A Body's Burden

Advocacy Based Biomonitoring Studies

An ES Thesis by
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Outline of Presentation

- Introduction:
  - Definition of biomonitoring
  - History of biomontoring use in science
  - Developments leading to use of biomonitoring by advocacy organizations
  - Emergence of advocacy based biomonitoring studies

- Methods and overview of case studies
  - Interview sample
  - Coding Process
  - 3 case studies

- Results:
  - Ways in which advocacy based biomonitoring represents a new philosophy of research ethics
  - Participants' perspectives on the experience of receiving body burden information

What is biomonitoring?

- Biomonitoring refers to the measurement of exogenous agents in a biological medium such as hair, urine, breast milk, and blood.
- Chemicals tested for include flame retardants, DDT, phthalates, perflourochemicals, mercury, and lead.

History of Biomonitoring

- Not a new science
  - 1940's- Blood testing for lead
  - 1950's- Biomonitoring for pesticides

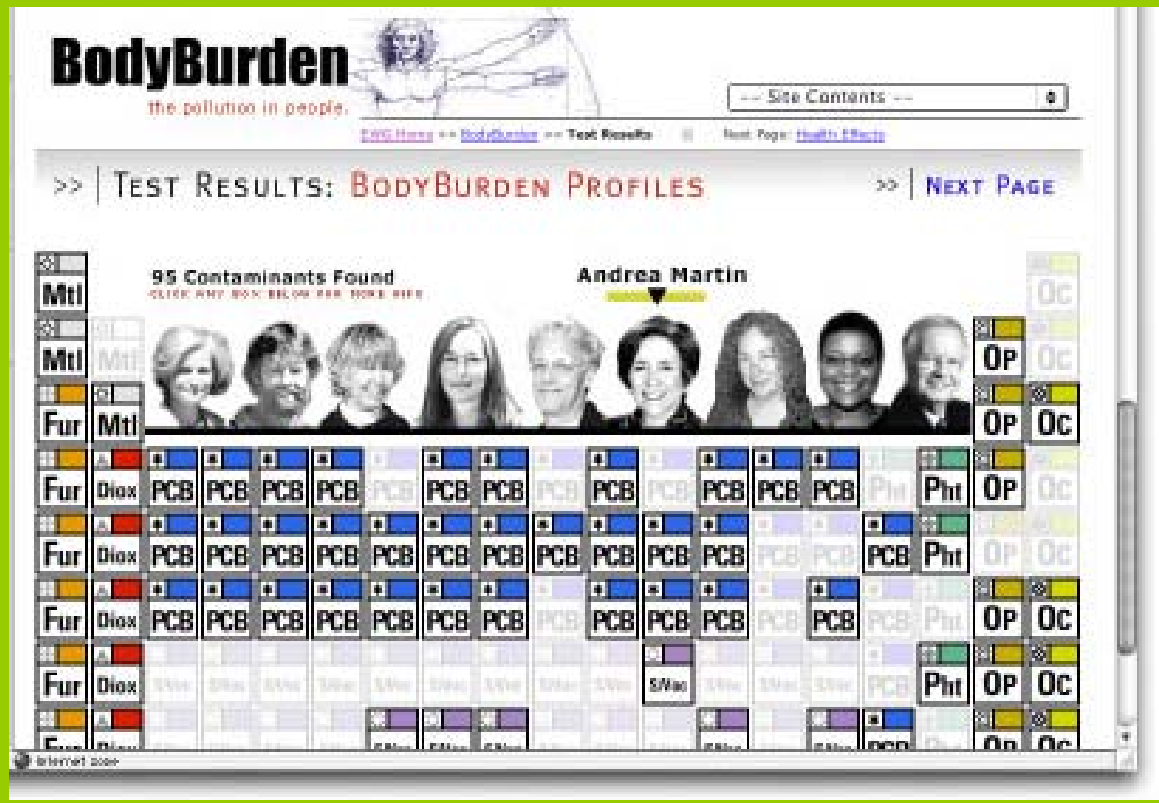
- However, biomonitoring remained an obscure research tool until the past few decades.
  - Testing techniques were often invasive
  - high cost of testing
  - In the past 10 years, developments in testing technology has led to decreased costs, greater testing sensitivity, and less invasive procedures.

