
- Nutritional survey of ~400: exams, blood tests, x-rays
- Elders “almost starved” and “plainly not getting enough food to enable them to much more than keep alive.”

(LAC Report by Dr. Percy Moore, March 26, 1942)

- High rates of TB
  - TB death rate (per 100,000): 1400
  - TB death rate for MB non-Aboriginals: 27.1
- High mortality rates
  - General mortality: 5x provincial rate
  - Infant mortality: 8x national rate



# The Chief's conclusion

“A lot of us are living in the bush, trying to live off the country, but, for the scarcity of fur and eatable animals, we sometimes have a very hard time to supply our families with food.

If it wasn't for the patience and kindness of the Hudson's Bay Company, a lot of us would have nothing....”

Chief Andrew Crate Sr., Norway House, Manitoba

# The Superintendent's conclusion

“As a result of the survey one of the first steps considered necessary in any program to improve the health of the Indian through better nutrition was to demonstrate whether provision of some of the food substances or food factors found to be lacking in their diet would result in an improvement in their health.”

Dr. Percy Moore, Superintendent of Medical Services for Indian Affairs and, after 1945, director of Indian Health Services Branch, to House of Commons Special Committee, 1944

# Northern Manitoba study: 1942

- ~300 Aboriginals, 2 groups
- Intervention (125): Nutritional supplements (riboflavin, thiamine, ascorbic acid)
- No intervention (175)
- Nurse checking adherence
- Physicians doing physical exams + eye exams + photos of eyes, gums, tongues
- Ophthalmology paper published; no other publications





# The Superintendent's Rationale

Dr. Moore believed that Indian Affairs administrators needed “a base of scientific knowledge on which to build successful programs for Indian integration.”

Dr. Moore described by Mosby as representing “the new, professional voice of the bureaucracy.” He intended to modernize Indian Affairs.



# Residential Schools study, 1948-52

- 6 schools: BC, AB, ON, NS
- All schools previously investigated by federal Nutrition Division + Indian Affairs staff
- Leadership by Lionel Pett: Nutrition researcher and from 1941, Director, Nutrition Services Division, allies with Dr. Moore to investigate the schools

# Residential Schools study, research questions

- Are conditions observed in Northern Manitoba found elsewhere in Canada?
- What type of food service in residential schools will provide the best maintenance of health?
- Will foods fortified with vitamins and minerals provide results over the course of 5 years?

# Residential Schools study: Port Alberni, BC

- Q: What are the effects of tripling the children's milk consumption?
- Current milk serving = 8 oz/day
- Research Design:
  - 1. Obtain baseline data.
  - 2. Raise milk serving to 24 oz/day
  - 3. Assess results through physical and oral health exams

[L. B. Pett, "Values from Tripling the Milk Used, in an Institution," *Federation Proceedings*, vol. 12 (1953), p. 426.]

Is there a problem with this research?



# I. CANADA'S FOOD RULES

*Approved by the Canadian Council on Nutrition*

THESE ARE THE FOODS FOR HEALTH. EAT THEM EVERY DAY. DRINK PLENTY OF WATER



1. *Milk*—Adults,  $\frac{1}{2}$  to 1 pint. Children,  $1\frac{1}{2}$  pints to 1 quart.



2. *Fruit*—One serving of citrus fruit or tomatoes or their juices; *and* one serving of other fruit.



4. *Cereals and Bread*—One serving of a whole-grain cereal *and* at least four slices of Canada Approved Vitamin B bread (whole wheat, brown or white) *with butter*.



5. *Meat and Fish*—One serving of meat, fish, poultry or meat alternates such as beans, peas, nuts, eggs or cheese. Also use eggs and cheese at least three times a week each, and liver frequently.



*A fish liver oil, as a source of vitamin D, should be given to children and expectant women, and may be advisable for other adults.*



*Iodized salt is recommended.*

# Residential Schools study: Shubenacadie, NS

- Q: What are the effects of supplementing the diet with 100 mg of ascorbic acid (Vitamin C)?
- Study design: experimental and control groups
- Study results: Physical and oral exams; photos
- Outcomes: effects on gums and on hemoglobin

G. F. Oglivie & L. B. Pett, "A Long Term Study on Ascorbic Acid Supplementation," *Canadian Services Medical Journal*, vol. 10, no. 3 (October 1954), pp. 191-197



Is there a problem with this research?



## DEPARTMENT OF NATIONAL HEALTH AND WELFARE

INTRADEPARTMENTAL CORRESPONDENCE

Dr. O. Leroux,  
Assistant Director, Indian Health Services

File No.

Chief, Dental Health Division

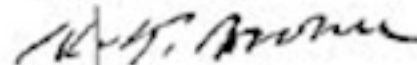
Date: 16-1-50

*med*  
Nutritional Study - Indian Residential Schools

I am associated with Dr. I.P. Pett in the nutritional study of Indian children in certain residential schools, of which the school at Shubenacadie, N.S. is one. The condition of the teeth and gums is used as one of the indices of nutritional status. Both Dr. Pett and I wish to avoid the possibility of any specialized type of dental program using sodium fluoride or dental prophylaxis being instituted in any of the schools under study as these procedures would affect the clinical picture. If your Directorate employs a dentist to render service in the Shubenacadie school or in any other school included in this study, it is requested that the dental service be limited to fillings and extractions and that the use of sodium fluoride and dental prophylaxis be specifically excluded. A filling and extraction service will not affect our observations.

