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Environmental Estrogens and Vulnerable Bodies: A Sociological Analysis of Activist-Initiated Research

Author

Thomson, Laura Katherine

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Environmental estrogens and vulnerable bodies: A sociological analysis of activist-initiated collaborative research

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Abstract

This dissertation analyzes the current era of activist-scientist collaborations on environmental causes of breast cancer. The guiding questions are: As women's health organizations in the U.S. are becoming institutionalized within biomedical research, how are these alignments shaping knowledge on women's health? What bearing do the collaborations and products of research have on activist/ advocacy organizations?

The primary site of data collection was the Breast Cancer and the Environment Research Centers (BCERC). Beginning in 2003, BCERC is studying how environmental exposures might cause early pubertal onset in girls and breast cancer. It is one of the most collaborative research projects funded by the NIH to date. My data consisted of 22 in-depth interviews with researchers and advocates, observations at conferences and meetings, and a content analysis of 54 newspaper articles from 2005-2008 discussing toxins, early puberty, and breast cancer. Peer-reviewed medical journals and breast cancer advocacy websites supplemented my data.

This dissertation is informed by grounded theory and social worlds methodologies, and by situational analysis. I engage biomedicalization, feminist science studies theories, and health social movements, including the growing body of literature on public understandings of science.

I observed that the research being produced by scientists and activists is painstaking, slow, and difficult to interpret. As a consequence, the collaborations themselves are being discussed as major contributions, for they can be analyzed and discussed by researchers and advocates as they unfold. My content analysis data highlighted implicit lines of discussion among scientists, advocates, and popular newspapers. Scientists portrayed journalists as popularizing issues without adequately conveying results, and journalists criticized scientists for not providing enough information on avoiding exposures. The content analysis emphasized difficulties in distinguishing inside/outside boundaries in science.

The central story of this dissertation follows the advocates as they renegotiate boundaries of expertise and claim recognition as scientific researchers in their own right. As Callon (1999) has argued, when advocacy groups push for and claim roles in shaping research, their collective identities strongly influence the knowledge that becomes co-produced. With the rise of cooperative formats of breast cancer research, new boundaries are being drawn around "what counts" as science.

TABLE OF CONTENTS

Page

CHAPTERS

CHAPTER 1: INTRODUCTION

In 1969, Dr. Howard Ulfelder met with the mother of a patient to discuss the rare cancer afflicting her teenage daughter. The mother indicated that she had been prescribed diethylstilbestrol (DES) while pregnant with her daughter and had a hunch the medication caused her daughter's cancer. [1]

Between 1967-1969, five other young women had been diagnosed with clear-cell adenocarcinoma of the vagina, and one of them eventually died. Ulfelder, along with colleagues Herbst and Scully at Harvard Medical School and Massachusetts General Hospital discussed the cases of these 6 women at scientific conferences but not the conjectured causes.   Meanwhile however, they were collecting informal surveys on DES use. In 1971, the researchers published an article that described the cases and formally stated their belief that DES had caused cancer in these girls.[2] Shortly after NEJM published the study, Herbst took a copy of their paper to other physicians he knew had prescribed the drug. As Herbst recalled in an interview,[3] "They were very upset and gave me all their records to contact people they had given DES to." When it was first published, the article received little attention. But within the following year, increasing numbers of young women had been diagnosed with DES-related cancer, and the issue gained considerable attention.

Women who had been prescribed DES shared stories, organized, protested, and cumulatively became recognized as one of the many interconnected social movements involving women's protests of hormonal medications and their health hazards. As Bell (2009: 18-19) says, "Before 1971, a mother could suggest an explanation for a rare medical condition, but during the old DES regime of practices it was up to her gynecologist to listen to her and to produce knowledge. She could provide a 'clue to etiology,' but only he could provide the scientific explanation for it; he received public recognition, but her contribution was not acknowledged."

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[1] Myers, 1983: 93-100; Bell, 2009: 18-19
[2] Herbst, Ulfedner, & Poskanzer, 1971
[3] Cohen, 2007:118

Scenario 2:

On July 2nd, 2002 UCSF researcher and clinician Mary Beatty[4] met with colleagues in a hotel room at the annual OBGYN conference in Hawaii. She, Rayann, and Nikki[5] were practicing presentations and sharing slides in preparation for their panel on women's health and preventive medicine the next day. Rayann had recently moved to San Francisco to begin work at UCSF, and because Mary and Nikki were unfamiliar with her work, they all agreed that Rayann should be practice first. Shortly into her presentation on estrogen replacement therapy, Nikki interrupted: "You know Rayann, your talk is very pro-hormones. I just heard this morning that the Women's Health Initiative hormone trials have been stopped. I don't know why yet, but I don't think you should present this tomorrow. Or at least, rethink it."

The Women's Health Initiative (WHI), launched in 1991, was the largest clinical research study of health and disease outcomes among postmenopausal women. Mary and Nikki's supervisor, Deborah Grady, [6] was a leading researcher on hormone replacement therapies (HRT) and a frequent commentator of the WHI. She and her research team had privileged to this news.
On July 9th, the National Institute of Health released a press statement: NHLBI Stops Trial of Estrogen Plus Progestin Due to Increased Breast Cancer Risk, Lack of Overall Benefit. The Data and Safety Monitoring Board (DSMB) of the Women's Health Initiative recommended the trials also be stopped due to evidence of higher rates of heart attacks, strokes, and blood clots. Over the next three years, estrogen-progestin prescriptions in the U.S. dropped from 61 to 18 million. Before 2000, incidence of new breast cancer diagnoses in the U.S. had been rising an average of 1.6% per year. From 2003 to 2004, rates of new breast cancer diagnoses in the U.S. fell 6% per year and declined 2% per year through 2006. This cancer decline has been directly attributed to reduced use of HRT.[7]

Scenario 3:

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[4] M. Beattie, personal communication, October 20, 2003.

[5] Names have been changed

[6] Dr. Grady and colleagues designed the Heart and Estrogen/progestin Replacement Study (HERS). Based on the resulting data, they suggested that hormones do not reduce the risk of heart attacks for women (Hulley, et al., 2008).

[7] Ravdin et al., 2007

On November 3rd, 2006, Stacey returned from the grocery store to her Cincinnati apartment and saw she had a phone message from an unidentified caller. The voice message left by Frank Biro, a pediatrician from the University of Cincinnati, contained urgent advice: “If you can, please attend the meeting being held in the cafeteria of your daughter’s school tomorrow at 5 p.m. regarding preliminary findings from the pilot study your daughter has been participating in.” He proceeded to discuss details about the meeting along with contact information.

Stacey’s daughter Nora[8] was participating in a pilot study coordinated through the Breast Cancer and the Environment Research Centers (BCERC). Investigators were studying the links between environmental toxins, early puberty in girls, and breast cancer. If the pilot study proved feasible, additional girls would be recruited for a five-year clinical study from three regions: East Harlem, Oakland, and Cincinnati.

The next day’s meeting was held in the cafeteria of a local public school, where BCERC researchers and women’s health advocates explained to parents that they had detected higher rates of [undisclosed chemical][9] in Nora’s cohort than among girls participating in BCERC’s East Harlem and Oakland branches. “We shared information with the parents,” Biro later reflected in an interview. “We weren’t sure if we should; most researchers probably wouldn’t have. After all, we didn’t know the source of the higher levels or what to do about it, so why tell the parents, some would ask. But the advocates urged us to move forward with the issue and inform the families.”

After this disclosure, parents, advocates, and epidemiologists worked in conjunction with the Center for Disease Control (CDC) and ultimately discovered the community’s drinking water was being contaminated by a Teflon manufacturing plant whose factory was located upstream from the community’s river-fed water supply.[10]

The stories above describe three instances over the past 50 years in which biomedical disclosures on the hazards of ingested hormones have trailed decades behind the lived experiences of women and repercussions from the hormones. Landmark research studies are often conveyed in scientific journals and popular publications as catalysts for new ways of thinking about health, research, medicine, and health policies. However, these portrayals belie the continuous efforts, occasional coincidences, and

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[8] Stacey and Nora are pseudonyms.

[9] I have agreed to keep this information confidential until the results are officially presented.

[10] One or more organization intervened to fix this particular source of water pollution, but I am unaware of how this occurred because it involves unreleased information on legal matters with the manufacturers. More information will become available in 2009 or 2010.

frequently contentious interactions shaping women's health and research. Activists have protested against and at other times become involved with biomedical research. Both approaches are ambivalently pursued and experienced. This is particularly true with estrogenic hormones and compounds, whose uncertain health effects have been a central focus of women's health activism and medical research in the U.S. since the 1930's.

In the first scenario, the 1971 publication on multi-generational health consequences of women who had taken DES occurred along with what Bell describes as a turning point in women's health activism. Unlike the "old regime of medicine" (Bell, 2009: 3; Seaman, 1969), in which health complaints were treated merely as symptoms for medical researchers and clinicians to understand, "new regimes" prioritize the embodied health experiences of women. Patients and communities become recognized as co-producers of knowledge that can test and contest the accuracy of science, thereby changing institutionalized medical science, clinical practices, and federal policies (as this dissertation details in later chapters). The 1971 NEJM article prompted DES sufferers to organize and participate in scientific research on hormones and they did so Bell, 2009).

By the time the WHI began in 1991, women's health research had gained enough prominence and public attention to support the large, government-supported clinical study. As a result of WHI's findings, hundreds of thousands of women stopped filling their HRT prescriptions, thereby reversing what had appeared for half a century to be an unstoppable growth market for hormone replacement therapies. In the third and most recent scenario, the BCERC demonstrates how the institutionalization of collaborative research facilitates participation by lay community members. The discovery of faulty water pipes made visible and spotlighted the lived environments of girls, women, and communities, thus pulling race, class, and urbanization into discussions on the women's health and hormones in more concrete and quite dramatic ways.

> [The researchers] didn't want to report [the PFOA levels] to the parents of the kids, and there was a huge discussion about it. All of a sudden, I felt like I was in a group therapy session. No one was speaking rationally. They finally did it, they told the parents… And, guess what, nobody freaked out. The parents went home, did some research, and found out there were problems with the water pipes where people were dumping chemicals. But, stories like this are very rare (BCERC advocate).

The story of the water pipes in Cincinnati has become a shining success story for BCERC researchers and advocates. It was a case in which activist-scientist collaborations and community participation led to exactly the sort of research findings and community-based interventions that form the ideal-type for this kind of research.

With the rise of collaborative formats of researching on hormones and women's health and the subsequent institutionalization of many of these collaborations, new boundaries become drawn around "what counts" as science and who has authority to claim what poses a health risk and who should be informed about these risks. And yet, there are remarkable consistencies across these stories. In each, communities of women were exposed to hormones for decades without adequate regulatory guidelines on these exposures, despite many organized protests against the deleterious health effects of DES, HRT, and environmental toxins. All the scientists "held their data" until they could state with certainty that the medications and exposures were putting women at risk. BCERC scientists and advocates have still not published results on the Cincinnati story and have convinced eager newspaper journalists to refrain as well.[11]

As some women's health organizations are becoming institutionalized within collaborative scientific research projects in the U.S., how are these new alignments contributing to knowledge about women's hormones, bodies, and health? Also, what bearing do these collaborations and eventual products of the research have on women's health advocacy organizations?

These issues are consequential for women's health at each step of the scientific process, beginning with which scientific research studies are decided upon, pursued, interpreted, reported, coordinated with other groups of scientists and lay persons, translated into clinical settings, turned into policy, and regulated by the Food and Drug Administration (FDA) or Environmental Protection Agency (EPA). Discourses on hormones also reflect and shape views as to which bodies and behaviors are viewed as "normal" at any stage of a highly gendered life course.

WOMEN'S HEALTH RESEARCH AND HORMONAL BODIES

This dissertation analyzes the current era of biomedical knowledge production about hormones, risk, and activist-scientist collaborations in women's health research. Some of my guiding questions include: What brings these particular individuals and groups together and at this time? What is prompting these collaborative relationships and how do their interactive practices shape what has come to be known in regards to hormonal bodies and women's health? How do the legacies of "old regimes" persist within "new science?" How does the explicitly collaborative project design of the

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[11] F. Biro, personal communication, July 21, 2009

BCERC influence the meaning or practices of “community”, “advocate”, and “collaboration”? Aside from the groups specifically enrolled as researchers or participants, what other groups and players are contributing to the knowledge production on hormones and women’s health, and to what degree are these contributions acknowledged by researchers and advocates?

I investigate these issues by reviewing and analyzing historical and medical literature, conducting content analyses of Internet and newspaper publications, and through participant-observations at BCERC meeting and events. Research at the centers was designed to explore environmental causes of breast cancer by researching whether and how environmental exposures lower the age of pubertal onset in girls.[12] Since the 1990’s, the concept of “endocrine disruptors” has gained public prominence through popular trade publications such as Our Stolen Future (Colborn, Dumanoski, & Myers, 1996) and related media coverage. Found in plastics, personal care products, water sources, foods, soil, and other materials, endocrine disrupting chemicals may attach to hormone receptors and result in a “scrambling” of chemical messages, often through mimicking or suppressing existing hormonal processes. With varying levels of certainty, endocrine disruptors have been linked to multiple health problems, including birth defects, learning disabilities, impaired sexual development, early or delayed puberty, and infertility (National Institute of Environmental Health Sciences, 2006). In 1996, the U.S. Food Quality Protection Act was passed, instigating a major screening program for potential endocrine disrupting contaminants (Environmental Protection Agency, 2006).

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[12] Early menarche is considered a prominent risk factor for breast cancer, as I describe in Chapter 4.

Initiated in 2003, BCERC is the first project to study the mechanisms of how environmental exposures might be linked to early pubertal onset and breast cancer risk, rather than merely correlating different data sets. It is also one of the most collaborative medical research projects funded by the NIH to date. The centers operate across 4 sites (centers) in the United States.[13] The centers are not buildings unto themselves but are situated within preexisting research universities and professional advocacy organizations. Each center contains basic scientists, clinical epidemiologists, and advocates as well as a "Communication Outreach Translation Core" - - a group of scientists and advocates who mediate between and are responsible for facilitating communication across disciplines and regions. At 3 of these centers, laboratory and clinical (epidemiological) research are being conducted in tandem, so that each may inform the other and both can converse with the laboratory and clinical research occurring at the other centers.

The advocates, who come from traditions established by DES, breast cancer, and other women's health activists beginning in the 1970's, have been involved from the very earliest stages of the project. They organized planning meetings, wrote the request or proposals, and participated on panels selecting which of many scientific research centers would be funded and incorporated into BCERC. Community advocates and activists also engage in outreach and recruitment as a way of encouraging the transference and application of knowledge between scientific and public audiences. BCERC has explicitly incorporated community activism and collaborations into the very framework. As a consequence of this, members needed to establish methods of communicating across regions and across groups of scientists and advocates. The approaches to doing so are

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[13] UCSF Bay Area, Fox Chase Cancer Center, Michigan State, and University of Cincinnati (bcerc.org).

based on transdisciplinary theories and practices of science and have rapidly become institutionalized and integrated into the very research design (Hiatt, 2009). In this usage, transdisciplinary science refers to collaborative science involving one or more disciplines whose members work to integrate research findings; as a consequence of these experiences, they additionally seek to pioneer approaches to collaborative science (Rosenfield, 1992; Hiatt, personal communication on July 10, 2009). In this way, transdisciplinary science is uniquely reflexive. BCERC then is in some ways an answer to ongoing calls for collaborative research put forth by governmental and private funding agencies. It is also the result of coordinated (and contested) action among activists and researchers.

I have focused on BCERC to describe the multiple events and interactions that comprise hormonal activism and knowledge production in the particular domain of BCERC. The collaborative project and my analysis of it encompass countless perspectives that cumulatively contribute to a much larger story of institutionalized research on hormones and women's health activism in the U.S. today. One result of an increasingly interdisciplinary approach to producing scientific knowledge is a shared focus on variable risks within and across demographic groups. As age has become an increasingly important variable for studying risk, hormonal conceptions of disease causation across the life course have elaborated. This has resulted in intensely biomedicalized discourses vis-à-vis girls, women, and aging. A paradox results: as the format for discussing these issues becomes more open, transparent, and collaborative, the information produced targets ever-narrowing slices of populations according to factors such as age, race, and lifestyle.

In today's era of hormonal research, many activists and scientists share goals of producing research that can be used in the contexts of preventive health. Through their collaborations with others, they contribute to their own disciplines and organizations. New information provokes the need for invested individuals and groups to reevaluate what "prevention" and "women's health" may mean now and in the future. As groups strive to jointly answer these questions, their priorities and identities shift, and new players arrive at the scene to fill in the gaps (or to create gaps to be filled).

THEORETICAL APPROACHES

As a qualitative researcher, the process of finding, selecting, and building upon theories is an ongoing part of the research process. I did not choose certain theories based solely on how stories of women's health activism and hormones could "fit" within a given perspectives, nor did I begin with a set of philosophies and look for empirical examples to build on or challenge what has been written, although I engaged in all these exercises at various points in my data collection and analysis. Until I engaged in several rounds of empirical observations and synthesized my data via interpretive, analytical processes, I was not sure which specific theoretical approaches would speak most loudly to my data, or conversely, would provide the platforms from which I could fully communicate my findings in a way that remained true to my observations and kept my own theoretical contributions in relevant dialogue with predecessors. At an overarching level, I share many of the perspectives discussed by poststructuralist theorizers of health and medicine as well as science studies scholars. Within these realms, I engage in direct conversation with biomedicalization theories, feminist science studies theories on gender and the body, and health social movements, including the growing body of literature on scientific democratization.

Poststructuralist Perspectives on Science and Medicine

The intersection of medicalization, the sociology of knowledge, and science and technology studies comprises a theoretical space that has largely built on and extended the works of Michel Foucault (1926-1984). Perhaps best known for the conceptual links Foucault made between power and knowledge, an equally significant contribution was his notion of fields of discourse as primary and fluid spaces through which people, knowledge, and institutions arise. For Foucault, the discourses of modern medicine constitute objects, in part, through the medical gaze, a scientific vision that looks on, over, and through bodies, perceiving humans and bodies that can be separated into categories of internal and external, dead and alive, normal and deviant (Foucault, 1975). The medical gaze is significant for social scholars of science and medicine not only because it calls attention to an institutionalized and omnipresent modus operandi of control over bodies, but also and renown because we are reminded that bodies themselves are unstable and nonsolid discursive constructs that come to be known through power, practice, and performance. Scientific knowledge circulates prominently in medicine, and Foucault argued that scientific assertions are never disinterested. More accurately, scientists and non-scientists vie for claims to knowledge about health and medicine. The arrangements of power that constitute medical institutions structure and direct which combinations of power and discourses are able to take hold. Poststructuralists attune to possibilities, contradictions, and complex relationships among sets of knowledge, people, and institutions; social processes are fluid and consequential at every moment.

Biomedicalization

Biomedicalization refers to the enacted biomedical and technological and mediations of American medicine since the 1980's (Clarke et al., 2003; 2009). Through the dynamics of processes and products, and interplays of knowledges and technologies, biomedicalization transforms the situation of inquiry. Five interactive processes of biomedicalization include: 1) the growing corporatization and globalization of medical services, products, and their organization; 2) a growing focus on health, risk, and surveillance; 3) increasing technoscientization of biomedicine; 4) changes in knowledge production, organization and distribution and the transformations of knowledge; and 5) transformation of bodies and identities. In contrast to medicalization theories, which emphasize the ways in which western medicine reflects and is built from the cultural values of rationalization, replication, and distribution, biomedicalization seeks to capture the complexities and interconnections of multiple actors and technological regimes, highlighting potentially transformational characteristics of bodies and identities.

Biomedicalization theory builds from a diverse set of sociological perspectives, including Foucauldian and symbolic interactionist traditions. While functionalists or those scholars orientated towards organizational sociology might deliberate inputs and outputs, symbolic interactionists emphasize complexity and the contingent aspects of situations. By this very grasp of social processes, meanings cannot be singular: assorted groups and heterogeneous actors will always be positioned in ways that relate to the unique perspectives held by each, continuous with the near past and impending future. "Embeddedness" and co-constitution are at the very heart of organizational phenomena

(Clarke, 2005). By looking more closely at time-space intersections that are uncertain and in flux, it becomes possible to observe biomedical practices more clearly.

Feminist Science Studies: Gender and the Body

Hess (1997: 1-3) describes STS as a format for interdisciplinary conversations across a wide range of topics and perspectives, wherein scholars convene to build conceptual tool kits for thinking about scientific expertise, science as a social institution, and the philosophy of scientific knowledge. Feminist STS scholars demonstrate ways of recognizing how gendered cultural values and health inequalities become naturalized. By focusing on the interplays of patriarchy, power, and culture, feminist perspectives challenge the view of "science" as a singular entity and instead read contemporary scientific and technological events as inextricable from their social milieux. As different groups intervene within or form alliances across venues of scientific work, the parameters of science are transformed.

Some prominent feminist science studies scholars[14] whose work influences my own include: Donna Haraway (1985), who offered the "cyborg" as a conceptual and political strategy for challenging the dichotomies that perpetuate essentialism in gender and science; Sandra Harding (1986), who pointed to the ways in which the sciences (including the social sciences) have failed to consider the bodies and perspectives of women; Emily Martin (1987; 1997), through her demonstrations of how scientific portrayals of women's bodies and women's experiences of their own bodies are culturally shaped; and Evelyn Fox Keller (1995), who described the area of gender and science as a

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[14] Here, I include a very small sampling of contributions to feminist science studies. This selection is extremely limited, both in regards to the number of individuals I mention as well as which concept/contribution of each scholar I chose to highlight.

"domain of cross talk" that sits on multiple disciplinary borders and rethinks significant beliefs about gender, feminism, women and men, and femininity and masculinity.

In Beyond the Natural Body, Nelly Oudshoorn (1994) described how negotiations in scientific and pharmaceutical settings in the early-to-mid twentieth century led to the idea of sex hormones as biochemical objects. Her archaeology further destabilized notions of sex, gender, and femininity as encapsulated, biological manifestations. By mid-century, what she named the "hormonal body" has become accepted as a natural phenomenon, one of the most powerful and universalized formats for understanding bodies. As sex, sexuality, and gender have acquired biochemical identities, gendered health problems and inequalities are increasingly seen as inherent to the individual. It therefore becomes all the more important to study the social arrangements and networks of practice which construct and maintain such interpretations, which this dissertation does.

Health Social Movements: "Periodization" Studies and the Democratization of Science

In this dissertation, patterns of communication across scientific, scientized activist, and community circles are of central importance, largely because health social movements are communicative events in which spokespersons negotiate actions and debate priorities. Oftentimes, parties involved have to create shared frames of discussion before communication is even feasible (Tesh, 2000). Rather than finding new ways of translating ideas on "risk" from scientists to the community, or "priorities" from the community to scientists, my dissertation research assumes that all participants are actively creating knowledge based on their various priorities, from differing perspectives and contexts of power (Kaufert et al., 1993).

There is a large body of social science literature on the "public understanding of science" which regards the dynamic processes in which biomedical decision-making and interventions shape each other (Bucchi & Neresini, 2007; Henderson & Kitzinger, 1999; Locke, 2001). Phil Brown and colleagues (1992; 2006) speak of "popular epidemiology" to refer to the form of public participation in science wherein laypeople become health advocates and/or researchers in response to health hazards detected in their communities: "Popular epidemiology stems from the legacy of health activism, growing public recognition of problems in science and technology, and the democratic upsurge regarding science policy… Lay and professional approaches to knowledge and action on environmental health risks are structurally divergent" (1992:278). Brown and colleagues significantly assume that conflicts between laypersons and scientists are practically inevitable.

In his 2008 article, "Patient Groups and Health Movements", Epstein argues that science studies scholars are well-suited to provide in-depth, systematic accounts of how social movements develop through critical periods of time, in specific contexts, for brief durations of time. He refers to this analytic approach as "periodization" studies (525) and notes that few scholars have described distinct epochs within a movement. [15] Epstein notes that STS researchers increasingly rely on multiple sites for data collection, and the Internet has become a particularly potent site to investigate patient groups and health movements. On-line data collection might consist of ethnographic observations,

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[15] As an example of a periodization study, Epstein (2008: 525) points to Klawiter's (2004) notion of "disease regimes". In this article, Klawiter describes the sequential events initiated by breast cancer activists and scientists that moved discourses on breast cancer from regimes of "disease" to those of "risk". Garrity (1998) theorized how events can be turning points in enduring controversies.

analyses of list serves, collecting data through surveys, various forms of content analysis and studying how specific websites change over time (507). Some of my data were drawn from websites, and watching their changing content and organizational restructuring over time allowed me to better "see" women's health research as collections of social movements that are continuously being transformed (Bucher, 1962).

RESEARCH METHODS

My dissertation does not pose concrete hypotheses or adhere to concrete courses of action. Instead I engaged in ongoing data collection and analysis focused on elements that illuminated more complex understandings of hormones, women's health, and collaborative science. At each stage in the research process, my data analysis informed the direction and nature of subsequent data collection in classic grounded theory theoretical sampling (Strauss, 1978; Charmaz, 2006). Social worlds theory and methodology also guided my approaches.

Grounded Theory and Social Worlds

Grounded theory methodology is an empirical approach to qualitative research and analysis (Charmaz, 2006; Strauss, 1978, 1987; Strauss & Corbin, 1998; Adele, 2005). In grounded theory practices, data are collected and inductively coded into analytic categories. In order to collect data that achieves this study's three specific aims, a combination of literature and archival searches, interviews, and participant observation approaches will be employed. The social worlds/arenas framework stems from interactionist traditions and serves as a major contribution to science studies of disciplines and controversies. Strauss (1978) and Becker (1982) described social worlds as interactive units who were defined by their shared commitments, resources, and ideologies. As “building blocks of collective action” (Clarke & Star, 2003: 546; Strauss, 1978), multiple social worlds might come to (and comprise) a particular arena of interest. Arenas are meeting places, and topics of concern have complex histories, as do the invested people and groups who comprise a social world (Clarke & Montini, 1993). Studying the boundaries, collaborations, and conflicting perspectives of these social worlds is a useful approach for studying disciplinary formations from a science studies perspective. By investigating the ways in which various social worlds maintain their boundaries and/or claim legitimacy, it becomes possible to illuminate key aspects of a given scientific controversy or negotiation (Clarke & Star, 2008).

All arenas, regardless of size or scope, involve questions about directions of action. To elaborate on the ways multiple perspectives and relations of power constitute and define social processes and understand how medical and scientific concepts become established despite the multiple perspectives of the people involved, individuals and groups must be analyzed in relation to their various positions of power and through interrogations of how that power comes to be concentrated in certain groups. Social worlds perspectives readily support analyses of scientific knowledge-making in areas such as: physiology, reproductive science, abortion, cancer research, heart disease, and cholesterol (Star & Griesemer, 1989; Clarke, 1991, 1998; Clarke and Montini, 1993; Fujimura, 1988; Garrity, 1998).

DATA COLLECTION AND ANALYSIS

The bulk of my data was derived from in-depth qualitative interviews with BCERC researchers and advocates, as well as from attending professional conferences, observing BCERC meetings, and analyzing the BCERC websites.[16] I also conducted a content analysis of newspaper articles published between 2005 and 2008 that discussed endocrine disruptors, early puberty, and breast cancer risk. I drew from peer-review medical journals scholarly and breast cancer advocacy web sites to supplement my other data. Although my data collection process was not linear, most of my data was collected through the following steps:

#1) Archival investigation of toxins and breast cancer.

I gathered information from historical, theoretical, and substantive social science publications that addressed scientific practices and social movements relating to toxins and breast cancer. To understand the perspectives of individuals working for environmental health versus more generally-encompassing health organizations, I reviewed a variety of governmental and agency websites on scientific research and policy measures

#2) Interviews with BCERC researchers, advocates, and officials from the NIH.

I conducted 22 in-person interviews with BCERC researchers and BCERC advocates in the Bay Area (San Francisco, Oakland, and Marin), and then proceeded to interview BCERC members from other regions by telephone.[17] If the interviewee told me that he or she was planning to attend a regional or national BCERC meeting, I also arranged to interview him or her in person at the meeting. All but three interviewees agreed to be "on the record," allowing me to quote them by name. I completed data

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[16] Between 2004 and 2008, the BCERC boasted 64 publications emanating from their research centers. The citations for these articles were posted to their central website (bcerc.org); I scanned all of these and read those which were within my range of reading comprehension.

[17] Appendix A contains a map of BCERC, Appendix B consists of my interview guide, and the chart in Appendix C describes the professional backgrounds of my interview respondents.

collection in December, 2008, with the exception of follow-up conversations with people I previously interviewed. I spoke with 8 of my respondents on multiple occasions.

Most respondents live in or nearby the following 7 hubs: The San Francisco Bay Area, New York City, Philadelphia, Cincinnati, Birmingham, Durham (North Carolina), and East Lansing (Michigan).[18] While all interview participants agreed to be "on the record," a few requested that their responses to certain questions remain anonymous. To ensure this, I have occasionally disguised the identities of interview respondents by not indicating their role in BCERC and/or disguising their profession or regional association; to the best of my ability, I have done so in a way that does maintains congruency with the sentiments contained in a given quote. Interviews were recorded and transcribed by the researcher and uploaded to ATLAS.ti for organizing and managing qualitative data coding.

#3) Participant Observations:

I attended 6 seminars and conferences related to the BCERC project. Some of these contained multiple sessions over multiple days, so this portion of my ethnographic data was drawn from approximately 50 hours of observations, including:

January, 2007: 2-day symposium in San Francisco: Environmental challenges to reproductive health and fertility, sponsored by the Collaborative on Health and the Environment (CHE) and UCSF.

January, 2008: 2 x 3-hours of training seminars held for environmental health educators in San Francisco sponsored by UCSF.

March, 2008: Daylong regional meeting for BCERC in Oakland.

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[18] See http://bcerc.org/links.htm for a complete list of external collaborators and U.S. locations containing working group members.

February, 2008: 2-hour Cygnet meeting in Oakland.

April, 2008: 2-hour Community Outreach Translation Core (COTC) meeting in Marin.

November, 2008: 3 days of meetings at the National BCERC convention in Birmingham.

#4) Analyzed cultural messages and portrayals through media sources.

I conducted searches for articles published between 2005 and 2008 that appeared in The New York Times, The Los Angeles Times, and The Pacific Sun, a newspaper in Marin County. I sought articles that discussed two or more of the following concepts: Environmental estrogens, early puberty, and breast cancer.[19] These searches resulted in 42 articles: 23 from LAT, 14 from NYT, and 5 from Pacific Sun. Beginning January 2008, I also signed up to be included on the monthly email list for Breast Cancer Fund and received hard copies of quarterly newsletters from Zero Breast Cancer. I analyzed these sources and retrieved any references to external articles that mentioned breast cancer in relation to environmental estrogens or early puberty. After collecting these, I had 12 additional articles written between 2001 and June 2008. My eventual collection consisted of 54 articles, which I loaded into ATLAS.ti to perform content analyses.

My data analysis consisted of spatially situating, or "mapping" the ways in which knowledge was created and communicated across disciplinary, geographic, and lay/scientific divides, and then assessing the implications for women's health, biomedical expertise, and future forms of research organization and sponsorship. I analyzed the discourses emanating from interviews, observations, and written text as a way of conceptually tracing that links between social practices, scientific knowledge, as the cumulative transformations of "regimes of truth" (Foucault, 1972). To analyze the

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[19] See Appendix E for information on content analysis search terms, a list of articles in my sample, and the codes.

heterogeneous actors, processes, and histories, I attended to how actors and events positioned themselves and/or were positioned by others as a way to "characterize the situation of inquiry" (Clarke, 2005: xxii). This analytic work was useful for finding points of silence within my data and was effective for thinking through the discourses that have comprised hormones and women's health.

CHAPTER 2:

In this chapter 2, I historicize women's health activism movements that have arisen around hormones and describe the ambivalence among women's advocacy groups towards hormones and biomedicalization. I begin by providing a brief overview of the emergence and marketing of sex hormones in the late 19th and early 20th centuries. Scientific researchers and women's health activism around estrogen have always been in conversation in the United States. At times, the relationships have been quite antagonistic, and at times, they have been so closely aligned that the boundaries between the two were indiscernible. To elucidate this point, I summarize women's health activism around hormones, tracing it from DES concerns originating in the 1930's, through the women's health movement in the 1970's during which key feminist activists and physicians advocated a cautious attitude towards DES, HRT, and Tamoxifen, into the breast cancer activism that burgeoned in the 1990's, and the recent relationship between breast cancer and environmental activism that has led to a focus on prevalence of environmental hormones and the "endocrine disrupting compound hypothesis".

In addition to detailing the DES and HRT controversies and activism, Chapter 2 discusses how breast cancer activism in the U.S. led to the institutional mandates at the NIH that activists participate on scientific research panels. This set a new precedent for women's health activism, collaborative research in health and clinical research designs more broadly. In 2002, the abrupt termination of the progestin-estrogen HRT trials of the Women's Health Initiative (WHI) provoked further discussions of the importance of how research on hormones and women's health is structured and implemented from the planning stages. When the HRT trials were prematurely canceled due to unacceptable levels of health risk, activists, researchers, and U.S. consumers amplified discussions of the profit-driven incentives of hormone manufacturers, calling into question the supposedly unbiased research studies which had long concluded that hormone therapies were safe and health-promoting. Debates continue about the results of the WHI regarding whether HRT is a protective or detrimental option. At the same time, there emerged a general agreement that health risks due to estrogen exposures need to be studied across different stages of women's life course. Specifically, pre-menopausal, menopausal, and post-menopausal stages should be more carefully defined and women's health should be researched in age-specific ways. The WHI also brought widespread attention to the risks associated with ingested estrogens and demonstrated the importance of researching older women's health, which coincided with the turn towards studying increasingly specific age groups. Those who endorsed the precautionary position (we should be wary of all xenoestrogens until proven safe) and those standing by the certainty position (we do not have solid proof that xenoestrogens are dangerous) were both somewhat in agreement that xenoestrogens might be dangerous to certain age groups but not others.

I conclude by explaining the conciliatory, though still shaky appeasement of what had been antagonistic positions among scientists, governmental organizations, and women's health activists. In some instances, scientists and "lay" women's health activists are now working together in government agencies and in research universities, but many women's health activists, both those who are positioned within these collaborative groups as well as those who have remained separate) are ambivalent about collaborating with biomedical institutions. I end chapter 2 by briefly introducing the Breast Cancer Environmental Research Centers (BCERC) as a prime site where these historically entrenched, traditionally antagonistic positions are being institutionally reconciled through new forms of collaborative research, hence the focus of this project.

CHAPTER 3:

Chapter 3 describes the series of meetings and negotiations that resulted in the BCERC. It is a story of collaborations. Drawing from interview data, I relay how BCERC researchers and advocates conceptualize the organizational and ideological components of "collaborations" and "collaborating" and the structural barriers and power imbalances that prevented full communication across groups. Despite agreements among interviewees that communication and cooperation are needed in medical research, some viewed "collaboration" as a strategic term utilized to promote the BCERC centers, rather than as a means of producing integrated research results. Indeed, some interviewees understood BCERC's central hypothesis as an interrogation of collaboration itself (Can it work? Did it? How?). All twenty-one respondents agreed that collaboration was an area of interest regardless of the content of the research being produced, though the attitudes about this statement varied considerably.

Through interviews, advocates conveyed views on their contributions to the research, describing the strategic use of the term "advocate" rather than "activist", which they see as reflecting a movement away from grassroots activism and towards professionalization and institutional legitimacy. Some advocates continue to press for more research on the direct links between toxic exposures and breast cancer, while yet others have used concern with xenoestrogens as an opportunity to raise awareness about and politicize prescription practices regarding all hormonal medications (such as oral contraceptives and hormone replacement therapies).

I also interviewed scientists about advocate contributors to the BCERC and describe a few encounters I observed at meetings and conferences that demonstrate how researchers and advocates position themselves in relation to one another. The "implicated actors" (Clarke & Montini, 1993; Clarke, 2005) most commonly referenced in this study but who were not present were the regulators. I have several examples from interview data and observations at meetings where people expressed frustration about not having representatives from oversight organizations, especially the EPA and FDA.

However, the true phantom of this study is the "community." They are discursively present, which makes their physical invisibility striking, especially since so much of this study is geared towards translating findings from scientific research to "the community". To draw out these observations and my analyses of them, I turn to Reardon's (2001; 2004; 2007) notions of "democratization in biopolitics." She argues that the incorporation and politicization of lay persons within controversial scientific research may actually depoliticizes many issues, because it can create a false distinction between science-as-neutral and community-as-political. Reardon (2007: 254) argues: "If we seek to build a science that better serves human ends, then it is not enough to understand how human concerns and interests shape scientific ideas and practices. We must also understand how scientific ideas and practices help form a people with common concerns and interests." This distinction between scientists and community members, she asserts, protects scientists from having to take responsibility for ethical and political decisions. It also erases the ways in which many decisions are internal and intrinsic to scientific practices and have little to do with lay input, regardless of "presences."

CHAPTER 4:

In Chapter 4, I focus my analysis around the question: Why are BCERC scientists studying the falling age of puberty in girls as a means of researching breast cancer prevention? To show how these hypotheses developed, I reference influential research findings published in medical journals beginning in the 1920's. Other sources of data for this chapter are interviews with BCERC researchers and my observations at clinical epidemiology meetings. I show how the growing imperative in medical research to synthesize research across multiple perspectives has pushed life course research to the foreground along with elaborations of "windows of vulnerability" theories. The windows of vulnerability hypothesis states that bodies are more susceptible to changes in the structural and chemical environment during certain life stages. Here, I analyze the scientific content of research being produced among those trying to understand how and under which conditions estrogen and environmental toxins raise the likelihood of breast cancer at which life stages.

Some BCERC interviewees told me that the focus on puberty, including interrogations on the lowering age of puberty in girls and whether puberty is a window of vulnerability for breast cancer risk, was chosen because it held widespread appeal for advocates, researchers, and public supporters. The topic had the potential to "Motivate the largest number of people to get involved" (BCERC advocate), and it was a research focus many people could agree on. It coincided with the importance of early life, or "upstream" prevention efforts, which many advocates promoted. It is an understudied topic, which appealed to basic scientists. And it sets the stage for a possible long-term, longitudinal clinical study following the girls for life, which appealed to epidemiologists and government officials. Controversies arose between epidemiologists (including clinical researchers), basic scientists, and activists about how to define "the environment", provoking a need to reexamine the boundaries that distinguish what is "internal" and "external" to the body. In BCERC, the epidemiologists are looked to as the gatekeepers to the research results, because they have access to the full gamut of "cells to society" data and tend to present the research in language that is more accessible than that of the basic scientists. At the same time, BCERC advocates expressed the most frustration with the epidemiologists and epidemiological methodologies, accusing them of "holding their data" and "taking too long" to report findings.

I end the chapter by highlighting the difficulties BCERC researchers have run into as a consequence of studying exposures at puberty and breast cancer risk. Because there is little standardized research on which exposures are toxic and because there is a paucity of national data on what constitutes "normal" pubertal development, BCERC researchers struggle to find the mere words to discuss puberty in the contexts of eventual women's health, let alone measure or correlate it to outcomes or understand the racial and ethnic variations of development. Puberty is a moving target, defined by change and development. So much uncertainty circulates about risk and origins of risk, and the flexible concepts of "window" and "vulnerability" can theoretically accommodates unknowns about exposures, outcomes, and variability between populations. In-utero development, infancy, and pregnancy have all been conceived as windows of vulnerability. In BCERC, studies on puberty, exposure, and breast cancer risk take center stage.

CHAPTER 5:

This chapter turns to the clinical and cultural venues that present puberty in girls (particularly early puberty and precocious puberty and early puberty) as a period of vulnerability both to environmental exposures and to risk for health problems later in life, including breast cancer. The data from this chapter is based on my content analysis of newspaper articles. I probe the ongoing significance of the hormonal body and demonstrate how managing the hormonal body is framed and practiced not merely as gendering due to sex hormones. Rather it has become a gendered duty to manage the hormonal bodies of family members. In this chapter, I turn my focus to the recent concerns about the life stage of puberty in girls as a risky time both for breast cancer susceptibility and socio-culturally. I also discuss the implications for responsibility, biomedicalization of women's health across the life course, and how this relates to heightened attention on the family unit as a unit of responsibility, control, and risk management.

The expectations for research and how it should be structured (how large, how diverse, the duration of the research, the number of questions a research question should seek to answer) do not wholly precede research but are produced through its practices. Hormonal models of bodies and danger persistently impact understandings of selves and especially of gendered selves, despite – or, perhaps because of – the uncertainties about emerging hypotheses of hormonal mechanisms of action, including the endocrine disrupting compound (EDC) hypothesis. Breast cancer researchers and activists have been paramount in pushing all three of these practices - collaboration, integration, and research on hormones – into more vivid investigative focus. So, it follows that breast cancer would be the research topic that has drawn together one of the most explicitly collaborative research projects to-date.

CHAPTER 2: WOMEN'S HEALTH ACTIVISM AND HORMONES: FROM DES TO EDC's

Since the endocrinological paradigm gained momentum in the early 20th century, hormones have served as powerful elements of gender, health, and disease, shaping discourses and technologies designed to mediate gender and aging and improve women's health. In this chapter, I describe some of the key events in the scientific knowledge production of sex hormones in the U.S. within the larger histories of the medicalization of women's health as well as the array of feminist responses that has been generated. I argue that women's health activism around hormones can cumulatively be read as stories of ambivalence: individual women have long grappled with choices about whether to refill their prescriptions for oral contraceptives, HRT, and other medications, and these struggles are wound up within larger conflicts about whether and when women align themselves western biomedical models of health and bodies. At the group level, the feminist organizers and breast cancer activists who gained prominence in the 1970's continue to disagree about whether the growing bodies of mainstream women's health research projects (such as the Women's Health Initiative and collaborative science) should be embraced as a feminist causes. Among the women's health activists who have worked to raise consciousness about the health hazards of ingested hormonal medications, an added layer of uncertainty and ambiguity has arisen with recent research on environmentally-derived endocrine disrupting compounds (EDCs), which pose health risks that are similar to hormonal medications but are much harder to single out and identify; unlike the manufacturers who intentionally suppressed research data on and continued to market hormonal medications, EDC's are not the direct, clear-cut result of sexist medicine. And yet, they are every bit as consequential to understandings of gender and to the health of communities of girls and women.