National Averages are Compiled

- CDC National Report on Human Exposure to Environmental Chemicals
  - Part of NHANES survey.
  - 2001: First Report, 27 chemicals tested for.
  - 2003: Second Report, 116 chemicals tested for.
  - 2005: Third Report, 148 chemicals.
  - Provides data on national averages.

Advocacy Based Biomonitoring Emerges: 2003 EWG Study

- EWG tested 10 individuals for 167 chemicals.
- The results from this study was placed on a website
- Viewers can click on a participant's photo and learn about their body burden, their biography, and the potential health implications of the results.



http://www.ewg.org/reports/bodyburden/dynam-contams

Advocacy Based Biomonitoring Emerges: 2003 EWG Study

- Bill Moyers chronicled his own experience receiving his body burden in his PBS special, Trade Secrets.

- This program, coupled with the press generated by the CDC survey, triggered a flurry of public interest and discussion around the issue of chemical contamination.

http://www.pbs.org/tradesecrets/problem/bodyburden.html

An Explosion of Advocacy Based Biomonitoring Studies: 2003-2006

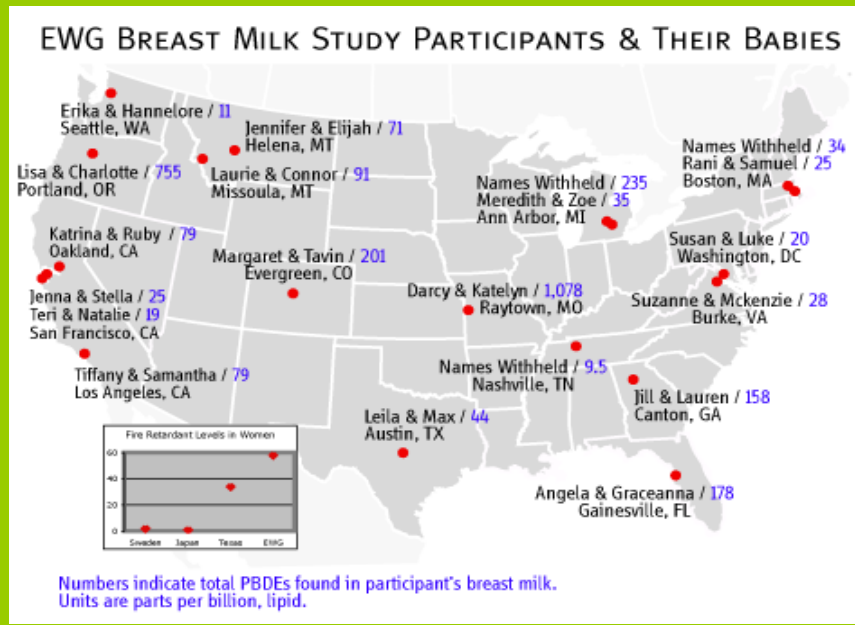
- January 2003: EWG “BodyBurden: The Pollution in People” tests 9 individuals, mostly environmental health scientists, for 210 chemicals
- September 2003: EWG “Mother’s Milk”: found unexpectedly high levels of flame retardants in breast milk.
- November 2003: WWF UK “Contamination” individual biomonitoring study of 155 volunteers from across England.
- October 2004: WWF UK “Contamination: The Next Generation” Family biomonitoring tour
- July 2005: EWG “BodyBurden II: The Pollution in Newborns” tests a random sample of cord blood and finds an average of 200 chemicals.
- August 2005: Commonweal’s “Taking it All In”, California, tests 11 “luminaries” for 6 categories of chemicals.
- March 2005: Oakland Tribune prints a series on the body burden of a family of four.
- April 2005: WWF releases “Bad Blood,” a study testing the blood of environment and health ministers from 14 European countries for 110 chemicals
- May 2005: “I’m a Celebrity, Get it Out of Me!” WWF tests the blood of 8 British celebrities
- September 2005 Greenpeace Netherlands and WWF UK “A Present for Life” examines maternal and cord blood samples.
- October 2005 WWF UK Generations X: 3 generations of families from 13 countries across Europe are tested for 107 chemicals.
- February 2006: Ottawa, Canada: Environmental Defence tests 11 Canadians for 88 chemicals.
- May 2006: Northwest Toxics Coalition “Pollution in People Project” tested 9 individuals for 7 categories of chemicals, results are due out this spring..

