How Community Based Participatory Research (CBPR), Outreach, & Education Impacts American Indian Breast Cancer Programs to Address Inequities

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Community-based Participatory Research (CBPR) - *definition*

CBPR is a partnership approach to research that equitably involves community members, organization representatives and researchers in all aspects of the research process.

Israel BA, Eng E, Schulz AJ, and Parker EA. Eds. *Multiple Methods for Conducting Community-Based Participatory Research for Health.* 2005 from Jossey-Bass

Definitions (as used in this presentation)

- "Partners" may include:
  - Native communities
  - Academic institutions
  - Cancer centers
  - Research institutions
  - Public health departments
  - Government agencies

"Outside" Partners

meanwhile, back at the ranch …

- Although Indian Health Service / Tribal / Urban health programs may not use the actual phrase, "community based participatory research (CBPR)", this is the type of protocol the communities want implemented
- Unfortunately, many academic institutions say they are doing CBPR, but in fact it is traditional research just labeled as CBPR

CBPA/CBPR vs. Traditional Research

- "Letters of support" vs. true partnerships
- Natives used to collect data
- Natives "volunteers" while "outside partners receive salaries

Who is the boss? Or can we be *true* partners?

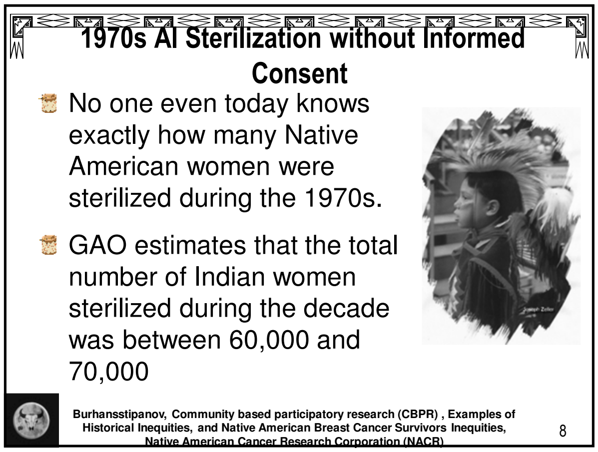
CBPA/CBPR vs. community-driven

- CBPA / CBPR is desired strategy
  - Community-*driven* project is usually acceptable substitution (based on the topic, such as "ATM")
  - Some projects are more appropriate as "community-driven" rather than CBPA/CBPR
- Linda B's CBPR checklist

First They Took Our Land …Then They Took Our Children

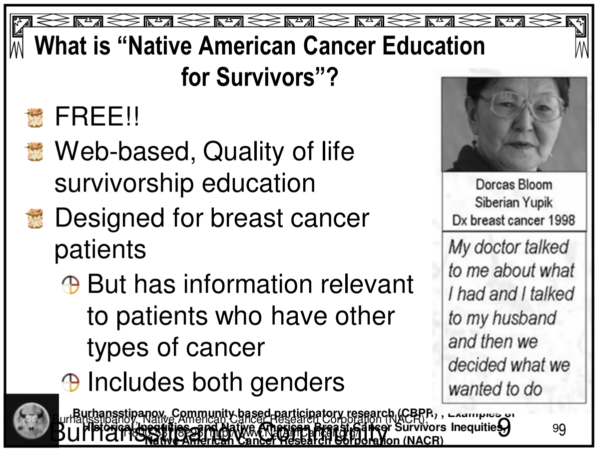
Tom Torlino (Navajo) as he appeared upon arrival to the Carlisle Indian School, October 21, 1882.

Three years later



1970s AI Sterilization without Informed Consent

- No one even today knows exactly how many Native American women were sterilized during the 1970s.
- GAO estimates that the total number of Indian women sterilized during the decade was between 60,000 and 70,000

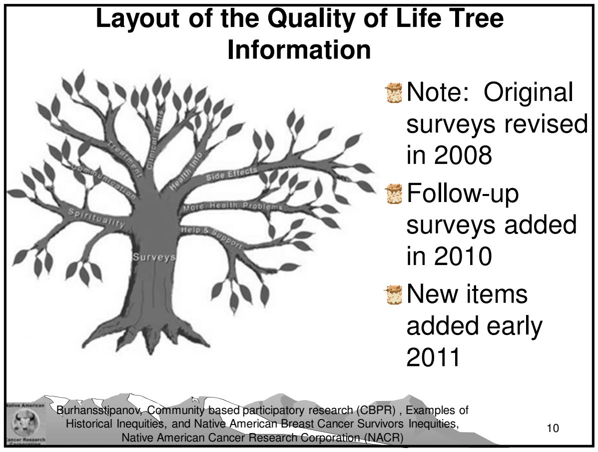


What is “Native American Cancer Education for Survivors”?