The interplay of biomedicine and women's health activism has centered around topics and debates relevant to health priorities taking center stage within particular decades, based on actions of both formal and informal interest groups. Activist involvement has ranged from protests against medical treatments, to separatist and alternative movements in health care, strategic participation by women's health activists within major biomedical research projects, and direct cooperation with scientific researchers. There is a long history of antagonism between those who perpetuate views on the need for supplemental hormones as a way of regulating gender, age, and behavior, and those pointing to the multiple dangers of both intentional and unintentional exposures to estrogenic products.

The production of scientific knowledge about hormones and medical treatments to diagnose, remedy, prevent "diseases", or normalize women's health across the life course have been constituted through complex interactions among invested social worlds that include scientists, activists, manufacturers, medical professionals, and other institutional and grassroots organizations and organizational leaders. More often than not, the boundaries between these social worlds have over recent decades become blurry, evidenced by the number of people and groups who identify as both scientific and activist, or scientific and manufacturing, etc. Yet, the overall patterns of negotiations and conflict have unfolded through series of events that are retrospectively observable as somewhat distinct (though overlapping and heterogeneous) epochs in women's health science and activism around hormones.

Here I address the history of what came to be called "hormones" in scientific and medical thought since the mid-19th-century, the introduction of and controversies around diethylstilbestrol (DES), the renaissance of the U.S. women's health movement in the 1970's, breast cancer movements and their ties to environmental health, controversies surrounding findings from the Women's Health Initiative, and growing concerns among researchers and activists about environmental estrogens. Women's health research, and breast cancer research in particular, has set a precedent for activist/scientist partnership in ways that are both public and often implemented at the outset of research projects. Over time and in more arenas, collaborative science has gained appeal and is understood by many as a new "gold standard" for clinical research.

I conclude with a discussion of the breast cancer environmental research centers (BCERC), the NIH-funded activist/scientist research project that is activist-initiated and transdisciplinary. It is a product of ongoing, cumulative events that have rolled into one collaborative stream of research on women's health and hormones to investigate the influence of environmental exposures, hormones, and other risk factors, testing the hypothesis that girls at puberty are passing through a 'window of vulnerability' of increased susceptibility to environmental exposures and health problems (including breast cancer) later in life.

THE POTENCY OF SEX HORMONES: CHEMICAL MODELS OF BODIES AND POISONOUS MEDICINE

The identification of sex hormones and coinciding marketing of hormonally-based medications and injections to ease symptoms and manipulate bodies of men and women has provoked controversies that sustained the 20th century, taking new shape as different drugs and players entered the arena. The intersection of agricultural research and clinical applications formed the basis for much of early scientific and clinical research on substances subsequently named hormones. Scientific discourses during the latter half of the 19th-century were built upon a growing fascination with sex gland secretions (Clarke, 1998); animal research formed the basis for much of the early scientific and clinical endeavors. Between1850 and 1920, some physicians in Europe, Australia, and the U.S. sought therapeutic uses of internal secretions, proclaiming remarkable "rejuvenation" benefits from injecting animal testes extractions into male humans (Clarke, 1998; Hamilton, 1986; Borrell, 1978; 1985). In 1905, British researchers Ernest Starling and William Bayliss introduced the term hormone into scientific use (Borrell, 1976). When Edward Doisy reported that he had isolated the crystalline estrogenic hormone in 1929, his news was well-received (Watkins, 2007).

Once sex hormones had been singled out and named, numerous subcategories of sex hormones were identified over the next 10 years, including estradiol, estrone, progesterone, testosterone, and androstenedione (Freeman et al., 2001), and although all these substances were found in blood samples of women and men, scientists categorized them as "female" (estradiol, estrone, progesterone) and "male" (testosterone, androstenedione) according to whether each compound had "feminizing" versus "masculinizing" effects. The gendering of sex hormones enabled the hormonalizing of gender, wherein behavioral differences between women and men could be ascribed to specific sex hormones.

From a social constructionist science studies perspective, hormones are both materially and socially produced, and so they never have been nor ever could be the "known" objective, predictable, chemical messengers that they have been deemed throughout much of 20th-century scientific and cultural thought (Oudshoorn, 1994). Regardless, this chemical model of sex revolutionized scientific and popular beliefs about bodies and behaviors. As had been the case with anatomical theories of gender differences that dominated scientific thought in earlier decades, hormones were now thought to be responsible for visible differences between the sexes and provided explanations for gendered behaviors, masculinity and femininity, and a range of social phenomena that could be linked to observable differences among bodily forms.

Meanwhile, hormones (sex and otherwise) were entering scientific and popular language, thereby contributing to a chemical model of human bodies and behavior. With the rise of hormonal thinking, sex and gender were also thought to stem from within the body at cellular and biochemical levels. Through the activities of scientists, pharmaceutical manufacturers, physicians, and other invested actors, the hormonal body became accepted as a "natural phenomenon". Even in the current biomedical boom of genetics, genomics, and gene-environment interactions, the hormonal body – and gendered hormonal body in particular – persists as one of the most powerful frameworks for understanding bodies, [1] partly due to its having been made accessible to non-scientists (Oudshoorn, 1994).

In Disciplining Reproduction, Clarke (1998) lays out the major social worlds that contributed to the early formation of the reproductive sciences, including reproductive endocrinology (the biochemical study of sex hormones). From 1925 until 1940 in the United States, a growing number of research projects on reproduction were forming a discipline that was beginning to coalesce around endocrinology. Reproductive endocrinology, with its links to the prestigious field of biochemistry, became the privileged wing of the reproductive sciences during this era. Thus, the ability of leaders representing other related professional social worlds (including sexologists, contraception advocates, and gynecologists) to garner legitimacy depended on their ability to align with reproductive endocrinology, and biochemistry.

For knowledge claims to be accepted as natural facts, they must be introduced within receptive situations (Fleck, 1935). Like Clarke, Oudshoorn (1994) argues that research on sex hormones emerged through efforts by many powerful groups and individuals who were furthering their professional, political, and intellectual objectives. Focusing on the development of hormones in The Netherlands, she found that laboratory scientists created alliances with gynecologists, who had access to ample research materials (ovaries and urine) and test subjects (female patients). In turn, gynecologists gained access to expert knowledge and could increase their professional prestige and legitimacy. Pharmaceutical companies were able to purchase and refine large quantities of raw material from gynecologists and provide laboratory scientists with a constant

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[1] The immune system and chromosomal genetic models for human health and behavior are two other powerful paradigms.

supply of requisite experimental materials. In exchange they generated formulas for the manufacturing of hormonal treatments. These interdependencies were created based on differential access to and needs for materials, money, and prestige. All of the negotiations relied on shared understandings of estrogen and testosterone as material substances.

The concept of sex hormones was successful because it could be used to explain gendered behaviors and gendered health in causal ways congruent not only with biomedical but also with social and cultural expectations (Oudshoorn, 1994). Female sex hormones, especially estrogen, were of course linked to "female diseases" with alacrity.[2] Preexisting institutions and networks for monitoring and intervening in women's health were able to be quickly pulled into play through the designation of female sex hormones.[3] Sex, sexuality, and gender acquired chemical identities, and behaviors could be linked back to chemical releases or shortages of estrogen and testosterone, thus reinscribing sex roles and sexism within the neutral scientific landscape of hormone-laden blood streams.

In 1938, Edward Charles Dodds and his colleagues introduced a synthetic estrogen, stilbestrol, first to scientists and physicians. Diethylstilbestrol (DES) was invented in 1938 and released for sale in 1941 as the first widely distributed synthetic estrogen in the United States, although it was never patented (Bell, 1994: 42). The Federal Food, Drug, and Cosmetic Act, also passed in 1938, required evidence that a drug

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[2] When male animals (e.g. stallions) were found to produce estrogenic hormones, there was some questioning of the thoroughly sexed/gendered hormonal nomenclature. However, one of the major reproductive scientists of the era, Frank Lillie, insisted that the "traditional" sexual division of hormones remain in place (Clarke, 1998: 80-82).

[3] This asymmetry has cultural and organizational roots. For instance, there are far fewer specialists and health clinics that attend specifically to men's sexual and reproductive health in comparison to gynecology and obstetrics, which are ubiquitous. This limits the most immediate steps of conducting scientific research, such as obtaining research subjects and specimens.

be safe before entering the market, which resulted in a great deal of clinical and agricultural research on DES.

By the 1950's, DES was also being used as a food additive for fattening beef cattle in the feedlots at the slaughterhouses just prior to their sale. The original research on weight gain in cattle occurred at Iowa State University, demonstrating that DES increased cattle growth both by accelerating appetite and by increasing the ratio of weight gain per quantity of cattle feed (Clarke, 1998: 160-162). Its use dramatically increased profits. From the outset, some researchers were concerned about the drug's probable carcinogenic effects on animals.

The first attempt at a human study had to be discontinued because two thirds of the women dropped out due to pain, nausea, and vomiting. When called upon by the FDA to explain these severe reactions, clinical researchers suggested that the afflicted women were either neurotic or experiencing nausea and vomiting due to menopause (Bell, 1995). The clinical researchers who were promoting DES during these years held prestigious positions in teaching hospitals and medical and health policy venues. Their confident assessments of the safety of DES greatly influenced the FDA's decision to approve the drug. DES was then used to treat various conditions associated with "estrogen dysfunction", including menopause and for preventing miscarriage (Bell, 1994: 42; Bell, 2009: 16-17; Watkins, 2007). [4]

The FDA approved DES for preventing pregnancy loss until 1971 and for fattening cattle until 1976, but the drug was never banned in the United States (Clarke,

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[4] From the 1920's-1950's, clinicians, pharmaceutical entrepreneurs, and some activists for contraceptives supported hormonal research, the development of hormone therapies, and subsequent hormonal testing that eventually led to the FDA approval of oral contraceptives in 1960. Many of the techniques enabling the production and marketing of synthetic hormones had been established by the development and release of DES three decades earlier (Krimsky, 2000; Bell, 2009).

1998: 160). It is estimated that between 1938-1971, 10 million people were exposed to DES, with resulting cases of cancer, autoimmune disorders, infertility, and neurological disorders. Current research projects are investigating health effects among the children and grandchildren of women who were given DES (http://www.desaction.org). The effects of DES in cattle feed remain under explored. Clarke (1998: 246) describes how the FDA's decision to withdraw approval for the use of DES in feedlots did not stop the use of DES implants in cattle. Concern by consumers added to the DES controversies and bolstered the views held by some breast cancer activists that rising rates of breast cancer in the U.S. might be linked to "additives such as DES in meats and other foods" (Clarke, 1998: 246). The influence of DES cuts across time and domains: The drug has crucially defined FDA guidelines, pharmaceutical industry procedures, and the food industry. "The transformation of DES from wonder drug to cause of the first known human occurrence of transplanted carcinogenesis, from live-stock-fattener to suspected cause of premature sexual development in children under ten who eat meat, is a story of 'reluctant regulation'" (Clarke, 1990:35).

More recently, the drug's chemical structure and systemic effects on bodies have provided a model for those researching endocrine disrupting compounds, described in more detail below. The history of sex hormones in the realm of women's health activism is highly consequential, because hormonal models of bodies naturalize sex and sexism. Furthermore, prescriptions of hormones such as DES have severe and lasting health consequences. The following section describes key organizations, activists, and scholars who launched and contributed to women's health activism around, and critiques of, hormonal medications.

WOMEN'S HEALTH ACTIVISM AND HORMONES

The women's health movement has been described as a "megamovement" by Weisman (1998:30) to highlight the multiple groups and waves of movements that it has entailed. The wave of women activists of the 1970's were able to galvanize a movement towards gender equity by publicly drawing attention to sexism and the both inadequate and sexist medical responses to women's health needs. Using two main strategies, educational and policy outreach and grassroots clinics and organizations, feminist activists of this era became primary players in changing public consciousness about women's health (Worcester & Whately, 1992).

The success of the U.S. women's health movement has been largely due to the integration of agenda-setting and philosophy, and analysis and activism, much of which has been prompted by concerns about the medicalization of women's health in general and the burgeoning prescriptions of synthetic hormones given to women for a variety of conditions, many of which lent to and reinforced the narrow, sexist expectations that women should place extreme importance on normalizing menstrual cycles and prolonging youth and fertility. Activists initially focused on health concerns of women of child-bearing ages, which were demonstrated by their mobilizing around causes such as improved gynecological services, contraception, safe abortion, and women-centered childbirth. The health concerns of other age groups, such as teenagers, middle-aged women, and elderly women, were less frequently articulated or addressed. As Riessman (1983: 3) describes it, these activists "identified the sexual politics embedded in conceptions of sickness and beliefs about appropriate care," and "provided the analytic basis for a social movement that has as its primary goal the reclaiming of knowledge about and control over women's bodies."

The 1970 edition of Our Bodies, Ourselves by the Boston Women's Health Book Collective (BWHBC) was an important marker for the beginning of second wave feminism in women's health and the related growth of feminist health organizations (Clarke, 1998). This guide changed public consciousness by stressing the importance of defining health within its broader contexts, thus allowing for discussions of the importance of preventative health as well as the social structures, communities, and interactions that shape the ways that women's experiences coincide and differ across various communities and settings, characteristic feminist health organizations including women's health centers, women's health policy organizations, and women's health researchers and clinical professionals. After the 1970's, women's self-help groups and clinics proliferated, many of which were modeled after organizations like the Feminist Women's Health Centers.

Feminist health researcher and activist Barbara Seaman (1969; 1978; 2003) ignited conversations on the under-researched dangers of oral contraceptives as well as the political and physiological risks of long-term menopausal hormone regimens, HRT. She was a cofounder of the National Women's Health Network (NWHN) along with Alice Wolfson and Belita Cowan, women's health education and policy organization based in Washington DC and still active today. The National Women's Health Network, (NWHN) was developed as a consciousness-raising organization in 1975 with a central goal of working to influence U.S. political decisions concerning women's health (Narrigan et al., 1997: 551). Currently, NWHN states its mission to "improve the health of all women by developing and promoting a critical analysis of health issues in order to affect policy and support consumer decision-making. The Network aspires to a health care system that is guided by social justice and reflects the needs of diverse women." Their long-term goals are to:

1) Ensure that women "have self-determination in all aspects of their reproductive and sexual health."
2) Create a "cultural and medical shift in how menopause is perceived and addressed."
3) Establish "universal access to health care."

Continuing in the tradition of Barbara Seaman and other founders, NWHN also describes its intention to "shape policy and consumer health decisions and options by developing and promoting a critical analysis of health issues" by monitoring "the actions of federal regulatory and funding agencies, industry and the health professions, identifies abuses and makes change by exposing the abuse and catalyzing grassroots action" ("About NWHN," 2008). The NWHN and OBOS, as major feminist organizations, have been major disseminators of information on women's health and encouraged feminist political activism on a number of issues.

One of the early successful movement strategies among leaders of the NWHN was to generate patient package inserts (PPI) for birth control pills and HRT. They organized a protest that occurred December, 1975, to coincide with Congressional hearings on DES and FDA meetings on whether to mandate PPI's for menopausal hormones. The activists' protests at the FDA instead of focusing on pharmaceutical manufacturers or the AMA was novel, as was the decision to link the protests with a memorial service for Donna Jean Walter, who was the late wife of activist Jim Luggen; Donna had died of pulmonary embolism due to the birth control pill. It all occurred on the steps of the FDA and was described as a memorial service for every woman who had died from DES, the pill, or estrogen replacement therapies (ERT). Many activists spoke at the event, including DES daughter Sherry Leibowitz. In response to the protest, the FDA began the process of requiring patient package inserts for HRT in 1975 and began enforcing this new policy in 1977 (Berglas, 1995).

In addition to organized women's health policy work and direct activism, a number of feminist scholars of women's health began to address the broader issues of health and medicine. For example, Ruzek, Clarke, and Olesen (1997) discuss the importance of continuously refining models and understandings of the terms health and women's health. One goal is to call into question biomedical models of health which frequently perpetuate philosophies of mind-body dualism, physical reductionism, and individualism, and discuss health and illness through linear processes of cause-and-effect, often incorporating metaphors of industry, warfare, and body as nation-state. In contrast, feminist models place women centrally when setting priorities and conducting analyses. Here, analytic models challenge and complicate the philosophies that underlie western views of health and bodies and thus make visible some of the ways in which biomedical discourse is not only limiting, but also serves to reflect and perpetuate larger patterns of oppression through upholding values of individualism, competition, and hierarchies. These values are especially detrimental to low-income women and communities, who are institutionally excluded from, and implicitly blamed for, health problems. However, feminist activism against discrimination in health is not a simple task, because biomedicine and its strategies continuously change shape; similarly, women's health needs are never monolithic and change as well. The past thirty years of feminist health activism has broadened the scope of feminist health concerns, including diverse groups of women and diverse health issues. Health experiences and health needs differ drastically according to race, ethnicity, socioeconomic status, sexual orientation, place of origin, age, and urban versus rural environments.

In Sherwin's (1998) edited volume: The politics of women's health: Exploring agency and autonomy, the authors problematize the usage of women's health agency and autonomy. In their usage, "agency" refers to culturally pervasive understandings of informed choice and free will, while "autonomy" points to "a more comprehensive notion of freedom where not only is the immediate choice uncoerced but the circumstances that structure that choice are also free of the coercive dimension of oppression" (12). Sherwin argues that even though autonomy better captures the freedom to manage one's health (whereas agency implies selecting among available options), "autonomy" is problematic because it implies a separatist/outsider position (25). To go beyond the agency versus autonomy understandings of women's health empowerment, like Ruzek and colleagues, she proposes a relational theory, which understands that individuals make choices and act "within a configuration of relationships, both interpersonal and political" (35). The work of the following feminist scholars demonstrates such subtleties and appreciation for the complex situations and ambivalent attitudes that co-construct women's attitudes towards hormonal medications and bodies.

Canadian Patricia Kaufert (1982) was among the first feminist social scientists to discuss hormones and age from the perspective of a feminist sociologist of health and medicine. She analyzed the issues within the context of the North American women's health movement, heeding the discrepancies between medical and feminist perspectives on menopause. Her observations captured struggles and negotiations surrounding whose knowledge and practices provide appropriate interpretations of women's bodies and whether menstruation, childbirth, and menopause warranted medical interventions and, if so, under which circumstances. The mythologies of aging, she noted, inform both medical and feminist perspectives of aging. As a consequence of some of the polarized convictions among medical professionals and feminists in regards to women's health across the life course, new mythologies are also constructed. According to Kaufert, most of the fears of menopause voiced by her interviewees pointed to negative perceptions of aging itself. Across the spectrum of medical professionals and feminists, concerns were voiced about both over and under involvement of practitioners in the realm of health and aging. Conflicts manifested as to what constitutes an adequate response by clinicians.

Virginia Olesen (1982) also investigated feminist versus medical models of menopause, arguing for more critical and complex feminist analyses of estrogen replacement therapy rather than a knee-jerk version of over-medicalization. All too often, she writes, feminists condemn women users, implying that they are choosing: 1) vanity over health; 2) immediate comfort over long-term solutions; and 3) their individual needs over those of society. Instead, Olesen spotlighted the social structures shaping women's circumstances and needs for hormones. Olesen reframed the issues in light of prevailing attitudes towards aging: "The psychological experience of loss of youthfulness for some menopausal women may constitute not only discomfort but also suffering. For these women, estrogen replacement is more than cultural management, it is indeed 'therapy'"

(353). By acknowledging that there are very real and consequential social structures provoking some HRT users to risk their health and conform to sexist guidelines, feminists and social scientists are better situated to make decisions that are conducive to women's empowerment and more apt to recognize the complexity of medicalization.

McCrea (1983) built on Kaufert's research by analyzing the institutionalized medical myths of aging as vehicles of social control. In one research project McCrea described the ways in which medical scientists, practitioners, and sources of medical knowledge more generally perpetuate the view that women's physical and mental capabilities depend on the functioning of their reproductive organs (117).

McCrea and Markle (1984) expanded the critique of institutionalized medicine by comparing the differences between US and UK prescription practices of ERT. The scholars investigated how controversies surrounding ERT developed in the US and in the UK within communities of physicians, feminists, consumers, regulatory bodies, and consumer groups. Their research points to striking differences between the two countries: in the US, the pharmaceutical- driven medical-industrial complex has provoked feminist criticism of over-medicalization in the face of health risks; in the UK, government-run medicine is more regulated and cautious, which has provoked feminist outcries about the lack of access to ERT. British family practice focuses on health, coping, and everyday working situations, whereas the drive in American medicine is to diagnose and treat illness (17).

Their analyses highlight how group alignment shapes controversies. "Alignment often comes first, and only then does the new partisan construct a rationale for the alignment" (15). McCrea and Markle argue that sexual politics and group alignment not only precede scientific findings, but alliances often enable particular sets of opinions and attitudes about women's health concerns. In the case of ERT, they note that the feminists' opposition to dominant medical organizations is what mobilizes the push towards better women's health rather than articulating a committed stance against the medication. Struggles involve competing definitions of menopause, and in each country, biomedicine is criticized for attempts to define women's physical and psychological needs. In the US, feminist counteract the stigma of menopause by normalizing the life stage and event, while feminists in the UK demand sensitivity and services for menopause. The US and British women's movements have developed along different ideological and political lines, accounting for differing positions. "Given the differences between the US and Great Britain" the authors show how "the ERT controversy cannot be explained through the traditional ideology of scientific universalism" (18). Group positions on medical controversies are the outcomes of political, ideological, and economic relations, although they also contribute to the ways that knowledges unfold and are accepted or rejected.

At the time when Kaufert, McCrea, and Markle were offering social commentaries on women's health in western medicine, heath activists were disrupting institutions and sexist practices of women's health. The written works of scholars such as Kaufert and McCrea documented a period in which the momentum of sexism and medically-sanctioned sexism came into conflict with feminists and other women's health activists. The interactions of power, myths, and priorities led to new visions of health and social justice. Feminist activism was changing institutionalized medical knowledge in publicly visible contexts and setting new precedents.

More recently, in a case study of online support groups for menopause, Goldstein (2000) argues that the Internet provides a space where women can form intimate support groups despite geographical divides. In this process, they create their own medical cultures and vernaculars that, on the one hand, endorse medicalized understandings of menopause, while on the other hand is empowering because the women regard themselves and each other as experts on their own health (313). Though discussions among members in these online forums framed menopause similarly to medical models of menopause as hormonal deficiency, the conversations are "experience-centered, beginning with the shared observations of sufferers and moving out to include relevant research" (314). Empowerment was viewed as possible due to the absence of medical authorities in the chat groups, the high-levels of interest and motivation among many of the women who create the groups, and the primacy of lay experiences and "local" discourses (315).

In addition to DES and HRT, other hormonally-related medications have targeted women. At times, ideologies of breast cancer prevention have been co-opted by medical industries. The medication Tamoxifen has been researched and prescribed in ways that demonstrate this dynamic. Tamoxifen is a selective estrogen receptor modulator, which means it blocks estrogenic activity in some tissues (including breast tissue), but acts as an estrogen in other regions (such as the endometrium). Its anti-estrogenic effects in breast tissue have led to use of the drug for preventing estrogen-receptor positive versions of breast cancer. However, the American Cancer Society and World Health Organization classify Tamoxifen as a known carcinogen due to its role in provoking endometrial cancer ("Known and Probable Carcinogens", 2008). Tamoxifen also increases the incidence of life-threatening clots in the lungs and major veins (Fosket, 2004: 292).

In 1997, Raloxifene was approved by the FDA for the treatment of osteoporosis; preliminary trials had also suggested its potential effectiveness in preventing breast cancer. Sociologist Jennifer Fosket (2004: 292-293) followed the Study of Tamoxifen and Raloxifene (STAR) is the largest randomized controlled clinical trial on breast cancer prevention. To enlist a population of participants for these trials, researchers had to agree upon appropriate measurements for determining which women were at "high risk" for breast cancer. Following the lead of the Breast Cancer Prevention Trial (BCPT), STAR set its boundaries for inclusion at "risk level" "1.7," a number that could be calculated from the Gail Model[5], a statistical formula based on self-reported data for determining breast cancer risk. For BCT and STAR, 1.7 became the number that demarcated high-risk women from the general population, and pharmaceutical manufacturers also highlighted "1.7" as a way of advertising the drug to potential consumers. Likewise, women seeking the drug could inform clinicians of their risk value. Because a value at or above 1.7 does not mandate treatment, it is a flexible tool that enables researchers, manufacturers, clinicians, and women themselves to selectively medicalize being "at risk" for breast cancer (304-306).

Lerner (2001) describes how this occurred when pharmaceutical companies began marketing Tamoxifen:

> The dual issues of the meaning of 'prevention' and the role of industry arose explicitly in 1992 with the growing use of tamoxifen. In learning that tamoxifen was an effective adjuvant treatment for women with breast cancer, researchers also found that it lowered the incidence of cancer… The question thus arose: was

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[5] See chapter 4 for more information on The Gail Model.

> it reasonable to give tamoxifen to high-risk women who had never had breast cancer? (263-264).

Lerner discusses debates about tamoxifen among women's health advocates:

> The National Women's Health Network (NWHN) and others argued that "giving a potentially toxic drug to healthy women distorted the meaning of 'prevention'… Moreover, reliance on tamoxifen for such a purpose reinforced the control of medical professionals and pharmaceutical companies over women's bodies" (264).

In 1991, the NWHN opposed the research trials on Tamoxifen in defense of research subjects, who would be exposed to medications already have shown as harmful. However, they failed to rally enough support to stop the trials (Fugh-Berman, 1992). As the women's health movement has grown and become institutionalized through women-run centers as well as government-run departments of women's health, women's health activists articulate increasingly diverse views on how and whether to support biomedical research on women's health.

THE WOMEN'S HEALTH INITIATIVE: A PIVOTAL (AND POLARIZING) RESEARCH PROJECT

In addition to grass-roots feminist activist organizations such as OBOS and NWHN, another "branch" of feminist work was spearheaded inside the NIH by career professionals. The establishment of the Office of Research on Women's Health (ORWH) in 1990 within the NIH was viewed as a "victory" among many women's health political activists (Narrigan et al., 1997: 565). It was the direct result of the Women's Health Equity Act of 1989, presented to Congress by the Caucus for Women's Issues and with the support of the Subcommittee on Health and the Environment (564). The primary goals of the ORWH were to: a) address and research a greater number of conditions that affect women’s health; b) ensure that biomedical research projects include women in clinical trials to assess sex/gender differences in health outcomes; and c) to encourage and support women to pursue careers in biomedicine (Narrigan et al., 1997: 566).

One direct result of the ORWH’s formation was the Women’s Health Initiative (WHI), launched through the leadership and oversight of Bernadine Healy, the first woman to serve as Director for the National Institute of Health (NIH). Women’s health activists, epidemiologists, and cardiologists were instrumental in garnering support for this research project, groundbreaking for being the largest clinical study to carefully monitor the effects of hormone replacement therapies. The WHI has also been widely acclaimed for its impressive research design and for successfully operating as the largest, best-funded and intentionally planned randomized controlled trial of its kind. Feminist perceptions of the WHI were mixed. “Despite the agenda’s comprehensiveness, it focuses primarily on clinical dimensions of health… Feminists question whether this agenda will ‘provide explanations about women’s health that are liberating, that have the capacity to be used by women for women’s good’ (Woods 1994:475 quoted in Narrigan et al., 1997: 566). Narrigan remarked that (569): “It is tempting to think that these changes herald a major shift in the way biomedical research is done,” but the shortcomings of these large studies should not be ignored, and “Women’s health activists need to hold the biomedical research community accountable” (569).

Since 1991, 161,808 postmenopausal women have participated in either its observational trials or its randomized, controlled trials. Those in the clinical trials of the WHI took part with the understanding that they would either be taking estrogen-progestin pills, estrogen pills,[6] or placebos for 15 years. The study was double-blinded, meaning neither participants nor researchers knew who had the placebos or which drug. In addition to studying the influence of estrogen supplements, the WHI tracked the roles of diet, calcium, and vitamin D on a shared set of health outcomes: heart health, cognitive function, risk of stroke, quality of life, menopausal symptoms, bone density, and a variety of cancers ("Findings from the WHI", 2009).

Women's health NGO's including both the Boston Women's Health Book Collective and the National Women's Health Network had warned women of the risks of HRT for decades. In 1998, the NWHN conducted a major review of the medical literature on HRT and publicly stated their opposition to the deficiency model of menopause; they further stated that research on how women can age healthfully without HRT was needed but difficult to achieve, since so many medical researchers and clinicians are financed by drug companies (Lock, 1998:189).

To address the tensions between the need for women's health to be better researched on one hand, but to remain wary of institutional legacies of medicalization and sexism on the other, the NWHN stated their position on the ORWH and WHI, expressing cautious support for the division of the NIH and strong support for their prioritization of preventive research (Narrigan et al., 1997: 570). They concluded that "The NWHN will make our positions known to, and will collaborate with, the Office of Research on Women's Health" (570). At the same time, the NWHN drafted a list of current women's health research that needed to be prioritized but were not included in the ORWH-supported WHI, such as: AIDS/HIV, violence against women, chemical dependency,

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[6] The "estrogen only" condition only included women without uteruses, because estrogen without progestin had previously been shown to increase risks of uterine cancer ("Frequently asked questions," 2004).

occupational health, gallbladder disease, and an "evaluation of differences in medical decisions by provider gender" along with "consequences of gender differences in patients' use of health care services" (Narrigan et al., 1997: 572-573).

On July 9th, 2002, press releases around the world announced shocking findings: The WHI had been halted due to preliminary evidence of unanticipated health dangers among those participants assigned to receive estrogen-progestin supplements. The WHI was originally supposed to conclude in 2006,[7] but routine tracking procedures revealed that these women were faring worse than those on the placebo. The clarification that cardiac disease was to blame angered some and intrigued others. Connections between HRT and heart disease had been noted before and studied through several observational trials with conflicting results and competing interpretations of the data. However, when the WHI news reached public audiences, panic, anger, and confusion erupted, largely due to the many women who were refilling HRT prescriptions for the sole purpose of preventing heart disease and osteoporosis. During the twelve months following the initial press releases, annual prescription rates for HRT declined dramatically: In comparison with 2001, Prempro's sales dropped 66% and Premarin's dropped 33% (Hersh et al., 2004: 50).

During this time, WHI researchers continued to publish findings from the hormone trials. By 2004, they had written 18 articles in JAMA and the NEJM linking ERT with numerous diseases. The WHI's "observational study" is still under way. It is examining the relationships among lifestyle, health, risk factors, and specific disease outcomes. This component tracks the medical history and health habits of over 93,000

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[7] The "estrogen plus progestin" trial stopped early in July 2002, and the "estrogen alone" trials were stopped in March 2004 (WHI Participant Website, 2004).

women. Recruitment for the observational study was completed in 1998 and participants were followed for a minimum of 8 years. Participants from all trials within the WHI are being followed without hormone interventions and will be until closeout in 2010. Researchers recently compiled WHI data to assess overall risks and benefits of estrogen plus progestin treatments and reported higher rates of heart disease, breast cancer, ovarian cancer, blood clots, cognitive function, urinary incontinence, and risk of stroke (Heiss, et al., 2008). In terms of benefits, HRT was shown to alleviate menopausal hot flashes and to prevent osteoporosis and colon and endometrial cancers. With the exception of easing hot flashes and reducing vaginal dryness, HRT was not shown to significantly improve women's quality of life, at least not when these measures were averaged across populations (Hays et al., 2003). These "Quality of Life" findings were summarized on the Women's Health Initiative Participant Information web page:

> No significant improvements on perceptions of general health, energy, social functioning, mental health, depression, or sexual satisfaction. There were slight improvements in women's physical functioning, bodily pain, and sleep disturbances at one year. These effects were very small, however. The average increase in physical functioning, for example, was less than one point on a 100-point scale. Most women would not notice such small differences in every-day life (http://whi.org/findings, 2003).[8]

Of the numerous results from the WHI, the increased risk for heart disease as a consequence of ingesting estrogen-progestin[9] remains the mostly hotly debated among medical researchers and clinicians. Particularly pertinent here, many argued that the WHI was flawed for not comparing results between groups of participants according to

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[8] In 2008, the British Medical Journal featured an article by Welton and other researchers who concluded that HRT improved quality of life according to 3 of 9 general areas of consideration among women who began HRT several years after menopause. These areas of reduced symptoms were observed in regards to vasomotor function, reduced vaginal dryness, and improved sleep. Based on this, the authors said there was no overall benefit to HRT users in terms of quality of life, since other measures of quality of life were negative (breast tenderness, vaginal discharge) or neutral (depression, cognition, quality of life in general).

[9] Findings from the estrogen-alone study found no heart disease risks or benefits but was stopped due to increased risks for strokes ("Frequently asked questions," 2004).

age. Some investigations are now being conducted on the “narrow window of opportunity” theory which argues for the heart benefits of estrogen use in younger menopausal women (45-55 years). The reasoning behind this perspective states that older women are more likely to have preexisting blood clots, and the blood-thinning properties of ERT could dislodge these clots and cause heart problems or stroke. For young women, the blood thinning properties are theorized to be beneficial as long as the hormones are taken for no more than a few years (Grodstein 2005; Slomski, 2009).

Among medical researchers who believe that estrogen endangers women’s health and that prescriptions should be limited to short-term treatment for severe menopausal symptoms only, upcoming research projects are increasingly dedicated to studying the behavioral and lifestyle characteristics that promote health and prevent disease among women over 50. In an interview with The New York Times (Rabin, 2006), Dr. Wulf Utian, director of the North American Menopause Society, explained: “Twenty years ago, estrogen was the only game in town to consider for preventing cardiovascular disease in women, as well as for combating osteoporosis. Today, there’s smoking cessation, dietary changes, antihypertensive drugs, and diabetic agents.”

One key legacy of the WHI is that it pointed out the questionability of findings from laboratory or observational research when executed without comparison to clinical experimental trials. Earlier studies that concluded that HRT prevents heart disease were based on observational and laboratory research. These methods, which helped endocrinologists and gynecologists gain substantial scientific prestige throughout the 20th century, are today being challenged by epidemiologists, cardiologists, and other population-based researchers, including physicians. The WHI scientists, with the backing of many women's health advocacy organizations, today argue that a variety of research approaches are required to adequately and empirically conclude the risk or health benefits of a substance.

Given the public and scientific attention focused on questions about whether, when, and how hormone therapies are harmful, there has been little consideration of other questions. One consequence of heated controversies is that debates in one area provide a platform for proponents of related issues to take center stage and reframe those debates as well. Krieger and her many coauthors (2005) carefully highlight "missing elements" of the HRT controversy that have largely gone unnoticed by the general public but have been quite influential in shaping recent events in women's health research:

1) Renewed and increased attention to the "invisible industrialists" (especially Big Pharma) whose long-term vested financial interests in HRT influenced the ways in which it had previously been researched and marketed.
2) Regulatory agencies were drawn into discussions regarding who should monitor the relative importance of public safety versus personal choice vis-a-vis risks of treatments.
3) Both proponents and critics of hormones tended to discuss the issues in ways that furthered individualized understandings of risk.
4) The WHI contributed to the growing body of research dedicated to understanding preventive health.

In addition, the clear relationships between prescribed synthetic hormones and breast cancer provoked a larger number of researchers and lay persons to consider the health effects of synthetic estrogens more broadly. Exposures to environmental estrogens (found in soil, water, and food) are being researched in greater detail, as are estrogen mimicking compounds emitted from pesticides and plastics (Krimsky, 2000:170). The WHI also prompted discussions on how hormones might differentially affect women based on their life stage and whether a given toxin has more of less of an effect based on the age at exposure. Similarly, ORWH has recently highlighted four "themes" that organize their current research and philosophical positions: 1) lifespan research on how women's health changes across time and which health concerns are age-specific; 2) understanding how sex and gender influence women's health across levels of analysis: chromosomes, anatomy, behaviors, societies, etc. 3) prioritizing research on health disparities; and 4) supporting interdisciplinary research (Pinn, 2009: 3).

In sum, the ORWH and WHI have influenced national research on and attention to women's health and hormones in powerful ways, although many women's health advocacy groups are hesitant to support their "preventive" research given past performance.

BREAST CANCER ACTIVISM

Breast cancer activism has been woven throughout the major action issues of the women's health movement. Some breast cancer activists attribute the disease to hormonal medications they were given, and so activism around hormones and breast cancer overlap; the dual objectives to eradicate breast cancer and raise awareness about the dangers of hormonal medications are frequently articulated in tandem. In this dissertation, the history of breast cancer activism is particularly important to the arguments I make, because the advocates who comprise BCERC and first and foremost breast cancer activists. As part of the U.S. women's health movement activism around hormones, breast cancer activists have voiced many concerns about the carcinogenic properties of estrogenic and estrogenic-mimicking medications. 1974 is often noted as a turning point for U.S. breast cancer awareness. That year, Betty Ford and Happy Rockefeller both publicly announced their breast cancer diagnoses, and Maryland-based journalist Rose Kushner vividly portrayed her experiences with breast cancer through the lenses of feminism and patients rights, describing how breast cancer invades women's lives, including family dynamics, sexual relationships, and work (Kushner, 1975; Lerner, 2001).

Soon after, communities of women began organizing across the U.S., most of whom were concentrated in California's San Francisco Bay Area and Long Island, New York. As these groups grew and scientized/professionalized, they took heterogeneous political stances and varied considerably as to how much they collaborated with corporations, governmental agencies, and scientific researchers. Breast cancer activism exploded in the early 1990's in ways that highlighted how breast cancer and women's health is bound up within organized medicine and other major social institutions, such as insurance companies, the media, the U.S. government and health care policies, and the lack of national health insurance. In 1986 and 1991 retrospectively, the National Alliance of Breast Cancer Organizations (NABCO) and National Breast Cancer Coalition (NBCC) were created as major hubs for research, activism, and political lobbying. Lerner (2001: 258) explains how these two organizations "Helped to unify the publicity and fund-raising apparatus for breast cancer in the United States. The early activism… has matured into a pragmatic and flexible advocacy movement." They aggressively pressed for public and institutional support for breast cancer research in the U.S.

Thereafter, they served as primary organizations for coordinating and linking breast cancer research at the federal level to community-based organizations.

By 1993, California's Breast Cancer Research Program and the U.S. Department of Defense's Breast Cancer Research Program both mandated that breast cancer advocates be included in research processes (Love, 1993: 2417).[10] "In 1989, NBCC members organized letter-writing campaigns and testified before Congress… The Coalition had alerted Washington legislators that 'women had declared war on breast cancer, and they'd better find a way to fund that war.' By 1996, funding levels had jumped [from 74 million] to over $550 million. This figure included an unexpected annual appropriation of over $100 million from the Department of Defense, only too appropriate for financing a "war on breast cancer" (Lerner, 2001: 259).

At local levels, Klawiter (1999: 104) has referred to breast cancer activism as a "culture of action." Cultures of action are flexible and transform in relation to "the actions of their members… and the discourses and practices of the regimes they seek to change" (Klawtier, 2008:44). To achieve this, they "enact, embody, and emote" (44). Klawiter describes three cultures of action that formed around breast cancer in this new regime of biomedicalization: early detection, patient empowerment, and prevention and the environment. In the first culture of early detection, organizers ally closely with individual and corporate donors. Individuals and groups comprising this "culture" popularized the "pink ribbon" movement and portrayed individual cancer "survivors" as

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[10] Although the Department of Defense Breast Cancer Research Program was novel for integrating advocates within their review process, their research priorities very much reflected the status quo in breast cancer research, which tends to favor research geared towards cellular biology and cancer treatments. For instance, of the $30,000,000 awarded to California by the DOD BCRP in 1993-1994, the 42 research grants broke down the following way: Fifteen for understanding the pathology of breast cancer, 10 on treatment, 8 on etiology, 6 on early detection, 2 on improved access, and 1 on breast cancer prevention (CBCRP.org).

the primary activists (Klawiter, 2008:45). For instance, the Susan G. Komen Breast Cancer Foundation was established in 1982 by Nancy Brinker and became well known for its annual “Race for the Cure” (Lerner: 258). The Foundation, now called “Susan G. Komen for the Cure”, has raised $1.8 billion since 1982, and in 2008 received over $40 million from corporate donations alone. In 2009, the organization scheduled more than 500 races. Their large operating budget and expansion into Italy, Germany, Hungary, Bosnia, Herzegovina, and Russia has led to their self-identifying as “The global leader of the breast cancer movement” (komen.org, 2009).

While the culture of early detection emphasizes how women can regain their precancerous lives through family support and “normalizing” procedures such as prosthetic implantation, those who congregate within the culture of patient empowerment and feminist treatment criticize medical institutions and popular culture for not acknowledging the experiences of diverse groups of women living with breast cancer (Klawiter, 2008:46-47). In 1992, Andrea Martin established the Breast Cancer Fund (BCF), the first breast cancer organization that focused solely on issues of breast cancer prevention. This was founded soon after Breast Cancer Action (BCA) in 1990, whose founders politicized the lack of scientific knowledge about, and limited support for patients with breast cancer. BCA drafted and supported the enactment of California’s Breast Cancer Act in 1993, which ensured advocate input in research decisions; they also successfully lobbied for a 2-cents tax increase on tobacco products to raise money for breast cancer screening and to support breast cancer research (Parthasarathy, 2007:4; Klawiter, 2008:42). Although they remain primarily committed to supporting individuals with breast cancer, they declare support for preventive and population-level research

(BCA, 2009). Of the ten Core Principles and values listed on BCA's website, the organization chose to highlight bullet point #7 in bold lettering, which states: "We can't be bought." In congruence with this philosophy, they launched a "Think Before you Pink" campaign in 2002 to encourage questions and discussions as to the duplicity tendencies of corporations to "Promote the pink ribbon campaign and manufacture products that are linked to breast cancer" (Bell, 2008: 23).

The third major group of activists who constitute the culture of cancer prevention and environmental activism rally to gain support from private and governmental organizations to blatantly contest industrial contamination. An East Coast group prominent in efforts to publicize connections between toxins and cancer was the Long Island organization 1 in 9. They formed in 1990 to draw attention to the high disease rates in the Long Island area, although "1 in 9" refers to the likelihood that an American woman will develop breast cancer in her lifetime, without taking region of the US into account. Two decades later, 1 in 9's website describes its purpose as follows:

> It is our mission to promote awareness of the breast cancer epidemic through education, outreach, advocacy, and direct support of research, which is being done to find the causes of, and cures for breast cancer and other related cancers. Since a high majority of breast cancer incidence falls outside the known risk categories, we are unique in looking at environmental factors as possible causes and in seeking and promoting ways to keep the environment healthy (1in9.org).