“An explosion of new studies are showing that small amounts of toxic chemicals can have large effects on health, especially for pregnant women, babies in the womb and young children.”

– Commonweal Luminaries Study

Advocacy Based Biomonitoring Studies: 2003-2006

- EWG Sept. 2003
- 20 mother/ daughter pairs
- Tested for PBDEs



http://www.ewg.org/reports/mothersmilk/appendix3.php

Advocacy Based Biomonitoring Studies: 2003-2006

CONTAMINATION
THE RESULTS OF WWF'S BIOMONITORING SURVEY

- WWF UK November 2003
- Tested 155 people around England for 75 chemicals

http://www.wwf.org.uk/chemicals/biotourindiv.a

Advocacy Based Biomonitoring Studies: 2003-2006

Contamination: the next generation

- WWF UK October 2004
- Tested 7 families around England for 104 chemicals

Advocacy Based Biomonitoring Studies: 2003-2006

- EWG July 2005
- Tested 10 cord blood samples from all over US

http://www.ewg.org/reports_content/bodyburden2/pdf/bodyburden2_final-r2.pdf

Advocacy Based Biomonitoring Studies: 2003-2006

Bad Blood?

A Survey of Chemicals in the Blood of European Ministers

- WWF April 2005
- environment and health ministers from 13 European countries

http://www.wwf.pl/publikacje/ministrowie.pdf

Research Questions

- *How do advocacy based biomonitoring studies represent a new field of scientific inquiry in which activism and scientific research intersect?*

- *How does the experience of participating in grassroots body burden studies blend a private embodied experience with public activism efforts?*

- *How do participants in advocacy based biomonitoring studies come to understand their results, and how does the experience of learning one's personal body burden affect the way individuals think and act on environmental health issues?*

Methods

- Interviews:
  - 14 participants
  - 9 scientists
  - 20 total
  - Analytic coding of interview transcripts
- Content Analysis of 10 study publications
- Literature Review

Sample Interview Questions

Scientist Interviews

- Why did you or your organization have an interest in conducting a biomonitoring study?
- How did you decide what chemicals to test for?
- What were the most commonly asked questions among participants?

Participant Interviews

- What were your motivations to participate?
- How did you first react to the results?
- Have you made any changes in your consumer habits as a result of participating in the study?

Interview Analysis: Coding Process

- Experience of Participating
  - 11 master codes
  - Sample codes:
    - Emotional reaction to results
    - Initial concerns
    - Interpreting/understanding results

- Intersection of Science and Advocacy
  - 17 master codes
  - Sample codes:
    - Media contact
    - Effect on personal level of activism
    - Critique of science
    - References to policy developments