Your assistance in the matter will be greatly appreciated.

Yours sincerely,



H.K. Brown, D.D.S.



# The harm done

- “no specialized, over-all type of dental service should be provided [to the students], such as the use of sodium fluoride, dental prophylaxis or even urea compounds.”
- Dental caries and gingivitis = “important factors in assessing nutritional status,” so any significant dental interventions would interfere with the results of the study



# The Researcher's Conclusion

The work in the schools “was not a deliberate attempt to leave children to develop caries except for a limited time or place or purpose, and only then to study the effects of Vitamin C or fluoride.”

Lionel Pett to David Napier, 2000



# Tuberculosis in Saskatchewan

- Qu'Appelle Reserves, southern Saskatchewan
- Research director: Dr. R. George Ferguson, Medical Superintendent, Qu'Appelle Sanatorium
- 1921: Saskatchewan Anti-TB Commission tests children for reaction to tuberculin
  - Non-Aboriginal children: 54.0% positive
  - Aboriginal children: 92.5% positive
- 1924: settlers anxious about living adjacent to “Indian bands” per Canadian TB Assoc.
- Band leaders “agitating for...diagnosis and treatment”

# TB Research: 1924-1932

- 1924: Qu'Appelle Sanatorium accepts Aboriginals
- 1925: TB death rate on Qu'Appelle and File Hills reserves 20x higher than settler communities
- 1925: National Research Council appoints TB research committee
- 5 research centres include Qu'Appelle Sanatorium
- Indian Demonstration Health Unit formed
  - Replaces huts w/ frame houses, sinks wells
  - Provides hens, garden seed
  - Special nourishment for schoolchildren & pregnant women
  - Full-time PH nurse hired; persons w/ active TB hospitalized

# TB Research Results: 1932

- Qu'Appelle Health Unit results
  - TB death rate cut in half among Aboriginals
  - Mortality and Infant Mortality rates also fell
- Ferguson credits policy of segregating infected individuals: “a very marked improvement”
- 1930 Lubeck Germany BCG results



# Saskatchewan BCG Vaccine Research: 1932-45

- Infants: 306 vaccinated, 303 unvaccinated controls
- Outcomes:
  - Vaccinated group: 6 cases TB, 2 deaths
  - Unvaccinated group: 29 cases TB, 9 deaths
- Conclusion:

“Valuable protection in a highly infectious environment”

Is there a problem with this research?



# BCG Vaccine Research: 1932-45

- General mortality in Qu'Appelle study: 127/K; 125/K
- General mortality in Montreal study: 86/K; 73/K

“poverty, not TB, was the greatest threat to  
Native infants” Maureen Lux



# The Tuskegee Syphilis Study, Alabama: 1932-1973

- Study Rationale:
- Study Design: A 2-arm, 6-8 month study planned of men untreated for the disease, and men w/o the disease
- 1936: “Untreated syphilis in the male Negro: a comparative study of treated and untreated cases.”
- 1937: “Bad Blood Wagon” staffed by PHS, runs treatment program.
- Men from the study are supposed to be kept from treatment

# Macon County, Alabama: 1943-1954

- 1943-44: Observational trials in infected army recruits show PCN is effective & U.S. Army adopts PCN as standard tx for VD 1946
- 1946-54: 4+ study reports published, titled: “Untreated syphilis in the male Negro” (one on mortality and one on morbidity)
- 1951: PHS reviews study procedures

# Macon County, Alabama: 1955-1965

- 1955-64: several more study reports published
- 1962: FDA amendments require informed consent for experimental treatment
- 1965: CDC meeting: “Any questions can be handled by saying these people were at the point that therapy would no longer help them. They are getting better medical care than they would under any other circumstances.” (A letter sent, no reply)

# 1972: Whistleblower talks to a reporter

## The New York Times

### *Syphilis Victims in U.S. Study Went Untreated for 40 Years*

By JEAN HELLER  
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they

have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,



# Historical unethical research: what can we learn?

- Exposure
- Disclosure
  - Would-be whistleblowers
  - Journalists
  - Historians

# Historical unethical research: what can we learn?

- The role of national federal-level commissions and offices
  - Codes of conduct (Belmont Report, TCPS, Chapter 9)
  - Offices of oversight (REBs, IRBs, Secretariat, OHRP)
- The importance of an apology



**Truth and  
Reconciliation**  
Commission of Canada

Commission de  
**vérité et  
réconciliation**  
du Canada

The truth of our common experiences will help set our spirits free  
and pave the way to reconciliation.

**English**

La révélation de nos expériences communes aidera à libérer nos  
esprits et à ouvrir la voie à la réconciliation.

**Français**





QUESTIONS?

THANK YOU