By drawing attention to the importance of "advocacy and direct support of research," 1 in 9's mission statement reflects what has become a goal of many professional breast cancer organizations who have grassroots origins: to sustain themselves and increase their impact by becoming directly involved with research. Doing so means building at least partial, and sometimes substantial, bridges with research related institutions in the U.S. 1 in 9 has affiliated closely with the Silent Spring

Institute, a researcher-activist collaborative center in Massachusetts whose focus on environmental research and breast cancer prevention is fused through "an activist vision that goes beyond the science-as-usual approach" (Silent Spring, 2009).

According to Laura Potts' (2007: 135) findings from interviews with breast cancer epidemiologists focusing on environmental causes of cancer, the breast cancer/environment activist movement synthesizes substantive concerns and theoretical perspectives extending beyond bounded health research and medically-mediated experiences of risk and disease.

> [The movement] goes beyond how people and environments fit together… in debating environmental concerns we can observe the collapsing of the categories of economy, politics, science and culture. This process of hybridization, in which different elements are bound together by 'fragile threads', informs the more holistic approach to epidemiological enquiry espoused by the breast cancer/environmental movement.

In her new book From Pink to Green, Barbara Ley (2009: 7) argues that within the larger umbrella of breast cancer activism, the environmental activists are "perhaps the most active and outspoken critics of the dominant breast cancer paradigm and the broader disease culture surrounding it." The Toxic Links Coalition (TLC) of the Bay Area, for instance, first introduced themselves by picketing at and rallying against the "Race for the Cure" in 1994. TLC criticized industrial manufacturers, medical institutions, and even breast cancer activists for perpetuating the profit-driven actions that cause breast cancer (Klawiter, 2008: 203-205). And yet, there is a great deal of variability among organizations within the prevention and environment culture of action. Klawiter describes the organizations as positioned along an ideological and political spectrum, in which organizations such as BCA and TLC are more comfortable with confrontation and public protests, while the BCF is willing to cooperate with politicians and biomedical research institutions (221). Somewhere in the middle of the spectrum, she places Marin Breast Cancer Watch (MBCW), which was founded in 1995 and has produced the largest number of the most prominent advocates in BCERC, not only in the Bay Area branches of BCERC, but nationally. Klawiter describes the politics and attitudes of MBCW as following:

> Marin Breast Cancer Watch fell somewhere between, or rather, on both sides of the issue. On the one hand, it was a product of the confrontational politics… On the other hand, many of the women who contributed the most to MBCW's development remained deeply ambivalent about this more contentious style of activism and did not participate in it. Women who became involved with MBCW through the environmental health movement tended to be more comfortable with confrontational politics. Women who found their way to MBCW through a diagnosis of breast cancer usually preferred the more collaborative style that, over time, became the dominant organizational culture of MBCW (221-222).

The MBCW's characteristic ambivalences and active efforts to collaborate with scientists and become published authors persisted into the 21st century and have shaped the BCERC in substantial ways. When MBCW began collaborating with BCERC, the advocacy group had just completed a five-year study titled: Adolescent Risk Factor Study and the Development of Breast Cancer. MBCW members surveyed 300 women diagnosed with breast cancer to gauge whether their lifestyles, experiences, and living environments as teenagers differed from the experiences and environments of a control group of 300 women never diagnosed with breast cancer. The researchers revealed very few differences between the case and control groups (Wrensch et al., 2003). MBCW approached the BCERC planning meetings with an established interest in, and preliminary research elucidating, adolescent health, and they played a prominent role in shaping the research BCERC would eventually undertake. In 2006, MBCW became

Zero Breast Cancer to reflect their more active and ambitious orientation to eradicating breast cancer (Zero Breast Cancer, 2008).

In sum, in less than 20 years, breast cancer advocacy in the U.S. had migrated from the responsibility of individuals, families, and clinicians, to grassroots movements centered around the West and East Coasts, to public advocacy and educational movements that had been institutionalized in affiliation with major U.S. government research projects. Yet despite the impressive gains in breast cancer research focused on environmental causes of cancer and efforts to organize via collaborative formats, prevailing attitudes towards breast cancer still describe it as an individualized problem. Endogenous hormones have been more emphasized and researched than environmental hormones, and it is difficult to work against that current.

THE ENDOCRINE DISRUPTING HYPOTHESIS

In the late 1960's and early 1970's, biologist John McLachlan produced extensive research on what would come to be known as endocrine disruptors (Krimsky, 2000:9-11). His graduate work was based on studying the effects of drugs on animal fetal development, and he began using DES as a surrogate for DDT, because it was less expensive to study. He analyzed his own research results in light of findings he had reviewed that had been conducted by wildlife researchers on DDT's effects on animals and ecosystems. McLachlan eventually accepted a position in toxicology at the National Institute of Environmental Health Sciences (NIEHS), and in 1976, he headed its laboratory for Developmental Endocrinology and Pharmacology. In 1979, McLachlan organized "Estrogens in the Environment," the first of many symposia on this topic. By the late 1980's, in addition to laboratory and clinical researchers, these interdisciplinary meetings were drawing people from ecology as well (Krimsky, 2000: 9-11).

DES is, by definition, an endocrine disruptor. Although it does not resemble the chemical estradiol found in humans, it "mimics" the action by causing thickening in the lining of the uterus. DES directly affects the hormonal system and also passes through the maternal/fetal blood barrier, which had been theorized as essentially unbreachable.[11] In the 1970's, many were surprised that a drug taken by a pregnant woman could show delayed effects in her child, sometimes not manifesting until puberty or later (Colborn et al., 1997). In fact, much of the research on endocrine disruptors and their delayed effects is based on the models used to assess the effects of DES on animals. In 1995, the NIEHS called for continued observational research on patients and offspring exposed to the drug, explicitly suggesting that the associated cancer rates might not yet have peaked among children of women who were given DES; in fact, some speculated that cancer rates and other health complications would continue to be elevated among the grandchildren and subsequent generations. They also recommended that more basic research be undertaken on endocrine disrupting compounds (EDC's), using DES as a model (Krimsky, 2000).

In 1996, the Environmental Protection Agency (EPA) allotted $3.5 million to research endocrine disruptors, which are defined as "any exogenous agents" that interfere with hormonally-mediated processes of homeostasis, reproduction, and/or development in humans (Krimsky, 2000: 82). The Endocrine Disruptor Research Program was galvanized in response to pressures the NIEHS, and activists who represented scientific,

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[11] See Clarke's (2004) account of the prolonged research on primates informing these scientific views.

environmental, and health-related organizations, and biomedical[12] and wildlife researchers. By this time, a growing body of literature had documented the detrimental effects of certain industrial chemicals, carcinogens, “xenoestrogens,”[13] (such as estrogens and by-products from pesticides) but the coinage and definition did not appear until the late 1990’s. The cumulative concept is broad when literally interpreted and includes substances from animals, humans and synthetic, food, and agricultural products. Since 1996, screening program has been underway through the Environmental Protection Agency, with the goals of developing ways of identifying which chemicals need to be screened, constructing screening tests, establishing screening criteria, and communicating outcomes to the public. To date, four main categories of chemicals are widely accepted as posing hazards to human hormonal processes:

1. DDT = pesticide, banned in 1972.
2. DES = synthetic hormone prescribed primarily to prevent miscarriages and given to beef in feed lots for fattening.
3. PCB’s = polybrominated biphenyls, found in some plastics; banned in 1977.
4. Dioxins = chlorinated by-product that is regarded as extremely toxic.

To date, few substances are widely agreed to be EDC’s because there is so much uncertainty about how to best define and measure the substances and their effects. Theorizing the mechanisms of biological action poses yet more difficulty. Many scientists argue that the concerns have been overstated and over-generalized. The

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[12] According to Krimsky (2000: 82), with the establishment of the Endocrine Disruptor Research Program in 1996, preexisting NIH-funded reproductive toxicology research was repositioned as a subsection of this now-larger focus on EDC’s.

[13] One medical dictionary defines xenoestrogens as by-products of industrial or chemical processing that have estrogen-like effects. This includes unintentionally estrogenic substances, such as pesticides, as well as drugs manufactured specifically for the purpose of manipulating hormones, such as oral contraceptives and estrogen replacement therapies (medilexicon.com).

molecular mechanisms are not well understood, but certain chemicals are theorized as mimicking, blocking, and/or scrambling hormonal messages in the body. The results may be delayed and remain undetected until manifesting in succeeding generations (Landrigan, Garg, & Droller, 2003). Among these proposed effects are rises in cancer, disorders of the neurological systems, impaired sperm quality, a larger number of female births than males, and lowering the age of pubertal onset in girls (Auger, et al., 1995; Kaplowitz, et al., 2001; Longnecker, et al., 2002).

For decades, environmental exposures have concerned lay audiences and activists. Many environmentalists and advocates for less industrial intervention in women's health were influenced by Rachel Carson's (1962) widely-recognized book: Silent Spring. Here, she described how animals such as the bald eagle were producing nonviable eggs as a result of DDT exposure. DDT contamination was then linked to reproductive abnormalities in male alligators in Lake Apopka, Florida in the late 1970's. PCB's and DDT's were believed to alter the sexual behavior and reproductive outcomes of gulls in Southern California, the Great Lakes, and Puget Sound (Landrigan et al., 2003).

In 1996, the bestselling book Our Stolen Future, written by Theo Colborn, Dianne Dumanoski, and John Myers popularized the endocrine disrupting hypothesis by making the concepts accessible to a wide range of readers. Like Carson, Colburn and her coauthors argued that the same toxins and pollutants that have caused developmental peculiarities and ecological imbalances in wildlife are exacerbating conditions and diseases among humans. Specifically, their view is that the post-World War II industrial boom and rise of plastic manufacturing has produced estrogen-mimicking substances that leak not only into our surroundings but also into our bodies. Our Stolen Future has been tremendously influential, recognized as the sequel to Carson's Silent Spring.

In 1992, Al Gore wrote the foreword to the 30th anniversary edition of Silent Spring, and in 1996, he composed a foreword in Our Stolen Future that drew connections between the two books:

> We are only now beginning to understand the consequences of this contamination. Our Stolen Future takes up where Carson left off and reviews a large and growing body of scientific evidence linking synthetic chemicals to aberrant sexual development and behavioral and reproductive problems… Last year, scientists declared that human activity is changing the earth's climate. Today, reports in leading medical journals point ominously to hormone- disrupting chemicals' effects on our fertility--on our children.
>
> …A wide range of manmade chemicals disrupt delicate hormone systems. These systems play a critical role in processes ranging from human sexual development to behavior, intelligence, and the functioning of the immune system. Although scientists are just beginning to explore the implications of this research, initial animal and human studies link these chemicals to myriad effects, including low sperm counts; infertility; genital deformities; hormonally triggered human cancers, such as those of the breast and prostate gland; neurological disorders in children, such as hyperactivity and deficits in attention; and developmental and reproductive problems in wildlife (Gore,1996: vii-viii).

According to Gore then, the hazards resulting from endocrine disruption is best understood as another chapter in the saga of industrialization and destruction. He introduces the significance of EDC's within the framework of 1960's and 1970's-based critiques on environmental contamination. He highlights the unwieldiness of EDC's, as they stem from "a wide range" of substances and produce "myriad effects" among humans, animals, and ecosystems. Scientists are, he says, "just beginning" to understand how these substances produce such a vast array of health problems, and in wording it as such, Gore captures a portrait of EDC's at the cutting edge of environmentalist and scientific concerns, while at the same time portending drastic consequences for global-level human health and environmental sustainability.

As Krimsky has argued (2000: 104), the term “endocrine disruptor” challenges previously held notions as to whether a topic belongs within the domain of health, geography, molecular biology, environmental science, and so-on. This wide range of possible effects initially confused scientists and media reporters as seemingly divergent issues (such as animal reproduction, the effects of DES on lab animals, and sperm count and breast cancer rates in humans). Now they were discussed under a singular rubric, despite their differing processes, etiologies, and contributing disciplinary research teams.

What links EDCs under the same conceptual umbrella is neither their shared mechanisms (because they vary greatly) or their shared effects (which are numerous and heterogeneous) but rather the joining hormonal model through which they are theorized to operate on and work within. EDC’s reinforce an understanding of the endocrine system as a master operating system of organisms. There is a primacy of the endocrine system per se, and an idea that despite a century of endocrinological research, we are oblivious to its power and triggers. Moreover, the boundaries of our bodies are also increasingly understood as porous. Any number of chemicals can enter our bodies through of variety of modalities (mouth, skin inhalation) and provoke hormonal shifts. So for women’s health activists, it becomes more difficult to pinpoint a substance that needs to be avoided or lobbied against; there is no identifiable manufacturer responsible for these new sets of hormonal hazards.

EARLY PUBERTY AND BREAST CANCER RISK: CREATING THE BCERC

In 2002, the first International Summit on Breast Cancer and the Environment was held in Santa Cruz, California. The primary result of this meeting was the early formation of the Breast Cancer and Environmental Research Centers (BCERC) (Klawiter, 2008:255), the primary site of research for this dissertation.

As I briefly described in chapter 1, the BCERC is a major research study of the sources and health risks of endocrine disruption, puberty, and breast cancer. In this multi-sited, interdisciplinary, collaborative study, breast cancer advocates, basic scientists, and epidemiologists are together executing a large, multi-sited basic/clinical science research project initiated in 2003 and slated to end in 2010. Known collectively as the Breast Cancer and Environment Research Centers (BCERC), collaborating groups from the University of Cincinnati, the Fox Chase Cancer Center in Philadelphia, Michigan State University, and the University of California at San Francisco are conducting research to understand the links between environmental exposures and the early onset of puberty in girls. The studies are jointly funded by the National Institute of Environmental Health Sciences (NIEHS) and the National Cancer Institute (NCI). They consist of three somewhat distinct sectors: biologists who study mammary development in rodents; clinical epidemiological researchers who are tracking 1400 prepubescent girls to study environmental and genetic determinants of mammary gland development and the onset of puberty; and community advocates who are tasked with public/community outreach. Specifically, each of the four centers has a Community Outreach & Translation Core (COTC) who is responsible for ensuring that the views and concerns of breast cancer advocate communities are heard and that the research findings are disseminated to the public. Members of the COTC include breast cancer advocates, public health professionals, researchers, and community-based organizations. While each COTC has its own goals, they also collaborate on issues of mutual concern. All the centers work with advocacy groups to add their insights and experiences to the research effort, collaborating on several fronts. The BCERC's from across the country meet annually to discuss their respective research projects, collectively referred to as research on "Early Exposures." This title primarily denotes how exposures early in life can influence disease rates many years later, but it also speaks to "early puberty" as a risk factor in itself. Early menarche is considered a risk factor for developing breast cancer.

Klawiter (2008:255-256) remarks on the ambivalent attitudes among women's health activists towards BCERC:

> Although the NIEHS interpreted 'environment' quite broadly to mean the 'social, chemical, and physical environment,' the focus of the research was heavily weighted toward gene-environment interactions, focusing in particular on breast maturation and vulnerabilities during puberty… For this reasons, the response to BCERC by participants in the cultures of feminist and environmental activism has been mixed.

This dissertation captures the BCERC "in progress".

CONCLUSIONS

When scientific collaboration entails the explicit inclusion of laypersons, deeply entrenched power dynamics play themselves out in new ways. The women's health movements in the 1970's criticized U.S. medical institutions for operating in accordance with the values and economic interests of white, male elites (Hubbard, 1990; Ruzek, 1978). Most grassroots women's health centers struggled to remain autonomous from the financial support and ideological legitimization of mainstream biomedicine, alliances which compromised initial values and resulted in the centers becoming less radical (Ruzek, Clarke, & Olesen, 1997; Weisman, 1998).

> If health care policy is defined to include all decisions made by society, through both governmental and nongovernmental means, to define and allocate health care resources and to shape health care institutions, then it is clear than American women have always been involved in health care policy-making. The waves of the women's health megamovement are the most conspicuous examples of women's influence on health care policy… Yet there is no consensus on how to incororporate gender in health care policymaking, what the roles of women's health groups ought to be, or which women's health issues might form the basis of a policy agenda within the changing health care environment (Weisman, 1998: 189).

My dissertation research builds from a substantial history of sex hormones and women's health activism. The layers and heterogeneity of positions taken and not taken on hormones by women's health activists only becomes more elaborate as the decades unfold. In this chapter, I highlighted feminist views on hormonal medications such as oral contraceptives, HRT, DES, and Tamoxifen to demonstrate the series of choices and compromises women are faced with when deciding whether to take medications and to adopt western frameworks of women's health, menopause, and so on. At the organizational level, leaders of women's health centers argue about how much support should be lent to large-scale research projects on women's health such as the WHI. From one angle, the resources now being allotted to women's health demonstrates that it is finally a national and even international priority. However, the agenda are set early on and usually decided upon by those "from above" rather than being determined by large numbers of women and communities. Breast cancer activist organizations are similarly scattered across political fields, with radical groups such as 1 in 9 and TLC articulating the most oppositional stances to mainstream scientific research.

So then, these sets of ambivalences about the use and research on hormones held by women users, women's health organizers, and breast cancer activists form pieces of larger streams of conflict about how women's bodies will be known within western biomedical contexts, and how women will negotiate the conflicts between sexist medicine and embodied struggles to thrive, individually and collectively.

In the BCERC, these complexities are compounded by two "new" elements: 1) The introduction of EDC's, which are diffuse and poorly understood by scientists, and 2) The beginning of an era in which the mark of "good science" often depends on demonstrating that the projects were developed and executed with input from activists and communities. We are presently observing an era of biomedicine in which community participation in research increases the dominant institution's scientific legitimacy (Brown et al., 2006). This stems, in part, from the perception that community and activist participation in health social movements have successfully garnered attention and resources. And yet, as Epstein's (1996) research on early scientific research and AIDS activism demonstrated, science can never be purely democratized in a society characterized by deeply historicized and stratified group identities and politics (see also Reardon, 2007). My research takes on a sliver of these dynamics. I am looking at one area of research designed to further understand hormones while building relationships between governmental funding agencies, biomedical researchers, and women's health activists - - The BCERC. By studying the contemporary events in the BCERC in light of a historical lens on scientific research and activism around sex hormones, a window opens through which to analyze the motivated actors and organizations that have pushed towards and resisted against research on hormones. This has shaped current collaborative research efforts and ultimately constructs views on gender, age and hormones within specific historical contexts, as we shall see.

CHAPTER 3: PUBLIC CONFIGURATIONS

The BCERC will have a legacy through their model of collaboration. Sitting in at those meetings, I was amazed at all the aspects they considered. It's no small feat. I can't think of any other project that has involved so many regions. Oh, and they might really come up with something about breast cancer (Advocate and COTC member).

In this chapter, I detail the internal organization and processes of the Breast Cancer Environmental Research Centers (BCERC). BCERC is innovative in many ways. It is a research project, multi-faceted consortium, and in fact, a social movement, funded by the National Institutes of Health (NIH) whose scientists are charged with studying possible connections between environmental exposures, pubertal onset in girls, and breast cancer risk. It is also the first project to study the mechanism of how environmental exposures might be linked to early pubertal onset and breast cancer risk, rather than merely modeling differing data sets. It is also one of the most collaborative medical research projects funded by the NIH to date.

The explicit goal or raison d'etre of BCERC is to produce information on environmental exposures and thus breast cancer prevention. Yet the collaborative structure of the project is so thoroughly webbed across professions, disciplines, regions, and institutions that the collaborations themselves – rather than the research being produced - have emerged as perhaps the primary object of interest to advocates of breast cancer research, community members, non-profit organizations, and governmental funding agencies. In fact, BCERC interviewees described collaboration as the primary contribution and legacy that BCERC offers the scientific community. In many ways, this focus on collaboration has usurped the actual content of research on environmental exposures and breast cancer, although that is partly due to the slowness with which formal scientific research is executed, published, and made available and accessible to larger audiences (assuming the research is indeed carried though all these steps and doesn't fall short somewhere along the way). Scientists and advocates decided on the collaborative aspects of the study before there was even a clear view on the specific research projects.

The first section of this chapter describes the players and process that led to the formation of BCERC. My purpose is not to describe it in vivid detail just to marvel at its internal complexity; nor do I wish to draw the broad conclusion that BCERC is emblematic of "where breast cancer research is now." Instead, I embark on a "periodization study" (Epstein, 2008: 525), meaning that I examine the development of a piece of a social movement as it develops through a brief, yet highly consequential, timeframe. Gibbon (2006:158) employed a similar approach through her research on breast cancer genetics and gendered morality. Though she did not use the term periodization per se, she sought to "move beyond a narrowly defined 'impact' approach… [and instead] build on a broader field of recent social science work exploring rapid changes or innovations in medical or scientific knowledge in relation to emergent and ethical practices and various forms of patient activism." I echo her commitments while adding the intention to focus on the institutionalization of women's health activism occurring in one specific study over a short period of time: the BCERC.

The second section of this chapter draws from interview data to show how BCERC members conceptualize and discuss the significance of "collaboration" on their own terms. I offer BCERC members' descriptions of what it means to "collaborate," along with their views on structural and communication barriers. Many interviewees viewed collaboration as the main scientific hypothesis of this study (Can it work? Did it? How?). Others view "collaboration" as a strategic term for mobilizing action and promoting the centers, rather than as a means of producing integrated research results. Regardless, all participants remarked that collaboration was a site of analysis, and as BCERC enters its seventh and final year, it is increasingly being promoted as a "transdisciplinary" study.

The third purpose of the chapter is to reveal the "implicated actors" (Clarke & Montini, 1993; Clarke, 2005) in this project, referring to groups whose participation was crucial to the project and yet who had no tangible presence. For example, many BCERC participants expressed frustration by the lack of representation from oversight organizations, particularly the FDA. As I observed, the "community" also served as an implicated actor: discursively present but not identifiable.

The forth and most important component of this chapter builds from points #1-3 by examining where advocates are positioning themselves in relation to medical research, being positioned by others, and why. One of the most unique aspect of the BCERC is the heavy involvement of advocates, who constitute more than 50% of BCERC and actively guide the project each step of the way. They organized the earliest planning meetings, wrote requests for proposals, and participated on panels to select which of many competing scientific research centers would be funded and incorporated into BCERC. There are more advocates in BCERC than scientists or clinicians - a far cry from the early days of “advocate inclusion” in which a single “community member” would be invited to sit on a review panel. Despite their greater numbers, however, they are not equal participants in the production of scientific knowledge. Interviews with advocates and scientists revealed a range of views on how each contributes to research, thus highlighting the underlying beliefs and unequal access to research venues that perpetuate traditional scientific hierarchies while giving rise to new ones.

SITUATING BCERC

Shortly after choosing BCERC as my case study, I found myself wading through an alarmingly complex mini-bureaucracy whose rules and organization are being devised at it develops. Because there are no research projects like BCERC, its members had no models for, or examples of, how they might structure their collaborations. I wanted to know: How did the project begin, and what were members’ views on the formation? What kinds of knowledge, practices, and alliances are being created through the BCERC?

BCERC operates across 4 sites (centers) in the United States. The centers are not buildings unto themselves but are situated within preexisting research universities and professional advocacy organizations. Each center contains basic scientists, clinical epidemiologists, and advocates as well as a “Communication Outreach Translation Core”, which is a group of scientists and advocates who mediate between and are responsible for facilitating communication across disciplines within centers and regions.

Despite the aura of innovation associated with this project, it is a direct result of efforts by highly structured, institutionalized interest groups in biomedical research. Well-established individuals and groups instigated BCERC, many with accolades for their earlier contributions within the arenas of breast cancer advocacy, biomedical research, and NIH. Everything on the table for negotiation stems from other forms of 1) legitimized medical sciences (such as microbiology and epidemiology); 2) sustained and successful breast cancer activism (spearheaded by women's health activists and advocacy organizations such as the National Breast Cancer Coalition (NBCC)); 3) politicized debates with much at stake (as environmental concerns loom large in public consciousness); and 4) governmental institutions. Most notably here are NIH and its rapidly expanding branch of Environmental Health Sciences (NIEHS) in Research Triangle Park, North Carolina.

The Players

The BCERC is an "amalgam of people," as described by one basic scientist. It consists of government officials, scientists (epidemiologists and basic scientists), advocates and community members, external reviewers, and communication liaisons (COTC). These seven groups warrant separate introductions, as do the specific research projects being conducted at each of the 4 regional centers across the U.S. In this chapter and the larger dissertation, I consistently refer to interviewees according to these titles. Certainly, many BCERC participants are positioned across several categories:

Government officials who are involved in BCERC are few in number, but they hold leadership positions and are quite visible. Representatives from NIEHS figure most prominently, but there is also considerable input, funding, and oversight by the National

Cancer Institute (NCI). I interviewed 3 NIEHS officials and 2 from the NCI. All of these members were trained as basic scientists, and some of them were also trained as epidemiologists and clinicians.

Epidemiological Scientists head the clinical project of the BCERC. Because epidemiologists gather data about and correlate large numbers of data, spanning everything from population demographics (such as race, gender, and socioeconomic information) to neighborhood factors, psycho-social, physiological, and genetic elements, they were well-suited for this longitudinal project following girls through puberty as a way of determining whether environmental exposures influence development.

Basic Scientists all apply experimental methods and laboratory designs to researching aspects of mammary development and malignant cell division. The projects vary considerably across the four regions. Some are studying human cell tissue, while others are using specimens from rats or mice. Unlike the epidemiologists in BCERC, who strive to standardize the clinical practices of each region and draw from each to produce coordinated research findings, the basic scientists practice with considerable autonomy. In this way, their sense of contribution comes from producing results that are unique but complementary to other BCERC researchers.

Advocates are mostly professionals employed by breast cancer prevention and education agencies and often have backgrounds in public health, nursing, and/or health education. All of the advocates I identified were women.[1] Many advocates head organizations that used to be "grassroots" centers, and some are original founders. Many of the organizations described in chapter 2 are integral to BCERC, such as: The Breast

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[1] This was my observation based on attendance at multiple meetings. However, at annual meetings, I observed male advocates present on behalf of other causes, such as childhood obesity.

Cancer Fund and Zero Breast Cancer of the San Francisco Bay Area and the Silent Spring Institute in Newton, Massachusetts. The Cincinnati and Michigan centers partner with state-level breast cancer coalitions and with Susan G. Komen. The NBCC is instrumental to BCERC at the national level by negotiating with officials at the NIH and NIEHS, but they are not involved in the actual research. Advocates in BCERC provide scientists with feedback on the relevancy of the clinical and basic research, and many also hope to produce publications of their own.

External Reviewers with expertise in clinical epidemiology, breast cancer research, and breast cancer advocacy periodically assess and weigh in on BCERC's organization and research. Environmental and toxicology experts also comprised the panel of reviewers.

Communication Outreach and Translation Core (COTC) consists of BCERC members (both scientists and advocates) who facilitate communication across disciplines and across regions. This involves making sure that discipline-specific meetings are attended by someone external to that discipline. For instance, an advocate might sit in on a meeting held by basic scientists.

Throughout this dissertation, I primarily refer to interview respondents according to their professional affiliation in relation to BCERC. It is important to note that while most people self-identified as either "government official", "basic scientist", "epidemiologist", "advocate", or "external reviewer",[2] these were not clear-cut categories. All of the government officials had previous experience as scientific

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[2] I use the category "external reviewer" to refer to members who are either external consultants to BCERC or who participate in the "working group" but are otherwise not directly involved as researchers or advocates. Working group members are slightly more involved in the study than other types of consultants because they are expected to attend some of the meetings.

researchers, for instance; a majority of the respondents could be considered health advocates (there was a general sentiment that often was communicated in joint meetings that the long-term solution to all these health problems must include national health insurance, for instance). Furthermore, the advocates and educators were frequently writing grants and conducting their own survey-style research, and almost half the advocates/educators had backgrounds in Public Health, which included some training in epidemiology. And finally, everyone in the study is part of their "community". I asked one Bay Area advocate for the technical definition of "community" in relation to her work, and she explained that community referred to "Anyone who lives in Marin County, San Francisco County, or Alameda County who had an interest in breast cancer and preventing breast cancer." She admitted that it is a "really broad" definition.

Before beginning the interview portion of my data collection, I expected respondents' overlapping identities to be challenging to sort out and wondered if the overlap might be a finding in itself. I was surprised to discover that everyone I interviewed identified their position in the BCERC succinctly and singularly, either as an official, basic scientist, epidemiologist, advocate, or external reviewer. No one offered an alternative title, although many elaborated on the nature of their professional training and current work. This emphasizes one paradox of research projects that are explicitly collaborative from the most formative stages: In order to enlist proportionate numbers of people with differing backgrounds, there is often an initial naming process, and once people are "on board", their purpose can be traced back to the disciplinary and/or regional identities that led to their incorporation in the first place. As a consequence, individuals readily identified with their titles, which created divisions within BCERC. In some regards, these distinctions facilitated collaboration, because they encouraged individuals to offer advice or skills that were solidly grounded in a particular perspective, therefore enabling BCERC to benefit from the specialized sets of knowledge that have been cumulatively developed through well-established disciplines. However, the epistemological divides and differing value systems of particular disciplines also led to gridlock.

Many BCERC respondents were capable of wearing different "hats" and could have readily – if not quite as elaborately – contributed to BCERC from a perspective other than the one they maintained for purposes of collaboration in this particular study. At the conferences and meetings I observed, people used the jargon and pushed towards the goals set by their professional roles, whether as officials, basic scientists, epidemiologists, advocates, and reviewers. The overlapping understandings BCERC contributors had of one another's fields included widespread familiarity with survey-style health research and disease prevention. Despite the segmented ways BCERC contributors positioned themselves at meetings, I observed the subtle manifestations of an audience who, in many ways, consisted of professional health researchers sharing much in common. This was evident through the ease with which people responded to and commented on one another's presentations and the widespread laughter emanating from jokes about difficulties collecting and reporting on survey data, and to comments on the political roadblocks thwarting national health insurance in the U.S.

Origins of BCERC

The BCERC project was conceived on the heels of many of the breast cancer research initiatives described in Chapter 2. It is noteworthy for the unique sets of events that catapulted the study into being. The project was from the outset organized differently from other federally-funded research conglomerates of similar size. The concept originated in 2002, at a Marin County Town Hall Meeting, consisting of breast cancer advocates and the director of the NIEHS, who was visiting California as part of a “listening tour” across the United States. The regional advocates expressed concern about recent scientific findings and news reports on the higher incidence of breast cancer in California’s Bay Area. After years of consciousness raising and fundraising by women’s health and environmental activists, the health impacts of estrogenic chemicals in the environment were just beginning to be prominently acknowledged, especially for the ways they might affect reproduction and children’s health. The National Children’s Study had begun in 2000, and there was considerable discussion about critical periods of development. The National Institute for Children’s Health and Development (NICHD) had some studies that were following girls and boys through puberty, and they were bringing together teams of pediatric endocrinologists who attended the BCERC workshop. The popular book Our Stolen Future (Colburn et al., 1997) had recently been published, which cataloged scientific evidence linking synthetic chemicals to changes in sexual development and reproduction. It contained a highly publicized forward by Al Gore, who described the book as a sequel of sorts to Rachel Carson’s Silent Spring (Carson, 1962), famous for its emotional, personalized accounts linking environmental destruction to cancer.

In addition to these events, at least three other aspects directly impacted the initial organization of the BCERC: 1) the previous experiences of BCERC members, including individuals who had recently served on integrated breast cancer research review panels;

2) the rise of the NIEHS under the leadership of Ken Olden, who served as director from 1991-2005; and 3) the actual negotiations that occurred at subsequent Town Hall Meetings across the country before the Request for Applications was written.

In the early 1990's, NBCC led the initiative to secure breast cancer research money through the Department of Defense. In 1992, the DOD Breast Cancer Research Program (BCRP) was initiated, and a bill was passed by Congress that required the participation of lay persons on all BCRP breast cancer review panels. Since then, over 2 billion dollars of breast cancer research money has been funneled through the BCRP. Hence, however oddly, the DOD was the first organization requiring breast cancer advocates and researchers to work together. By the late 1990's, this structure was well-established. Though researchers have had to periodically reapply to the funding stream under the DOD, the unique model of integrating panels of advocates and community members on breast cancer researcher review panels was being incorporated into the infrastructure of other organizations, such as The American Cancer Society (ACS) and NCI. One of the epidemiologists in BCERC had previously conducted breast cancer research under the Department of Defense funding stream. "Because it was started by breast cancer advocates, they were intimately involved in deciding how much money got administered and what the funding mechanism would be." He described his commitment to holding a leadership position with the BCERC as an extension of his experience with the DOD. "From my perspective working from the DOD, it was clear to me there was a totally different perspective that really helps inform what is worth funding."

The NIEHS, established in 1966, began as a loosely affiliated branch of the NIH. It is located in North Carolina rather than D.C., which reflects and perpetuates what one

NIEHS official[3] proudly state as a “tangential” association with NIH, acting as a sort of “black sheep” within the NIH family. By 1986, the NIEHS had expanded from a leased office space to a multi-acre center (Hawkins, 1987); it was well-integrated within the Research Triangle, but lacked financial autonomy from these clusters of universities and research centers. In 1991, Ken Olden was appointed Director of the NIEHS. This was 5-10 years before the fervor of environmentalism had gripped large numbers of U.S. politicians, voters, researchers, educators, artists, and journalists. Olden, during his time as director, negotiated fiercely for the opportunity to collaborate more fully with the NIH - - and therefore garner resources that could be applied to environmental health research as well as to outreach activities designed to publicize and legitimize the center at national and international levels. By the time Olden stepped down as director in 2005, the annual NIEHS budget was more than four times what it had been in 1991. Although this shift cannot be attributed entirely to Olden, it does point to a rise in the environmental health sciences more generally, which is particularly striking in context of a decade marked by nationwide budget cuts across other health and government funding sources.

When I interviewed Olden on April 21, 2008, he had recently stepped down as director of the NIEHS to help found an Urban School of Public Health at CUNY, Hunter. Through our discussion, he reflected on the conversations that transpired among NIEHS and the NBCC at a “Brainstorming Workshop on Breast Cancer and the Environment,” held in Charlotte, NC on April 20th, 2002.

> At that time, I realized that I had met with breast cancer groups all over the country. So, I called Fran Visco, the president of the Breast Cancer Coalition and said, ‘Let’s do a brainstorming session.’ We did it the very following Saturday. At the meeting, we had representative from the National Cancer Institute,

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[3] Taken from personal interview.

> American Cancer Society, and all the breast cancer advocates and researchers we could get to Charlotte, North Carolina on such short notice.

This meeting was held a year before the May 2003 International Summit on Breast Cancer and the Environment in Santa Cruz, and the following October, Olden attended the Town Hall Meeting in Marin in 2002 that led to the formation of the BCERC. There, he promised breast cancer advocates that he would develop a mechanism enabling them to decide upon and participate in research on the environmental causes of breast cancer. In my early interviews, Olden was frequently mentioned among basic scientists, epidemiologists, and advocates as “sympathetic,” “motivated,” “a pioneer,” “effective,” “a great leader,” and “creative.” His contributions directly impacted the status of BCERC and helped establish it as a role model for environmental health research projects.

In her research on cholesterol and heart disease knowledge production, Garrity (1998) discusses the importance of “staged intersections” in certain arenas, singular events or brief series of interactions in which multiple social worlds convene, often paving the way for future negotiations between these social worlds and transformations in the arena itself. The meetings leading up to and culminating in the meeting in Charlotte constituted a staged intersection in the most explicit sense. By the end of that Saturday, participants had decided that puberty would be the topic of study. It is when breasts change the most and there was little information on breast development and the structural, biological transitioning during this life stage; there was even less research on the relationship between environmental exposures and human female pubertal development in humans. Olden explained that the topic of puberty was suggested by the advocates, after which, the scientists confirmed that it was an important avenue of research. "Everyone more or less agreed. All the NIEHS had to do was listen, take notes, and write the Request for Applications." Dr. Olden's descriptions of these initial planning meetings convey a picture of meetings where invested people all participated in the planning stages, which were marked by efficiency and cooperation. It was speedy, cooperative, and virtually seamless.

Other interview respondents affirmed that there was a good deal of cooperation and generative energy at those Town Hall meetings. For example, a COTC member from California said, "I'll never forget one of the first meetings we had. A lot of people said, 'This is interesting, this is great, this should have been done 20 years ago.'" However, most interviewees highlighted the numerous instances of gridlock and frustration that arose during the planning stages of this ambitious project and the infeasibility of incorporating multiple regions as well as interest groups. One advocate who had attended the initial meetings said, "We all like to think that scientists have all their ducks in a row, but scientists are very competitive, high propriety… I couldn't believe the rationale the scientists on the review panel gave for funding certain research over others." Although respondents voiced widespread respect for Dr. Olden as an organizer and leader, their recollections of the meetings highlighted the experimental, chaotic, and haphazard elements of the process.

An epidemiologist confided, "So, let me tell you how it was. Everyone came in with priors, their own ideas about what they wanted to do, right? Then, they learned they wouldn't be able to do that. And then, the conversation really began." An NIEHS official described the early meetings as a somewhat comical play-by-play:

> So, the advocates give a list of research concerns to the scientists, who see the list of 30 and reduce it to 5. And, the advocates say, "What are you talking about?

> The list needs to be bigger, more inclusive." And, they think the researchers are so conservative, because they say things like, "Well, we can only measure something that we know a lot about." And the advocates say, "How do we know until we get the measures?" And the scientists say, "There are no methods at all to measure this substance. That chemical is in the body for a millisecond. It can't possibly have a biological effect." And, the advocates say, "But we live in neighborhoods where we're exposed to these things every day!"

These arguments were consequential, as they impacted the "what's" and "who's" of the research. There was pressure to quickly decide upon a research trajectory, so contributors did not have the luxury of debating and promoting one perspective over another; the disagreements themselves were direct impediments to moving their project forward that had to be grappled with from the onset, and they have persisted. It is ironic that BCERC, a trailblazer in promoting thorough, reciprocal communication across divides and ensuring understanding, was "agreed upon" so hastily.

The above narrative is also indicative of the ways governmental officials in this project sometimes positioned themselves as unbiased onlookers from the BCERC's margins who occasionally took on the task of mediating disputes. Scientists and advocates also noted these mediating roles but discussed government officials as directive and intervening. An advocate from Long Island said, "I remember that Ken said, 'You can't put all these people together and expect them to play equally. We have to devise checks and balance system to tweak and change the project.'" The checks and balance system implemented was the formation of the COTC and a complicated schedule of meetings, where groups checked in monthly with other "arms" of the project as well as other regions.

The discrepancy between how NIH folks defined their own role versus the ways they were perceived by others… The ability of the NIH actors to frame themselves as neutral, unbiased onlookers – despite evidence pointing to the contrary – protects the autonomy of their actions, motivations, and agendas. It also supports a larger point in this chapter that power differences were created and maintained through a variety of strategies. These differences concern the power and complexities of deciding what's considered internal versus external to scientific research, and what gets overlooked even in attempts to show/uncover/rebalance the power differences that scientists – at least in this project – are becoming aware of.

Though several BCERC players were involved from the initial planning stages, most were recruited after it had begun. These scientists and advocates entered the scene without a great deal of knowledge of the project or research ideas on hand. "To a large extent, the breast cancer advocates were pushing this, and we researchers were dragged into it kicking and screaming," stated one basic scientist. "But, having been dragged kicking and screaming into it, I see the value now."

In contrast to this assessment of a lop-sided process in which scientists were the only ones "dragged in," I found a large number of advocates had been recruited by the NIH in a similar manner. Four advocates told me about their invitations to serve as peer reviewers due to the reputations of their organizations. One advocate described the process in the following way:

> Ken Olden took a listening tour, and he had heard about me, so he actually sought me out. My advice to him was that we needed to put all health issues in a room together, such as autism, asthma, and breast cancer, and find the common threads. Ken said it was important to look at old things in multiple ways simultaneously, to shine a light on how important centralized models are for understanding. I was eventually asked to be a working group member.

A third advocate described the rationale for her recruitment according to the individual skills she brought to the table. "A lot of advocates prefer to work with community members, not scientists. I was one of the only people who wanted to directly engage these issues with these people. I was very outspoken and was [therefore] invited to be on the review panel."

This recruitment approach was pointed out by some participants as a major weakness of the entire research project. "The RFA was structured before the researchers were included," a basic scientist complained, "which resulted in a lot of micromanagement and frustration. There were huge expectations that all of us would get integrated. There are so many different personalities, it's an experiment even seeing who is able to work together." An external reviewer said, "The teams didn't understand the expectations of the project when they formed. It's unfortunate that the teams didn't figure it out during the proposal stage, but the NIEHS and activists were pushing for collaboration. The scientists didn't know what was going on."

The frustrations emanating from unclear research expectations along with high expectations for collaboration were not entirely overlooked by Dr. Olden or other leaders of the NIEHS, including Gwen Collman and Leslie Reinlib. All officials reflected on challenges, but described them in terms of communication blocks rather than conflicts of interest. Olden viewed the frustrations as "language problems," leaving each group wondering, "Why people don't just say what they mean." He also noted the "Major cultural barriers to the way one does science." The government officials and scientists I interviewed (NIEHS officials, scientists, and epidemiologists) frequently introduced terms such as "communication blocks" and "cultural barriers." As one epidemiologist affirmed, "The main challenges have to do with realizing that people really do have somewhat different languages and levels of tolerance for different types of activities." A basic scientist commented here:

> Epidemiology uses its own language of statistics, and basic science has all sorts of jargon, so we have to think about the essence of what we're trying to communicate. The greatest challenge is communicating to the lay public. We try. Some are more successful than others, but we're working at it.

A basic scientist reflexively noted that the work he does is "very technical," and that in order to "get through the day" he uses jargon. "Then what happens is I forget what is jargon and what isn't. It becomes an impediment for communicating. I constantly have to check myself and say, 'what will people be familiar with?'"

These discussions reflect the presumed difficulty lay persons have trying to understand scientific jargon and ignored the ways in which scientists fail to fully comprehend the language of lay advocates, as well. Later in this chapter, I will discuss theories on the "democratization" (Reardon, 2001; 2004; 2007) of science by including lay participation, and how this both highlights and reformulates power asymmetries between scientists and non-scientists.