Interview Analysis: Coding Process

	Master Nodes/Trees	Nodes/Codes	Coding Rule
Analytical Coding I: Participating in the study			
1.	Rationale for Study Participation	Individual health concerns	Code if the participant cites individual health endpoints as a motivation to participate in the study, such as curiosity about individual levels, breast cancer history, etc.
2.		Desire to help advocacy organization	Code if the participant mentions a desire to support the specific organization sponsoring the study, such as if he/she is a board member.
3.		Broader advocacy goals	Code if the participant mentions broader goals such as increasing the knowledge base or generating more support or awareness.
4.	Reflections on study design	-	Code if the participant evaluates the study design or the “professionalism” of the study
5.	Awareness of issues prior to participation in the study		Code when the participant discusses previous experience with these issues before participating in the study.
6.	Sampling and survey process	-	Code when the participant describes or discusses the actual experience of having samples taken or going through the questionnaire.
7.	Expectations about study findings	-	Code instances where interviewee discusses initial predictions about the body burden results.
8.	Exposure history/previous personal habits leading to exposure	-	Code any instance when interviewee discusses previous exposures, such as a childhood spent near orange groves with pesticides or years eating meat.
9.	Concerns about study experience	-	Code when the participant mentions concerns he/she had going into the study experience, or discusses reasons why he/she had no concerns.

Case Study #1: Sick of Dust

- I interviewed 2 participants and one study coordinator.
- March 2005 study conducted by Clean Production Action, tested the household dust of 70 homes across the United States.
- Chemicals tested for included phthalates, alkyphenols, pesticides, PBDEs, organotins, and perflourinated chemicals.

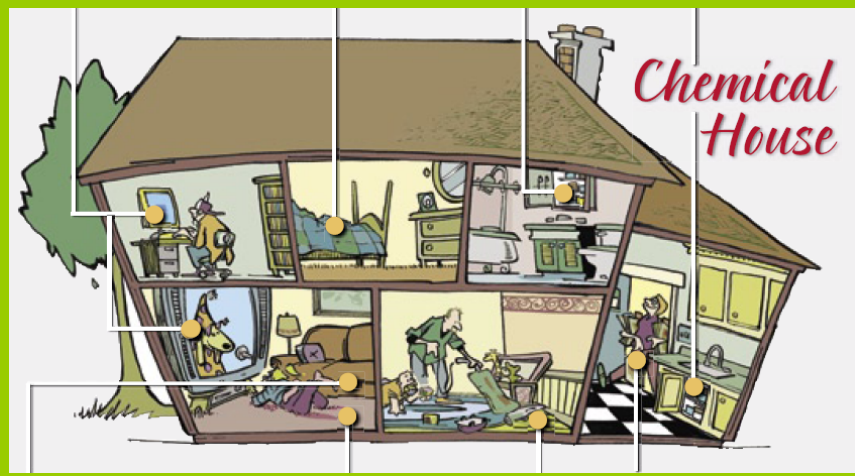
Case Study #1: Sick of Dust

Advantages:

- Local study sample
- Extensive media training and opportunities to speak with press.
- Recruited individuals already involved in activism around the issue.
- Study report describes four levels of action:
  - Federal policy
  - Statewide initiatives
  - Consumer behavior
  - Progressive industry

Disadvantages:

- Household exposure, not body burden
- Results pooled at state level, with option for paying extra for individual results.



Case Study #2: Oakland Tribune

- I interviewed all adult participants and the reporter in charge of the project.
- Reporter Douglass Fischer tested family of four including 1 year old Rowan and 6 year old Mikaela.
- The Oakland Tribune did an extensive series on body burden testing, covering the first page of the newspaper with the family's story.

- The two children have the highest levels of PBDEs recorded at that time outside of occupational exposure.
- The newspaper was advised by doctors to retest them, to confirm the accuracy of the findings.
- The levels went down but were still extremely high, indicating that the first tests were accurate.

Case Study #2: Oakland Tribune

Advantages

- Because they were such a small sample, the process of interpreting the results was unique.
- The entire experience was documented by the media.
- This was the only study I looked at that included children's levels.

Disadvantages

- Small sample size made it impossible to draw conclusions from my interviews.

Case Study #3: Commonweal Luminaries Project

- I interviewed 7 out of 11 participants, and 2 scientists in charge of the project.
- This project selected 11 local "celebrities" to have their blood and urine tested for several chemicals.
- Participants included movie star Peter Coyote, several local politicians, and a journalist for Los Angeles Times.