- FREE!!
- Web-based, Quality of life survivorship education
- Designed for breast cancer patients
  - But has information relevant to patients who have other types of cancer
  - Includes both genders

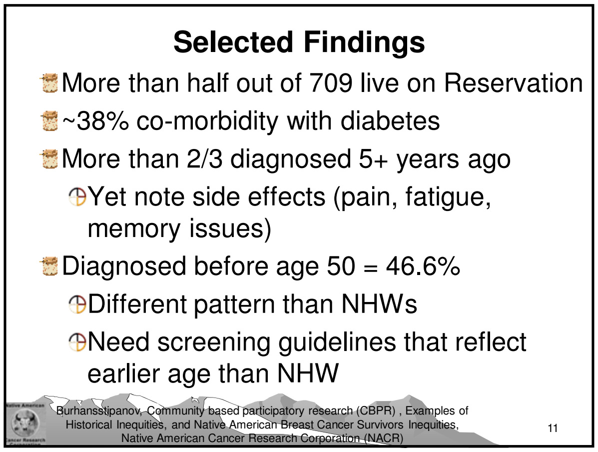
Dorcas Bloom
Siberian Yupik
Dx breast cancer 1998

My doctor talked to me about what I had and I talked to my husband and then we decided what we wanted to do



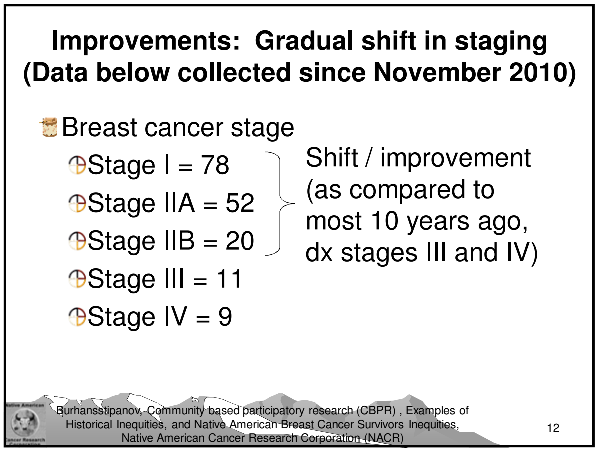
Layout of the Quality of Life Tree Information

- Note: Original surveys revised in 2008
- Follow-up surveys added in 2010
- New items added early 2011



Selected Findings

- More than half out of 709 live on Reservation
- ~38% co-morbidity with diabetes
- More than 2/3 diagnosed 5+ years ago
  - Yet note side effects (pain, fatigue, memory issues)
- Diagnosed before age 50 = 46.6%
  - Different pattern than NHWs
  - Need screening guidelines that reflect earlier age than NHW



Improvements: Gradual shift in staging (Data below collected since November 2010)

- Breast cancer stage
  - Stage I = 78
  - Stage IIA = 52
  - Stage IIB = 20
  - Stage III = 11
  - Stage IV = 9

Shift / improvement (as compared to most 10 years ago, dx stages III and IV)

Excerpt of Findings

- Survivors can choose to not answer any item (thus, many responses have ~690 participants)

Gender		
Male	138	19.30%
Female	575	80.30%
Total	713	99.60%
Missing	3	0.40%

Item added April 2008

Sexual Orientation / Identity			
	M	F	Total
Heterosexual	45	192	237
Gay, Lesbian, Homosexual	9	14	23
Bisexual	1	1	2
Other	0	1	1
DWTA	7	28	35
Don’t know / Not sure	0	2	2
Total	62	238	300

Education		
<HS	161	22.50%
HS/GED	185	25.80%
Tech / Some Coll	199	27.80%
Asso/ BA/ Master / Doc	124	17.30%
Total	669	93.40%
System	47	6.10%
Total	716	100.00%

Primary Health Insurance (and inequities)		
Private	247	34.3%
Tribal / Village/ ANMC	301	31.7%
IHS (but not really insurance)	87	12.1%
No insurance	43	6.0%
Public Care (Indigent)	10	1.4%
VA	9	1.2%
Medicaid/Medicare	6	0.8%
Have Ins (don’t know what)	6	0.8%
Total	709	98.3%

Travel Time (one-way) to treatment			
	Males	Females	Total
< 2 hours	24	183	207
2-4 hours	15	72	87
4-6 hours	26	87	113
6-18 hours	21	77	98
18-24 hours	0	12	12
Total	86	431	517

Cancer Experience Side Effects: Long-term “A few days each week / every day”

- Fatigue: n=206 / 709 (28.6%)
- Weakness: 149 / 704 (21.1%)
- Pain: 127 / 706 (18%)
- Pain side effect: 131 / 703 (18.6%) (~internal reliability)
- Infections side effect: 49 (7%)
- NOTE: logistical regression with variables e.g., age, diabetes, arthritis, etc.