COLLABORATION AS THE OBJECT OF STUDY

Because so many BCERC contributors either embarked upon – or were recruited within - the collaborative project prior to decisions about which specific research topics would be pursued, the collaboration itself soon became a major aspect of the study people centered on and hoped to evaluate. During the 2007-2008 period in which I collected interviews, it was quickly apparent that people were more willing and able to discuss the structure of the project than the actual research being produced. I determined a few reasons this was so: 1) The molecular-level research of basic scientists is encased in its own language and relies heavily on understanding of the mechanics of specific chemicals and particles. As an example, refer to figure 3.1 to see a snapshot of the partial list of articles that were published by BCERC scientists and posted to bcerc.org in 2007; 2) The clinical/ epidemiological research was frequently discussed as “inconclusive.” Also, their data was heavily protected due to human subjects requirements concerning the girls, and in addition to this, individual epidemiologists desired to protect their rights to authorship of unpublished research, which meant not discussing it; and 3) The collaborations themselves have become primary objects of study for BCERC, which is what I am choosing to emphasize here.

Gear R, Yan M, Schneider J, Succoop P, Heffelfinger S, Clegg D (2007). Charles River Sprague Dawley rats lack early age-dependent succeptibility to DMBA-induced mammary carcinogenesis. *Int J Biol Sci* 3(7):408-416.

Jenkins S, Rowell C, Wang J, Lamartiniere C (2007). Prenatal TCDD exposure predisposes for mammary cancer in rats. *Reproductive Toxicology* 23:391-396. DOI:10.1016/j.reprotox.2006.10.004

Kariagina A, Aupperlee M, Haslam S (2007). Progesterone receptor isoforms and proliferation in the rat mammary gland during development. *Endocrinology* 148(6):2723-2736. DOI:10.1210/en.2006-1493

Lum DH, Tan J, Rosen S, Werb Z. (2007) Gene trap disruption of the mouse heparan sulfate 6-O-endosulfatase gene, Sulf2. *Mol. Cell. Biol.* 27:678-688 PMID:17116694

Moral R, Wang R, Russo I, Mailo D, Balogh G, Lamartiniere C, Russo J (2007). The plasticizer butyl benzyl phthalate induces genomic changes inn rat mammary gland after neonatal/prepubertal exposure.. *BMC Genomics* 8:453.

Oketch-Rabah HA, Barcellos-Hoff M (2007). Stroma, microenvironment and radiation carcinogenesis.. *Reviews Cancer Biology & Therapeutics* VNUN Kasid, A Haimovitz-Friedman & M Bar-Eli, editor. Transworld Research Network, Kerala, India.

Page-McCaw A, Ewald A, Werb Z (2007). Matrix metalloproteinases and the regulation of tissue remodeling. *Nat. Rev. Mol. Cell Biol.* 8:221-233. PMID:17318226

Wolff MS, Teitelbaum S, Windham G, Pinney S, Britton J, Chelimo C, Godbold J, Biro F, Kushi L, Pfeiffer C, Calafat A (2007). Pilot study of urinary biomarkers of phytoestrogens, phthalates, and phenols in girls. *Env Hlth Perspective* 115(1):116-21. DOI:10.1289/ehp.9488

Figure 3.1   Partial List of Articles Appearing in 2007 on BCERC’s Website

When I asked interviewees how they conceptualized BCERC and the project's contributions to science, respondents shared many thoughts, suggesting collaboration itself could be the project's major legacy. However, some expressed uncertainty about whether BCERC could really bring different groups together in a meaningful way or yield integrated results.

> External Reviewer: They did it right. I don't care what the outcome is on this. I love the process. It was fair and everyone learned something.
>
> Basic Scientist: I don't know what the legacy will be, but I will be interested to see what the NIEHS thinks about the success of implementing such a direct approach to collaboration. Will they say it worked? Did they get better results than if the scientists were alone in their monocultures?

A second but related theme asserted by interviewees proclaimed the successful cooperation as the major legacy.

> NIH Official: The legacy will be the changes in the scientists. Most scientists don't want to be bothered by lay people… One of the most basic of the basic scientists is now motivated to form partnerships, and he now writes about it passionately.
>
> NIH Official: This project has stimulated a lot of interest, and I think it will turn out to be a project that people will point to, years from now, that will show other groups that different kinds of expertise can work together.
> Epidemiologist: I think the connection between the scientists and advocates will be written about and appreciated.
>
> Advocate: Everyone played well together in the sandbox. This project shows the importance of passion and getting the word out in lay terms.

Again, these themes on the anticipated legacy of collaboration highlight the tension between trying to figure out whether the project is a study of collaboration, or it if is the "successful" collaboration itself that warrants the program's ongoing success.

Intermediate processes and specific successes were pointed out as well. An advocate told me, "Each year, I have seen amazing transformations in the communication. I am most impressed with how the disciplines talk to one another. It has been dramatically successful." An NIEHS official said, "They're all learning from each other, that's for sure. But, it's so ploddingly slow. The work itself takes a long time. I think we've seen the most changes in scientist-to-scientist communication. There is a lot more appreciation of the human research by the animal research and the human study side of things has added to the scientific evidence. Personally, where I think we are right now in the program, the basic scientists are learning the most." Another scientist said, "I'm always caught up in how complicated everything is. But, it's more encouraging to have a lot of other people who think it's complicated, too. And, sometimes, you get some useful piece of advice or a new direction to explore."

The current NIEHS Program Director for BCERC told me in March, 2008, "Everyone has to understand that we need to look forward together. And whether that works is the real wild card in this program." This description evokes an image of collaboration and cooperation as undergoing the scrutiny of an experimental design, wherein researchers manipulate variables to observe direct effects. Though this statement describes the results of the collaboration as the major question mark of the study, whose answer has yet to be revealed, he quickly followed this statement by saying that the collaboration "has actually been a success. Scientists, advocates, and members from the community are moving this whole project forward." On the one hand, the collaboration is one of the most remarkable contributions of BCERC. On the other hand, to say it is too early to tell whether it has been successful undermines the original justification for the project: explicit collaboration.

Claims about effectiveness in communication were contested. One COTC member told me, “I spend the bulk of my time interacting with scientists and lay persons, and it’s really a natural manifestation; an organic going-back-and-forth process. The idea about integrating research findings though, it’s really just lip service for the most part. It’s a huge step just to have any communication across the divides.” Several interviewees mentioned that “transdisciplinarity” was a post-hoc term or simply did not accurately reflect the structure and process of BCERC. A COTC member who agreed to an informal interview we conducted during a banquet at one of the national conferences told me, “This project is all about process. That’s how it’s been set up, and that’s what’s interesting about it. The downfall is that they’re using the word “transdisciplinarity” the way hard scientists do. They make it sound like the content is driving the interactions and research results, but that’s totally off-base.”

In 2008, “transdisciplinary framework” was added the BCERC website, suggesting it was a major component of the research project. By January of 2009, the first sentence on the BCERC homepage read, “The Breast Cancer and the Environment Research Centers is a network of four national centers created in September 2003 by the National Institute of Environmental Health Sciences and the National Cancer Institute to support transdisciplinary teams of scientists, clinicians, and breast cancer advocates.” The word transdisciplinary was the only bolded word in this sentence, and the entire introduction is in contrast to earlier versions of the website, which had focused more prominently on studying environmental toxins, puberty, and breast cancer.

IMPLICATED ACTORS

Implicated actors (Clarke & Montini, 1993; Clarke, 2005; Clarke & Star, 2008) are those places, institutions, objects, individuals, or social groups that are constitutive of a given situation yet are strategically silenced or rendered invisible in it. Such erasures are due to the marginalization of a group or the lack of available platforms to foster expression or acknowledge the participation of the full range of contributors. Frequently, the silencing itself is crucial to a given configuration of the situation at hand. In such instances, the un-silencing of implicated actors might rupture inter-organizational ties, challenge taken-for-granted assumptions about the "nature of things", or otherwise disrupt the work and practices of actors representing one or more invested social worlds. There are at least three kinds of implicated actors: Those who are crucial to the situation but not present, those who are physically present but silenced, and those who are "solely discursively present" and "constructed by others for their own purpose" (Clarke & Star, 2008: 119).

Across all interviewees, "regulators" was the most prevalent response to my two-part question: "What group of people would you like to see involved, if there was 1 extra group added?" and "Who, if anyone, do you think is missing from the BCERC conversations?" Regulators can be thoughts of as implicated actors in the first sense: those who are crucial but not present. A scientist elaborated in the following way: "We scientists still have a very vague concept of how regulations are made. The lawyers, the politicians, the officials… It would be worthwhile to understand how that information gets used, because that might influence how we gather the information. We have so little control over how that information gets used." There was a sense that the regulators were the ones who really effect change in a direct sense, that scientific research is encapsulated until some other group or professional organization chooses to – or is convinced to – take on the issues and formulate actual policy.

"Regulators" referred to representatives from organizations such as the Environmental Protection Agency (EPA) or the Food and Drug Administration (FDA). Regulators are implicated actors due to a lack of available platforms (and incentives) to draw them into research and discussions about implementing policy measures. All of the regional and national meetings I observed had concluding "Questions and Answers" panels in which conference attendees could address questions to the BCERC steering committee. That committee was predominantly comprised of NIH officials and epidemiologists. The most frequently raised questions at all of these meetings resembled something along the lines of: "Is this information making its way to governmental regulating bodies?" At the 2008 national meeting, NIEHS officials who were fielding questions from the audience explained, "We're always trying to bring policy members to meetings, but we just haven't been able to pull it off." Another said, "I'd love to see this goal pushed forward as we push forward." A third official dismissed the concern: "We're a data collection organization, not policy makers." A fourth panelist switched the question around to discuss how BCERC might participate in conversations among regulators, rather than attempting to draw regulators to the BCERC: "Individual researchers have been called upon to advise regulators based on the findings of the BCERC, which is increasingly held in high esteem. Several members of our working group are asked to testify on cancer panels." Collectively, these four answers emphasize what seems to be an uneasily traversed boundary between research and policy and regulatory representatives. There was also a tone of deference toward regulating agencies by researchers, notable by the difficulty BCERC members had drawing regulators to their own meetings, along with the pride BCERC members expressed in response to invitations to serve as advisors on review panels.

However, I believe that the true phantoms of this study are the “community.” BCERC participants have mobilized through the goal of translating findings from scientific research to the “community”, and yet they do not describe who or what constitutes the community. Within BCERC discussions, it is not immediately obvious that the group is not present, because the community is continuously addressed. The scientific encapsulation of BCERC was caught up with constructions of the “community.” The presence of this group was omniscient and invisible throughout BCERC events, nearly phantom-like. All of my interviewees referred to “the community”, yet no one – aside from 1 interviewee – identified one’s self as a “community member.” I asked several respondents to define “community” for me. An NCI official said, “You ask how to define community? I couldn’t tell you. I think it comes from ideas about families and neighborhoods, merged with preexisting advocacy centers. Quite frankly, ‘community’ is a term that carries meaning at the institutional level. The term has organizational purposes, not practical, applied ones.” Terminologically, “the community” was frequently enlisted to refer to the bigger picture and landscape that gave rise to the BCERC. It was discussed as both the impetus for and eventual receptor of this project. And yet, “the community” was voiceless and faceless. An external reviewer described the dynamics in the following way:

> There is an important but frequently skimmed over difference between advocates and community. The advocates want information for political purposes to help

> them “fight the good fight.” The community wants information to improve neighborhood health directly. Obviously, the kinds of information these groups are seeking are somewhat different. Advocates need numbers, statistics, and documentation. The community wants practical, useable advice. Community is supposed to be the target audience for advocates doing outreach work, but outreach has different meanings for different groups. The lay community needs tend to be very general, such as wanting information on accessing services and health care. So yes, there are different expectations about “outreach” based on the stage at which people joined. There were a select few who wrote the RFA, a larger number who helped write proposals, and many more who were pulled in later, once the project was set up.

A Bay Area advocate who was also a COTC member relayed the following to me:

> A: Marin County, SF County, and Alameda County comprise our “community” for the BCERC project. So, it was very general. It was also defined by, “Anyone who lives in those counties who had an interest in breast cancer and preventing breast cancer.”
>
> I: So, essentially, the Bay Area researchers are defined as the community as well, since they’re living in those regions and they’re interested in breast cancer?
>
> A: Right, right. It’s a really broad definition of community.

Later in this same interview, she said, “Some point out that this isn’t truly integrated research because the community didn’t define the question.” I asked her, “But they did, didn’t they? In the Town Hall Meetings?” To which she adamantly responded, “Yes, they did! It just wasn’t at the local level. The original questions didn’t come from the general community, it came from professional advocates.” She went on to explain that her group was trying to include more general public audiences. “We try to arrange our agenda to try to draw in different people and new groups and stakeholders. Last year we marketed weekend events to different community groups, but nobody wanted to come on a Saturday!” Her statements capture the frustration among advocates in BCERC who are simultaneously constrained on the one side by the NIH officials expecting them to “reach out” to the community, and on the other side by a “community” who is hard to locate and engage.

In Cancer in the Community, Martha Balshem (1993) draws on her own experience as a medical anthropologist and a cancer health educator in Philadelphia to analyze the complex dynamics that prevent cancer health educators from being fully empowered, autonomous, and from truly advocating for the people they are employed to represent and assist. Through her investigations of views on causality and gaps between medical professionals and patients/community members, Balshem described the structural guidelines and limitations placed on health educators. She concluded that ultimately, these limits result from the fact that health educators and advocates working within biomedical institutions are accountable to and constrained by medical authorities.

Although knowledge claims and influence are exerted by lay groups as well as clinicians and scientists, the balance between groups is unequal vis-a-vis whose knowledge and perspectives count as “legitimate” and who is meant to be educating whom on health risks. Medical authorities have an upper-hand, largely because they can enlist more people by offering better-paid positions and building a workforce. Balshem explains how people in the community pointed to the environment and fate as causing cancer, whereas medical authorities – and hence, the educators – prioritized lifestyle-based preventive measures and interventions. Because educators were supervised by medical professionals, they sometimes abandoned or patronized lay epistemologies. I observed similar dynamics between BCERC NIH officials and advocates. Yet at BCERC, the community is less visible and certainly less proximal than the patients/community members Balshem worked with. It is constructed by NIH as present and quite well accounted for, and since the community is continuously addressed, it is not immediately obvious that individuals from the community are not self-representing. Scientists and advocates discuss the community in vague terms, bringing to mind visions of an omniscient social medium that needs and gives rise to the scientific research, and to whom the benefits return.

THE ADVOCATE/ACTIVIST DISTINCTION

The collaborations between researchers and advocates produced power dynamics, competition, and silencing, but they also highlighted the ambiguous roles of advocates in a wider sense. In this project, the advocates raised the initial concerns, helped structure and write the RFA, and deliberated with scientists about what should be researched. To understand what distinguishes research from advocacy, and how these boundaries are constructed according to the circumstances at-hand, I examined how advocates are positioned in this project, defined both by themselves and by others. I also examine how contribution is applauded or lamented based on the goals and purposes that various actors promote.

As mentioned earlier, most of the BCERC advocates are professionals. Yet, at times they also represent the murkier categories of lay participants: advocates, activists, and the community. While it might seem that these three terms could be interchangeable, each name serves distinct – and largely unspoken – purposes in the BCERC. Of the 3 groups I differentiate between, advocates are most heavily and centrally involved in BCERC. Many of these advocates are professionals who want to integrate within science research projects and publish results (such as Zero Breast Cancer), other advocates are already published authors in public health and health communication journals (such as advocates who are employed within county-level public health contexts), and others are dedicated to pursuing legislative aspects of breast cancer research and activism (such as the NBCC). These forms of participation in science differ considerably from efforts pioneered by those who self-refer as activists, who were described themselves as more radical. Beginning in the early 1990's, breast cancer activist organizations directly and indirectly led to the institutionalization and professionalization of breast cancer advocacy, such as the NBCC.

The presence of lay participation is a major reason BCERC can claim to be conducting cutting-edge research. Scientists made this point most often, remarking on the importance of their inclusion within the research model: "This was a great example where the science was directly traceable to the public concern." Others reported that painting the project as a community-initiated affair was misleading, and the cooperation was artificially constructed. A basic scientist attributed the lay inclusion to mandates set up by the NIH: "They wanted the community to have a voice, but I'm not sure all the scientists are buying into it." Some of the scientists were admittedly uncomfortable with advocate inclusion. One scientist confided, "When this first came about, one of my colleagues summed it up very well: 'It's going to be a pain dealing with these outside people, but then again, it is 7 years of funding.'"

In interviews, advocates did not mention how their presence contributed to the public image of BCERC. Instead, advocates were concerned with directing, producing, and communicating research findings. Many advocates raised the importance of authorship. An external reviewer for BCERC who was also a breast cancer advocate remarked:

> There is a lot of tension on the part of the advocates, especially those who are also serving as COTC members. They are asking, 'How can we be authors?' The scientific community doesn't see the COTC folks as having authorship, but the advocates and community are the ones making the novel contribution to this project. They have sought money to make booklets and found ways to publish about breast cancer communication.

Most of the advocates I interviewed had earned bachelor or master's degrees in fields related to health advocacy, like education, public health, social work, and nursing, and so they were and protocols of academic research.

One advocate said the "major problems" in BCERC stemmed from competition among the scientists. "It's hard to get things published across divides, because everyone is critical and people don't want to share. Publications – the way they're handled now – cannot be the yardstick or reward for research." A director from a prominent breast cancer organization and one of her employees shared their experiences with me in a joint interview format. The director noted that the BCERC advocates are "frustrated" with how long scientific research takes. "Our advocates want to be part of the process, but it's hard to integrate in a meaningful way." Her colleagues elaborated, "We're trying to produce educational materials based on the research, but there isn't much to report on." Her supervisor followed up by saying, "It's a struggle to do this kind of work. You have to want to do this. You have to be committed." One feature of the work commitment is, in fact, efforts towards becoming formally recognized as contributors to biomedical research, often through authorship.

I interviewed one self-proclaimed activist from Long Island who at one point also referred to herself as an "advocate by accident". Her early career had been in real estate. When she was diagnosed with breast cancer in the late 1980's, she became furious about the inadequate and sexist ways women's health is handled by medical and other research institutions, and she ambitiously set out to exert whatever constructive change she could.

> There was no cancer in my family, and I was a devoted athlete. I was low-risk. It came as such a shock… I wanted to make a difference and work to get more information out there on how to prevent breast cancer, but at the time, all the breast cancer groups were coming together to improve patient care. I knew I didn't want to be a nurse.

She said she didn't think of herself as a feminist before that point, but that quickly changed after her experience as a breast cancer patient and ensuing frustrations with the limited scope of breast cancer activism at the time.

> I wanted to end the cycle of women doing public health movements focused only on breast cancer and within that, only on patient care… The real issue isn't even about breast cancer, I don't think… It's about the demon I confronted when I was diagnosed. For the first time, I saw how vulnerable I was to a system that doesn't care about women's health. As women, we don't get the answers and resources we need.

She said her group was automatically perceived as "fringe and radical," because they weren't focused on patient support. "Our goal was to focus on prevention and keep successes local with hopes we would make a difference nationally." They conducted their own survey research on breast cancer in the area and were quite successful. When NCI first asked if she would serve as peer reviewers of a grant they were reviewing, she was "thrilled". Her group discussed this internally and decided to participate but only after inviting representatives from NCI to meet them in Long Island. When NCI accepted her group's request, the activists automatically began making phone calls, searching for and racing to reserve "the most elite boardroom" they could find "to show them we were powerful." With laughter, she joked: "I used my experience in real estate to our advantage… sealing a deal depends on location, location, location."

This story of moving from activist to collaborating with the NIH explained why she now called herself an "advocate by accident." She clearly understood her position as something between – or on both sides of – an activism and advocate. Another way she explained it was: "We were virtually thrown in [to the NCI and later to the NIEHS]… It wasn't predesigned. But it wasn't by accident either."

Her statements and interview depict the ambivalent and paradoxical views she has developed about being pursued by researchers from the U.S. government. At times in the interview, she expressed opposition to mainstream, sexist medical research; in other instances, she bragged about having been recognized and sought out by representatives from these very same organizations. Later still, her tone was humble and perhaps even apologetic about the partnerships, remarking that her group was "thrown in" to the NIH and that it wasn't "predesigned." Despite her vigor and enthusiasm, I found it heartbreaking to observe her conflicts about being dedicated to her oppositional, feminist organization while also deeply wanting to be recognized, respected, and legitimate in the eyes of NCI. And yet, I was also intrigued by her ability to express the in-between and both-ness she inhabited within the fields of radical/fringe and institutional medical research. In retrospect, the most striking part of the interview was how she identified as an "activist" (which she still embraces) who had also become an "advocate by accident" somewhere along the way. Although I was not aware of the significance of this labeling at the time of our interview, through subsequent interviews and analyses I observed that BCERC members use the term "activist" to refer to grassroots, community organizing work, and this differs from work typically undertaken by "advocates". A self-proclaimed advocate I interviewed from the Bay Area grappled with how her group's newer commitment and identity as professionals contrasted with the grassroots activist formations that originally had established their groups.

> In our organization, our original founders were activists. Really, they were environmental activists before they were breast cancer activists. In the beginning, the group participated in "Toxic Walks," and they would do demonstrations at Chevron and organize boycotts. They were a very political group, and they were not very… well, let's just say they were focused on anything that came up! They were very much environmental activists. And the problem is when you get involved with research – which is the way our organization decided to go – you have to become somewhat more conservative. It's kind of a tradeoff, you know? We've become much more conservative.

> We're not an organized group of community members, we're professional. But we were that! You see, that's the whole point of getting involved, to build community and organizational capacity. So, that's why our involvement with BCERC and other large organizations is a success. We've built community capacity, and when we started, there was no money coming in for research. No one was aware of the high rates of breast cancer. There were no education programs. We fought with Marin County to do something about breast cancer, but it was 6 years before the county did anything. I mean, really, even now, that department is running out of money. The whole question is: How do you get the information out, and how do you do good public health? It takes time. It takes longer than the grants actually run.

Scientists described the advocate participation favorably, offering terms like "Knowledgeable" and "dedicated." An epidemiologist serving as an external reviewer for the project said, "They're not intimated, and they're very important to their study." However, he quickly followed this statement by admitting, "I don't know what their projects are, exactly, but I think that's because there's often nothing to report on, which means they have to focus on education and outreach." Scientists repeatedly emphasized how smart, reasonable, agreeable, and patient the advocates were. Another epidemiologist said, "The advocates involved are really good. They're smart about science, they take reading seriously, and they've taken real responsibility to communicate and evaluate the process." They offered these adjectives as compliments and seemed to assume that anyone (including me, as the interviewer) would agree that these are favorable qualities for women's health advocates participating in science. However, hidden not too far beneath these assessments was an unspoken list of what the advocates were not, and should not be in this venue: irrational, demanding, insistent, or rowdy.

Democratization

In joint meetings, I observed several moments when the directors and organizers, all of whom were researchers and government officials, made comments that highlighted the researcher/lay audience divide. "I always try to tailor my messages to the level of the audience I'm talking with, and as scientists, we don't do that enough. But we need to, we need to be able to sell our science and understand who our customers are." An epidemiologist similarly explained,

> When we, as scientists are sitting in a room talking to one another, we tend to forget the larger context. Even with a public health perspective and broader societal awareness, we tend to be somewhat insular. To have someone sit there and say, 'Maybe this is cutting-edge science, but I just can't see how it's going to be relevant to me as someone who wants to prevent breast cancer' is important, even if they don't totally understand why the scientists might be interested in something.

In response to a question put forth by an advocate at a regional BCERC meeting about how to bridge the gap between "precautionary approaches in policy" versus "certainty approaches in science," the meeting organizer, who was a scientific researcher, said, "We're not trained to sort that out. We don't even know which areas of knowledge to focus on. Basically, we need your help to do that." Statements such as these served several purposes. On the one hand, they validated the incorporation of advocates into the project. This was important given the great deal of frustration among advocates about how to meaningfully contribute to research or outreach, given the technical, slow, contested mechanics of scientific research and ambiguous nature of who should be performing which tasks within the project. Second, by naming and claiming their own blind-spots, researchers and government officials carved out some "breathing room" to carry on with research without having to be culpable for social or ethical consequences. By incorporating an entire wing of the project devoted to these issues, scientists could be assured they were taking responsible measures. However, in order for these relationships to play themselves out and guarantee that everyone maintained an important role in the project, there had to be a shared language for describing who the recipients of this responsible science might be. Notions of "the community" captured the spaces characterized as "not science."

Irwin (2006) points to a few key aspects that tend to be emphasized among large research or institutions attempting to make science more democratic: a) rebuilding trust in institutions; b) operating in a transparent manner; c) engaging with wider publics; d) creating a "situation in which direct dialogue becomes a normal and integral part of the policy process" (299). Although movements towards democratization are conceptually appealing to many, results become complicated and are rarely idyllic when put into practice. Bell (2003) describes the steps and processes of microbicidal research that was designed through partnerships between women's health advocates (WHAM) and the Population Council, a non-governmental agency (Rockefeller) that had previously organized around population control, but never STI-prevention concerns. She argues that this collaboration marks an important step in opening up dialogues between groups, but that science is far from being democratized. International inequalities and complexities of women's health concerns are still poorly understood by most research agencies and scientists themselves. In this instance, WHAM feared contributing to oppressive formats of development.[4] In turn, the Population Council was taking a risk by embarking on new research processes and topics incongruent with their earlier approaches.

Boundaries are drawn not only between scientists and advocates, but are constructed in ways that keep regulators and general "community members" on the periphery. It is not always clear how these boundaries are negotiated and what characterizes the distinctions made between the groups. These questions provoke an analysis of the "effectiveness" of lay participation in biomedical science projects as a democratizing measure for encouraging more socially relevant and responsible scientific research. Jenny Reardon's (2001; 2004; 2007) notion of "democratization in biopolitics" becomes useful here. She argues that the incorporation and politicization of lay persons within controversial scientific research may actually depoliticize many issues, because it creates a false distinction between science-as-neutral and community-as-political. This distinction, she asserts, allows scientists and the protocols of scientific institutions to avert responsibility for ethical and political decisions and veil the ways in which judgment calls are intrinsic to scientific practices, with or without lay input.

Reardon (2004; 2007) theorized that efforts to democratize science by consulting with ethicists, advocates, and community members have furthered attitudes and practice that position science as inherently lying outside social responsibility, simultaneously positioning scientists as professionals who lack the ability to be self-reflective.

> Too often, passionate calls for democratization take the place of substantive analysis of what democratization might mean and how it happens… If we seek to build a science that better serves human ends, then it is not enough to understand

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[4] See also Adams & Pigg (2005).

> how human concerns and interests shape scientific ideas and practices. We must also understand how scientific ideas and practices help form a people with common concerns and interests" (253-254).

While Reardon's arguments discuss how science uses lay panels to insulate its own techniques from ethical or social self-scrutiny, I argue that it is useful to look at the multiple levels at which this occurs, shedding light on matters such as: why are advocates, activists, and community members – all of whom comprise the "lay audience" – participating in research in such varying ways?

In fact, it is the relationship between researchers and professional advocates – hierarchal as they are – that conjointly construct the "community" as an audience and silent listener that is at once in-need and whose moral judgments are pure, free of scientific cynicism. As one scientist remarked, "This is policy, this is politics, this is values, and somewhere down here, there's a little bit of science."

CONCLUSIONS

The BCERC is being pointed to as a pilot study in some respects, an exercise in innovative collaboration meant to pave the way for future research collaborations. And yet, it is having to reestablish itself throughout the process and admit to considerable uncertainty and an open-endedness both about research findings and the feasibility of conducting scientific research that is not yet established or financially protected. In particular, in seems as though three unknowns about the future rest on this research project: How do advocates and community members contribute to the research?

Here, I examine "collaborative research" as an ever-transforming object of analysis. Thus, rather than simply locating the sites of collaboration, I ask why cross-disciplinary studies are important to biomedical research at this time, who brought them to foreground, and what this set of studies looks like in concrete practice.

My arguments are in conversation with ideas put forth by Callon (1999) and Callon and Rabeharisoa (2003). These authors discuss the values, processes, and technologies of scientific collaborations. Other scholars (Shapin, 1995; Bell, 2003) have more explicitly assessed the outcomes of collaborative research, drawing attention to the ways different micro and macro structural patterns of communication produce various results. In contrast, I analyze how participants in BCERC describe the organizational and ideological components of "collaboration."

Most interesting is the way the breast cancer advocates are being positioned and positioning themselves. On its website homepage, BCERC is described to consist of "teams of scientists, clinicians, and breast cancer advocates." Closer looks show that within the realm of "advocacy," there are multiple and fairly distinct groupings: community members, activists, and advocates. My research investigates how, when and whether lay participants distinguish themselves from one another. For those researchers and advocates central to BCERC, it is extremely clear that BCERC's professional advocates have a great deal of responsibility and possess a certain research finesse that are not consistently found across members of groups who are recognized as "community collaborators". As I collected data, it became clear to me that the relative ease of the collaborations and initial successes of the program was partly due to the high levels of professionalism among the advocates, who have skills such as grant-writing, producing polished newsletters, and conducting themselves with ease during formal meetings and conferences. This was not an entirely different dynamic than those found among basic scientists and epidemiologists: those who were most central to the project were – on average – more established, professional, and well-known than the scientists on the periphery. In some ways, this is a common dynamic within all complex groups that rely on formal systems of leadership. The difference with the "advocates" was that aside from those who are privy to the workings of BCERC, it is not at all evident that there is a distinction between "advocates" and "activists", yet the differences are quite crucial to the project. I did not grasp the distinctions until I had been in the field for several months, and I still struggle to understand the ways in which various advocacy and community groups work with one another and with the scientists. I believe one reason these hierarchies are not self-evident is because advocacy is frequently thought of as a "bottom-up" endeavor, whose leaders are merely spokespersons on behalf of their people rather than exerting power over the larger community. In contrast, institutional science is more readily perceived as a bureaucracy ruled by a select few who possess more authority, seniority, and/or prestige.

Even within and among BCERC members, the distinct purposes of advocates, activists, and community members become lumped within a shared category of "community," and in those cases where "advocacy" is used, there is no additional, overt clarification about who exactly is being referred to. I have attended many of BCERC's meetings over a period of 3 years, and based on hours of observations at public meetings, close readings of pamphlets and websites produced by BCERC, and interview data, I do not have data leading me to believe that its members are trying to remain unclear about who the "community" and "advocates" are. I suggest that a "naming" process is emerging through BCERC and perhaps also in other research projects or contexts in which activists have become professionalized. I offer this advocate/activist/community distinction, because they were the terms most frequently used by interviewees to differentiate the purposes of one group from another.

While collaborations themselves have been consequential for the content of research pursued in the BCERC, Chapter 3 focused on the primacy of collaborative negotiations and arrangements as ends in themselves. I analyzed how different BCERC players bring issues to the table, and how this may both reflect and configure relationships of power and biomedical hierarchies. As such, “a collaboration” cannot be accurately understood as a rigid structural object, and BCERC scientists and advocates described the collaborative aspects of their project as flexible and uncertain and subject to multiple interpretations.

Undoubtedly, the research findings also influence the terrain, conversations, and collaborations play out. I chose to approach “collaboration” in Chapter 3 and “content” in Chapter 4, because that was the order through which: 1) BCERC was formed - - as stated earlier in this chapter, the impetus for the collaborative research project preceded decisions about what would be studied; and 2) I became familiar with the data and concepts. The topic of collaborations and their processes comprised the brunt of my interview data and they were easy to observe at BCERC’s meetings.

Many aspects of research, science, and health are being jointly negotiated as a result of the pioneering efforts to understand interactions between environmental exposures, development, and breast cancer risks. Studying these issues first requires organizing new tools and models to measure the presence and effects of potential carcinogens, both in the environment and in people. It also requires devising theories as to why certain life stages, such as puberty, may be conceived as developmental windows of vulnerability in which exposures to momentary or cumulative chemical substances are particularly likely to result in cancer later in life.

In Chapter 4, I discuss how BCERC advocates, basic scientists, and clinical scientists engage the research per se within their specific professional contexts, as organizations, practices, and products of scientific research are always inextricable. How are these research findings being shaped and interpreted across groups in BCERC? Are understandings of women's health across the life course being redeveloped in light of concerns about environmental toxins and breast cancer? Chapters 4 and 5 address these questions.

CHAPTER 4: MANAGING UNANSWERED QUESTIONS AND CONSTRUCTING “WINDOWS OF VULNERABILITY”

> Within the epidemiology groups, there was a lot of discussion over a long period of time about which biomarkers are feasible and cost effective, appropriate, measurable… Do we know if any of these girls have any of these exposures? Or, what if we measure them and they’re all undetectable, because they’re children? We didn’t know anything about this age group! There is no national data that says anything about what the normal levels are. What’s normal? How do you decide what’s normal? We are so at the beginning stages of this. There is no normal. We don’t know the distribution. But we kind of vaguely know we’re looking at estrogen and chemical levels (NIEHS official).

Clinical research on the life course has long captured the attention of scientists and the public, and medical inquiries and conjectures on the events and risks of ‘adolescent girlhood’ in the U.S. trace back at least to the 1800’s (DeLuzio, 2007).[1] In other words, contemporary biomedical scientists are not the first to frame puberty as important avenue of research. However, erupting concerns about the lowering age of onset have provoked media frenzy about early puberty in girls, which in turn has generated a “flurry of research” (Ginty, 2007) on causes of and events at puberty. Simultaneously, there has also been a push among some biomedical scientists and epidemiologists to find new ways of talking about risk across the life course in more finely-honed process-oriented terms. In this chapter, I describe how 20th-century research findings on breast cancer risk factors led biomedical researchers and breast cancer

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[1] Refer to chapter 5 for a more in-depth discussion on the life course, gender, and constructions of puberty.

advocates to collaboratively research environmental exposures and their effects at puberty. This research formed the basis for The Breast Cancer Environmental Research Centers (BCERC), which houses some of the most collaborative biomedical research to-date. [2]

Two important questions for BCERC members are: 1) How do events at puberty relate to breast cancer later in life? and 2) Why are so many girls in industrialized societies beginning puberty earlier? In the BCERC, a key goal for researchers and breast cancer advocates has been to integrate their research in ways that could be framed as a unified pursuit, despite fragmented and often conflicting aspects of the multiple projects that make up BCERC. Ironically, attempts to synthesize existing knowledge on breast cancer risk, fill in the gaps, and reconcile contradictory disciplinary perspectives has actually landed BCERC members in the somewhat tangential yet publicly appealing research terrain of exposures, puberty, and vulnerability.

"What continues to be a controversial study," stated an advocate, "is that some people look upon this as a breast cancer project, others want to focus on environmental toxins, and other collaborators see this as a puberty study." One of the research questions of this dissertation is: How did this come to be?

> The BCERC name sounds all-encompassing, but it's actually very narrow. We pushed to get more information on breast cancer and pollution. They pushed for gene-environment research. The compromise became: Which topic will motivate the largest number of people to get involved? There is a widespread interest in studying the pubertal age, because they're children, because of prevention. And, lot of people are concerned about early puberty and the environment (BCERC advocate).

The BCERC could have anchored its central research questions to any number of pivotal unknowns about environmental exposures and breast cancer risk. For instance,

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[2] Refer to chapter 3 for an analysis of negotiations among interest groups who launched BCERC in 2003.

investigations might have been organized around studying the effects of a discrete number of environmental toxins, which would still allow for the full range of collaborating players and geographical regions. Or the project could have looked further into why other life events correlate with breast cancer risks, perhaps investigating why breast cancer rates tend to be higher among women who have never been pregnant or among those whose initial pregnancy was later in life. According to reports on these correlations, number of and maternal age at full-term pregnancies are stronger predictors of breast cancer than is the age of menstrual onset.

To account for this chosen direction, I argue that the broad interest in researching puberty is: 1) Partly a result of the goal to study unknown risk factors in breast cancer, which relates to larger preventive health research agendas. But puberty is also: 2) Embroiled with many issues and questions that currently captivate biomedical researchers, such as how to understand racial/ethnic disparities in age at onset, where and whether to draw boundaries between genetic and environmental risk factors, and why interplays of risk factors exert influence and produce effects at different stages of life.

> It is known that the age of first menstruation is a risk factor. We have that one solidly nailed. But general concepts in toxicology, such as windows of vulnerability and certain times in a life course are emerging areas we are beginning to get some information on (BCERC external reviewer).

Thus the turn to puberty would to some degree, place the BCERC at the cutting-edge of the environmental health sciences. This generated initial commitments to participants and has helped sustain the project over time and across its diverse participants.

Increasingly, scientific and media venues - - including the BCERC - - are beginning to discuss puberty as one among several significant “windows” of vulnerability. Theories on “windows of vulnerability” (WOV) have been prominent in military literature and computer science, and have also been used to discuss the optimal timing to administer vaccines (Arbaugh et al., 2000; Ferris et al., 2008). Within life course research, toxicologists were among the first to coin “windows of vulnerability” as a way of capturing the specific theory/phenomenon that people at certain stages of life are more susceptible to toxins, and that effects of these toxins are often delayed (Faustman, 2000). “Windows of vulnerability” is often used interchangeably with the term: “windows of susceptibility”. In this dissertation, I use “windows of vulnerability” to highlight the cultural constructions of puberty as a chaotic, precarious stage of life.

Environmental exposures, which are broadly defined to include chemical, social, and psychological influences, are thought to exert stronger effects that can translate into health problems in adulthood including breast cancer. The most striking support for the idea that girls are more susceptible to carcinogenic exposures at puberty comes from observational research on radiation exposures during early and late childhood. Girls who were under age 20 when the United States dropped atomic bombs on Hiroshima and Nagasaki had 27% higher incidence of breast cancer than girls who were not exposed. Among grown women who were exposed to the 1945 bombings, their breast cancer rates were only slightly higher than other women their age. This increased incidence was far less pronounced among women whose exposure occurred after age 30 (Tokunaga et al., 1994; Land, 1995: 404). Similar age-related patterns were found among girls and women living near the radiation contamination site of Chernobyl in 1986 (Pukkala et al., 2006). In the latter part of the 20th century, American girls who were exposed to medical radiation as teenagers developed cancer (including breast cancer) in large numbers, but these higher rates were not found among women who had undergone radiation treatment as adults. These reports come from longitudinal studies on scoliosis, Hodgkin's lymphoma, and Tuberculosis (Morin-Doody et al., 2000).

Basic scientists, epidemiologists, and advocates have all contributed to the "window of vulnerability" in their own ways due to this line of reasoning. Yet the scientific theorizing is largely coordinated by epidemiologists who head the clinical study of exposures and puberty which has attracted considerable public attention. Epidemiologists are often asked to explain these research findings to groups such as: bench scientists, advocates, clinicians, external funders, politicians, and spokespersons for public media venues. The fundamental questions for this national study were all also framed at the population level. For these reasons, epidemiologists figure prominently in this chapter.

This chapter describes and historicizes epidemiology in regards to scientific knowledge about age, race, and exposures as they have been conceived through epidemiological research on puberty and breast cancer. In the BCERC project, the decision to study was made rapidly, but it was also done based on numerous scientific understandings – and question marks – about why events at puberty might provoke or protect against breast cancer later in life. During the initial stages of BCERC's development, NIEHS officials, BCERC researchers, and breast cancer advocates searched for an overarching research question that would further laboratory and clinical research within a preventive framework. The epidemiologists, as directors of the clinical research, have in many ways become situated between BCERC groups who have divergent philosophies on prevention and women's health research. For instance, health care providers and policy workers frequently rely on scientific data that can correlate (if not explain) dangers, harms, and risks to children and adults. Epidemiologists then are often responsible for interpreting and conveying research results, acting as spokespersons and translators for several invested social worlds. Those epidemiologists who explicitly focus on preventive research (as do all the epidemiologists in BCERC) are funneling resources towards answering questions on the variant, age-specific, internal, and external triggers of breast cancer. Studying these relationships requires models and tools for studying change itself, and I describe the work this entails.

The second part of this chapter takes up how BCERC is carrying out studies on toxic exposures, puberty, and racial differences through a large, longitudinal study that follows approximately 1180 girls across three regions (New York, the Bay Area, and Cincinnati). There are roughly equal numbers of African American, Asian American, Latina, and white girls enrolled, all born around the turn of the millennium (currently about 9 years of age). My observations at BCERC's Bay Area clinical meetings (called Cygnet) revealed a few of many difficulties researchers face as they attempt to correlate the effects of poorly understood chemicals that lack standardized thresholds of safety, with subjects who are moving through early adolescence. Both exposures and puberty are classified on tentative, speculative grounds; few agreed-upon tools are available to differentiate girls from women, and even fewer standards exist regulating how and when "normal" progression between these life stages should occur.[3] BCERC researchers are not only faced with decisions about how to describe the transition from childhood to adulthood within scientifically legitimate understandings of time, development, and sex,

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[3] The one exception is the "Tanner scale", developed by English physician James Tanner in 1969. This staging system classifies boys and girls into 5 supposedly distinct stages of puberty based on external genitalia, breast size, and the presence of pubic hair. See Chapter 5 for more detail.

but they are also trying to measure and make claims about "moving targets," since their participants age each year. Meanwhile, the ultimate goal is to learn and report something about how all these fluctuations provide insight into which environmental exposures, lifestyle factors, and racial and socioeconomic disparities relate to breast cancer, and how they do so.

The collaborative aspects of BCERC have certainly been pointed to as the most outwardly remarkable part of the research project. But digging deeper into the actual practices of these health-related biomedical webs of knowledge, it becomes clear that the transdisciplinary, transregional organization of BCERC is inextricable from the research directives and hypotheses about breast cancer risk. At the 2008 BCERC annual meeting, one scientist on a question and answer panel remarked, "There are no studies as complex or extensive as this." Other panelists nodded in agreement, as the first panelist elaborated, "It's the first to look in detail at environmental exposures and pubertal development."

Despite interest in collaboration for its own sake and how BCERC participants point to their model of collaborative organization as their main contribution to scientific research to date, questions and concepts are actually mutually generated, negotiated and pursued by scientists, advocates, and other invested social worlds. In turn, the flows of research procedures and findings reconfigure the objectives of each participating social world and influence the overall organization of these groups. To produce a full analysis of this situation, all of these factors need to be specified. As Clarke (2003; 2005: 30) explains, the "so-called contextual elements are actually inside the situation itself. They are constitutive of it." By looking at the interplay between collaborations and research results, neither one can be seen as containing the other, but rather, they are wound up together. In other words, "There is no context" (Clarke & Star, 2008: 128).