Case Study #3: Commonweal Luminaries Project

Advantages:

- Study report features extensive individual commentary on reactions.
- Report was directly tied to a local political issue, the California Biomonitoring Bill.
- The participants I interviewed had a diverse range of backgrounds.

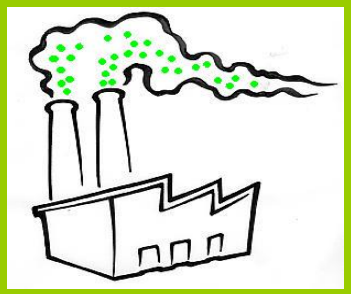
Jo Rupert Behm, MS, RN

INDIVIDUAL CHEMICAL PROFILE

Chemical	Specimen	Units	Jo Behm	Median
Mercury	hair	ng/g	283	1,882
Pesticides:				
4,4'-DDE	serum	ng/g fat	396	396
4,4'-DDT	serum	ng/g fat	3.7	4.6
DDE/DDT	serum	ratio	108	61
Flame Retardants:				
BDE-47	serum	ng/g fat	37.4	14.1
BDE-99	serum	ng/g fat	3.2	3.1
BDE-100	serum	ng/g fat	3.6	2.1
BDE-153	serum	ng/g fat	2.7	3.4
BDE-154	serum	ng/g fat	0.2	0.28
Perfluorochemicals:				
PFOS	serum	ng/mL	28.9	25.6
PFHxS	serum	ng/mL	1.79	2.44
PFOA	serum	ng/mL	8.28	5.30
PFPeA	serum	ng/mL	0.56	0.23
PFHpA	serum	ng/mL	0.24	0.14
PFNA	serum	ng/mL	1.67	1.67
PFDA	serum	ng/mL	0.49	0.43
PFUnA	serum	ng/mL	0.40	0.40
PFDoA	serum	ng/mL	0.13	

Disadvantages:

- Because the study report came out on the heels of several other environmental health studies done in the area, there was little press coverage of the project.



Biomonitoring's appeal for advocacy organizations

- Personalizes the issue
  - *"this is a way to make it very personal, emotional, story-based. Because this is about me and my daughter, you know, not about this chemical with a long name. So we saw it as a great opportunity to get the message across in a really different way."- Erica Shreder*
- Makes the scientific issues easier to understand
  - "*Almost everyone can understand that carrying many chemicals in our bodies and passing them on to the next generation cannot be good for us or for our children. It's simple common sense"*
- Motivates strong response from people
  - *"Every time I reported [about] pollutants in our bodies, I would get just a deluge of emails almost exclusively from women concerned about what is in them, how do they find out, how do they get tested, and what are they doing there?" –reporter from Oakland Tribune*

http://www.chemicalbodyburden.org/whatisbb.htm

A New Philosophy of Research Ethics

- Study design decisions prioritize advocacy
- Anonymity and confidentiality are cast aside
- A new style of publication of scientific data

A New Philosophy of Research Ethics

Study Design Decisions Prioritize Advocacy

- Recruitment of participants
  - "*what we were looking for was basically people who …could effectively carry our message to groups that we wanted to reach.*"

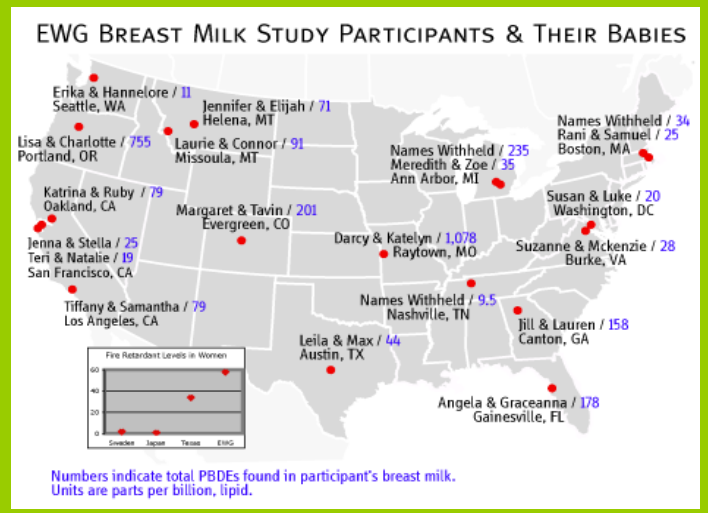
- selection of chemicals is based on political priorities and advocacy appeal.
  - *"We wanted to test for chemicals that people would feel affected their lives directly, so chemicals that were in household products or in food. And we also looked for chemicals where there would be a policy opportunity, or that you told an interesting story for some reason"*

