Kahnawake Schools Diabetes Prevention Project
Center for Research and Training

Use of Participatory Research

Kahnawake Schools Diabetes Prevention Project 1994 - 2006

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Outline of presentation

• Participatory research (PR)
• Diabetes in Aboriginal Peoples of Canada
• Kahnawake Schools Diabetes Prevention Project as a case study for PR
• Questions and discussion
Conventional Research
(nicknamed ‘helicopter research’) is when researchers make all the decisions

“outside research teams swooped down from the skies, swarmed all over town, asked nosey questions that were none of their business and then disappeared never to be heard of again”

*Aboriginal physician Dr Louis Montour 1987*

Montour LT, Macaulay AC. *Diabetes Mellitus and Arteriosclerosis: Returning research results to the Mohawk Community. Canadian Medical Association Journal 1988;34:1591-93*
Participatory Research (PR)

“Systematic enquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and taking action or effecting social change.”

The Royal Society of Canada- Study of Participatory Research in Health Promotion. 1995 Green LW et al
Guidelines available at http://lgreen.net/guidelines.html
Research Goals in PR

• Is the purpose of the research to facilitate the empowerment of individuals, groups and the community?
• Will the project help community participants (and others) to deal with factors that influence their health and that of their community?
Type 2 Diabetes in Aboriginal communities of Canada

- Rare before 1940’s
- Today 2-5 times higher than National average
- High rates of complications
- Some communities
  - 26% age adjusted prevalence rate of diabetes
  - 50% of 50 year olds with diabetes
  - mothers with diabetes and gestational diabetes have children with increased rates of diabetes (x 4)
  - type 2 diabetes in children
Etiology of Type 2 Diabetes

Genetic & Environmental
- Aboriginal ancestry (thrifty gene theory)
- family history
- mother with diabetes/gestational diabetes in pregnancy
- bottle feeding (impacts mothers and children)

Lifestyle
- obesity (degree, length, central distribution)
- sedentary habits
- high fat & low fibre diet
- stress, social determinants of health
Kahnawake Schools Diabetes Prevention Project

(KSDPP)
• Kahnawake is a Kanien’keha:ka (Mohawk) community of 7,500 (2004) inhabitants 15 km from Montreal

• community control of education (1967) and health (1970)
Kahnawake Prevalence of Disease
(1981 and 1985 chart reviews for patients 45-64 years)

- 12% diabetes (twice national average, reconfirmed in 2006)
- 86% obesity (with diabetes)
- 48% ischemic heart disease
- 50% retinopathy after 15 years of disease
- Macro-vascular complications 6 times higher for those with diabetes (matched for age and sex)

Montour LT, Macaulay AC. High prevalence rates of diabetes mellitus and hypertension on a North American Indian reservation. CMAJ 1985;132:1110-12
Macaulay AC, Montour LT, Adelson N. Prevalence of diabetic and athero-sclerotic complications among Mohawk Indians of Kahnawake. CMAJ 1988;139:221-224
1987 Results Returned to Community

(knowledge translation)

Resulted in ..... 

• Legitimisation of diabetes as a community health issue --- diabetes previously seen as a disease of individuals or family

• Elders requested family MDs to “do something” to prevent diabetes with focus on the children

Principles of KSDPP 1994 - present

“Health promotion is the process of enabling people and communities to take control over their health and its’ determinants” WHO 1984

- Promote Kanien’kehá:ka (Mohawk) values for activities & decision-making
- Promote ecological changes to support physical activity and healthy eating
- Use participatory research with community and researchers as equal partners

Potvin LP, Cargo M, McComber AM, Delormier T, Macaulay AC. Implementing Participatory Intervention and Research in Communities: Lessons from the Kahnawake Schools Diabetes Prevention Project. Social Science and Medicine 2003;56(6):1295-1305
Multi-faceted Roles of the Community Advisory Board

- +40 volunteers over 12 years aged 26 – 82 years
- Represent the community
- Protect community values
- Guide intervention, research and training
- Provide input and comments on results and papers
- Represent KSDPP at conferences and meetings
Involved throughout the research
• Finalising the research questions
• Advising on data collection
• Interpreting the results
• Disseminating the findings
1994: researchers and community jointly developed document outlining obligations of all partners, with protection of both individuals and the community (2006 updated version soon to be released)

KSDPP Objectives
1994-present

- Reduce prevalence of diabetes among future generations in Kahnawake
  - Increase physical activity
  - Increase healthy eating habits

- Mobilise community resources

- Increase community capacity and maximise sustainability

Interventions 1994 to present
combines interventions in schools and community

School interventions (partnership with schools)

• KMHC Health Education Program for Grades 1-6
developed by community professionals
  - delivered by teachers - ten lessons per year in Mohawk and English
  - supported by school extra-curricular activities

• Schools Nutrition Policy
  bans ‘junk food’