CHANGES IN EPIDEMIOLOGY

The "epidemiological transition" refers to the changing thrust in epidemiology and public health from addressing acute illnesses to researching and intervening within chronic diseases. In the 19th century, mortality and morbidity rates from acute diseases began to decline in western societies. As chronic diseases gripped larger segments of the population, scientists began developing new ways to measure, understand, and treat conditions that appeared to arise as a consequence of complicated combinations of numerous situational factors, via patterns that differed across and within populations. By the end of the 20th century, when microbiology came into prominence, many epidemiologists developed a "risk factor" orientation towards studying disease. By isolating certain risk factors, one could make predictions about – and therefore potentially prevent – the disease burden within a specific population. However, this focus has led some epidemiologists to become less concerned with population health in a broad sense and more concerned with investigations of "risk groups", such groups are defined not only on traditional demographic factors of epidemiological interest such as race, class, gender, and age, but also group according to behaviors and lifestyles (Frankenberg, 1993).

Frankenberg (1993: 227) explains that epidemiologists and clinicians are consumed with the task of identifying "prepatients" based on risk criteria. The crux of prevention strategies, then, entails simultaneously determine which healthy people might eventually transition into the status of "patient" while also considering and recommending interventions to prevent or halt this transition. Accurate measurements of risk become crucial for justifying public health treatment and intervention. Because epidemiology requires enormous amounts of data collection, analysis, prevention campaigns and treatments, the discipline has exploded in recent years. Today, entire branches of epidemiology are devoted to determining the legitimacy and validity of its own measures (233).

Despite its focus on individual-level risk factors, the field and sub-disciplines of epidemiology have complicated conceptualizations of the purviews of public health and social responsibility and has come to involve a larger repertoire of actors. More community and environmental health concerns fall within the scope of medicine and biomedicine and larger numbers of lay persons are implicated or publicly acknowledged as contributors to epidemiological knowledge-making. The phenomenon of "popular epidemiology" is a case in point. The term popular epidemiology was developed by Brown (1992: 267-270) as part of a larger social movement in which lay participants are active and publicly acknowledged in building scientific knowledge, health advocacy, and policy.

In effect, what this has means is that epidemiologists, other researchers and clinicians, and activists are each and all reconceptualizing population health. People are increasingly described through their memberships in various risk groups as well as according to their individual risk factors. The focus on "risk" creates a time gap between those who are 'at risk' and those who might eventually become 'ill', thereby expanding the domain of patients (or locations or manufacturers) who can be targeted as objects of surveillance and sometimes warrant interventions.

Particularly significant to this dissertation project, epidemiologists and other clinical and public health professionals have long attempted to simultaneously gather data on risk groups while fulfilling applied public health objectives to prevent and treat disease by instigating large-scale screening programs. Such efforts alter perceptions of clinical pasts and clinical futures, because once precursors are identified in conjunction with certain conditions, how active disease is seen as having origins much further back in time. Epidemiology and its screening practices have widened areas that are debatable, because negotiations encompass current diagnoses and treatments as well as ideas of disease probabilities and prognosis. Research and treatments in population-based health contribute to prevailing notions that it is an individual's moral duty to know one's biological and genetic and even risk factors. Kaufert (2000: 167) recognizes this as "powerful forces of biomedicalization" that are "densely controversial" because such implicit mandates are based in "cultural views of bodies as dangerous [wherein] women's bodies are far more likely to be targeted." For preventable conditions, epidemiologists and clinicians are more likely to devote resources towards identifying and targeting individual behaviors for change rather than addressing collective prevention efforts to locate and address the social determinants of disease.

Some epidemiologists, including many working with the BCERC, have demonstrated a sustained interest in understanding which biological and socio-cultural factors provoke illness. Although they research the interplays of both population and individual dynamics, many have backgrounds as "social" or "population" epidemiologists, which informs their commitments to studying illnesses caused by such phenomena as discrimination and environmental pollution and their consequences (Shim, 2002; 2005). These epidemiologists frequently espouse a “deductive ethic” to researching illness; that is, they focus analytic attention and resources to intervene in diseases already appearing as public health problems. This contrasts with “inductive” approaches among epidemiologists who pursue open-ended investigations to determine new calculations of “risk” for individuals (Shim and Thomson, 2007; 2008). Differences in population characteristics, kinds of exposures, and timing are also linked to different kinds of breast cancer. For example, premenopausal-onset breast cancer is thought to differ from postmenopausal-onset. Women with strong family histories of breast cancer experience disease patterns unlike those without such history. Some breast cancers are estrogen sensitive and others are not. And of course, there are gradients of breast cancer severity at time of diagnosis and in response to treatment.

Further, some causes of cancer are believed to exert effects cumulatively over time (such as a toxic body burden), while others are reasoned to trigger physiological changes in an individual within a short timeframe, although this many not actually manifest as observable cancer for decades after the triggering event. The views that breast cancer risks vary according to age and race, and that environmental pollutants influence cancer risks, combined with rising pressure from and incorporation of lay participants into biomedical knowledge production has resulted in the need for conceptualizations of life course epidemiology that better take into account these historically contentious constructs and account for their distinction.

DISPARITIES IN BREAST CANCER: SEEKING CLUES THROUGH RESEARCH ON MECHANISMS OF ACTION

Among BCERC collaborators, the decision to study environmental exposures at puberty was prompted by internal and external pressures to contribute to the ever-expanding knowledge base for breast cancer prevention and to fill existing gaps in understanding, which largely stem from a lack of knowledge about how risk factors convene to provoke certain kinds of breast cancer at distinct stages of life and why this differs according to race. A NIEHS official explained how these topics are connected:

> I think you have to step back and say, what are the established risk factors for breast cancer? And we have late age of first child, not breastfeeding, family history… And, you go down the list, and there are really very few, and what you find is that they're extremely unsatisfying. In other words, there's very little that a person can do with any of these different kinds of risk factors. I guess you could say, well, have a child, but I don't think people are going to plan their families around what's going to reduce their risk of breast cancer. So, what we have left is the onset of puberty. So, in our brainstorming sessions, onset of puberty emerged as one area that might be influenced by environmental exposures.

The decision to focus on puberty occurred rapidly, which is remarkable given the large number of BCERC participants who had difficulties agreeing on many aspects of the study, such as how to narrow down the types of exposures that would be studied and how broadly to define an "environmental influence." Ultimately, the rationale for focusing on puberty stems from many studies over several decades, in which early menarche has been correlated with higher rates of breast cancer.[4]

In order to explain the correlations between breast cancer and timing of reproductive events such as puberty and age of first childbirth, scientists and clinicians

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[4] These are not the only aspects that led to the focus on puberty, but they are the ones arising from my interview data and archival research on the scientific rationale. In Chapter 5, I investigate scientific and cultural concerns about the falling age of puberty in girls and the ways these concerns circulate between scientific research findings, political movements, and newspaper articles.

point to observational research that linked certain reproductive events in women's lives to higher or lower breast cancer rates. As long ago as the mid-1750's, Italian physician Bernardino Ramazzini surveyed disease prevalence across 52 occupations, and one of his findings was that nuns had high rates of breast cancer (Griffiths, 1991: 798). This was later attributed to their extremely low pregnancy rates. Many other scientifically observed risk factors for breast cancer date back to research conducted by English physician and epidemiologist, Janet Elizabeth Lane-Claypon (Winkelstein, 1996: 622). In 1923-1926, she designed the first published epidemiology questionnaire, assessing which lifestyle factors correlated with higher rates of breast cancer. She reported that early menarche and late menopause correlate with higher breast cancer rates, while groups of women who were pregnant or lactating for long periods of time during their lives had lower rates of breast cancer. Beginning in the 1920's and persisting today, the prevailing consensus among biomedical researchers is that breast cancer is chemically mediated by endogenous hormones, or hormones originating from within the body.

In my interviews and in the literature, medical researchers and clinicians still point to 'endogenous' explanations for hormonally-mediated breast cancer. This perspective is reflected in the widespread use of the "Gail model" (Gail et al., 1989), a commonly used statistical formula that serves as the "gold standard" to assess whether a woman is at "high" or "low" risk for developing breast cancer. As Fosket (2004) demonstrates in her careful analysis of the construction and legitimization of the Gail model, it was initially used to establish participation criteria for breast cancer research, but it has remained popular because it readily and flexibly validates a broader range of treatment options for "high risk" women. This tool is now available on the Internet, providing women with the opportunity – and implied responsibility – to calculate their own level of risk.

The Gail model was recently updated with different sets of questions and risk assessments for African American women. These figures were based on findings from the 2007 National Cancer Institute's (NCI) research study on Contraceptive and Reproductive Experiences (CARE), and the statistics were validated by comparing breast cancer outcomes to those of African American participants in the WHI (NIH, 2007). The NIH news report explains that a primary purpose of the new calculation tool is to "determine eligibility criteria for a number of breast cancer prevention trials"(Par. 7). The researchers analyzed the eligibility screening data from African American women who participated in the 1999-2004 Study of Tamoxifen and Raloxifene (STAR) using the traditional Gail model and compared it to their updated Gail formula; using the classical Gail model, only 15% of African American women were eligible to participate; with the new Gail model, those numbers are closer to 30%.

Beginning in the 1990's, epidemiologists and clinicians focused more on the ways breast cancer risk was related to age of exposure as well as – and in combination with - race. "In the future, we won't be thinking of breast cancer as one disease, it will be seen as different based on different ages at which it develops" (BCERC external reviewer). The idea that "age matters" was a prominent conclusion of the Women's Health Initiative. As I described in Chapter 2, the hormone trials were prematurely halted in 2002 due to shocking findings that instead of decreasing risk as predicted, these medications actually increased the likelihood of developing a range of conditions including: blood clots, heart attacks, strokes, ovarian cancer, dementia, general cognitive decline, and breast cancer (Krieger et al., 2005).

Despite the general appraisal that the study was very well-conducted and produced legitimate findings, pockets of researchers, clinicians, and pharmaceutical spokespersons said it was too early to conclude that HRT is dangerous. WHI researchers stood by their conclusion that hormone therapies at any age should only be prescribed sparingly, but they did agree with dissenting scientists that the dangers and side effects of HRT might be stronger among certain age groups and that more research was needed on age-specific reactions to ingested hormones.

African American women experience earlier menarche and later menopause, both of which are scientifically argued to be related to higher rates of breast cancer. Actually, breast cancer prevalence among African American women is lower than that of the general population. However, African American women under age 40 have higher breast cancer rates than white women of the same age, they are more likely to have advanced, aggressive, and fatal cancer, and prevalence rates are increasing in African American communities. In 1998, African American breast cancer deaths exceeded those of white women by 28% (Jones & Chilton, 2002) and recent estimates suggest the mortality rates are now comparatively 33% higher (Jones, 2009). African American women in the United States have among the highest breast cancer deaths in the world.

In her review and critique of genetic explanations for aggressive breast cancer among African American women, Happe (2008) notes that geneticists have been quick to explain racial differences in terms of inherited DNA markers. Although the complexity of cancer causation has been documented through many observational and clinical studies, genetic and biomedical techniques are now producing detailed accounts of the exact processes at the sub cellular level and as the field of epi-genetics[5] continues to gain momentum, these scientists are beginning to conclude that environmental factors play a bigger role than previously thought. The view that complex interactions of social factors probably underlie the differing kinds of breast cancer experienced across age and racial groups was pointed out early on by Krieger (1989). She highlighted differences between black and white Americans and argued that racial and ethnic variations in breast cancer are likely due to exogenous substances and variations in breast susceptibility.

PUBERTY IN WESTERN THOUGHT: AN ANCHOR FOR THE GENDERED LIFECOURSE

Most medical, environmental, and psychological scientists of childhood focus their research on the years between infancy and puberty, framing childhood as a life stage in which significant amounts of protection and intervention are warranted.[6] Data on childhood have also becomes scientifically tied to and predictive of earlier and later stages of development, as evident by the burgeoning number of studies on fetal exposure levels and attempts to link childhood health to disease later in life.

In contrast, those who apply a hormonal lens to studying development (especially development that is tied to sex hormones) are less likely to focus on these early and middle years of childhood, which have been described as involving relatively few sex hormone-mediated processes. Puberty, on the other hand, has been described by some endocrinologists as a continuation of the “mini puberty” that occurs during early infancy

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[5] The term epigenetics was first coined in 1942 to refer to the non-inherited factors influencing an organism’s development. Contemporary studies on epigenetics more narrowly focus on how non-inherited influences “trigger” genetic expressions.

[6] See, for example, the National Children’s Study (NCS) and the Child Health and Development Studies (CHDS) (van den Berg et al., 1988; Longnecker et al., 2003).

(Sisk and Zehr, 2005; Whitlock, 2006; Steingraber, 2007). This term is applied because infants actively produce GnRH sex hormones until they are 3-9 months of age, which sometimes provoke genital changes and temporary acne. After this, childhood then is a "hormonal hiatus" - - a long stretch of time between "two puberties" (Steingraber, 2007: 19), or a non-territory.

Environmental health researchers and activists have relied on discourses and images of prototypical children and concerned parents to organize and gain momentum. Recently, as environmental health sciences turn more closely to studies on chemical exposures, including endogenous and exogenous hormones, the target group "children" takes on qualitatively different constructions across small age ranges. The bulk of attention is now being paid to the beginning and end points, or borders, of childhood. This, in combination with 150 years of scientific discussions on adolescence (especially female adolescence), is contributing to views on female puberty as a chemically-determined, risky stage of life.

As historians and sociologists have pointed out for decades, the "life course" is socially constructed and strongly gendered. Lock (1993) points out that Aristotle, in the tradition of other Greek and Arab scholars, understood the human life course as divided into a series of "chunks." The 7th "chunk" of life was considered the pinnacle of an individual's power and glory, which was followed by the inevitable decline into old age and thus, a loss of vitality and productivity. For males, each of these chunks consisted of 7 years at a stretch. Thus men reached their peak at age 49. For women, a chunk was 3 years, which meant that her 7th-age glory arrived at age 21 and then began to fade (305-306).

Over the past century, at least two models predominate in discussions on the female life course in Western thought (Clarke, 1990:4). The Timing of events model is more frequently used and visualizes a person's life as a linear timeline between birth and anticipated age of death; the normative crisis model "describes that individuals must pass through the often stressful stages of development in the proper sequence or risk impaired development" (Clarke: 4). My research on puberty shows how discourses of the normative crisis model figure prominently and are being reshaped and rearticulated to accommodate new information from basic scientists, clinical researchers, and activists of the BCERC, and the knowledge produced through their interactions.

With industrialization, female youth encompasses an increasingly larger range of ages.[7] (Livingston, 2003:134). In western societies, this movement coincides with longer, more active lives experienced by many women over age 50 (Clarke, 1990: 28), but as women's lives are largely constructed on notions of potential fertility, it intensifies pressures to prolong youthful appearance. The prerogative to avert aging has subsumed increasingly younger groups of women; anti-aging creams are marketed to women in their 20's, and women in their 30's have the option of buying perimenopause testing kits so that they might "regularly check" hormone levels as they age to "determine when your ovarian function slows and your menopause transition begins" (hormonecheck.com). However, while the extension of youth into adulthood is publicly celebrated, the earlier onset into youth is not. One touted culprit and potential cure for unsatisfactory changes in the female life course is hormones. Crista DeLuzio's (2007) research on19th and 20th-century scientific and medical constructions of female adolescence reveals that concerns

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[7] See Livingson (2003) for a discussion on earlier pubertal onset among girls in Botswana and the refashioning of the female life course.

about early puberty have a long history. She draws on Foucault's method of discourse analysis to argue that "the child and the adolescent are 'cultural interventions'" (4). She shows how in the 19th-century, European and American thought constructed the "age of puberty", which was considered "a problematic and auspicious period of life, to be both managed and enabled by adults enlightened by scientific knowledge" (7). She echoes the views of Brown and Gilligan (2002), who argue that adolescence has been marked as a risky period for girls since the late 1800's. She traces many contemporary views on the psychosocial significance of puberty to American developmental psychologists and neurologists, most notably Stanley Hall and William Healy. Hall (1904) [8] proposed that puberty was a time of "storm and stress" due to physiological changes, while William Healy (1924) attributed mild and severe criminal behavior among teenagers to the biology of puberty. Healy believed that boys were more likely to misbehave if they suffered from delayed puberty, while teenaged girls behaved badly as the result of overdevelopment or premature development (DeLuzio, 2007:144).

In 1877, the average age of first menstruation (menarche) was calculated to be 15 for girls in England (Chumlea, 2003). This calculation dropped quickly in the late 1800's in Western Europe and the U.S. along with the rise of industrialization and better nutrition (Wyshak & Frisch, 1982). Over the past 100 years, menarche has continued to drop but at a slower rate, to a 1-month drop per decade since 1970, which is now estimated to occur at around 12 years of age and varies based on girls' geographical region and racial/ethnic background. Nationwide data, especially "average ages" for entire nations and parts of continents are clearly problematic calculations for understanding any historical phenomena. This data about age of puberty in preindustrial

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[8] In 1887, Stanley Hall founded the American Journal of Psychology (Parry, 2006:1161).

and postindustrial contexts is important to note, because the information is readily pulled into conversations by scientists and non-scientists.

Studies on puberty that attempt to measure pubertal onset in ways other than menarche have resulted in discrepant findings and provoked controversy about whether the age of puberty among girls in postindustrial societies is continuing to drop (Euling et al., 2008). This is due to the range in interpretation as to what constitutes physiological sexual development and various ways of measuring it.

> Contemporary and historical studies of puberty timing have focused on girls' age at menarche, in part because it is relatively easy to collect retrospectively…Puberty-timing measures used in studies have expanded in the past century to include measures that capture onset and progression of puberty… [Yet,] researchers disagree about whether children are entering/progressing through puberty earlier today than in the mid-1900's (Euling et al., 2008:167).

When the Tanner Staging system was created in 1969 by English physician James Tanner for tracking pubertal growth, the standardized clinical measurements for pubertal onset in girls increased from one factor (menarche) to four: Menarche, breast development, presence of pubic hair, and hip width (Marshall & Tanner, 1969). Additionally, Tanner and colleagues described change among girls by increased height and weight, lowered voice, underarm hair, and oilier skin. Their device for measuring puberty is divided into 5 visually-assessed stages that are theorized as qualitatively different from one another. According to Tanner, the diagnosis of precocious puberty for a girl was warranted if she attained stage 2 before age 8.

Forty years after Marshall & Tanner's publication, there are a variety of technologies available to measure puberty: X-ray tests to determine bone growth, ultrasounds or MRI's of the ovaries and uterus, and blood tests to measure hormones: 9LH, FSH, estradiol, testosterone, gonadotropin, and thyroid ("Endocrine, Metabolism, and Diabetes", 2009). But Tanner's staging is still the accepted, standardized method for determining pubertal growth; it was the tool employed by the research Herman-Giddens conducted and published in 1997, and their conclusions (that girls are entering puberty earlier) has anchored many of the debates about early puberty over the past 12 years.

Different aspects of pubertal development have been linked to different hormones. Adrenal androgens (adrenarche) contribute to the development of underarm hair, pubic hair, acne and changes in body odor and are theorized to develop on a parallel track to "central puberty", which includes changes to reproductive and sex organs. Some children have highly active adrenals and therefore develop acne and body hair at early ages, independently of others signs of puberty (Sizonenko, 1978). Another complicating factor in attempts to determine whether pubertal onset is indeed lowering among girls in postindustrial countries is the "tempo", or time between breast development and first menstrual period. The "tempo" used to be about 18 months, and it is now 3 years. Perhaps most significant for this dissertation, over the past 30 years, age at breast development is reported to be falling more rapidly than age of first period (Herman-Giddens, 2006). Also, clinicians and scientists used to report clear-cut relationships between when breast development began, menstruation started, and breast development ended. They charted breast development and correlated it with menarche in a predictable pattern; but for women who were born after 1950, that is no longer the case (244).

In the scientific literature, precocious puberty and early puberty are qualitatively distinct concepts. The first term is a medical diagnosis that began appearing in scientific journals in the late 1940's (Wyllie, 1948; Freed & Goldberg, 1949), while the latter usually refers to the "secular trend" of normal puberty, which argues that the average age of onset of puberty (especially among girls) is dropping. Thus precocious puberty has largely been medically treated an individual abnormality or potential pathology warranting hormonal interventions, while early puberty is a gradual trend charted in normal populations. The issues are discussed in very different ways. Precocious puberty is diagnosable whenever a child begins puberty at an age lower than the current boundaries of “normal” puberty. Although precocious puberty is frequently attributed to the presence of unusual (and measurable) hormonal and neurological physiological events, a medical diagnosis hinges on the age of the child: if a child is young enough to be outside the boundaries of normal puberty, clinicians can recommend subsequent hormonal and neurological testing to determine the severity of the precocious puberty. But, pubertal development in an 8-year-old girl is not considered precocious, even if her development follows the hormonal/neurological trajectory of “true” precocious puberty.[9] In short, two qualitatively different events are distinguished (at least in the medical literature, though perhaps not in clinical practice) according to biological age more than developmental trajectory. For girls, age “8” has served as the boundary ever since the Tanner Staging was devised and tried out on girls in Great Britain.

In the late 1979, reports from Puerto Rico challenged the view that precocious puberty is an individualized pathology caused by an internal glitch of the hormonal system. Pediatric endocrinologists reported alarming rates of precocious puberty among 6-months-to 8-year-old girls. In 1987, the Puerto Rico Department of Health was required by law to create a registry for studying premature puberty, which is still the only center devoted to this area of research. Between 1969 and 1998, rates of early puberty

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[9] Frequently, clinicians do administer hormones or other medical treatments to girls who are above the age limit for precocious puberty, especially in cases where the development is extremely rapid and/or unusual.

were 18.5 times higher in Puerto Rico than Minnesota (Bourdony, 1998; Van Winter et al., 1990). Explanations for the high rates in Puerto Rico included: hormonal contamination of meat and dairy, soy-based infant formulas, toxins produced by inappropriately disposed pharmaceuticals, and plastics and industrial pollution. In one study of Puerto Rican girls with precocious puberty, phthalate levels were extremely high. Di-2-ethylhexyl phthalate (DEHP) was found at levels exceeding 450 parts per billion in girls with precocious puberty, which was six times higher than that of most girls in Puerto Rico (Colon et al., 2000).

More recently, environmental toxins and endocrine disrupting compounds (EDC's) have been implicated in the declining age of puberty in girls, although the mechanisms that link exposures, early puberty, and breast cancer are unknown aside from the assumption that these relationships are hormonally mediated. As described by a BCERC epidemiologist: "Puberty, while associated with breast cancer risk at some later date, is not well understood, although we know it has something to do with estrogen levels in girls. And, we have information from animal studies that DES – which is an endogenous estrogen and endocrine disruptor – was heavily correlated with breast cancer." Thus, scientists and toxicologists reason that any environmental factor contributing to the lowering age of puberty could, through indirect means, also provoke subsequent breast cancer. A recent scientific publication disputes a genetic explanation for the lower age of pubertal onset (Braithwaite et al., 2008: 714).

> Explanatory pathways [of menarche] remain poorly understood. Efforts to identify the explanatory mechanisms are further complicated by the multidimensional nature of socioeconomic status, since its relationship with outcome varies according to how it is measured… Nevertheless, some aspects of

> SES[10] likely play a role in black-white differentials in the onset of menarche in the United States.

Since puberty occurs at younger ages in African American girls in comparison with other racial/ethnic groups in the United States, and the onset of puberty is occurring at increasingly younger ages among American girls in general, studying the environmental influences at puberty is reasoned to provide information on how to prevent breast cancer and reduce health disparities.

IS SYNTHESIS IS POSSIBLE? THE HETEROGENEOUS METHODS AND OBJECTS OF EPIDEMIOLOGICAL RESEARCH

To reconcile social, hormonal, genetic, and environmental hypotheses on breast cancer causation and account for racial/ethnic differences, scientists have reasoned that environmental influences during especially hormonally-responsive stages of life (puberty, pregnancy, childbirth, breastfeeding, and menopause) produce different kinds of cancer in different groups of women. As a BCERC NIEHS official remarked, the genomes stay the same, but they are silenced or un-silenced over time, allowing for “flexibility and increased or decreased risk at different life points.” This assumption drives the focus on learning about how exposures act and how bodies change during certain windows of time. Two BCERC scientists described the results of mouse and rat experiments that support the growing consensus that breast cancer is not solely determined by endogenous factors.

> When we first started researching genes, everyone thought we would find genes that separated big from smaller-group risks. It’s not turning out that way. We’re trying to understand and redefine what “susceptible” even means, and it turns out it’s all about interactions and modifications of risks (BCERC basic scientist).

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[10] Socioeconomic status

> Pathways we're just beginning to understand have the ability to say: 'grow, grow, grow, cancer cells,' in ways we used to think only endogenous hormones could (BCERC basic scientist).
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> We came out with a study a few years ago where we used a new technology, microarray analysis to look for genes that were interesting and came up with a gene called GATA-3, a transcription gene. And what we noticed was that it was the most abundant factor in breasts in mice. And when we went through the public database, we found its loss was a predictor of poor prognosis. It was at least as strong as the loss of estrogen receptors (BCERC basic scientist).

Thus, several endogenous and exogenous substances are theorized to trigger or suppress GATA, leading geneticists to conclude that DNA alone does not cause chemical changes, but chemical changes can influence whether genes exert an influence. It then has become difficult for scientists to dispute environmental causes of disease, and instead they are more likely to speak of the interplays between genes and environments. However, this may not a movement away from genetic paradigms of causation as much as it is a changing constructions and ways of operationalizing "environments", bringing the focus from ecological and social environments into the "environments" within cells (Shostak, 2003; 2005; 2007).

A BCERC basic scientist I interviewed estimated that 80% of cancer causation is now considered to be environmental. As he explained, this calculation refers to the percentage of influence within an average person, meaning that all cancer is caused by a combination of environmental and genetic factors. This differs from claiming that 80% of people have cancer caused by environmental factors and 20% have genetically-determined cancer. Most medical researchers now believe that few illnesses are caused exclusively by either genetics or circumstances. Rather, an illness such as cancer is the cumulative result of internal and external events. With the aid of recent technologies and elaborate statistical equations, genetic researchers and others seek to distinguish among internal and external triggers and then calculate the relative impact of each in regards to the illness in question. Risks and percentages must now be elaborately quantified, since they involve determining relative impacts and potential impacts of multiple causes within a person while simultaneously comparing those calculations across individuals and populations.

All of the concerns demonstrate that the epidemiological tradition and wide range of epidemiological knowledge on breast cancer risks both influenced and constrained the research course BCERC members could pursue. Their lines of inquiry had to draw upon multidimensional understandings of population health, racial disparities in health, and the importance of age-related vulnerabilities to breast cancer. To conceptually grasp the interplays of such large multi-leveled systems of causation, epidemiologists have developed sophisticated methodological and theoretical tools to study cancer risks as multi-directional and dynamic, allowing for the full range of causes derived from both within and outside of the body (exogenous).

The interview segments below contain explanations on the need for BCERC to go beyond merely organizational collaborations of communication by developing collaborative models to guide and synthesize understandings:

> We need to put all health issues in a room together and find the common threads. It is important to look at old things in new ways, simultaneously, to shine a light on how important centralized models are for understanding (BCERC advocate).

> One thing we've been pushing for is the lifespan approach. The model takes into account social and biological frameworks, which goes from genes to society. Different things happen at different levels of analysis over the lifespan, and whereas most basic scientists had been talking about phenomenon at a cellular level, they weren't thinking about where the genes were expressed or pathways were activated over a lifespan (BCERC epidemiologist).

> We've been thinking about risk factors, but the model has helped us think about how exposures act. For instance, do phthalates make the age of menarche earlier, therefore exposing women to more estrogen as the pathway, or is it something that disrupts hormonal function later in adult life during the 20's and 30's? Both are possible. Having a model helps us all think together (BCERC NIEHS official). [11]

At the same time, researchers were also under pressure to overcome what are seen as limitations intrinsic to scientific publication protocols. Specifically, epidemiological research takes a long time to conduct and the findings can often only be tentatively reported. This is due, among other things, to the notoriously contradictory nature of some research findings and the oscillating conclusions as to what is healthy or harmful. Several BCERC advocates said they had hoped for stronger claims and quicker results from the epidemiologists. For the most part, they attributed the slow results to the publication protocols in epidemiology rather than to individual researchers. One advocate remarked, "What really constrains epidemiology is the whole publication thing. They can't give their data out. It seems like that's really part of epidemiology, to hold your cards and then publish, go public." She reasoned that it probably does make sense for epidemiologists to withhold data from the larger scientific community until the results are "solid enough to withstand scrutiny", but this makes integrated research hard to carry out in BCERC. That is, the slowness of "going public" impeded responsibilities to conduct outreach. As another advocate stated: "We're expected to do outreach based on

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[11] Two such models were devised, although as of July 2009, neither have been published and therefore cannot be included in an appendix to this dissertation. One of them was developed at University of Cincinnati and contains a diagram of a host of factors that influence health at puberty, such as environmental chemicals, psychosocial support, and nutrition. The other model is unnamed; it consists of a long pole that represents the life course and several "windows" drawn around the pole at critical stages of development, including puberty and menopause. Each of these "windows" has concentric windows within and so looks like a thin slice of a rectangular rainbow. These stripes represent different levels of analysis: gene, cell, tissue, individual, family, neighborhood, and society (Hiatt, 2008; 2009).

this research, and our organizations were angry at us for not doing anything, but we didn't have anything to work with. We had to explain the epidemiological, peer review process to them." This process, as she explained to her colleagues, consists of, "Epidemiologists collecting their data and waiting for it to give them an 'ah ha!' moment. It's all based around that."

A primary goal of BCERC leaders (specifically, the NIEHS officials) has been to facilitate communication and promote integrated research across participating groups: basic scientists, epidemiologists, and advocates. Here one advocate proclaimed, "The epidemiologists haven't made much progress… I see more change among the basic scientists. Biologists engage in more of a dialogue. It's much more interesting. With epi, you're just waiting." Another advocate noted that the epidemiologists have been somewhat insular, whereas, "The basic scientists have been willing to accept and involve us." This contradicts the assumption frequently conveyed at BCERC meetings and on their websites that experimental science is inaccessible to lay persons and that laboratory scientists work in isolation. Basic scientists pursue extremely specific research whose results are non-interpretable to most audiences, so there are few fears of their research being taken out of context or being "leaked" to competing scientists. At conferences, basic scientists drew heavily on descriptive metaphors to convey findings to epidemiologists and advocates, such as: "Early cancer growth looks like a little zit;" "Transcription genes make sure your nose doesn't turn into your elbow." And "Some exposures have the ability to change the soil in a cell, even if nothing grows in that changed soil for years." Epidemiologists presented findings in chart and graph forms to depict differences between groups and changes over time. They were more protective of their results and relayed few of their findings, and were especially guarded about information on toxin levels in the girls.

However, the results that were communicated by the epidemiologists were applicable to the work of advocates and basic scientists, at least in some instances. For instance, the series of discussions that ensued from the shocking findings of the contaminated river and water supply in Cincinnati provoked BCERC basic scientists at MSU to research how PFOA's affect two strains of pubertal mice. Their results showed that PFOA's altered the liver and hormonal functioning in the mice, but each strand reacted in unique ways, so researchers were hesitant to make conclusions other than to emphasize the heterogeneity of disease susceptibility among rodents exposed to toxins. They then compared this with data taken from rats. A basic scientist at MSU told me, "One of the most exciting findings so far has been that rat and mice models are totally different from one another. Rats seem to be more close to humans. There are very different results between the 2 species." Hiatt, the P.I. of BCERC, noted that all research findings of the project so far suggest that environmental toxins exert a range of influences that are experienced quite differently from one person to the next (2009).

MANAGING UNCERTAINTY FRONT STAGE AND BACK STAGE

> We needed a cohort of young women. Not just young women, girls. We needed to be able to follow a group through time, and hopefully be able to reinterpret some of the other research that has been done based on what we observe in pre and early adulthood (NIEHS official).

The angle of the BCERC project that consistently receives the most attention is the clinical component which has been studying the environmental exposures, genetic data, and pubertal development of 1180 girls across 3 regions in the U.S during the timeframe June, 2005 to June, 2010. It is the first research project of its kind, employing a longitudinal, cohort-comparison research design as a way of correlating an ambitious array of possible triggers to pubertal onset in girls. The clinical study has widespread appeal among attendees at regional and national meetings. Clinical researchers at the three regional centers have chosen symbols to capture their branch of the project.

a) In the San Francisco Bay Area, the name is CYGNET (Cohort of Young Girls' Nutrition, Environment, and Transitions), and the symbol is a mother and baby swan. These 444 girls are African American (20%), Latina (26%), Asian (11%) and Caucasian (42%).

b) In East Harlem, the symbol is a cartoon soccer-playing girl with pigtails. The girls are Latina (60%) and African American (40%).

c) In Cincinnati, Growing up Female participants are Caucasian (60%) and African American (40%); their logo contains a narrowly outlined, pink Venus symbol.

For the study, lifestyle and socio-demographic data are collected through surveys; anatomical data about pubertal development are taken from physical examinations, and while chemical and genetic data are derived from blood and urine samples. Due to the youth of the subject population and types of data collection, this study is controversial. Because consent laws are so rigorous, if a girl expresses any hesitancy at all or seems as though she might be wavering during the annual clinical visit, they do not proceed. Thus far, girls have been much more resistant to giving blood than answering survey questions or being examined for development, although some clinicians say this might change as the girls age. There has been some difficulty getting girls to stay in each year, but retention rate is higher than anyone had estimated, especially in the San Francisco Bay

Area, where Oakland's Kaiser serves as the center for data collection. In Cincinnati and Harlem, finding and retaining the girls as study subjects has been a bigger challenge and advocates have done much of the recruiting. They also coordinate and help run the clinical components of the project, such as by preparing the girls for blood work and giving them juice afterwards. The girls were 6 when the study began and for the first few years, the survey component of the clinical data collection was answered by the girls' mothers. The girls were encouraged to attend and "chime in." Over the 18 months that I have followed BCERC, I observed no discussions of involvement in the study by girls' fathers or other care providers. However, there were numerous conversations about the need to reconstruct questionnaires that can be given directly to the girls. At the end of 2009, the girls (aged 11) will for the first time submit their own data on daily behaviors and emotional health.

While this clinical study does raises questions on children's rights as research participants, the most heated discussions have focused on how to measure and make sense of data that is collected. "It's almost impossible to measure human breast development" (BCERC basic scientist). Through this study, boundaries are being called into question around what is safe and risky in chemical blood levels vis-à-vis race and socioeconomics, and in childhood versus adulthood. This study and the girls are the nexus of differing opinions and perspectives that mostly convene around two main issues: variable vulnerability to breast cancer by race and age. The epidemiologists and clinicians become spokespersons in these discussions, because they have jurisdiction to announce findings, which are intended to be translated into educational and outreach messages. Most of the publications are anticipated to be derived from data collected between 2007-2009. I next describe how this occurs, first in the context of public, transdisciplinary BCERC meetings and then at a small meeting that took place behind closed doors, where only people directly involved in the clinical research were present.

Public Meetings

The annual San Francisco Bay Area BCERC Town Hall Meeting was held in Oakland on March 1, 2008 and attended by approximately 100 people. Several tables were set up with brochures and email lists for becoming involved in breast cancer activism as well as issues pertaining to supporting cosmetics made with natural ingredients, lobbying against soft plastics in baby toys, and supporting political measures to reduce the chemically hazardous environments faced by employees in nail salons. People meandered in and out of the conference room throughout the day, although a steady presence was maintained by many panelists and others in the audience. The conference was professionally filmed, and a smattering of journalists sat in the front row. Lunch consisted of all-organic whole grain pastas, sandwiches, and produce with dark chocolate for dessert, and a yoga instructor led voluntary “body breaks” after lunch and during breaks. In sum, the conference was carefully put together, demonstrating commitment to - and offerings of – professional research on preventive health.

Among the presenters that day was Larry Kushi, the clinical director for the Bay Area wing of the clinical research on girls, exposures, and puberty. The printed program for the conference indicated that he would be sharing initial results on the girls’ biomarkers for the first time, and it was clear that nearly all researchers, activists, journalists, and educators in the audience were invested in his presentation before he even began. He first introduced the Cygnet[12] project, pointing out that the name means "baby swan," and then sped through a few slides on methodologies, wasting no time in his objective to present preliminary data and research findings. Kushi referred the audience to a screen containing a giant grid that listed over 40 chemicals on a vertical access, with the 4 racial groups and 3 clinical locations of BCERC on the horizontal access. The grid between the axes was full of numbers ranging from .9 to 40,000. Kushi explained that researchers are still trying to make sense of exposure levels in children, since most information on toxin levels is both calculated and normed around adult exposure levels. His next slide contained a duplicate chart with measurements from a more recent year to, indicating that the toxin levels had changed since BCERC began. Subsequent slides contained similar charts with percentages of the girls who had begun puberty (by race and region).

He then summarized segments of the findings, first reporting on the racial differences in pubertal onset among this cohort of girls. At age 8, fewer than 20% of the girls had begun puberty, but of those who had, there were three times as many African American girls reaching puberty than Caucasians, Latinas, or Asians. Among the African American girls studied in Cincinnati, 33% had started puberty. These girls, Kushi remarked, also had very high phthalate levels, even by adult standards.

Phthalates are 1 of the 6 broad categories of endocrine disrupting compounds BCERC researchers are studying.[13] The category "phthalate" contains over 20 distinct variations of the general chemical structure, 9 of which are being researched in BCERC's

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[12] In the margins of one slide, "Cygnet" was also shown to be an acronym for "Cohort study of Young Girls' Nutrition, Environment, and Transitions".

[13] BCERC researchers are also studying phenols, perfluoralkyl acids (PFAAs), and three kinds of phytoestrogens: (daidzein, enterolactone, genistein).

(bcerc.org). Phthalates are byproducts of many household items, such as: scented shampoos and lotions, cosmetics, medications, soft plastics, baby toys, food containers, and food wrap (EPA, 2008). They are carcinogens and some studies have linked exposure to diabetes, infertility, liver damage, testicular abnormalities in boys, and early puberty in girls (Cesario & Hughes, 2007: 265-268). Following Kushi's presentation, 4 people from the audience posed questions. Two asked for clarifications on research methods and measurements, one about the role of obesity in provoking early puberty, and the other wanted to know why "more isn't being done" about phthalates in the environment and household products. Although Kushi provided answers to each question, he also explained that very little is known about these toxins or the parameters for "normal" toxin levels or pubertal growth.

Clinical Meetings

In contrast to the formal, "front stage"[14] public meeting, in which uncertainty was expressed around information lacking standardized measurements, Kushi's clinical staff meetings were informal "back stage" formats for trying to create standards and coherency. I observed one meeting entirely devoted to discussions on standardizing questionnaire data. At 58 pages, the questionnaire is exceedingly thorough. The sections include: physical activity, product use, environmental exposures, child's health, household structure, family income, family environment, residential history, child's height and weight, mother's height and weight, and stage of pubertal development. This particular meeting was attended by: Kushi (clinical epidemiologist), a nurse, a

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[14] Erving Goffman (1959) first introduced "front stage" and "back stage" to differentiate between the high levels of impression management that people engage in within some contexts (usually but not always formal settings) versus the more spontaneous behavior individuals and groups exhibit when there is no audience to perform to.

community educator, a psychologist, a toxicologist, a physiologist, and a public health researcher who had expertise coding and analyzing survey data. Before the meeting was even called to order, the participants were informally strategizing how to coordinate existing data across regional divides. "Good luck," one person said, "It's a huge task," another commented.

Discussions were largely devoted to the survey instrumentation with hopes of arriving at decisions on how to delete or add questions that were appropriate given changing times and the changing age of the participants. The idea was to change the questions every few years to reflect the girls' increased maturity, such as adding more questions about the use of cell phones, cosmetics, and deodorant. They also discussed changing the range of options under the category of "play", and making room for possible sports girls might participate in as they become teenagers. One change made to the instrument was the addition of a question for distinguishing whether girls are swim for 'play' or 'exercise' along the following spectrum of options: swim team; swimming laps; swimming lessons; leisure swimming.

Other alternations to the instrument reflect changes both in the psycho-social development of the girls as well as capturing trends that have grown in U.S. culture more generally between 2003 and 2009, such as:

- Adding a question on MP3 player and iPod use.
- Modifying questions about natural and organic foods to "food that is often referred to as 'natural', 'organic' or 'green.'"

The following items for survey data collection were added by researchers wanting more data on environmental influences that they found to be inadequately addressed by BCERC:

- Gathering clearer information on whether television and microwave use more often occurred at day versus night.[15]
- An additional section on ‘parental wealth’ that includes questions on home and vehicle value, savings and checking account balances, and total debt load.

The public health researcher and toxicologist both criticized the flexibly interpretable and sometimes arbitrary lists of available responses to the questions. The toxicologist was the most critical of the current questionnaire and doubted that it could provide meaningful results. She thought the questions were too hard to quantify and standardize, that it already contained too many questions, and she doubted that “a bunch of questions on where people get their drinking water from and what kind of shampoo they use” would yield much information. She explained that toxicologists do not have solid data on the chemical impacts of one brand of cosmetics over the next, and the type of water or shampoo a family purchases doesn’t provide any information on how the items are stored or used. The public health researcher voiced similar complaints about the section on exercise. In children, she said, it is hard to calculate activity expenditures by sport or activity. Thus, trying to determine a girl’s activity level and total calories burned by distinguishing between “swim team” and “swimming lessons” would not make a difference in overall statistical calculations. It was unclear whether the difficulty was due to the absence of standardized activity measurements for children or whether child behavior was considered too variable to be standardized at all.