http://extras.insidebayarea.com/ot/gallery/index.asp

A New Philosophy of Research Ethics

Anonymity and Confidentiality Are Cast Aside

- Individuals had the option to keep their results private.
- However, they were encouraged to go public with the experience.
- Tension between personal, embodied health experience and communicating with the media and general public.

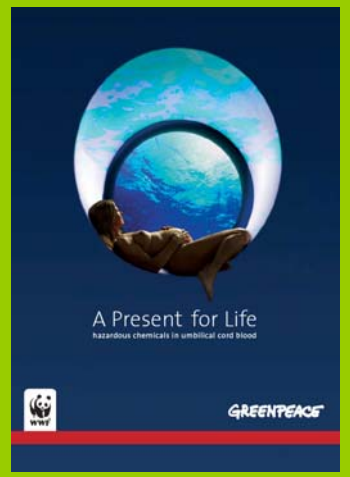


About the family | Results | Reaction | Results in detail

http://www.wwf.org.uk/chemicals/bio_0000001992.asp
http://www.ewg.org/reports/mothersmilk/es.php

A New Philosophy of Research Ethics

A New Style of Publication of Scientific Data



- **Outraged language**
  - "chemical cocktail"
  - "toxic trespass"
  - "chemical soup"

- **Designed for a lay audience**
  - Scientific techniques are explained using simple language.
  - Results are presented next to personal reactions and information.

- **Policy issues are stressed**
  - Recommendations for action are given
  - Many studies blame the current regulatory system.

    "The continuing contamination of the youngest family members with hazardous man-made chemicals clearly illustrates the failures of the current regulatory system."

Unique Elements for Study Participants

- Motivation to participate
- Process of digesting information
- Effect of study experience on lives of individual participants.

Unique Elements for Study Participants

Motivations to Participate

- Curiosity about individual health endpoints
- General altruistic motivation to support health research
- Loyalty to organization conducting the study

  "I did it I guess out of institutional loyalty and a feeling that I could be helpful in advancing the recognition and legitimatization of this work."
- Commitment to toxics reduction movement
- Desire to have a stronger leverage point for activist work.

  "*I knew that Andrea Martin had a heavy body burden, and I thought that if I knew what my body burden was or is that I could use that information to communicate to people in my community."*

Unique Elements for Study Participants
Process of Digesting the Information

- Some expressed disappointment that their results were not more shocking, that they were not one of the most contaminated in the study sample.

  "I was disappointed that I didn't have anything that I could go and shock people with."

- Tendency to compare values with other participants

  "You know, we compare. Because it gave me my results and then it gave me the results of other people. And I had a list of a little bit of the background on some of the other people."

- Concern over not understanding the scientific information well enough to communicate publicly.

  "Actually one reporter called me, and she wanted more of the science, so I'm a little bit uncomfortable yet. I almost feel like I need somebody to write me a script."

Unique Elements for Study Participants

Life Changes as a Result of the Study

- Almost all participants mentioned changing consumer behavior.
- Varying levels of increased activism around the issue.
- Most mentioned being contacted by media or other activist organizations, demonstrating a new identity as a spokesperson for the issue.

Reccommendations for Further Study

- Trend of individuals requesting their body burden from doctors or researchers.
- Advocacy-based studies being published in peer reviewed literature, and cited in peer reviewed papers.
- Barriers to lowering the cost of biomonitoring

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