• Teachers extra activities
Community Interventions 1994 - present

• Community wide events for extended families and all ages reinforce messages delivered in schools
  - reflect Kahnien’keha:ke cultural values and practices
  - developed in partnership with other community organisations
    (builds on strengths, develops capacity)
  - support healthy eating and daily physical activity
  - offer opportunities to eat well and be active

"Activity Implementation as a Reflection of Living in Balance: The Kahnawake Schools Diabetes Prevention Project."
Delormier T, Cargo M, Kirby R., McComber A.
Evaluation and Results
EVALUATION

Outcome Grades 1-6
- Obesity
- Physical Fitness
- Healthy eating habits

Impact Grades 1-6
- Knowledge
- Self-efficacy
- Parental support

Process
- School
- Community
- Intervention

Evaluation Effect
OUTCOME EVALUATION Grades 1-6

Anthropometric Measurements
- Weight & height
- Skinfold thickness (subscapular, triceps)

Fitness Test
- 1994-1999
  Run / Walk Test
  • One mile
  • Half mile
- 2002-2004
  Shuttle run test

Student Questionnaires
- 7 day questionnaires:
  - Food frequency
  - Activity frequency
  - Television watching
  - Video game playing
  - Organized sports

24-Hour Food Recall
Baseline results 1994

Grades 1-6

- Weight similar to N. American counterparts, but heavier children are heavier and carry their weight centrally
  

- Girls watching excess TV are heavier (not true for boys)
  
  Horn O. et al. Preventive Medicine 2001;33:274-281
Nutrition Results
24-Hour Nutrition Recalls Grades 4-6


• **1994 - 2002:** decreased sodas, french fries, potato chips, candy, fruits and vegetables (including juices and milk. Increased whole wheat bread. *Salmon L. Master’s Thesis. McGill University 2004*

• **1994, ’98, 02:** overweight (>95%ile) children consume more French fries. At risk of overweight (85-95%ile) consume more chips than normal weight children (5-85% tile). *Receveur O, Morou M, Gray-Donald K, Macaulay AC. Submitted 2006*
Physical Activity, Fitness and TV watching

- 1994 - 1998
  Improvements (statistically significant)

- 1998 – 2002
  Back to baseline

Change in Weight in 6-8 Year Old Boys

KSDPP 1994
- Overweight: 18%
- At risk of overweight: 12%
- Average weight: 70%

KSDPP 2002
- Overweight: 28%
- At risk of overweight: 17%
- Average weight: 55%

NHANES 1988-1994
- Overweight: 13%
- At risk of overweight: 12%
- Average weight: 75%

NHANES 1999-2000
- Overweight: 18%
- At risk of overweight: 15%
- Average weight: 67%
What do these results mean??

In comparison to other communities

Obesity in children (Aboriginal and Non Aboriginal) is increasing in Canada

Other studies to prevent obesity and diabetes

Cochrane data base 2005 included 22 RCT/Qex studies (10 long term and 12 short term)
Only 4 showed improvements in reducing obesity or body fat index
www.cochrane.org
Community Reactions Spring 2004
16 presentations to community organisations to discuss findings and to get community interpretation of results

“Message for parents to be a role model. Pay attention to your children - get involved!”

“We are fortunate to have 10 years of data but it is discouraging to see a return to baseline levels; don’t know how to reverse the trend.”

“What would be the results if the project didn’t exist?”
Other outcomes from partnering with community
Evaluating Community Ownership 1996 and 1999
(2004 results to come)

Project decision-making was a shared responsibility among multiple community partners

Although academic researchers’ influence was consistently low, researchers were satisfied with their level of influence

Community partners are the perceived primary owners of KSDPP

POSITIVE OUTCOMES

**Increased Community Knowledge**
- Link between lifestyle and disease
- No increase in incidence of Type 2 diabetes 1986-2003 (submitted paper under review)

**Environmental Changes**
- Schools nutrition policy (1994)
- Health curriculum taught by teachers
- Only healthy food at the youth centre
- New 1.2 km recreation path with plans for extension
MORE ......

Community Capacity Building

• Community Advisory Board full partner throughout research
• Kahnawake summer students
• Mohawk PhD candidate in health promotion
• Mohawk Masters student - now a family medicine resident
• KSDPP training program for other Aboriginal communities

Impacting National /International Policy

• Presentations to government, Canadian Institutes of Health Research
• KSDPP Code of Research Ethics cited by WHO
Current KSDPP plans

• Present results to community organisations to promote community ecological changes
• Continue and increase interventions in elementary schools and outreach in community
• Seek funding for new interventions for younger children
  - families of children aged 1-5 yrs, breastfeeding group, parenting groups, pre-school programs
  - add a schools wellness animator to increase physical activity at lunch time and after school
With many thanks to.....

KSDPP Staff

KSDPP Research Team

KSDPP Community Advisory Board

Students from Kahnawake, McGill University, U de Montréal, and Queen’s University

Dr Louis T Montour

www.ksdpp.org
Don't Ever Give Up!