That interchange provoked a discussion of when and whether they should include

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[15] Among researchers and educators in the BCERC, several were interested in research linking breast cancer to electricity and artificial light exposures at night. The theory on “Circadian disruption” argues that as people spend more time indoors due to industrialization, the lack of sun exposure and presence of artificial lights hinder melatonin functioning. The hormone melatonin mediates humans’ “circadian rhythms”, which guides different cells and body systems to function at designated times of the day and night. The “circadian disruption” view argues that changes in melatonin can affect other hormones in the body (such as estrogen) as well as the immune system, and so partly explains why breast cancer rates are higher in industrialized countries (Stevens, 2006: 501-502).

questions about smoking and drinking, although nobody suggested these questions be added this particular year. Within these interactions were mixed and personal concerns about how to define and measure, and how to distinguish girls from women. These conversations also reflected different approaches to prioritizing prevention efforts with this age group. For some, it seemed that puberty and subsequent adulthood were risks unto themselves, something that needed to be protected against, and any questionnaires that assumed precociousness in the girls would simply contribute to the very problem the activists and researchers were trying to ward against: girls growing up too fast. Others asserted the position that it is more scientifically and socially responsible to identify all possible risk factors, including those associated with "adult" behaviors in order to generate full information on what might influence the health of these girls across the study period. One proponent of this line of reasoning slipped at one point, referring to the subjects as women. After she corrected herself, another researcher said, "Well, they will be women in the end." The amount of teasing and laughter I observed at this meeting is important to convey, because it was grounded in the polarized attitudes people held about how to think about girls versus women. These clinical researchers, steeped in the topic and project, could easily draw from readily available discourse on how girls "should" behave and "should" be considered. Their discussions reflect generally held concerns about puberty and early puberty.

Overall, there is substantial uncertainty about whether this project fits more squarely in the domain of children's or women's health. The following segment from an interview with a NIEHS official captures the shakiness among those steering committee members who define and coordinate the BCERC: "I'm hoping [The BCERC] will be seen as a first, very innovative step in trying to give women - and their children - or their children…" at which point, he restarted: "To give girls control over reducing their own risk for disease, especially breast cancer." That is, it is unclear whether the target audience for intervention is preteen girls themselves or their mothers. The BCERC educational outreach materials that describe possible links between environmental exposures, puberty, and breast cancer have been geared towards both parents and girls in parallel outreach strategies, much in the same way that "puberty education" has been structured in the United States (Moran, 2002). Overall, in BCERC, more pamphlets, talks, and information have been directed more towards mothers than daughters.

BCERC members have partly taken on and in other ways have been handed the task of applying their various expertise on women's health and breast cancer to studies of girls. As they study the incubation period prior to 'women's health', these girls are classic examples of Frankenberg's (1993) "prepatients." While they have the potential to develop breast cancer, they are not yet women, and hence are not yet within the boundaries of the population that is typically defined as developing breast cancer. In some ways, BCERC researchers are asking: What initiates this transformation from childhood to adulthood, and what is risky both in that process and in the territory of 'women's health' more broadly speaking? The border between girl and woman marks an important category of risk that extends beyond breast cancer. Puberty is a window of vulnerability not only because it is a time when the body is believed to be particularly porous to radiation and chemicals and phytoestrogens, but also because it marks the socio-cultural passage from childhood to adulthood. This is a timeframe of vulnerable boundaries. Although children's health is often considered more fragile than adult health, especially in relation to environmental exposures, the pubertal transition lands a young woman squarely within the heavily medicalized and increasingly biomedicalized terrain of women's health. At adolescence, the female body is in some ways perched on a border while in other ways, it simultaneously inhabits a space of child/adult overlap.

The largest challenge for all the BCERC participants is finding ways to characterize and studying their research object, which ultimately is change itself. What seem to be resulting from many of these interactions are growing realizations that despite all the elements taken into account, neither the collaborative nor the integrated aspects of BCERC research are occurring with ease. Yet, everyone I interviewed, including those who wished the project had not been focused on puberty, hoped the cohort study would continue past 2009.

> This is the best opportunity we've had to understand breast development. We will revisit this cohort in the future. There is no other cohort that can give us this kind of information. It's a big chance to see the overlap between animals and humans, and between girls and women… Eventually, we will be able to correlate exposures with breasts. – BCERC epidemiologist.

CONCLUSIONS

> In the two years I've been involved with BCERC, I've noticed how unique the focus is in this project. We've known for decades that the timing of puberty is a risk factor for breast cancer. This is the first project on the timing of puberty, rather than just correlating it to risk later in life (BCERC external reviewer).

This study and the girls are the nexus of differing opinions and perspectives stemming from questions of variable vulnerability to breast cancer by race and age. The "windows of vulnerability" hypothesis/phrasing builds on and differs from establishing ideas of "risk factors" because it highlights an orientation to time and development. By and large, risk factors are ways of classifying difference, DNA markets, ethnic identities, or daily routines. Windows of vulnerability implies the need for protection and intervention after carefully calculating processes of susceptibility to dangers and protective elements. This form of vulnerability is also youth-specific, conjuring images of vulnerable populations (such as the baby swan symbol of Cygnet). Concepts of vulnerability are not only productions of scientific research based on the push for more gene-environment, centralized models and life course research. At the same time they are built from circulating knowledges often considered to be "outside of" scientific research.

Significantly, in addition to puberty being framed as a window of vulnerability, all of these conversations and research projects are occurring with the awareness that the onset of puberty in girls seems to be dropping in most industrialized countries. Puberty is a window of vulnerability not only because it is a time marked by particular embodied porousness to radiation and chemicals and endocrine disruptors, but also because the life stage itself is framed in terms of risk. It has historically been deemed a vulnerable life stage (Clarke, 1990; DeLuzio, 2007). And it continues to be discussed across multiple groups in the BCERC as a psycho-socially vulnerable time.

> The consequences of early puberty include earlier sexual activity, earlier unwanted pregnancies, sexual abuse, psychological problems related to being sexual too early, and STD's. So, there's a mess of things you can get into that are negative by going through puberty too early. There are reasons to worry about it just on that basis. There are consequences later in life. So, if this research documents all that, we should be thinking about the health of very young girls for numerous reasons. And, maybe it isn't such a good thing to develop early (BCERC epidemiologist).

The BCERC is in many ways a follow-up study for a slew of research projects whose findings raised numerous questions about internal/external hormones, age and race-based differences in puberty and breast cancer, and which environmental exposures might exert strong carcinogenic effects for girls at puberty. Because epidemiologists have been linking and correlating causes of chronic disease for quite some time and have maintained ties with preventive health, they have taken prominent positions heading new forms of research to study these relationships. The epidemiologists in BCERC were faced with the task of developing conceptual models that could synthesize different scopes of data (from cells to society) and overcoming some of the disciplinary traditions that provoke criticism among BCERC advocates and basic scientists, such as their tendency to "hold their data." One limitation of previous studies and of epidemiology as a discipline has been its limited capacity to describe processes.

The decision to study the processes of exposures and development across the pubertal transition, then, has been an ambitious project for everyone involved. Rather than tying up loose ends or reconciling opposing epistemologies, it has thrown all the major research questions - along with BCERC members - into murkier waters. There are few standardized instruments to measure exposures or puberty. There are convictions and evidence to support that both environment and life style matter. However, studies on adults have not proven this to full satisfaction, so researchers have moved towards looking at the pubertal era, hoping that links between environmental exposures, race and ethnicity, and socioeconomic status will demonstrate links with breast cancer that can ultimately inform preventive interventions.

In the next chapter, I demonstrate the extent to which exposures (endocrine disruptors in particular) and the lowering age of puberty among girls has gripped public attention across activist groups and media venues, elucidating the position of formal, institutional knowledge production within the larger political and public fabric from which that knowledge is generated, consumed, prioritized, reciprocated, refuted, legitimated, or otherwise rendered meaningful to various groups of people.

CHAPTER 5: A DANGEROUS AGE

> With statisticians proving that "average" is younger than recently thought, environmental activists are asking whether hormones in food, pesticides in produce or phthalates in plastics and cosmetics could be contributing to breast buds in third-graders. Some scientists have lifestyle suspicions (Los Angeles Times, 1/21/08).

> The environmental pediatricians really pushed for the importance of research on puberty. But also, I think the whole society felt out of control. Every level of change has been accelerated. It was the beginning of the decade, George Bush made us feel like we were slipping away, and all of a sudden, the environmental movement gained momentum in a majorly public way. … getting people to think about what we use and what's using us (BCERC activist).

Members of BCERC are researching and producing informational materials on the puberty/breast cancer connection due to the argument that puberty is a window of vulnerability for environmental exposures and thus, breast cancer. While not everyone in BCERC had been a proponent for the research focus on puberty, there were representatives from each of the major social worlds who were willing to get on board with this line of research. For example, studying puberty as a window of vulnerability was of interest to: 1) Molecular biologists, because puberty and breast development are poorly understood; 2) Epidemiologists and clinical researchers, because earlier ages of pubertal onset are associated with higher breast cancer rates later in life. Also, girls exposed to toxins at puberty have higher risks for breast cancer, even if they do not begin puberty at young ages; 3) BCERC advocates, because the focus on puberty reflected clear commitments to finding root causes of, and thus preventing, breast cancer. In addition, advocates from the Marin Breast Cancer Watch (MBCW) - now Zero Breast Cancer - had been involved in the Adolescent Risk Factors Study on the potential links between events at adolescence and breast cancer later in life (Wrensch et al., 2003); 4) NIEHS, because puberty was an understudied topic.

In some ways, the focus on puberty as a window of vulnerability at which girls are more susceptible to carcinogens (covered in Chapter 4) and concerns about puberty because it is beginning at earlier average ages for girls in the United States (discussed in more detail in the pages to come) appear to be two separate arguments. In this Chapter, I map the connections between these two arguments (see Appendix D). BCERC advocates are expected to serve as a link between scientists and the public, and some of this communicative work has involved producing educational materials on environmental toxins and puberty. Here, I investigate how "the problem of puberty" is being discussed in public venues. My objective in doing so is to see whether BCERC is in conversation with others who report on science: journalists.

One goal of this dissertation is to more thoroughly investigate the constructions, debates, and paradoxes of puberty as they relate to the sometimes heterogeneous and at other times integrated knowledge production manifests in both scientific and lay publications. To do so, I conducted a content analysis of newspaper articles from 3 publications between 2006 and 2008. I chose 2 national newspapers: The Los Angeles Times and The New York Times. I intentionally selected newspapers from west and east coast cities that do not host any of the BCERC centers. I also chose Pacific Sun, a local newspaper in Marin County, California, because many of my respondents worked in the area and many are prominent breast cancer activists. In addition to these 3 publications, I included articles that were referenced by other newspapers in my sample, sometimes via an editorial response. The key word search functions were: 1) Breast cancer AND [any of]: environment, endocrine disruption, puberty. 2) Puberty AND [any of] environment, endocrine disruption, breast cancer. Many of the articles in my sample discussed changes in puberty among boys as well, although the topic is beyond the scope of this dissertation. The literature points to higher numbers of boys with breasts and rising rates of male infertility later in life. These trends are sometimes feared as leading to the "feminization" of humanity and are attributed to increased exposures to estrogen and endocrine-disrupting compounds (EDC's). For these reasons, EDC's have been nicknamed as: gender-bending chemicals (Birke, 2000).

This chapter is organized to address the following thematic issues through a combination of data sources. I include:

1. A discussion of the landmark clinical findings of Herman-Giddens and colleagues (1997) on the lowering age of puberty among girls in North Carolina.
2. Press coverage analysis of 50 articles in my content analysis (see Appendix E):
    a. To show how two journalists in particular have followed the debates on the lowering age of puberty, I discussed two major articles that were published before the other articles in my content analysis: Gina Kolata's 3/20/2001 article appearing in The New York Times, and Mary Beckman's contribution to the Los Angeles Times on 2/12/2007.
    b. Most other journalists voiced strong opinions on early puberty as a moral and social problem, sometimes citing scientific data to bolster their claims. The most prevalent themes here were: i) Early puberty marks a disturbing direction towards a "forever lost" childhood, individually and culturally; ii) Parents are responsible for preventing early puberty, which might mean

a complete “lifestyle” overhaul; iii) Environmental and breast cancer activist heroically respond to the lowering age of puberty and to environmental toxins more broadly.

3. Interview data:

   The contributors to BCERC and media sources are indirectly in conversation with one another, and BCERC interviewees described the ways they wished the media would report on their study (a “dissemination” philosophy of scientific reporting) versus the way they see the issues being taken up (“popularization”).

There are several theories stemming from sociology and communications about how journalists cover science research and phenomena. Two frequent theories are the dissemination theory, which envisions media sources as simply translating and transmitting scientific findings to lay audiences, and popularization theory, in which journalists only report scientific stories and angles that will appeal to appeal general audiences, often through sensationalized tactics (Shinn & Whitley, 1985). Both of these views were offered when I asked BCERC respondents to describe their views on media reporting of their research. My theoretical perspective on this matter is more strongly rooted in the “public understanding of science” branch put forth by science studies scholars (Wynne, 1992; Collins & Pinch, 1993; Oudshoorn, 1990). For instance, while it is true that newspaper journalists are reporting on highlights from scientific research (dissemination) and many are filtering and framing their coverage on the lowering age of puberty with stories and symbolism expressly intended to draw readership (popularization), these dynamics work both ways. Writers for newspapers and magazines describe the concerns emanating from lay communities (dissemination), thus informing scientists and funding agencies as to which research projects will be likely to gather support, whether in the form of publicity, tax dollars, or employees[1] (popularization). The dissemination occurs in both directions, and they are also voiced from and for larger audiences that inform the kinds of scientific studies that should be pursued. Indeed, journalists and lay audiences are part of the scientific research process, and many scientists are public figures or social activists. It isn't simply that communication flows both ways between scientific and popular circles, but particular issues are selectively taken up by journalists and by scientists. Just as journalists filter information on scientific research, scientists (and others who are directly involved in the details of a given research project) only partially acknowledge that newspapers and journals influence what they research and how they report their findings. This isn't a matter of ignorance so much as a testimony to the overlapping and reverberating streams of influence that circulate among scientists, journalists, activists. News travels quickly, and through the Internet readers can read a toxicologist's report on endocrine disruptors in one browser and contribute to an informal blog on the dangers of household chemicals in another.

I emphasize the agency of journalists. For instance, I say, "Journalists emphasized the role of breast cancer activists," rather than, "My sample reveals…" or, "An article stated…" I do so to emphasize that actors (journalists and others) and many other elements decide and frame – at every level – which situations eventually comprise

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[1] One of the NIEHS officials I interviewed said a primary of hers is to support research studies that will draw talented post-docs. Environmental health has fewer funds than other areas of biomedical research, which means post-doc salaries are often lower. Therefore, the research projects at NIEHS must be appealing enough to new scientists that they are willing to accept lower pay.

news coverage.[2] Obviously, individual journalists work within structured parameters, some with more leeway than others, but all must negotiate with other people and groups who influence which stories they report and in which ways. Because it was beyond the scope of this dissertation to analyze the "production" stages of newspaper articles in my sample, I do not have data on what journalists wanted to express and how and whether that differed from what was eventually published. Thus, I use the term "journalist" to acknowledge the main author, but urge readers to stay cognizant of all the other writers, editors, organizations, funding sources, and so on that influenced how each article was written.

In this chapter, I focus on themes that were discussed and elaborated across sources and over time. Because the timeframe I was analyzing was brief, I believe these slight changes were reflective of small reverberations between and across sources (scientific-to-lay, or lay-to-lay) and did not point to overriding shifts. For instance, some individual journalists figured prominently in my sample and heavily influenced my results in a way that certainly cannot be applied to assumptions about general coverage of the issues. Gina Kolata from The New York Times and Marla Cone and Mary Beckman of Los Angeles Times each wrote three or more articles in my sample, 3 of the 5 articles I collected from The Pacific Sun were authored by Moulie Cohen, and a physician from New York named Gilbert Ross wrote letters to the editors of both LAT and NYT. In other words, these articles and authors were in ongoing conversation with one another, and a limited number of people influenced the way these stories have been told across these publications.

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[2] See, for instance Klineberg's (2002) Heat Wave: A Social Autopsy of Disaster in Chicago.

Throughout the press coverage, breast cancer activists and researchers maintained a steady presence in these conversations and continuously brought attention to the role of chemical industries, including pharmaceutical manufacturers of sex hormones. The Pacific Sun reported more on specific activists and took clear stances on issues. Articles in this publication emphasized breast cancer activism in great detail, not surprising given the substantial breast cancer activism in Marin County. National newspapers were more likely to summarize and report on published scientific articles and to emphasize the uncertainties in scientific research and preventive efforts aimed at reducing breast cancer and early puberty.

THE LOWERING AGE OF PUBERTY IN GIRLS

In 1997, Pediatrics published results from a clinical study that provided fresh evidence for a position that many parents and clinicians had been arguing for years: Earlier puberty in girls is a “real phenomenon” requiring further research and possible interventions on “clinical, educational, and social” fronts (Herman-Giddens et al., 1997: 511). The average age of initial breast development in their sample population was determined to be 9.96 for white girls and 8.87 for black girls, which marked a 6 to 12 month drop from results published in the studies conducted in the 1970’s and 1980’s. The authors concluded with a call for public health reprioritization, favoring research on puberty in general and “any possible relationship to breast cancer prevalence” (511).

The 1997 article was a landmark partly because it was used as the rationale for the Lawson Wilkins Pediatric Endocrine Society to recommend that the official age of “normal” puberty initiation in girls be lowered one year (Kaplowitz, 1999: 936). Scientific and popular presses quickly latched onto the article and used it as a platform to debate a variety of concerns and convictions about puberty, medicalization, the environment, health disparities, and the sanctity of childhood, especially girlhood. Even before this controversial decision to lower the parameters of puberty was debated, the article was critiqued by those who do not adhere to a “secular trend” hypothesis of puberty (meaning, that puberty is occurring younger).[3] The clinical research base for the article was the Pediatric Research in Office Settings (PROS) study, which coordinated clinician-reported assessments of 17,077 girls in North Carolina. Critics argued that statewide findings are not inclusive enough to draw sweeping conclusions about a nationwide change in age of pubertal onset.

The debates became more heated when The Journal of Clinical Endocrinology used the findings of Herman-Giddens’ research as a basis for changing the parameters of “normal” puberty to accommodate a secular trend. According to this new standard, an American girl beginning puberty at 6 (if black) or 7 (if white)[4] would no longer be given the diagnosis “precocious puberty”. Early puberty, once called and still sometimes termed “precocious puberty” affects 1 in 5,000 children, 90% of whom are girls (Cesario & Hughes, 2007; Nebesio & Pescovitz, 2005). However, the clinical definition only applies to girls who reach puberty before age 8 and/or begin menstruating before age 9. In 1997, the Pediatric Research in Office Settings (PROS) network recommended lowering the age to only include girls who develop secondary sex characteristics before age 7 (for White and Asian girls) and before age 6 (for African-American girls)

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[3] The concept “secular trend” is a statistical term referring to a consistent inflation or deflation of a value over a long duration. The term is most commonly found in biology and economics and can be contrasted with “periodic” or “cyclical” trends (Mills, 2003).

[4] As is so often the case with U.S. biomedicine, scientists have narrowed discussions on puberty and race to comparisons between Black and white girls. Some studies conclude that age at menarche is similar for Asian, Latina, and white American girls (Cesario & Hughes, 2007; Wu et al., 2002), although one study reported earlier menarche among Mexican American immigrant girls (Bona & Marinello, 2000).

(Kaplowitz et al., 1999: 936). This coincides with the views of those scientists who maintain that the average age of pubertal onset has dropped since the 1960's (Cesario & Hughes, 2007: 264). Explanations as to why this age is lowering so rapidly are varied. Some point to biological and behavioral factors, correlating early puberty with genetics and/or childhood obesity. A growing number of studies has argued for connections between pubertal onset and environmental toxins (Blanck et al., 2000; Denham et al., 2005). The strongest evidence comes from a study linking industrial waste and environmental phthalates exposures to pubertal onset in Puerto Rican girls as early as 6 months of age (Colon et al., 2000).

In 2004, amidst the ongoing controversies, a panel of representatives from the NIEHS and FDA held a meeting to discuss the secular trend hypothesis. They concluded that the age of puberty in girls does seem to be dropping, most likely as a result of childhood obesity and environmental endocrine disruptors. Body fat is thought to store, trigger, or otherwise mediate hormonal processes, especially those related to estrogen functioning. Therefore, girls and boys with more body fat experience higher levels of circulating estrogen. Endocrine disrupting compounds (EDC's) are also often related to estrogenic processes, which is why the term is often interchangeable with "environmental estrogens."

Over the past 10 years, scientific researchers tried to find the causes of early puberty by focusing on 3 "environments" (Cesario & Hughes, 2007): a) The external, chemical environment, along with exposures to toxic chemicals; b) The family and "lifestyle" psycho-social environment, which includes nutrition, nurturance, emotions, and exposures to stress;[5] and the c) Cultural and social environments, which includes exposures to peer groups and popular media sources. The chemical and lifestyle hypotheses have directed most of the scientific research on this topic over the past 10 years (Cesario & Hughes, 2007). Of course, these two "environments" overlap. For instance, toxins in households are caused by toxins and by the people living there, and solutions for eradicating them can be seen as the responsibility of chemical manufacturers, home owners/renters, regulators, or many others. Research on puberty and cultural/social environments includes proponents of the "sexualization" hypothesis, which argues that sexually explicit information "triggers" regions in the brain, provoking puberty, has been widely criticized by biomedical and social science researchers and thus, has fallen out of favor, but "the problem of early puberty" continues to be discussed as a family-level, moral issue, as my content analysis data clearly demonstrates.

PRESS COVERAGE: EARLY PUBERTY IS CONTESTED AND COMPLEX

> The new '8… The new average age of puberty, some fear, may be like the average weight – typical, but terrible (LAT, 1/21/08).

To elaborate on how "secular trend" debates have been covered by journalists, I chose two articles, each of which highlighted a different set of arguments emanating from "expert" researchers and clinicians (i.e., specialists in pediatrics and endocrinology). The earlier of these articles was written by Gina Kolata and appeared in The New York Times (2/20/01).[6] It captures views among endocrinologists and other medical researchers on

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[5] The hormonal changes that endocrinologists associate with stress, such as increased cortisol production, have been theorized to change the balance of other hormones and occasionally induce early puberty. Delayed pubertal onset has also been theorized to be related to stress.

[6] Kolata wrote this article in 2001, too early to be caught by my initial search parameters of 2005-2008. However, her portrayal of the topic of early puberty has been pointed to by other journalists as a pivotal piece and has been officially criticized by authors of the website of Our Stolen Future for sympathizing

the secular trend hypothesis. Six years later, Mary Beckman published a story in the Los Angeles Times (3/12/07) covering scientific debates on whether early puberty is a marker of health or product of an obesity epidemic. Kolata (2001) covered debates about the validity of the "secular trend" hypothesis, and Beckman later described controversies surrounding the significance of the lowering age of pubertal onset in girls.

Kolata begins with experts' discussions of Herman-Giddens' (1997) findings on the lowering puberty of girls in North Carolina. To do so, Kolata distinguishes between "skeptics" who doubt a secular trend in puberty is occurring, and the "acceptors" of the secular trend hypothesis. The acceptors accuse skeptics as "clinging to old notions" by medicalizing[7] girls who are "normal, but developing at today's earlier age," (par. 13) while skeptics state that the scientific base for the secular trend hypothesis is "questionable" and relies on a "single study" (par. 11). In Kolata's words, these skeptics are trying to "stop the bandwagon" (par. 4) of clinicians and researchers who are convinced that the age of pubertal onset in girls is dropping, a metaphor that conjures images of increasing numbers of groups and individuals on a vehicle directed towards a public parade. But in fact, Kolata describes the "acceptors" as uninterested in taking additional medical action after lowering the age limit. She quotes Paul Kaplowitz, a pediatric endocrinologist and prominent spokesperson on these debates, as willing to embrace a new standard for normal rather than "overmedicalize" girls through the hormonal medications prescribed to halt early puberty.

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with skeptics of the "secular trend" hypothesis (http://www.ourstolenfuture.org/Commentary/News/2001-0305nytonpuberty.htm).

[7] When medically indicated, the synthetic hormone Anastrozole is given to counter estrogen. It is also sometimes prescribed as a breast cancer treatment. Histrelin acetateis, also a synthetic hormone, was approved in 1991 to halt precocious puberty in girls and boys by acting on the pituitary system.

> Maybe we shouldn’t be worrying so much about those girls. The chance of finding a serious condition in a 7-year-old with pubic hair is very, very small… What's worse? Puberty starting at age 6 or 7?... Or going through an exhaustive endocrinological work-up and monthly injections at $6,000 to $10,000 a year?

In Kolata’s framing, scientists on both sides of the debate share an unwillingness to fully investigate the causes of early puberty. Kolata does not offer additional perspectives, but by framing the phenomena of early puberty as scientifically contentious, she helps construct a platform for readers scientists, clinicians, NYT readers, and other columnists to discuss uncertainties about early puberty.

In 2007, Beckman revisited these debates, also interviewing Kaplowitz. Ten years after the Herman-Giddens study, the research and 1997 publication were still central to discussions. However, Beckman describes Kaplowtiz’ hopes to address the underlying causes of the lowering age of puberty, especially obesity. Kaplowitz maintains that early puberty is not pathological on an individual level but is a social symptom of unhealthy food and exercise behaviors that need to be prioritized in public health. His views contrast with those of endocrinologist Francine Kaufman, whom Beckman quotes as seeing puberty as a “sign of better health” and a product of better nutrition. Kaufman asserts that puberty might be thought of a “luxury” and conceivably as “something good.” The debates then were reframed as puberty as a symptom of either “over nutrition”, which is a problem and related to childhood obesity, or “better nutrition.” Both Beckman and Kolata encourage a broader set of interpretations to the research and public attention given to early puberty, demonstrating how issues are complex and uncertain.

PRESS COVERAGE: EARLY PUBERTY IS A MORAL AND SOCIAL PROBLEM

In contrast with Kolata and Beckman, journalists in my sample stated their own opinions directly, focusing on the destructive aspects of early puberty and attributing blame. To explore this journalistic approach to contributing to activism and scientific knowledge production, I turn to the most prevalent themes in my sample of articles: 1) Journalists' descriptions of early puberty as a "forever lost" childhood; 2) Parental responsibility to prevent early puberty; 3) Environmental and breast cancer activists heroically respond to the lowering age of puberty and to environmental toxins more broadly.

Early Puberty and a "Forever Lost" Childhood

> This acceleration of growing up comes precisely at a time when life should be less about Eminem and more about M&M's (Lemonick, 2000: par. 29).

The most prominent theme captured in newspapers was the framing of early puberty as indicative of a soon-to-be "forever lost" childhood. A Time article entitled "Teens before their time," (Lemonick 2000) paved the way for this "take" on early puberty in the press. Here, he set a writing style in which descriptions of how girls should be and how girls actually are, bookend the article, serving as lead-ins and conclusions to embedded pleas to preserve girlhood. In this way, he and other authors writing since then juxtapose how girls should be, versus the direction girls' bodies and culture are currently headed.

> It seems as if everywhere you turn these days… there are more elementary schoolgirls whose bodies look like they belong in high school… It's as if an entire generation of girls had been put on hormonal fast-forward: shooting up and filling out (Lemonick, 2000: par. 4).

In a similar manner, authors of recent newspaper articles describe early puberty as a threat to traditional views and experiences of childhood. In the following passage, also from the 1/21/08 issue of the Los Angeles Times, the journalist begins by offering an idealized picture of childhood:

> At 8 or 9 years old, the typical American schoolgirl is perfecting her cursive handwriting style. She's picking out nouns, verbs, adjectives, and adverbs in sentences, memorizing multiplication tables and learning to read a thermometer. She's a little girl with a lot to learn (Brink, 2008: par. 1).

This passage rings with nostalgia: Cursive, multiplication tables, and reading thermometers, while still integral to standardized public education, are also milestones of a classroom environment long predating computers and digital displays. The author encourages adults to reflect on their own childhoods and compare with "girls today", whom she describes as "running around" in shirts that "undeniably" reveal breast development. The important tasks of methodical classroom learning are juxtaposed with images of rambunctious, precocious girls. To emphasize how young these girls are, the author described games she thought were appropriate for children this age. "Eight and 9-year olds are learning to make change for a dollar… They're not even playing Monopoly yet; they're still playing Candyland (2008: par. 33). The classic board games enlist the cultural prototypes – and stereotypes - of 20th century childhood in America.

Coverage of early puberty ranges from nostalgia to examples taken from contemporary girls' culture. In both instances, the authors detailed girls' culture to emphasize how young 8 really is and to reinforce age-appropriate behavior, referencing "Hannah Montana" and "crop tops." Accelerated development is described as disturbing, and, "It may not be just 'tween fashion that's to blame" ("Blues of puberty too soon," 2008). Here, the journalist distinguishes between the questionably appropriate aspects of ‘tween fashion and physiological markers of adolescence. In these articles, authors appeared to be uncertain whether girls were too grown up for their own good or not grown up enough to handle their changing bodies and environments. In effect, this led to an ambiguous portrayal of “girls today.” In some passages, girls were portrayed as acting too old for their years, which tended to be attributed to fashion and celebrity influences. Some of these same authors also invoked arguments that girls of this age group are not savvy, to the point of not being able to carry a lunch box or play a board game. The contrasting images of girls seemed to paint a picture of where girlhood has been and where it is now headed. Although the conversations appear to be discussing girls in the sense of individual maturity and their life course, the differing portrayals of girls (even aside from the element of early biological puberty) seems to be discussing where girls’ culture used to be versus where it is now and where it is going. The threat of early puberty is framed as one more symptom of a disintegrating culture.

Lifestyle and Parental Responsibility

> It’s unfortunate that such vigilance has become necessary for the families of many girls, whereas a generation ago, most parents could relax until a girl was 16 or 17… Welcome to the 21st century” (Lemonick, 2000: par. 36).

Several articles expanded on explanations of puberty as dangerous and as a health concern. Just as the phenomena of early puberty has been largely framed as an individual-level problem and less linked to structural and political intersections of power, the solutions for early puberty were picked up on by journalists in ways that emphasized dysfunctions at the individual and family levels. Underlying all of this is a moral prerogative towards reformation at the individual and family-levels. Journalists in the sample sometimes cited scientific studies on African American girls entering puberty earlier than white girls, but they chose to highlight behavioral differences such as the use of personal care products:

> One hypothesis for the difference in race may shed light on the reason for the lowered pubertal age in general. Researchers believe African American girls may use more personal-care products that contain chemicals that mimic the female hormone estrogen than their white counterparts (Cohen, 2007a: par. 16).

In a 1998 article in Clinical Pediatrics, Dr. Chandra Tiwary, the former chief of pediatric endocrinology at Brook Army Medical Center in Texas, reported an outbreak of early breast development in four young African American girls who used shampoos that contained estrogen and placental extract. The early puberty reversed once the shampoo was stopped (Sanghavi, 2006: par. 3).

The same article described a family in which exposure to a father's testosterone cream was linked to his daughter's early puberty and his son's aggressiveness:

> The doctors realized that the girl's father was using a concentrated testosterone skin cream bought from an Internet compounding pharmacy for cosmetic and sexual performance purposes. From normal skin contact with their father, the children absorbed the testosterone, which caused pubic hair growth and genital enlargement. The boy, in particular, also developed some aggressive behavior problems (par. 7).

These stories were portrayed as if they provoked the discovery that hormones induce puberty. In fact, stories like these can be found in medical literature dating before the 1950's. So, while such incidents are perhaps more prevalent today due to a wider array of cosmetics and medications, current scientific interest is more focused on small differences in pubertal onset across populations over time.

Researchers at University of Arizona's Norton School of Family and Consumer Science led to a peer-reviewed article titled: "Impact of fathers on daughters' age at menarche: A genetically- and environmentally-controlled sibling study" (Tither & Ellis, 2008). The researchers claim that girls whose fathers have substance abuse problems or whose parents are divorced begin puberty early. This, in turn, kicked off a series of articles published in at least 30 print and online news sources across the country with different combinations of the words: “dysfunctional dads” in the title. For instance, the San Francisco Chronicle ran a short article titled: “Losing dysfunctional dad can speed up puberty” (Machelor, 2008). In this article and others, the researcher was quoted as explaining the findings within the rubric of: “a window of vulnerability” (par. 9).

The recommendations then begin to pile up: Fathers should maintain a steady presence in their daughters’ lives; mothers should monitor their daughters’ exposures to toxins; and fathers and mothers should be more careful when purchasing cosmetics, especially online. Framings of lifestyle “dysfunctions” and family disorganization sidestep and strategically overshadow discourses on public health concerns related to race and class. Discussions of socioeconomic differences of any kind were absent from my article sample. Among the 50 articles in my sample, none of the journalists mentioned poverty or socioeconomics or income. The only time economics were brought to attention was through discussions on how to fund research and the financial incentives of chemical industries. However, authors of 10 of the articles mentioned “lifestyle” in relation to early puberty and/or breast cancer prevention.

In contrast, examples of social and health responsibility were portrayed in passages such as the following:

> Thirteen-month-old Solange Dorsainvil plays with toys made from wood and cloth, drinks from a Swiss-made aluminum sippy cup and teethes on kale stems and celery. Her life is as plastic-free as her mother, Celina Lyons, can make it. Celina, a Berkeley-based acupuncturist, has become increasingly worried about the possible toxic effects of plastics. "I remember hearing -- I don't remember when -- that my Nalgene [water] bottle was no longer safe," Lyons said. Once

> pregnant, she stopped storing food in plastic and cut back on plastic wrap (Conis, 2007: par. 1-3).

Two months later, the Los Angeles Times published an article with a very similar message and tone:

> If Aly Hartman could have placed herself in a protective bubble for the duration of her recent pregnancy, she would have done so. The Marina del Rey woman, 28, cut out alcohol, sodas and caffeine. She replaced her sugary breakfast cereal with crackling oat bran… and began stocking up on organic fruits and vegetables. She ducked back into her car while pumping gas and, when driving, sped around vehicles emitting thick fumes. She avoided crowds and handshakes, bought all-natural cleaning products and stopped wearing perfumes and lotions. The child-talent agent admits her safety measures may seem a bit extreme, but she may actually be a model for all pregnant women (Roan, 2007: par. 1-3).

Even when read in context with the fuller article, it is unclear whether these journalists are heralding these women as role models or if they are providing a social commentary on the new standards for responsible pregnancy and parenting. These articles capture the life experiences of women living within middle or upper-middle class, Californian coastal cities.

Environmental and Breast Cancer Activists as Heroes

> Things ripen. The public gets more involved, more legislators get involved, it gets a little closer to the potential of an override. Things change (Kramer, 2006: par. 32).

Breast cancer advocates and activists figured prominently in newspaper articles on environmental exposures and puberty. As the journalists wrote it, the advocates contributed to the politicization of the issues, mainly by criticizing the inadequate environmental health measures taken by scientists, private organizations, and government regulators. As the previous sections demonstrated, journalists captured some of the debates among endocrinologists as to the validity of the “secular trend”, and portrayed pediatricians as mostly in agreement that a secular trend is occurring but split as to whether it is a problem. Jounalists' interviews with breast cancer activists highlighted clear opinions that puberty among girls is occurring earlier and is problematic. Further, breast cancer activists describe early puberty as a symptom of environmental problems and a predictor of future individual and environmental health problems.

Four articles in my sample contained partial or full interviews with Sandra Steingraber, a biologist who is at the forefront in crying for intervention in breast cancer. Her books merge disciplinary perspectives and are written in a personal, emotional writing style that has found a home among environmental health activists who write for general audiences in ways that speak of the links between various ecological and health concerns in a compelling, metaphorical manner. In Living Downstream (1997: 2-3) Steingraber addresses environmental contamination and the emergence of chemically treated corn and soybeans. To emotionally appeal to readers and relay memories from her own childhood, Steingraber walks readers through the cornfields of Illinois: "See how the shrouded bottomlands are distinguished from the uplands, the floodplains from the ridges, how the daytime perception of flatness belies a great depth…You are the food that is grown here. You are walking on familiar ground." Her nostalgic tone is similar to that of journalists who wrote on the "forever lost" childhood but with an emphasis on environmental health and protection.

In 1999, Steingraber was proclaimed: "The new Rachel Carson" by the Sierra Club, and she received the Rachel Carson Leadership Award in 2001. Like Rachel Carson (1962) and Theo Colburn (1997), Steingraber merges personal experiences, ethical views, and political convictions with scientific theories connecting across several disciplines. In a 2007 interview, an author from the online journal: Terrain.org quoted her about loyalty to Rachel Carson:

> Carson is my guiding spirit.... Like Carson, I seek to seduce my readers through some pretty tough science by finding a language beautiful and compelling enough to honor the loveliness of the biological systems that I write about (par. 7).

More recently, Steingraber has relayed opinions on early puberty and breast cancer at conferences, seminars, and in her 2007 publication: The Falling Age of Puberty, which was explicitly written for the activist organization the Breast Cancer Fund: "Puberty is less like a clock and more like a musical performance, with our bodies as keyboards and the environment as the hands of the pianist" (Steingraber, 2007: 20). The journalist explains that experts such as Steingraber are worried about shortening childhoods for girls in the U.S.: "Regardless of whether early puberty is a risk factor for breast cancer, it is troubling." Steingraber is also quoted as describing the situation as an ecological and societal "tipping point", which conveys the view that the lowering age of puberty in girls is part of a larger trend towards instability and destruction that has been unrecognized and inadequately addressed. The current state of crisis therefore commands intervention. The authors draw attention to her identity as a public figure who wears multiple hats. One such quote was: "My biologist brain says, 'There's not a lot you can conclude from the [environmental] evidence'… But, I've got a 9-year-old girl. And as a mother, I say, 'They've introduced all these chemicals into the environment, and they have no idea what it's doing. What are they, nuts?'"

Other breast cancer advocates were also quoted in ways that emphasized their advocacy for more scientific research. The following passage is a quote from Barbara Brenner, the executive director of the Breast Cancer Action Coalition (Kolata, 2005: par.

54).

> We think there is something going on, and we'd like to find out what it is… The scientists who say these kinds of environmental exposures are the smallest contributors, I'd like to know how they know that. If we haven't done the research, how can they say with assurance what is the contributor of anything?

In another article, pediatrician Philip Landrigan's[8] was quoted in dialogue with breast cancer and environmental advocates about how to reduce toxins and their effects. "We're in the terrible position of having to say that we mostly don't know" (Conis, 2007: par. 9). Dr. Landrigan researches at Mount Sinai Medical Center in Manhattan as chairman of the department of community and preventive medicine. This LAT article was the only one in my sample to present direct discussions between advocates and scientists, although it closely resembled conversations I observed between activists and scientists and BCERC meetings.

Journalists also quoted activists and advocates who did not favor more research if that research usurped resources from efforts to prevent and intervene into known environmental health problems. These advocates bemoan the fact that it has become obligatory to cite [scientific] proof of harm before being able to draw support for intervention measures. Here, an activist is quoted (Kramer, 2006: par. 35):

> Scientists continue to deny the obvious. Does anyone think it's acceptable that women have flame retardants in their breast milk? Can there be any justification for not banning known carcinogens that show up in our blood and fatty tissue? Yet, apparently, such things need to be explained.
>
> It doesn't take a rocket scientist to know you don't want to feed your baby flame-retardants. You can talk about all the studies that we need to be doing, but you can also say, we need a precautionary principle paradigm. So, in the presence of information that suggests that there's harm that can be caused in the environment, we need to take action. And you [the manufacturer] have to prove it's safe.

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[8] Landrigan appears on the BCERC website as an author of publications that have emanated from BCERC's research. See Galvez et al., 2005.

Four articles containing interviews with breast cancer advocates directly quoted views on the importance of discussing hormone replacement therapy as part of a larger conversation on industrial estrogenic products and subsequent health problems. These stories reminded readers to include pharmacological estrogens within the category of "exposures":

> Researchers believe a recent dip in Marin breast cancer rates resulted from a precipitous drop in the use of hormone-replacement therapy…Though environmental factors may play a role in breast cancer, a number of studies move suspicion off the Marin environment (Cohen, 2007a).
>
> We panic over environmental exposures because it is beyond our control, yet throughout our lives, we willingly take pharmacological estrogens, such as birth control pills, fertility drugs, or hormone replacement therapy…
>
> Reduction in the widespread use of long-term hormone replacement therapy also may have slowed the increase in tumors. Before we celebrate, however, it is important to recognize that breast cancer takes a long time to develop. Exposures happening today could reverse the downward trend in cancer rates in the years to come" (Love & Rochman, 2006).

In the following section, cancer researcher Donald Berry explains the strong link between the drop in breast cancer rates since the Women's Health Initiative was halted. His views reflect many of the people quoted above who endorsed a precautionary perspective.

> The precipitous drop was both amazing and unexpected, but, in retrospect, we understand it better. If there's a tumor being fed by hormones, and you stop the fuel, you can see this dramatic drop. Some people say we need more data. We don't need data to know this is associated with hormone-replacement therapy (Cohen, 2007a).

The similarity between his position and that of many breast cancer activists points to the merging identities and stances among scientists, activists, and journalists. Activists are directing their efforts towards a variety of desired outcomes, and the concerns that underlie these convictions have been voiced in scientific and lay populations for decades.

Despite the disagreements about the influences and responsibilities of scientists, the blame placed on manufacturers was nearly unanimous.

Journalists framed biomedical researchers, families, and even social scientists as being focused on individual causes of puberty, but interviews with breast cancer advocates and activists that they incorporated into their article infused socio-cultural perspectives to these stories and diffused the attention on individualized solutions:

> You can do absolutely everything right and there's still no guarantee you'll be OK. But more importantly, we can shift the consciousness. We can change buying patterns so that manufacturers will change the way they make products…There is such pressure to market pills for menopause. We know that a woman's lifetime exposure to estrogen increases [breast cancer] risk…There were women who came off HRT who found out they didn't need it as much as they thought they did (Kramer, 2006).

Underlying many of these interviews with breast cancer advocates were subtle but deeply politicized references to hormonal pharmaceuticals questioning why it is that in cultural and ecological climates where concern is mounting over environmental hormones, they are infrequently discussed in tandem with oral contraceptives and hormone replacement therapies.

INTERVIEWS WITH BCERC MEMBERS

While most of this chapter is geared to understanding how "outsiders" to BCERC are or have been engaged in public discussions on puberty and breast cancer, my interviews with BCERC resulted in several discussions that captured their views on the media. Most of these discussions were anchored around whether and how their stories had appeared in newspapers. An external reviewer remarked, "The media is reflecting, overall, a great deal of resistance in this area." She remarked that the paucity of articles on BCERC is a continuation of a trend emanating from at least 2003. "After the Long

Island study came out [finding little pollution among women with breast cancer] the newspapers were reporting: There is no link between breast cancer and the environment." She qualified her statement by noting that this trend isn't "monolithic" and that a lot of the one-sidedness stems from "[structural] barriers in reporting." She noted, for instance that, "The LA Times has been pretty good." This BCERC contributor, like most that I interviewed, understood the media as a vehicle to disseminate information from scientists and scientific publications to lay audiences. From her perspective, competent reporting consists of following pertinent issues through time and relaying scientific findings at regular intervals.

An epidemiologist from BCERC also noted a general lack of involvement by the media. He told me he has been interviewed by a few reporters and since then has periodically come across an article discussing BCERC. He said articles on BCERC rarely hit the press and when they do, they usually highlight a specific research finding. "They typically report if there's some kind of a breakthrough" and do not describe the research process or "uniqueness" of BCERC. An NIEHS official described his views on the media in the following way:

> Well, grudgingly, I would say [journalists] play an important role. It's too bad, however, that the media doesn't view its role as educational, because the mass media is what people pay the most attention to (NIEHS official).

Along with the statements by the external reviewer and epidemiologist, this official's statement reflects the view that the role of the media is to disseminate scientific research findings and thus educate the public. But while the external reviewer attributed the lack of thorough coverage to "barriers in reporting," the NIEHS official described the dynamic as one in which newspaper journalists and other media spokespersons do not recognize their responsibility. All 3 of these interviewees acknowledged that journalists and others have competing demands and priorities.

Another of my interviewees, a toxicologist and external reviewer to BCERC, reflected on her experience being interviewed by Oprah magazine. The Oprah columnist had asked several detailed questions about her research and the scientific research on toxicology, and so she was shocked to see the sensationalized story, replete with the headline: Is your furniture making you sick? (Harrar, 2008). "It's such a scary way to pull people in," the BCERC toxicologist told me. "I wish it wasn't that way." She proceeded to read the subhead to me: "Toxins can hide in bookcases, shower curtains, and ol' clocks. Scary, but protecting yourself is simple."

These participants highlighted journalists' use of fear to draw audiences. Two people I interviewed discussed the specific ways that "risk" has been, or might be relayed between scientists and public audiences. One of these interviewees who worked with the NIEHS wanted my assessment of whether journalists were using "fear tactics" when reporting on EDC's by communicating the message that EDC's are potent, immediate dangers rather than incremental and cumulative. From this interchange and throughout the interview in its entirety, the participant differentiated between media and scientific conversations on risk factors. Clearly, the research BCERC members are pursuing is designed to identify and lower risk factors to protect children and prevent breast cancer. For this NIEHS official, the difference between the two perspectives was the sense of urgency with which journalists discussed the environment and health, thus leading him to consider that their portrayals might be fear tactics, designed to sell ideas or capitalize on fear. This was the only time an interviewee solicited my opinions on the issues I was raising for discussion. It was a helpful reminder that I am also embedded in these conversations and part of the flow of communication.

Another interviewee described the media as a piece of a communication loop between scientists and the public. He emphasized the potential for media coverage to provoke social change:

> [The media] puts pressure on the industry and the government to do the right thing. That's just how things happen. There is this constant interplay between the press, activists, and scientists… You need the press so people know what their tax dollars are doing for them (NIEHS official).

The BCERC project was only directly cited in three articles in my sample (Dungjen, 2007; Cohen, 2007a; 2007b). The Pacific Sun newspaper interviewed Dr. Kushi, introducing him as the son of Michio Kushi, who is internationally renowned as the chief proponent of and author on "macrobiotics," a style of eating that falls within the realm of integrative/alternative medicine (www.kushiinstitute.org). The following segment appears in the Pacific Sun article:

> Kushi, whose father, Michio Kushi, introduced modern macrobiotics to the United States in the 1950s, finds the possible connection between early puberty and red meat intriguing. Cattle ranchers insert female hormones into the ears of some 90 percent of the livestock in the U.S., Kushi said. Kaiser is asking girls in the study about their meat consumption but Kushi said, "I don't know if we'll be able to disentangle this" (Cohen, 2007a).

By disclosing tangential but potentially relevant aspects of Kushi's background, the Pacific Sun offers readers a fuller view of the motivations that might be driving BCERC researchers to pursue particular categories of puberty/breast cancer risk factors over others. Framing Kushi as the son of internationally regarded leaders of nontraditional nutritional philosophy and healing also positions him as an atypical scientist and therefore, perhaps more trustworthy, given the dominant sentiments of disillusionment with mainstream biomedicine.

The News Record also quoted Dr. Kushi on preliminary results from the Cygnet study. Their ability to extract concise results surprised me, given the vague manner in which findings were presented (and predominantly withheld). I later realized the information is still confidential,[9] several newspapers and one science writer for a major magazine have persistently been seeking permission to cover the story. Dungjen had likely sat in on one of the meetings. The journalist reports:

> Researchers at the Breast Cancer and the Environment Research Center (BCERC) found that 20 percent of 380 Greater Cincinnati girls ages 6 and 7 are showing signs of puberty. The study detected endocrine disruptors, which alter normal estrogen production, in blood, urine and other bodily fluid of the girls… Of 10 kinds of phthalates studied, nine were present in 94 percent of the study's participants (Dungjen, 2007).

This same New York Times journalist quoted Kushi on results gathered from his research team, which he stated as showing “Fairly striking racial or ethnic differences,” particularly among African American girls. The article also relayed his observation that 30 percent of the girls are obese or at risk for obesity, which is twice the number researchers had estimated when BCERC began. The clear and concise results offered in this article does not coincide with BCERC participants’ views that media sources avoid reporting on findings in an educational manner or that they merely popularize issues. In fact, the article cited above is conveying results in a way that BCERC advocates and COTC members believed would be their responsibility. These concepts are not exceptionally complicated, but they are sophisticated and detailed enough to argue against the idea that journalists only popularize studies. It is unclear how the journalists

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[9] I am including limited information on the research findings within this dissertation with permission from BCERC P.I.’s. Three researchers shared results and additional points of interest that I have agreed to keep confidential.

or their readers influence subsequent scientific studies and further media portrayals, but the journalists are certainly doing more than “dissemination” or “popularizing” research.

By late 2007, BCERC advocates also reported findings in pamphlets and newsletters on phthalate levels and pubertal development in the cohort. However, their findings were embedded in much longer reports on other scientific findings from the study. Many BCERC advocates told me that they wanted to report findings to communities and public audiences in a more direct manner, but their position in the project as co-researchers and location in the nexus of several disciplines and regional centers caused them to report via language that was more careful and less conclusive.

CONCLUSIONS

Journalists have been able to frame issues in a way that highlight how BCERC scientists and advocates have made selective decisions about which avenues to research. Likewise, the journalists reporting on the study selectively choose which scientific findings and motivating forces are relevant to understanding BCERC and the larger phenomena of early puberty in girls. Missing from the scientific research and journalists’ reports are discussions on the social and cultural significance of puberty in western scientific thought. In this way, some of the most serious forms of societal discrimination become obscured. And while there has been consistent politicization of industrial contamination and the marketing of estrogenic pharmaceuticals, movements to address discrimination on the basis of race and poverty fall below the radar.

Traditionally, sociological views on medicalization have concentrated on the phenomenon in which growing numbers of people are diagnosed with medical conditions or diseases, and these diagnoses encompass clusters of symptoms that fall within increasingly complex systems of categorization (Bowker & Star, 1999).[10] For instance, the introduction and increasingly widespread use of the terms “perimenopausal, menopausal, and postmenopausal” have occurred as the medical definition of menopause has been transformed from a single boundary/event to a multi-decade life stage with gradual shades of variation. Women of ever younger ages can identify or be identified as perimenopausal, if not menopausal. By lowering the threshold of who is considered menopausal, more women are eligible for hormone therapies, hormone testing kits, menopausal herbs, supplements, and so on.

An opposite trend is occurring with puberty: By determining puberty as beginning at 7 or 8, girls on this boundary are less likely to warrant the medicinal hormones they might have otherwise been prescribed to delay puberty. My sample of newspaper articles contains several expressions and debates on this topic. Some of these expressions are stated by journalists, some contain the words of scientists and clinicians that the journalists interviewed, and other statements were offered via letters to newspaper editors. However, as technologies for measuring human development proliferate and a broader range of experts enter into discussions on the environment, puberty, and cancer, the life stage of puberty could become subdivided into specific stages, each with particular norms for development based on racial/ethnic variations. In medical and scientific thought, the total span of years that encompass “puberty” is more likely to grow than shrink. But one intriguing difference held within the research on and conversations surrounding early puberty is the point at which “medicalization” enters the picture.

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[10] Patients can also (and do) facilitate the process of being medicalized, since medical diagnoses often lead to increased access to treatments and provide culturally legitimate explanations for suffering; see, for example, Becker and Nachtigal (1992).

An individual girl beginning puberty at a young age today might not be labeled pathological the way a similar girl would have been 20 years ago, and in this way, the blame is lessened: the culprit is now the environment. However, efforts to politicize industrial pollutants, race, and socioeconomic status have morphed with conversations on how individual mothers can better monitor household chemicals and their daughters' behaviors; furthermore, in a society where life expectancy continues to climb and many women have babies well into their 40's, the lowering age of puberty seems a contrast. As most other stages are being extended, why is childhood being shortened?

Equally concerning are the ways in which early puberty in girls has been taken up as a women's health issue while perpetuating the views that early development in girls is pathological. As with so many health concerns, much of the onus for reform is placed on parents. Early puberty is a possible predictor of cancer and a symptom of environmental health hazards. It is described as reaching a "tipping point" that marks the disrupted balance of an exceedingly complex ecology. In this ecological system, any number of factors can disrupt the equilibrium, including deviations from culturally-specific standards of appropriate behavior for girls and their parents.

The questions surrounding early puberty in girls is rife with paradoxes. In movements to demedicalize precocious puberty, girls undergoing "normal" puberty (i.e. developing breasts, menstruating, and so forth at ages determined normative for today but earlier than previous generations) is discussed as pathological at the group level: rather than discussing puberty as dysfunctional on a case-by-case basis at the individual level (as was implied with the precocious label), there is now something wrong with puberty itself. Early puberty is now less likely to be labeled a medical illness, and so in this way, it is being demedicalized; in particular, the “condition” is less attributable to a dysfunction within an individual girl. However, now all U.S. girls may be conceived as “at risk” for being in the clutches of societal-level dysfunctions of early puberty, which in turn creates a link between puberty, all girls, and breast cancer risk later in life. Simply entering puberty at the now-earlier age of 9 or 10 is interpreted as a risk factor for breast cancer. Puberty is at once a passage from childhood to adulthood, and it marks the beginning of being at risk and monitoring oneself for breast cancer.

CHAPTER 6: CONCLUSION

Throughout this dissertation, my research question has been: As some women's health activists are undergoing institutionalization within collaborative formats for scientific research, what are the consequences for both knowledge about hormonal bodies and health, and for activist organizations? By following stories on feminist protests against manufactured hormones, I found myself within a nexus of players, including many breast cancer activists and advocacy organizations. Since the late 1930's, the administration of estrogen and estrogen-like medications has been ubiquitous. Examples of these are: DES, hormonal contraceptives, hormone replacement therapies, and Tamoxifen. Such medications have been criticized by some feminists and others since DES was introduced in the late 1930's. These critiques were not always blatant protests of the medications in entirety, since few products are unilaterally "bad" or "good" for entire populations of women, and such medications have both helped and harmed women in different situations. Instead, feminist critiques have focused on three main points: 1) these drugs were approved in the absence of adequate proof of safety and efficacy; 2) they have been over-prescribed, largely due to profit-driven pharmaceutical companies; 3) sexist expectations that medicalized women's health unnecessarily are embedded in their marketing and prescription practices. For instance, several leading physicians of the

1950's and 60's heralded hormonalization for all women, and advocated for what they called a "puberty to grave" estrogen regimen for all women (Watkins, 2007: 63).

Over decades, the women's health activism around hormones became intertwined with breast cancer movements. During the early 1990's, breast cancer organizations "caught the wave" (Weisman, 1998: 206) and grew in public prominence and financial capacity. My research builds on Klawiter's (1999; 2004; 2008) ethnographies of breast cancer activism in the Bay Area, which ultimately leads to the BCERC. The BCERC began in 2002 as an extension of women's health activism and biomedical research on the relationships between hormones, puberty, and breast cancer. The establishment of the BCERC demonstrated federal level recognition of activists' long-established concerns that some significant proportion of breast cancer was environmental in its etiology. I engaged in a periodization study of these centers, heeding the significance of mandated transdisciplinary research that incorporates and partly recognizes advocates as co-producers of that knowledge. Here, institutionalization has also been ambivalently pursued and experienced.

SUMMARY OF KEY THEMES

Understandings of hormones and preventive health have at times polarized and at other times united individuals and organizations. In Chapter Two, I described the ambivalent views among users and activists in the U.S. over the past seventy-five years concerning hormones and biomedicalization, showing how these resulted in a series of uneasy compromises and collaborations. Hormones have yielded particular and lasting types of power: many individual women have been and are ambivalent about taking hormonal medications, and women's health organizations are in conflict with one another over the ways in which contemporary biomedical research is portraying and addressing women's health. Women's health activist organizations have taken a wide variety of positions around governmental and corporate support of women's health research. Scientists and advocates cooperated with one another in research but in most cases, advocates were not in their view adequately represented or fully acknowledged within the research. U.S. women's health advocacy groups such as NWHN and BWHBC who have maintained that it can be risky to collaborate with corporate and governmental organizations have nonetheless maintained cautious supportive of aspects of the NIH's ORWH and the Women's Health Initiative, well as NBCC's pursuit of biomedical institutionalization.

Although collaborative work with scientists was in many ways a hard-won, uphill battle for DES and breast cancer advocates, these alignments and their consequences have been complicated and fraught, to say the least. Breast cancer activists have taken a range of stances in relation to scientific/lay partnerships. Klawiter (1998; 2008) describes various breast cancer "cultures of action" of the California Bay Area, they have ranged from conservative to radical. She points to Marin Breast Cancer Watch (MBCW) as falling "somewhere between, or rather, on both sides" of this spectrum (2008: 221-222). They grew from a radical group into one that became interested in actively informing scientists and shaping scientific research from the inside. MBCW – now called Zero Breast Cancer – is a leading organization among BCERC's advocates. The present era for women's health is interesting, because there is a movement occurring within institutional centers of scientific research (such as the NIH) for activist-inclusion within research projects.

I highlighted interactions among BCERC scientists and advocates in Chapter Three. In my interviews, these participants articulated different "histories" of BCERC and its formation. Some, such as NIEHS officials, described it as an energizing, rapid process that involved many meetings where issues got hashed out and agreed upon. They acknowledged differences among participants and reflected on the nearly impossible task of devising a research project that draws upon both clinical and laboratory science to study the effects of a bunch of chemicals whose impacts are not well understood. Both advocates and scientists held ambivalent views on the project. While most fully supported the goal of collaborative work, they held different perspectives on how well the collaborations and communication appeared to be working. Generally, interviewees understood BCERC as conglomerations of motivated stakeholders in breast cancer and/or biomedical research who were remarkably patient in efforts to participate in extensive formats of communication and translation across disciplines and regions. However, one scientist described his team as having been "pulled in" to BCERC "kicking and screaming." An advocate I interviewed maintained that BCERC was the result of "divine intervention" rather than strategic work.

In response to a question posed by an advocate at a San Francisco Bay Area joint meeting about how to bridge the gaps between policy initiatives and the scientific research, the meeting organizer who was also a biomedical researcher answered: "We're not trained to do that… We need to know what areas of knowledge to focus on. Basically, we need your help to do that." I consistently observed deference by scientists to the advocates regarding issues of ethics, communication, diplomacy, and the need to find relevant research projects. In her work on the Human Genome Diversity Project, Reardon (2001: 381) contributes to and expands upon the theoretical area of coproduction in biomedical research by focusing on the presumed scientific/ethical distinctions that run the risk of become reified within the contexts of activist-informed research. Coproduction framings of scientific/nonscientific partnerships demonstrate that the realms of 'science' and 'ethics' are "inextricably interconnected and come into being together."

BCERC's collaborative model quickly became discussed as the major contribution of the project. Unlike the slow speed at which research results can become analyzed, communicated across disciplines, and synthesized in meaningful ways, the collaborative processes themselves are immediate and readily lent themselves to discussion among and between BCERC's members. They can be analyzed as they unfold, and all players can talk to one another about the communication itself. In BCERC, there is no group claiming expertise on collaborations, and in so this way, the collaborations are democratizing.

Yet more complicating for activists, the hormonal research objects are EDC's, which are scattered and diffuse. As shown in Chapter Four, the substances themselves are scattered, but there is no clear manufacturer of the products, since they are derived from countless substances and are indirect byproducts; it then becomes more difficult to organize women's health activists around EDC's in comparison to the activism that has and continues to draw attention towards the health risks associated with hormonal medications like contraceptives, hormone replacement therapies, DES, and Tamoxifen.

BCERC researchers were also faced with the challenges inherent to devising ways to measure and interpret environmental toxins in girls. As one scientist said, "We know nothing about toxins in this age group." Much of this chapter described epidemiological reasoning as to why research on puberty is important for gauging risk and preventing breast cancer among individuals and within populations. Better understandings of puberty can lead to more accurate assessments of breast cancer risk for individuals and between populations. The "windows of vulnerability" diagram established by BCERC researchers provides a distinctly 3-dimenstional framework for spatializing the relationships between environmental exposures, levels of analysis, and breast cancer risks over the life course. The BCERC researchers apply a windows of vulnerability framework to studying toxins and puberty and reciprocally use their research results to 'test out' the windows of vulnerability models. This is coordinated with their objective to incorporate all levels of possible environmental exposures into a causal model that includes information on genes, organs, individuals, groups, and entire regions. However, the complexity of the models and multitude of disciplinary perspectives soon unravel and throw wrenches into any elegant theories on causes, effects, and standardized levels of anything. Their investigations and work to correlate data on puberty and exposures in meaningful ways produce discrepant findings, frequently uninterpretable results, and challenge standardized measurements.

"There is no normal!" an NIEHS representative remarked with some surprise during an interview in which she reflected on BCERC's initial meetings on which chemicals should be studied and how to track puberty onset among girls. BCERC scientists studying rodents similarly noted that xenoestrogens affected each strain of their mice differently, and when UCSF researchers compared their mice data to that of the rats at MSU, the differences were even more marked. The science on 'xenoestrogens' is infused with a variety of discourses on the hormonal body and female life course. Xenoestrogens are scattered and difficult to collect and measure, just as they were for U.S. and Western European scientists in the 1920's (Oudshoorn, 1994: 43-48; Clarke, 1987; 1998: 121-131).

The epidemiological/clinical branch of BCERC has received the most attention both within BCERC (i.e. during annual meetings) and in news coverage. Because advocates are waiting for the research results to trickle in from the epidemiologists, they have no research findings to communicate to general audiences. So, they have spent considerable time producing educational pamphlets on puberty and household toxins. However, this provides a platform for communicating additional information on the dangers of hormonal medications and politicizing environmental contaminants.

Chapter Five: Through my content analysis of newspapers and magazines, I noted that media attention to these issues has not focused on relationships between puberty and breast cancer, but rather has depicted the lowering age of pubertal onset as a symptom of a rapidly accelerating society. In 1997, Herman-Giddens and colleagues announced the age of pubertal onset among girls was falling, and over the next 4 years, scientific debates on the validity of a "secular trend" hypothesis (idea that the average age of pubertal onset is dropping among girls) were in conversation with journalists. Three journalists led coverage on the issues: Kolata (2001) from The New York Times, Beckman (2001) of The Los Angeles Times, and Lemonick (2000) of Time.

Then, between 2006 and 2008, journalists interviewed a number of key researchers and breast cancer activists about environmental toxins and the falling age of puberty. Many of these newspaper articles contained detailed descriptions of a "forever lost" girlhood. Anecdotal stories of early puberty and health focused on individuals' use of cosmetics and household products, contrasting the hormonally irresponsible parents of unstable, unsupervised homes with model parents who meticulously protect their children from EDC exposures in household products. Discussions on EDC's are often framed in ways that perpetuate sexism by positioning women as responsible for families' domestic health (and indirectly, for preventing breast cancer among their daughters and in future generations).

I found that BCERC and BCERC advocates are in conversation with the public and with journalists, but the links are not explicit. Most BCERC scientists portrayed journalists as popularizing issues without adequately conveying their science. Journalists portrayed scientists (both BCERC and others) as not providing enough information on how to avoid exposures to, or eliminate the "upstream" causes of hormonal health hazards. However, the lines between scientists, advocates, and the popular press are blurry. This was exemplified by the heavy newspaper coverage on Sandra Steingraber who has claimed a seat as a spokesperson on these issues. Her messages are situated somewhere between those of scientists and advocates, and her nostalgic, moralized messages bear resemblance to the writing style of journalists. Steingraber publishes primarily for popular audiences and is featured prominently by the Breast Cancer Fund (BCF), one of BCERC's collaborators in the San Francisco Bay Area. The methods for organizing and coordinating biomedical research are changing, as are girls and the environment.

NEW DEVELOPMENTS

Amidst all these unknowns about the future of BCERC, I perceive additional looming questions. Answers to these could address important issues in biomedicalization, especially regarding women's health activism vis-a-vis hormones. Where is the hormonal paradigm now? How are women's health, hormones, and lives changing as a result of collaborative science on hormones? How will research findings be interpreted within and beyond the BCERC, at the individual and the population levels?

On Tuesday, November 11th, 2008, at noon, I entered the main centered the main conference room of the Wynfrey Hotel in Birmingham, Alabama for the BCERC's 5th annual symposium. The last session of the morning had just adjourned, so I followed a trail of conference attendees next door for lunch. The conference attendees were surprisingly subdued. A month earlier, the Breast Cancer and Environment Research Act had been signed into law, which mandated $40 million additional funds towards integrated research of this kind. I had expected environmental health researchers and breast cancer advocates to be more energized.

The woman seated to my left, a longtime breast cancer advocate and organizer for the NBCC, said she was disappointed by the version of BCERCA that had been signed into effect. It differed substantially from NBCC's original proposal. She pulled out a manila folder from her bag and showed me the official letter composed by the NBCC lamenting the version of the BCERA that had been passed (NBCC, 2008). I later learned that other conference attendees were carrying this letter as well. The original bill had been endorsed by many high-level politicians, including Reid, Hatch, Clinton, and Murkowski, and was supported by 75% of Congress. As NBCC describes on their website, a single Senator with strong ties to pharmaceutical lobbyists had been powerful enough to prevent the bill from passing (NBCC, 2008).

Had the bill passed, it would have enforced the following:

1. Authorized NIH support for a collaborative, multi-institutional, multi-disciplinary research studying environmental exposures and breast cancer.
2. Embraced a "broad definition of environment."
3. Involved "trained consumers at all levels of the decision-making process."
4. Institutionalize collaboration between grantees and community organizations.
5. Authorized $40 million per year for these purposes.

Essentially, the bill would have institutionalized a research model and set of practices similar to what BCERC had been pioneering, but would also have raised the total budget to support research across broader sets of questions concerning the environment and breast cancer.

The version of the bill that was signed requires the Secretary of Health and Human Services to create an "Interagency Breast Cancer and Environment Coordinating Committee" to advise grantees on environment and breast cancer risks. It mandates communication between academic scientists, government officials, and breast cancer advocates. The BCERC will inform and participate in many of these discussions. Remarkably, the original funding request for $40 million per year was approved, only instead of being directed towards new research at the NIH, it has been funneled towards establishing an advisory committee to work across institutions, including the FDA and EPA.

On May 21-22, 2009, the NIH held a meeting to review programs and discuss plans for allocating the $187 million from the American Recovery and Reinvestment Act (ARRA), signed into law by President Obama on February 17th, 2009. BCERC was among four NIEHS projects seeking approval. In June, 2009, the NIH informed BCERC they had approved the project's continuation through 2014 (Hiatt, personal communication, July 10, 2009). The NIH voted to "support and expand upon the BCERC, which is the only NIH project supporting transdisciplinary research on the interaction of chemical, physical, biological, and social environmental factors with genetic factors" (Ball, 2009: par. 9). As part of this grant renewal, the NIES and BCERC will work to create long-term structures, including the establishment of a database that researchers from other projects can access. The bank will house data on girls' toxin levels, psychosocial environments, age at and progression through puberty, and conceivably on their breast cancer rates, if BCERC follows the girls for multiple decades. Beginning 2010, the Breast Cancer Environmental Research Centers (BCERC) will become the Breast Cancer Environmental Research Program (BCERP), marking a distinct stage in its institutionalization.

THEORETICAL CONTRIBUTIONS

The activist-scientist collaborations are generative. Conflicts realign and structure future protocols, which then guide the type of information pursued and which of these will "take hold" and further shape hormonal understandings of health risks. In BCERC, the structuring and collaborations themselves became significant products of the research. Because so much work was involved in coordinating a project that could operate across four sites and involve basic scientists, epidemiologists, and advocates, the collaborations themselves became an object of analytic and research attention for BCERC participants. Indeed, when I asked respondents what they thought the legacy of BCERC would be, 15 people mentioned the collaborative model of the project, while 10 remarked on research findings, and 2 did not think there would be a legacy. It also served as a way to promote the centers and justify the continuation of the project.

Callon (1999: 82) points out that within the contexts of many biomedical research projects beginning in the early 1990's, the dynamics between specialists and lay people "have been called into question" and the boundary between them "is wavering." Within traditional models and expectations of how science/lay interactions are believed to occur, scientists establish themselves as the producers of knowledge, and they then directly or indirectly educate lay audiences on their findings. In these scenarios, lay groups might be called upon to suggest issues of concern that are in need of scientific elaboration and technological interventions, but they are otherwise constructed as recipients and consumers of scientific knowledge. Callon refers to this as the public education model. In contrast, the public debate model for scientific/lay organization highlights the differences among various lay groups and draws attention to what each has at stake regarding a particular issue. Here, lay groups might push scientists to research certain topics in depth. Primarily, advocates dedicate their energies towards negotiating across groups. This model recognizes the valuable and unique sets of skills these groups possess. Thirdly, the coproduction of knowledge model investigates the ways in which non-scientific actors are involved in and essential to the research each step of the way.

One element that distinguishes coproduction from the debate model is that within debate models there can be pivotal instances in which scientific experts are "undermined" by an inability to capture the full range of complexity within their research, and "tired of resisting, the experts end up admitting that their expertise is partial"(85). By contrast, in coproduction models, both scientists and lay contributors begin with the awareness that their knowledge is partial and that they depend on one another. In many ways, BCERC is an example of coproduction. From the beginning, the scientists openly acknowledged they did not understand much of their data. In fact, they continuously emphasized this point to scientists and non-scientists alike.

Callon notes that coproduction formats are frequently comprised of preexisting advocacy groups, some of whom were already conducting their own research because conventional biomedical research failed to adequately study their topic of concern.

> Ignored by institutional medicine, these people organize themselves… [by] researching and identifying diseases; organizing and actively participating in the collection of DNA; producing films or compiling photo albums designed to be effective observation tools for monitoring and comparing the clinical development of the disease and establishing the effects of certain treatment; recording testimonies which transmit lived experiences; and carrying out surveys among patients, which sometimes go as far as the publication of articles in academic journals (90).

The above descriptions capture the work that many DES advocates and breast cancer advocates have been engaged in for the past 20 years (Bell, 2008; 2009). My interviews with BCERC advocates revealed that many of them headed this kind of research. Still, Callon points out that many groups continue to organize according to the public education model, even though the debate and coproduction model are more contemporary. Some organizational tendencies they note include: a) auxiliary organizations, in which both scientific and lay partners recognize the scientists as the primary producers of the knowledge, and lay partners support these scientists by disseminating the knowledge or taking care of technical interventions; b) opponent organizations, whose patients/advocates/lay partners actively distinguish themselves as holding different priorities than biomedical researchers; and c) partner organizations, who actively work to emphasize the "links of cooperation" among scientists and non-scientists as well as the "mechanisms that construct social identities" This model lends to "organized, instrumental, and reflexive" ways of conducting research.

I argue that groups can and do organize through combinations of all 3 models of 3 types of organization, which has certainly been true among the BCERC. What is interesting in the case of BCERC is that the project was initiated through ideologies of coproduction, yet over time its members have engaged in more activities consistent with the public education model. While Callon (1999) suggests that lay groups have become more empowered and openly recognized as a consequence of humility among scientists admitting to their partial knowledge and dependence on nonscientists, my research shows that the uncertainty and deference among BCERC epidemiologists were related to the slow speed of their research and the privileged value of their research methods. Advocates depend on this data before they can move forward with their projects. So, while advocates are actively involved in the clinical research (recruiting and suggesting changes to survey forms), they are increasingly tasked with disseminating general information on puberty and toxins that is not based on their own data or even by the BCERC at all.

Callon (1999: 92) discusses the prime importance of 'legitimacy' to advocates. This legitimacy "relies entirely on the ability of concerned groups to gain recognition for their actions" and so if advocates (such as those in BCERC) are unable to communicate their purpose to larger publics, they risk losing resources and support for research on the topic. However, advocates are also in the tricky position of on the one hand articulating a unique identity to form around while working to convince the public that research on the environment and breast cancer are generally held concerns and that advocate involvement in this kind of research will produce findings that serve the "common good" (93). This tension might underlie at least one of the reasons BCERC advocates 'got on board' to support puberty as a research topic. By framing the life stage of puberty as a window of vulnerability for girls during which absorbed carcinogens are more potent than at other ages, advocates can bridge concerns about breast cancer – an illness which is directly experienced by a [substantial] slice of society – with the more universal experience of puberty. Here, simply being female becomes a risk factor for breast cancer, and although many activists have made concerted efforts over the years to emphasize that all women are at risk for breast cancer and everyone is affected by the disease in one way or another, highlighting puberty as a risk factor expands the topic of concern to all U.S. girls and to their parents. As my media analysis shows, renewed and intensified concerns about the lowering age of puberty was catapulted by Herman-Giddens (1997) research findings, and in their discussion, they mentioned that early pubertal onset in girls is a risk factor for breast cancer. Shortly after, MBCW launched the Adolescent Risk Factors Study and the Development of Breast Cancer. In 2000-2001, concerns about the lowering age of puberty in girls began to appear in popular magazines and newspapers, although these concerns were rarely framed as problematic due to breast cancer risks. Approximately three years later, BCERC was established.

More recently, Callon and Rabeharisoa (2003: 194) have suggested the term "research in the wild" to refer to research projects in which scientists and non-scientists (often patients rights and advocacy groups) partner to research a medical or health topic. They note that the "consultation, participation, and public debate" occurring within research projects over the past 20 years is based in motives and has taken forms of organization that are distinct from the scientific-lay partnerships of earlier decades.

> "[These new partnerships] form not a logic of representation but one of intervention, which enables groups simultaneously to discuss their identity and their expectations and to feed the research process with their own experience. Groups that are concerned by particular techno-scientific developments are offered opportunities to express themselves and to progressively become stake holders… It might be fruitful to consider concerned groups as (potentially) genuine researchers, capable of working cooperatively with professional scientists. In doing so, they invent a new form of research, which we propose to call research "in the wild" (194-195).

By my view, my view, Callon and Rabeharisoa make a novel contribution by sidestepping discussions on whether or to what degree advocates are scientific produces of knowledge; instead, they embrace the more analytical stance of first viewing and accepting these patient/advocacy groups as co-producers, and indeed as co-researchers, and then analyzing how this is done and what results.

For instance, in 1998, Weisman wrote: "The politically active women's health advocacy and interest organizations are increasingly sophisticated… Although most of these groups do not have large budgets and some rely on volunteers for much of their work, they are increasingly professionalized" (202). Today, this is even more evident. Bell (2009) notes how DES knowledge production and activism has changed over the past 40 years, arguing that it is useful to think of recent activism within the framework of "new" regimes of medical and activist practices. These differ from "old" regimes by complicating expert/lay power dynamics and hierarchies. In "new" regimes, power is dispersed, stems from multiple locations, and assumptions about expertise are called into question. In the case of DES activism, this is largely a result of embodied health movements, in which patients and others directly impacted by DES claim and express their privileged knowledges about the lived experiences of disease. The boundaries of scientific knowledge production extend broadly and are generated at multiple sites. The institutionalization of a particular research focus or sets of collaborative centers (such as BCERC) tends to occur with other forms of institutionalization from other "centers" and to throw definitions of "science" "advocate" and "the public" into question. However, as a result of this, hierarchies can and do form among the activists (Bell, 2009).[1]

> By expanding the possible points of entry into knowledge-making, this reconfiguration also transforms the worldviews and power dynamics among activists themselves. For example, hierarchies within embodied health movements have emerged between those activists have and have not "sat at the table" (6).
>
> Hierarchies within the women's health movement between those activists who have "sat at tables" and become familiar with bureaucratic routines and protocols and those who have not, and between those who have developed sophisticated knowledge of science and technology and those who have not (29).

For those researchers and advocates central to BCERC, it is extremely clear that BCERC's professional advocates have a great deal of responsibility and possess a certain research finesse that are not consistently found across members of groups who are recognized as "community collaborators". As I collected data, it became clear to me that the relative ease of the collaborations and initial successes of the program was partly due to the high levels of professionalism among the advocates, who have skills such as grant-

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[1] See also Brown et al., 2004 and Epstein, 2006

writing, producing polished newsletters, and conducting themselves with ease during formal meetings and conferences. This was not an entirely different dynamic than those found among basic scientists and epidemiologists: those who were most central to the project were – on average – more established, professional, and well-known than the scientists on the periphery. In some ways, this is a common dynamic within all complex groups that rely on formal systems of leadership. The difference with the "advocates" was that aside from those who are privy to the workings of BCERC, it is not at all evident that there is a distinction between "advocates" and "activists", yet the differences are quite crucial to the project. I did not grasp the distinctions until I had been in the field for several months, and I still struggle to understand the ways in which various advocacy and community groups work with one another and with the scientists. I believe one reason these hierarchies are not self-evident is because advocacy is frequently thought of as a "bottom-up" endeavor, whose leaders are merely spokespersons on behalf of their people rather than exerting power over the larger community. In contrast, institutional science is more readily perceived as a bureaucracy ruled by a select few who possess more authority, seniority, and/or prestige.

CONCLUDING REMARKS

I began this research with an interest in how collaborative formats shape knowledge about hormonal bodies, health, and how these ways of organizing then change the practices of activism and identities of activists. As I pursued these lines of research and thought, I did gain insight on these matters. Namely, I noted that uncertainties and ambivalences have persisted among activists/advocates and scientists. These dynamics apply to the relationships BCERC members have with one another and to the knowledge they are co-producing.

However, the stories that spoke louder and became more clearly to me revolved around the ways activists are actively renegotiating the boundaries of expertise and claiming rights to be recognized as researchers. As McCrea and Markle (1984) argued in their comparative analysis of HRT in the US versus in the UK, group identities and alignments often precede the exact position that is taken around a given issue. They showed how feminist groups in the US and UK positioned themselves against institutional medicine first, and since hormone prescription practices were very different between the US and UK, the feminist arguments in the two countries were also quite different from one another. Similarly, Callon (1999) argued that in order to have a social movement wherein patient/advocacy groups push for and claim central roles in shaping the research, the identities of the groups precede the knowledge that becomes co-produced. Of course, through these processes, identities change as well. It is therefore important that social studies scholars continuously point to the motives and identities of advocacy groups at all stages of scientific knowledge production.

In her research on simplification in science, Star (1983) noted that the negotiations and decision-making processes that occur in complex research processes (meaning, research with many different kinds of actors and/or objects of inquiry) often undergo significant and multiple stages of reductionism. Puberty in girls is understood in paradoxical ways partly because of the wide range of people tracking the issue and the selective, conflicting views that are reported (Star, 1983). By following media reports in national and local news venues, showed how medical debates, cultural views on puberty in girls, the rise of publicly prominent environmental health cancer advocates, and scientific results are simultaneously lending to the shaping of the hypothesis that girls in the U.S. are beginning puberty earlier than those of previous generations. By the time results are published in scientific journals, the original research questions have often been completely reformatted, and the hours of negotiations leading to those changes becomes obscured, if not in fact erased.

The BCERC itself is situated within a "window of vulnerability" as a new research initiative. It is developing through a critical time in the midst of uncertain political, economic, and ecological developments. Its boundaries are porous and uncertain, given the vast geographical distribution and eclectic disciplinary backgrounds of the participants. It is an exercise in innovative collaboration that is meant to pave the way for future research collaborations. And yet, in the process, it has to establish itself and negotiate considerable uncertainty and open-endedness both about the research findings and the feasibility of correlating exposures to puberty without standardized measurements for toxins or puberty. Strict adherence to data protection laws and scientific publication protocols also hinders the application of research results.

Within the broader realm of research on cancer, women's health and collaborative science, the scientists and advocates at BCERC are among the few working within the still-marginal research terrain of breast cancer prevention. Within this sliver, BCERC researchers also fairly uniquely look "upstream" in search of broadly defined environmental and social causes of disease. Meanwhile, the vast majority of research on breast cancer remains devoted to developing new medications and procedures for detecting and treating cancer. Within Klawiter's (2008) framing of breast cancer activism in the Bay Area, BCERC is the result of “fields of contention,” a direct outgrowth of the third “culture of action” she identified: environmental health and prevention. The Breast Cancer Fund, Zero Breast Cancer, and Silent Spring Institute are three organizations she identified within this culture; all are now affiliated with BCERC.

The phenomenon of advocate and community inclusion within scientific research poses many challenges for researchers and even more for the advocates and communities involved. There are exemplars of how these arrangements should ideally work, and sometimes events actually unfold via the scientific narrative justifying community-based research projects. For BCERC contributors, one of their “model” stories is the series of events in Cincinnati that uncovered contamination of the water supply by a Teflon plant and led to rapid interventions by researchers, advocates, the community, and regulators. However, the more common reality is that most of the work being done is organizational. Given this pattern, how will BCERC advocates shape research, identify in relation to the project, and to what extent will they be recognized as co-producers of the scientific knowledge via publications or other means? What will happen with the pooled data bank? How will the formation of the BCERA oversight committee influence this research, and how and whether will that facilitate the involvement of regulatory agencies?

In some ways, this dissertation is a story of BCERC as a minority research project within the realm of grants funded by the NIH. When NBCC criticized the NIH for supporting BCERC, it was not because they disagreed with BCERC’s research. The critique was rather that NBCC viewed NIH support of BCERC as occurring in lieu of more encompassing measures to support breast cancer and environmental research. In a legislative update, NBCC (2008) quoted an article in Newsweek (Begley, 2008: par. 20) to emphasize their perspective on these funding dynamics: "Innovative ideas, ideas that might be grand slams but carry the risk of striking out, are rejected by NCI in favor of projects that promise singles." BCERC is in some ways a model study for the NIH, a shining star that shows how one innovative, idealistic, and moderately funded scientific project can "do it all" through painstaking attention to levels of analysis, advocate integration, and cooperation, or "playing nicely together in the sandbox," as one BCERC advocate described.

As science becomes more elaborately institutionalized and networked across organizations, regions, disciplinary perspectives, professions, and politics, sociological and STS research on social movements needs to acknowledge multiple points and nodes of influence (Epstein, 2008). As my research conveys, it has been difficult for scientists to study change as an object of analysis, especially in the absence of standards on which chemicals matter, in what quantities, and within which populations. As a sociologist seeking to understand this science and activism, I was similarly faced with the challenge of making sense of the significance of processes of innovative scientific institutionalization (collaborative science) and the institutionalization of researching a process (puberty). Feminist analyses of health social movements, especially by scholars coming from poststructuralist perspectives, have contributed much by describing movements as partial, contingent, heterogeneous, and overlapping, both ideologically and across time. My dissertation emphasizes that some social movements within biomedicine are comprised of heterogeneous people whose interactions with one another are becoming networked across regions and levels of analysis with amazing speed and complexity. This is facilitated by the Internet and other technologies of scientific research and communication.

Processes of biomedicalization and collaboration are sometimes contested and sometimes actively pursued, even within a single organization. We need to question ways in which the ideologies of prevention, collaboration, and inclusion have been heralded as hallmarks for progressive research, and how these proclamations obscure the promises, pitfalls, and overall complexity of the institutionalization of women’s health research on hormones and activism.

References

1 in 9: The Long Island Breast Cancer Action Coalition (2009). Committed to the fight against cancer. Accessed November 5, 2009 from http://www.1in9.org/.

About NWHN (2008). National Women's Health Network: A Voice for Women, a Network for Change. Accessed July 16, 2009 from http://www.nwhn.org/about/index.cfm?section=about.

Adams, V., & Pigg, S. (Eds.). (2005). Sex in development: Science, sexuality, and morality in a global perspective. NC: Duke University Press.

American Cancer Society. (2008). Known and probable human carcinogens. Accessed July 17, 2009 from http:www.cancer.org/docroot/PED/content/ PED_1_3x_Known_and Probable_Carcinogen.

Arbaugh, A. et al. (2000). Windows of vulnerability: System reliability security. Computer Online, (December), 52-59. Accessed February 1, 2009 from http://www.cs.umd.edu/~waa/pubs/Windows_of_Vulnerability.pdf.

Auger, J. et al. (1995). Decline in semen quality among fertile men in Paris during the past 20 years. New England Journal of Medicine, 332, 281-285.

Ball, E. (2009). Supplemental funding and new developments dominate council. Environmental Factor: Your Online Source for NIEHS News. Accessed July 24, 2009 http://www.niehs.nih.gov/news/newsletter/2009/june/council.cfm.

Balshem, M. (1993). Cancer in the community: Class and medical authority. Washington and London: Smithosonian Institution Press.

Breast Cancer Action. (2008). About Breast Cancer Action: Core principles and values. Accessed July 16, 2009 from http://bcaction.org/index.php?page=about-bca.

Breast cancer and the environment research centers: A transdisciplinary study of the effect of early environmental exposures on mammary development and potential breast cancer risk. (2006). National Institute of Environmental Science and National Cancer Institute. Accessed July 15, 2009 from http://bcerc.org/links.htm.

Becker, G., & Nachtigal, R. (1992). Eager for medicalization: The social production of infertility as a disease. Sociology of Health & Illness, 14, 456-471.

Becker, H. (1982). Art worlds. Berkeley: University of California Press.

Beckman, M. (2007, May 21). Chemicals and breast cancer; suspects, but not all perps; A report has linked chemicals to tumors in animals. But the risks to women are less clear. Los Angeles Times.

Begley, S. (2008, September 6). We fought cancer... and cancer won: After billions spent on research and decades of hit-or-miss treatments, it's time to rethink the war on cancer. Newsweek. Accessed July 24, 2009 from http://www.newsweek.com/id/157548/output/print.

Bell, S. (1994). From local to global: Resolving uncertainty about the safety of DES in menopause. Research in the Sociology of Health Care, 11, 41-56.

Bell, S. (1995). Gendering medical science: Producing a drug for women. Feminist Studies, 21(3), 470-500.

Bell, S. (2003). Sexual synthetics: Women, science, and microbicides. In M. Casper (Ed.), Synthetic planet: Chemical politics and the hazards of modern life. (pp. 197-210). New York: Routledge.

Bell, S. (2008). Breast Cancer Awareness. In V. Pitts-Taylor (Ed.), Cultural Encyclopedia of the Body. (pp. 21-25). Westport, Conn: Greenwood.

Bell, S. (2009). DES daughters: Embodied knowledge and the transformation of women's health politics. Philadelphia: Temple University.

Berglas, N. (1995). The first FDA protest. Network News, (Nov/Dec). Accessed July 26, 2009 from http://www.nwhn.org/about/index.cfm?content_id=82&section=About.

Birke, L. (2000). Sitting on the fence: Biology, feminism and gender-bending environments. Women's Studies International Forum, 23(5), 587-599.

Blanck, H. et al. (2000). Age at menarche and Tanner stage in girls exposed in utero and postnatally to polybrominated biphenyl. Epidemiology, 11, 641-647.

Blues of puberty too soon. (2008, February 28). Sydney Morning Herald.

Bona, G., & Marinello, D. (2000). Precocious puberty in immigrant children: Indications for treatment. Journal of Pediatric Endocrinology and Metabolism, 13(Suppl. 1), 813-814.

Borell, M. (1976). Brown-Sequard's organotherapy and its appearance in America at the end of the nineteenth century. Bulletin of the History of Medicine, 50, 309-320.

Borell, M. (1978). Setting the standards for a new science: Edward Schafer and endocrinology. Medical History, 22, 282-90.

Borell, M. (1985). Organotherapy and the emergence of reproductive endocrinology. Journal of the History of Biology, 18, 1-30.

Boston Women’s Health Book Collective. (1970). Our bodies, ourselves. Boston: New England Free Press.

Bourdony, C. J. (1998). Premature thelarche and early sexual development registry. Annual report. San Juan, Puerto Rico: Department of Health.

Bowker, G., & Star, S. (1999). Sorting things out: Classification and its consequences. Cambridge, MA: The MIT Press.

Braithwaite, D. et al. (2008). Socioeconomic status in relation to early menarche among Black and white girls. Cancer Causes Control, Dec 25, 713-720.

Brink, S. (2008, January 21). Girl, you'll be a woman sooner than expected: Puberty is arriving ever younger in American females - - 8 is no longer considered abnormal. Los Angeles Times.

Brown, P. (1992). Popular epidemiology and toxic waste contamination: Lay and professional ways of knowing. Journal of Health and Social Behavior, 33(September), 267-281.

Brown, P. et al. (2006). A lab of our own: Environmental causation of breast cancer and challenges to the dominant epidemiological paradigm. Science, Technology, & Human Values, 31(5), 499-536.

Brown, L. & Gilligan, C. (1992). Meeting at the crossroads: Women's psychology and girls' development. Cambridge, MA: Harvard University Press.

Bucchi, M., & Neresini, F. (2007). Science and public participation. In E. Hackett et al. (Eds.), The handbook of science and technology studies (pp. 449-472). Cambridge, Mass: MIT Press.

Bucher, R. (1962). Pathology: A study of social movements within a profession. Social Problems, 10, 40-51.

California Breast Cancer Annual Reports. (1995). Accessed June 13, 2009 from http://www.cbcrp.org/publications/reports/1995/page_05.php.

Callon, M. (1999). The role of lay people in the production and dissemination of scientific knowledge. Science, Technology, & Society, 4(1), 81-94.

Callon, M., & Rabeharisoa, V. (2003). Research "in the wild" and the shaping of new social identities. Technology in Society, 25, 193-204.

Carson, R. (1962/2002). Silent spring. Boston and New York: Mariner Books.

Cesario, S. & Hughes, L. (2007). Precocious puberty: A comprehensive review of the literature. Journal of Obstetric, Gynecologic, & Neonatal Nursing, 36(3), 263-274.

Charmaz, K. C. (2006). Constructing Grounded Theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage Publications.

Chumlea, W. C. et al. (2003). Age at menarche and racial comparisons in US girls. Pediatrics, 111(1), 110-113.

Clarke, A. (1987). Research materials and reproductive science in the United States, 1910-1940. In G. Geison (Ed.), Physiology in the American context, 1850-1940 (pp. 323-350). Bethesda: American Physiological Society.

Clarke, A. (1990). Women's health over the life cycle. In R. Apple (Ed.), The history of women, health and medicine in America: An encyclopedic handbook (pp. 3-39). New York: Garland.

Clarke, A. (1991). Social worlds theory as organization theory. In D. Maines (Ed.) Social organization and social process: Essays in honor of Anselm Strauss (pp. 119-58). New York: Hawthorne.

Clarke, A. (1998). Disciplining reproduction: Modernity, American life sciences, and the problems of sex. Berkeley and Los Angeles: University of California Press.

Clarke, A. (2003). Situational analyses: Grounded Theory mapping after the postmodern turn. Symbolic Interactionism, 26(4), 553-576.

Clarke, A. (2004). Reproductive physiological research at the department of embryology. In J. Maienschein, & G. Allen (Eds.), 100 years of the department of embryology of the Carnegie Institution of Washington (pp. 107-132). New York: Cambridge University Press.

Clarke, A. (2005). Situational analysis: Grounded Theory after the postmodern turn. Thousand Oaks, CA: Sage.

Clarke, A. et al. (2009). Biomedicalization: Technoscience and transformations of health and illness in the U.S. Durham, NC: Duke University Press.

Clarke, A., & Montini, T. (1993). The many faces of RU486: Tales of situated knowledges and technological contestations. Science, Technology and Human Values, 18(1), 42-78.

Clarke, A., & Star, L. (2003). Science, technology and medical studies. In L. Reynolds, & N. Herman-Kinney (Eds.), Handbook of symbolic interactionism (pp. 539-574). Lanham, MD: AltaMira.

Clarke, A., & Star, S. (2008). The social worlds framework: A theory/methods package. In E. Hackett et al (Eds.), The new handbook of science and technology studies, 3rd ed. (pp. 113-137). Cambridge, MA: MIT Press.

Cohen, J. (2007). Coming to term: Uncovering the truth about miscarriage. New Brunswick: Rutgers University Press.

Cohen, R. (2007a, February 28). Breast cancer reduction: Plunge in county rates linked to plunge in hormone therapy, say medical experts. Pacific Sun.

Cohen, R. (2007b, February 16). Girl, you'll be a woman soon: Environmental factors are herding girls into womanhood sooner than ever. Pacific Sun.

Colborn, T., Dumanoski, D. & Myers, J. (1996). Our stolen future: Are we threatening our fertility, intelligence, and survival? A scientific detective story. New York: Dutton Publishing.

Colborn, T., Dumanoski, D. & Myers, J. (1997). Our stolen future: Are we threatening our fertility, intelligence, and survival? A scientific detective story. New York: Penguin Group.

Collins, H., & Pinch, T. (1993). The golem: What everyone should know about science. Cambridge, MA: Cambridge University Press.

Colon, I. et al. (2000). Identification of phthalate esters in the serum of young Puerto Rican girls with premature breast development. Environmental Health Perspectives, 108(9), 895-900.

Conis, E. (2007, September 10). Are plastics safe? Some chemicals may affect the reproductive system, growing research suggests. But as consumers seek alternatives, scientists point out that human studies are few. Los Angeles Times.

DeLuzio, C. (2007). Female adolescence in American thought, 1830-1930. Baltimore: John Hopkins University Press.

Denham, M., Schell, L., Deane, G., Gallo, M., Ravenscroft, J., & DeCaprio, A. (2005). Relationship of lead, mercury, mirex, dichlorodipheneyldichloroethylene, hexachlorobenzene, and polychlorinated biphenyls to timing of menarche among Akwesasne Mohawk girls. Pediatrics, 115(127-134)

Diamanti-Kandarakis, E. et al. (2009). Endocrine-disrupting chemicals: An endocrine society scientific statement. Endocrine Reviews, 30(4), 293-342.

Dungjen, T. (2007, October 31). Cincy girls at high risk for breast cancer. The News Record.

Endocrine, Metabolism and Diabetes Conditions and Diagnoses. (2009). Cincinnati Children's Hospital. Accessed March 26, 2009 from http://www.Cincinnatichildrens.org/health/info/endocrine/diagnose/precocious.Htm,

Environmental Protection Agency. (2006). Endocrine Disruptor Screening Program. Accessed October 5, 2007 from http://www.epa.gov/scipoly/oscpendo/.

Epstein, S. (1996). Impure science: AIDS, activism, and the politics of knowledge. Berkeley and Los Angeles: University of California Press.

Epstein, S. (2008). Patient groups and health movements. In E. Hackett et al. (Eds.), The handbook of science and technology studies, 3rd edition (pp. 499-539). Cambridge: MIT Press.

Faustman, E. et al. (2000). Mechanisms underlying children's susceptibility to environmental toxicants. Environmental Health Perspectives, 108(suppl.), 13-21.

Ferris, G. et al. (2008). HPV vaccine acceptance among mid-adult women. Journal of the American Board of Family Medicine, 21(1), 31.

Findings from the WHI postmenopausal hormone therapy trials.(2009). Women's Health Initiative. Accessed July 16, 2009 from http://www.nhlbi.nih.gov/whi/index.html.

Fleck, L. (1935/1979). Genesis and development of a scientific fact. Chicago: University of Chicago Press.

Fosket, J. (2004). Constructing "high-risk women": The development and standardization of a breast cancer risk assessment tool. Science Technology Human Values, July(29), 291-313.

Foucault, M. (1972). The archeology of knowledge and the discourse on language. New York: Harper.

Foucault, M. (1975). The birth of the clinic. Harmandsworth, England: Penguin.

Frankenberg, R. (1993). Risk: Anthropological and epidemiological narratives of prevention. In S. Lindenbaum, & M. Lock (Eds.), Knowledge, power, & practice (pp. 219-242). Berkeley, Los Angeles, London: University of California Press.

Freed, S. & Goldberg, M. (1949). Constitutional precocious puberty in the female and its control by androgens. Journal of Clinical Endocrinology & Metabolism, 8(12), 1081-1087.

Freeman, E., Bloom, D., & McGuire, E. (2001). A brief history of testosterone. The Journal of Urology, 165(371-373).

Fugh-Berman, A. (1992). The high risk of prevention: Tamoxifen on trial. The Nation, 255.

Fujimura, J. (1988). The molecular biological bandwagon in cancer research: Where social worlds meet. Social Problems, 35, 261-283.

Gail, M. et al. (1989). Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. Journal of the National Cancer Institute, 81(24), 1879-1886.

Galvez, M. Forman, J., & Landrigan, P. (2005). Children's environmental health. In H. Frumkin (Ed.), Environmental health: From local to global. Jossey-Bass.

Garrity, K. (1998). Science, policy, and controversy in the cholesterol arena. Symbolic Interaction, 21(4), 401-424.

Gibbon, S. (2006). Nurturing women and the BRCA genes: Gender, activism and the paradox of health awareness. Anthropology & Medicine, 13(2), 157-171.

Ginty, M. (2007, March 30). U.S. girls' early puberty attracts research flurry. Truthout. Accessed October 5, 2008 from http://www.truthout.org/article/us-girls-early-puberty-attracts-research-flurry.

Komen.gov. (2009). Susan G. Komen for the Cure. Global initiatives. Accessed July 16, 2009 from http://ww5.komen.org/AboutUs/GlobalInitiatives.html.

Goffman, E. (1959). The presentation of self in everyday life. New York: Doubleday.

Goldstein, D. (2000). 'When ovaries retire': Contrasting women's experiences with feminist and medical models of menopause. Health, 4(3), 309-323.

Golub, M. et al. (2008). Public health implications of altered puberty timing. Pediatrics, 121(supplement 3), S218-230.

Gore, A. (1997). Foreword to Colborn, T., Dumanoski, D. & Myers, J. Our stolen future: Are we threatening our fertility, intelligence, and survival? A scientific detective story. New York: Dutton Publishing.

Griffiths, M. (1991). 'Nuns, virgins, and spinsters'. Rigoni-Stern and cervical cancer revisited. British Journal of Obstetrics and Gynecology, 98, 797-802.

Grodstein, F., Manson, J., & Stampfer, M. (2005). Hormone therapy and coronary heart disease: The role of time since menopause and age of hormone initiation. Journal of Women's Health, 15(November 1), 36-44.

Hall, G. S. (1904). Adolescence: Its psychology and its relations to physiology, anthropology, sociology, sex, crime, religion, and education. New York: Appleton.

Hamilton, D. (1986). The monkey gland affair. London: Chatto and Windus.

Happe, K. (2008). The rhetoric of race in breast cancer research. In S. Gilman (Ed.), Race in contemporary medicine. London and New York: Routledge.

Haraway, D. (1985). A manifesto for cyborgs: Science, technology, and socialist feminism in the 1980's. In D. Haraway (Ed.), The Haraway reader (pp. 7-45). New York and London: Routledge.

Harding, S. (1986). The science question in feminism. Ithaca: Cornell University Press.

Harrar, S. (2008). Is your furniture making you sick? O, the Oprah Magazine. February.

Hawkins, T. (1987). A history of progress: NIEHS, the first 20 years (1966 to 1986). Environmental Health Perspectives, 75, 7-10.

Hays, J. et al. (2003). Effects of estrogen plus progestin on health-related quality of life. New England Journal of Medicine, 348(19), HAYS-1-16.

Healy, W. (1924). The individual delinquent: A text-book of diagnosis and prognosis for all concerned in understanding offenders. Boston: Little Brown.

Heiss, G. et al. (2008). Health risks and benefits 3 years after stopping randomized treatment with estrogen and progestin. The Journal of the American Medical Association, 299(9), 1036-1045.

Henderson, L., & Kitzinger, J. (1999). The human drama of genetics: 'hard' and 'soft' media representations of inherited breast cancer. Sociology of Health & Illness, 21(5), 560.

Herbst, A., Ulfelder, H., & Poskanzer, D. (1971). Adenocarcinoma of the vagina: Association of maternal stilbestrol therapy with tumor appearance in young women. New England Journal of Medicine, 284, 878-881.

Herman-Giddens, M. et al. (1997). Secondary sexual characteristics and menses in young girls seen in office practice: A study from the pediatric research in office settings network. Pediatrics, 99(4), 505-512.

Herman-Giddens, M. (2006). Recent data on pubertal milestones in United States children: The secular trend toward earlier development. International Journal of Andrology, 29(1), 241-246.

Hersh, A., Stefanick, M., & Stafford, R. (2004). National use of postmenopausal hormone therapy: Annual trends and response to recent evidence. The Journal of the American Medical Association, 291, 47-53.

Hess, D. (1997). Science studies: An advanced introduction. New York and London: New York University Press.

Hiatt, R., Haslam, S., & Osuch, J. (2009). The breast cancer and environment research centers: Transdisciplinary science for the role of the environment in breast cancer etiology. Environmental Health Perspectives, June 16, print copy not yet available.

Accessed July 21, 2009 from http://www.ehponline.org/members/2009/0800120/0800120.pdf.

HormoneCheck. (2005). Accessed September 10, 2008 from http://www.hormonecheck.com.

Hubbard, R. (1990). The politics of women's biology. Piscataway, NJ: Rutgers University Press.

Hulley, S. et al. (1998). Randomized trial of estrogen plus progestin for secondary prevention of coronary heart disease in postmenopausal women. Heart and Estrogen/progestin replacement study (HERS) research group. The Journal of the American Medical Association, 280(7), 650-652.

International Summit on Breast Cancer and the Environment. (May 22-25, 2002). Santa Cruz, CA.

Irwin, A. (2006). Coming to terms with the ‘new’ scientific governance. Social Studies of Science, 26(2), 299-320.

Jones, L. A. (2009). The African American cancer burden. The American Cancer Society. Accessed January 10, 2009 from http://www.cancer.org/docroot/SPC/content/ SPC_1_Jones_Lovell_On_African_American_Cancer_Rates.asp

Jones, L, & Chilton, J. (2002). Impact of breast cancer on African American women: Priority areas for research in the next decade. American Journal of Public Health, 92(4), 539-542.

Kaplowitz, P. (2004). Early puberty in girls: The essential guide to coping with this common problem. New York: Ballantine Books.

Kaplowitz, P., & Oberfield, S. (1999). Reexamination of the age limit for defining when puberty is precocious in girls in the United States: Implications for evaluation and treatment. Pediatrics, 104(4), 936-941.

Kaplowitz, P. et al. (2001). Earlier onset of pubery girls: Relation to increased body mass index and race. Pediatrics, 108, 347-353.

Kaufert, P. (1982). Myth and the menopause. Sociology of Health and Illness, 4(2), 141-166.

Kaufert, P. (2000). Screening the body: The pap smear and the mammogram. In M. Lock, A. Young & A. Cambrosio (Eds.), Living and working with the new medical technologies: Intersections of inquiry. (pp. 165-183). Cambridge, New York, and Melbourne: Cambridge University Press.

Kaufert, P., & O'Neil, J. (1993). Analysis of a dialogue on risks in childbirth: Clinicians, epidemiologists, and Inuit women. In S. Lindenbaum, & M. Lock (Eds.), Knowledge, power, and practice (pp. 32-55). Berkeley, Los Angeles, and London: University of California Press.

Keller, E. F. (1995). Gender and science: Origin, history and politics. Osiris, 10, 27-38.

Klawiter, M. (1999). Racing for the cure, walking women, and toxic touring: Mapping cultures of action within the Bay Area terrain of breast cancer. Social Problems, 46(1), 104-126.

Klawiter, M. (2004). Breast cancer in two regimes: The impact of social movements on illness experience. Sociology of Health & Illness, 25(September 2004), 845-874.

Klawiter, M. (2008). The biopolitics of breast cancer: Changing cultures of disease and activism. Minneapolis, MN: University of Minnesota Press.

Klinenberg, E. (2002). Heat wave: A social autopsy of disaster in Chicago. London and Chicago: The University of Chicago Press.

Kolata, G. (2001, February 1). Doubters fault theory finding earlier puberty. The New York Times.

Kolata, G. (2005, December 13). Environment and cancer: The links are elusive; preventing cancer, a matter of risk. The New York Times.

Komen.org. (2009). "Our global reach." Susan G. Komen for the Cure. Accessed June 13, 2009 from http://ww5.komen.org/Emotional.aspx? id=6924&terms= global+reach).

Kramer, J. (2006, March 31). Preventing cancer: Breast cancer activist Jeanne Rizzo keeps pushing the precautionary principle – if a chemical appears harmful, stop using it. Pacific Sun.

Krieger, N. (1989). Exposure, susceptibility, and breast cancer risk: A hypothesis regarding exogenous carcinogens, breast tissue development, and social gradients, including Black/White differences, in breast cancer incidence. Breast Cancer Research and Treatments, 13, 205-223.

Krieger, N. et al. (2005). Hormone replacement therapy, cancer, controversies, and women's health: Historical, epidemiological, biological, clinical, and advocacy perspectives (59th ed.) Journal of Epidemiology and Community Health.

Krimsky, S. (2000). Hormonal chaos: The scientific and social origins of the environmental endocrine hypothesis. Baltimore: John Hopkins University Press.

Land, C. (1995). Studies of cancer and radiation dose among atomic bomb survivors: The example of breast cancer. Journal of the American Medical Association, 274, 402-207.

Landrigan, P., Garg, A., & Droller, D. (2003). Endocrine disruptors mini-monograph: Assessing the effects of endocrine disruptors in the National Children's Study. Center for Children's Health and the Environment, Department of Community and Preventive Medicine, and Mount Sinai School of Medicine.

Lemonick, M. (2000, Oct 30). Teens before their time. Time, 156, 66-74.

Lerner, B. (2001). The breast cancer wars. New York: Oxford University Press.

Ley, B. (2009). From pink to green: Disease prevention and the environmental breast cancer movement. New Jersey and London: Rutgers University Press.

Livingston, J. (2003). Pregnant children and half-dead adults: Modern living and the quickening life cycle in Botswana. Bulletin of the History of Medicine, (77), 133-162.

Lock, M. (1993). Encounters with aging: Mythologies of menopause in Japan and North America. Berkeley and Los Angeles: University of California Press.

Lock, M. (1998). Anomalous women and political strategies for aging societies. In S. Sherwin (Ed.), The politics of women's health: Exploring agency and autonomy (pp. 178-204). Philadelphia: Temple University Press.

Locke, S. (2001). Sociology and the public understanding of science: From rationalization to rhetoric. The British Journal of Sociology, 52(1), 1-18.

Longnecker, M. et al.(2002). An approach to assessment of endocrine disruption in the National Children's Study. Environmental Health Perspectives, 111, 169101697.

Love, S. (1993). Breast cancer: What the department of defense should do with its $210 million. Journal of the American Medical Association, 269(18), 2417.

Love, S., and S. Rochman. (2006, November 27). The cure for what we don't know; Breast cancer can't be prevented. That makes us suckers for rumors and anxious about the facts.

Machelor, P. (2004, September 24). Losing dysfunctional dads can speed up puberty. San Francisco Chronicle.

Marshall, W. & Tanner, J. (1969). Variations in the pattern of pubertal changes in girls. Archives of Disease in Childhood, 44, 291-303.

Martin, E. (1997). The woman in the menopausal body. In P. Komesaroff, P. Rothfield & J. Daly (Eds.), Reinterpreting menopause: Cultural and philosophical issues (pp. 239-254). New York and London: Routledge.

Martin, E. (1987). The woman in the body: A cultural analysis of reproduction. Boston: Beacon Press.

McCrea, F. (1983). The politics of menopause: The "discovery" of a deficiency disease. Social Problems, 31(1), 111-123.

McCrea, F. & Markle, G. (1984). The estrogen replacement controversy in the USA and UK: Different answers to the same question? Sage, 14, 1-26.

Meyers, R. (1983). The bitter pill. New York: Putman.

Mills, T. (2003). Modeling trends and cycles in economic times series. New York: Palgrave Macmillan.

Moran, J. (2002). Teaching sex: The shaping of adolescence in the 20th century. Cambridge, MA: Harvard University Press.

Morin-Doody, M. et al. (2000). Breast cancer mortality after diagnostic radiography: Findings from the U.S. Scoliosis Corhort study. Spine, 25, 2052-2063.

Narrigan, D. et al. (1997). Research to improve women's health: An agenda for equity. In S. Ruzek, V. Olesen & A. Clarke (Eds.), Women's health: Complexities and differences (pp. 551-579). Columbus: Ohio State University Press.

National Institutes of Health. (November 27, 2007). More accurate method of estimating breast cancer risk in African American women developed. NIH News. Accessed March 8, 2009 from http://www.nih.gov/news/pr/nov2007/nci-27.htm.

NBCC. (2008). Priority #3: Enactment of the breast cancer and environmental research act (S.579/H.R.1157). National Breast Cancer Coalition, Accessed July 24, 2009 from http://www.stopbreastcancer.org/index.php?option=com_content&task=view&id=334.

NBCC. (2009). Statement of the national breast cancer coalition on the Breast Cancer and Environmental Research Act. National Breast Cancer Coalition Fund. Accessed November 11, 2008 from http://www.stopbreastcancer.org/index.php? option=com content&task=view&id=890.

Nebesio, T., & Pescovitz, O. (2005). Historical perspectives: Endocrine disruptors and the timing of puberty. The Endocrinologist, 15, 44-48.

Olesen, V. (1982). Sociological observations on ethical issues implicated in estrogen replacement therapy at menopause. In A. O'Donnel, M. Voda & R. Sheryle (Eds.), Changing perspectives on menopause (pp. 346-360). Austin: University of Texas Press.

Oudshoorn, N. (1990). On the making of sex hormones: Research materials and the production of knowledge. Social Studies of Science, 20, 5-33.

Oudshoorn, N. (1994). Beyond the natural body: An archeology of sex hormones. London and New York: Routledge.

Our Stolen Future Website. (2001). The New York Times on early puberty. Accessed July 1, 2009 from http://www.ourstolenfuture.org/Commentary/News/2001-0305nytonpuberty.htm.

Parry, M. (2006). G. Stanley Hall: Psychologist and early gerontologist. American Journal of Public Health, 96(7), 1161.

Parthasarathy, S. (2007). Building genetic medicine: Breast cancer technology, technology, and the comparative politics of health care. Cambridge, MA: MIT Press.

Pinn, V. et al. (2009). Mission and initiatives: Current NIH priorities for women's health research. NIH publication no. 09-6448. Office of Research on Women's Health. .

Pukkala, E. (2006). Breast cancer in Belarus and Ukraine after the Chernobyl accident. International Journal of Cancer, 119, 651-658.

Rabin, R. (2006, January 31). Rethinking hormones, again. The New York Times.

Ravdin, M. et al. (2007). The decrease in breast cancer incidence in 2003 in the United States. New England Journal of Medicine, 356(16), 1670-1674.

Reardon, J. (2001). The Human Genome Diversity Project: A case study in coproduction. Social Studies of Science, 31(3), 357-388.

Reardon, J. (2004). Race to the finish: Identity and governance in an age of genomics. Princeton, NJ: Princeton University Press.

Reardon, J. (2007). Democratic mis-haps: The problem of democratization in a time of biopolitics. BioSocieties, 2, 239-256.

Riessman, C. (1983). Women and medicalization: A new perspective. Social Policy, 14(1), 3-18.

Roan, S. (2007, November 12). Living for two: Mounting evidence suggests that fetuses are surprisingly susceptible to outside influences such as food, environmental pollutants, even stress. Los Angeles Times.

Roberts, C. (2002). A matter of embodied fact: Sex hormones and the history of bodies. Feminist Theory, 3(1), 7-26.

Roberts, C. (2003). Drowning in a sea of estrogens: Sex hormones, sexual reproduction and sex. Sexualities, 6(2), 195-213.

Roberts, C. (2006). What can I do to help myself? Somatic individuality and contemporary hormonal bodies. Science Studies, 19(2), 54-76.

Rosenfield, P. (1992). The potential of transdisciplinary research for sustaining and extending linkages between the health and social sciences. Social Science & Medicine, 35(11), 1343-1357.

Ruzek, S. (1978). The women's health movement: Feminist alternatives to medical control. New York: Praeger.

Ruzek, S. (1997). Access, cost, and quality of medical care: Where are we heading? In S. Ruzek, V. Olesen & A. Clarke (Eds.), Women's health: Complexities and differences (pp. 183-230). Columbus, Ohio: Ohio State University Press.

Ruzek, S., Clarke, A., & Olesen, V. (1997). Social, biomedical, and feminist models of women's health. In S. Ruzek, V. Olesen & A. Clarke (Eds.), Women's health: Complexities and differences (pp. 11-28). Columbus: Ohio University Press.

Sanghavi, D. (2006, October 17). Preschool puberty and a search for the causes. The New York Times.

Seaman, B. (1969). The doctor's case against the pill. New York: Wyden.

Seaman, B. (1978). Women and the crisis in sex hormones: An investigation of the dangerous uses of hormones - from birth control to menopause and the safe alternatives. Toronto: Bantam.

Seaman, B. (2003). The greatest experiment every performed on women: Exploding the estrogen myth. New York: Hyperion.

Sherwin, S. (1998). The politics of women's health: Exploring agency and autonomy. Philadelphia: Temple University Press.

Shim, J. (2002). Understanding the routinised inclusion of race, socioeconomic status and sex in epidemiology: The utility of concepts from technoscience studies. Sociology of Health & Illness, 24(2), 129-150.

Shim, J. (2002). Race, class, and gender across the science-lay divide: Expertise, experience, and 'difference' in cardiovascular disease. (PhD, Department of Social & Behavioral Sciences, University of California, San Francisco).

Shim, J. (2005). Constructing 'race' across the science-lay divide: Racial formation in the epidemiology and experience of cardiovascular disease. Social Studies of Science, 35(3), 405-436.

Shim, J., & Thomson, K. (2007, October). Epidemiological “Ethics” and heart disease: Ways of knowing, scientific credibility, and social responsibility. Paper Presented at the Annual Meeting for the Society for Social Studies of Science (4S) in Montreal, BC.

Shim, J., & Thomson, K. (2008, August). The science of health disparities and divergent ways of knowing: Epidemiological "ethics". Paper Presented at the Annual Meeting for the American Sociological Association in Boston, MA.

Shinn, T., & Whitley, R. (1985). Expository science: Forms and functions of popularisation. New York: Springer.

Shostak, S. (2003). Locating gene-environment interaction: At the intersections of genetics and public health. Social Science & Medicine, 56(11), 2327-2342.

Shostak, S. (2005). The emergence of toxicogenomics: A case study of molecularization. Social Studies of Science, 35(3), 367-403.

Shostak, S. (2007). Translating at work: Genetically modified mouse models and molecularization in the environmental health sciences. Science, Technology, & Human Values, 32(3), 315-338.

Silent Spring. (2009). About Silent Spring. Accessed June 1, 2009 from http://www.silentspring.org/about-us.

Sisk, C., & Zehr, J. (2005). Pubertal hormones organize the adolescent brain and behavior. Fronteirs in Neuroendocrinology, 26, 163-174.

Sizonenko, P. (1978). Preadolescent and adolescent endocrinology: Physiology and physiopathology. Hormonal changes during abnormal pubertal development. American Journal of Diseases of Children, 8, 797-805.

Slomski, A. (2009). Yes. No. Maybe. Protomag.Com, 9, 26-33.

Star, S. (1983). Simplification in scientific work: An example from neuroscience research. Social Studies of Science, 13(1), 205-228.

Star, S., & Griesemer, J. (1989). Institutional ecology, "translations" and boundary objects: Amateurs and professionals in Berkeley's museum of vertebrate zoology, 1907-1939. Social Studies of Science, 19, 387-420.

Steingraber, S. (1997). Living downstream: An ecologist looks at cancer and the environment. New York and Massachusetts: Da Capo Press.

Steingraber, S. (2007). The falling age of puberty in U.S. girls: What we know, what we need to know. Breast Cancer Fund.

Stevens, R. (2006). Artificial lighting in the industrialized world: Circadian disruption and breast cancer. Cancer Causes Control, 17, 501-507.

Strauss, A., & Corbin, J. M. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed.). Newbury Park, CA: Sage.

Strauss, A. (1978). A social worlds perspective. In N. Denzin (Ed.), Studies in symbolic interactionism. Greenwich, CT: JAI Press.

Strauss, A. (1987). Qualitative analysis for social scientists. Cambridge: Cambridge University Press.

Tesh, S. (2000). Uncertain hazards: Environmental activists and scientific proof. New York: Cornell University Press.

Terrain. (2007). Sandra Steingraber: Ecologist, author, and cancer survivor. (2007). Terrain.Org: A Journal of the Built and Natural Environments, 3(24). Accessed March 1, 2009 from http://www.terrain.org/interview/20/.

Tither, J., & Ellis, B. (2008). Impact of fathers on daughters' age at menarche: A genetically- and environmentally-controlled sibling study. Developmental Psychology, 44, 1409-1442.

Tokunaga, M. et al. (1994). Incidence of female breast cancer among atomic bomb survivors, Hiroshima and Nagawaki, 1950-1980. Radiation Research, 138, 209-223.

Van Den, B., Christianson, R., & Oechsli, F. (1988). The California Child Health and Development studies of the School of Public Health, University of California at Berkeley. Paediatric and Perinatal Epidemiology, 2, 265-282.

Van Winter, J. et al. (1990). Natural history of premature thelarche in Olmstead County, Minesota, 1940 to 1984. Journal of Pediatrics, 116, 278-279.

Watkins, E. S. (2007). The estrogen elixir: A history of hormone replacement therapy in America. Baltimore and London: John Hopkins University Press.

Weisman, C. S. (1998). Women's health care: Activist traditions and institutional change. Baltimore: John Hopkins University Press.

Whitlock, K. E. et al. (2006). Development of GnRH cells: Setting the stage for puberty. Molecular and Cellular Endocrinology, 254-55, 39-50.

Winkelstein, W. (1996). Eras, paradigms, and the future of epidemiology. American Journal of Public Health, 86(5), 621-622.

Women's Health Initiative Participant Website (2004). "Frequently asked questions about the estrogen-alone findings." (2004). Accessed July 16, 2009 from http://whi.org/faq/faq_ealone.php.

Woods, N. (1994). The United States women's health research agenda analysis and critique. Western Journal of Nursing Research, 16, 467-470.

Worcester, N., & Whately, M. (1992). The selling of HRT: Playing on the fear factor. Feminist Review, 41(Summer 1992), 1-26.

Wu, T. et al. (2002). Ethnic differences in the presence of secondary sex characteristics and menarche among US girls: The third national health and nutrition examination survey, 1998-1984. Pediatrics, 110, 752-757.

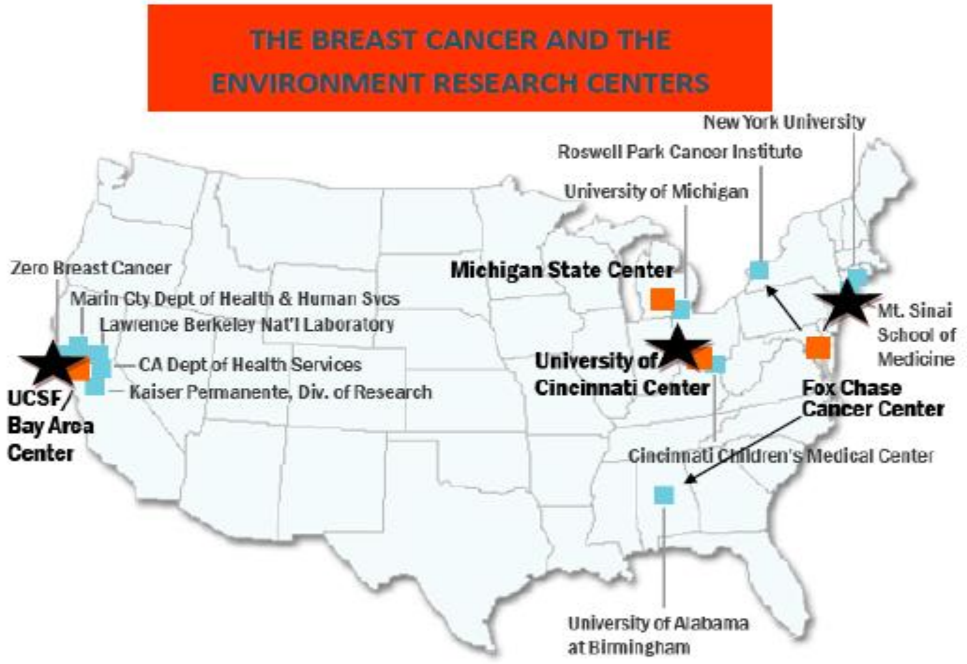
Wyllie, W. (1948). Three cases of precocious puberty. Journal of the Royal Society of Medicine, 41(6), 350.

Wynne, B. (1992). Misunderstood misunderstanding: Social identities and public uptake of science. Public Understanding of Science, 1, 281-304.

Yang, C. et al. (2009). Differential effects of peripubertal exposure to perfluorooctanoic acid on mammary gland development in C57BL/6 and Balb/c mouse strains. Reproductive Toxicology, 27(3-4), 299-306.

Zero Breast Cancer. (2008). History of Zero Breast Cancer. Accessed July 23, 2009 from http://www.breastcancerwatch.org/about/history.html.

APPENDIX A: MAP OF BCERC



🟧 Orange squares mark the primary research centers of BCERC, which house basic science research (UCSF, MSU, UC, and Fox Chase)

🟦 Blue squares show additional centers affiliated with each central research hub. These consist of additional scientific research centers and clinical research sites that are tracking the girls. Fox Chase Cancer Center is the only site whose affiliated locations are scattered across multiple states.

★ Stars indicate clinical research centers where girls are being studied (Oakland, Cincinnati, and Harlem).

Original outline for this map used with permission and can be found at bcerc.org.

Stars, arrows, and "key" added to this document by L.K. Thomson on December 1, 2009.

APPENDIX B: INTERVIEW GUIDE

Collaborative Research on Endocrine Disruptors and Breast Cancer Risk

A. Intro Questions

1. Please describe your professional training, job title, and current work.
2. How did you become involved with the Breast Cancer Environmental Research Centers?
3. Describe your role and contribution to the BCERC. What are the specific aims of your projects?
4. How has your work with the BCERC changed since the program began?

B. Endocrine Disruptors

1. Which types or categories of environmental exposures are relevant to the aims of your work/research?
2. What are the discussions and debates on environmental exposures and health risk that are occurring within your research/working group?
3. Do you these discussions and debates differ from those that are occurring across research communities (for instance, at the annual meetings)?
4. In your opinion, how have public perceptions of endocrine disruptors influenced your work/project, and has this changed since the BCERC was established?

C. Puberty

1. In your opinion, why or how did "puberty" become such an important part of the BCERC research and public health objectives?

2. Which of the following are most central to your work or research project: puberty, early puberty, or breast development? How?
3. In your project, how are environmental exposures believed to influence puberty, early puberty, and/or breast development?
4. In your project, how do understandings of puberty, early puberty, and breast development inform research or interventions in breast cancer?

D. Breast Cancer Research

1. In your opinion, what kinds of research on environmental exposures and breast cancer risk should be prioritized?
2. What do you notice about trends in structuring scientific research on breast cancer risk?
3. What is interesting to you about the interplay between breast cancer activism and scientific research?
4. What have you noticed about the media's portrayals of environmental exposure and breast cancer risk, and how has it changed over time?

E. Collaborative, Transdisciplinary Research

1. How would you characterize 'interdisciplinay', 'multidisciplinary', 'transdisciplinary research' and 'translational research'?
2. Describe the process and challenges in communicating your work/research across disciplinary divides in the BCERC.
3. What do you notice about regional differences and communication across BCERC?
4. Why now? What allowed this project (BCERC) to occur when and where it did?
5. How do you envision the transdisciplinary research on endocrine disruptors influencing the form or content of 'basic research'? 'clinical research'? 'public health?'

6. What group of people would you like to see involved, if there was 1 extra group added?

   Who do you think is missing from this conversation?

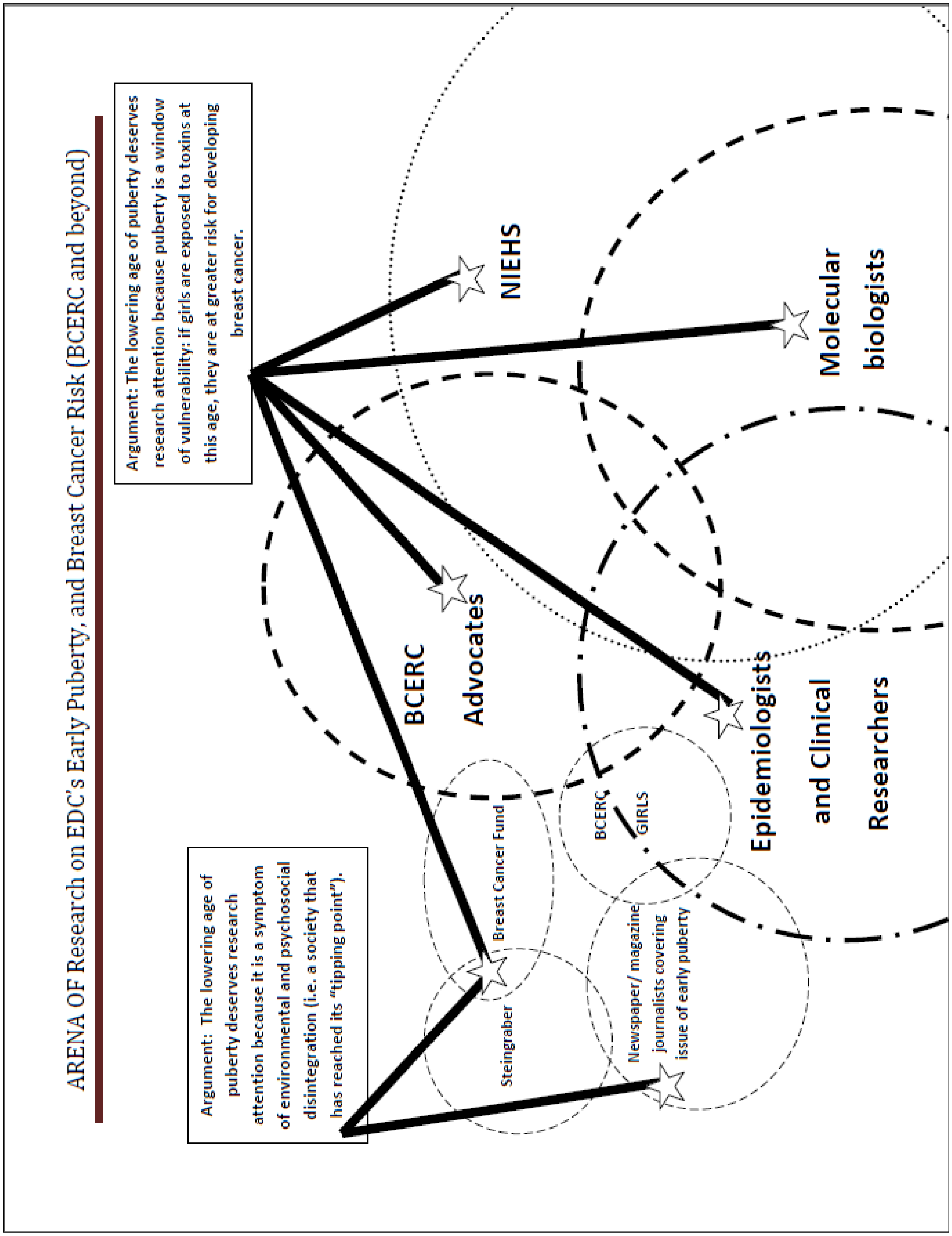
7. What do you think the legacy of this project will be?

8. Is there anything you would like to add or emphasize?

APPENDIX C: INTERVIEWEES

NAME	Role in BCERC	Profession
Hiatt	P.I.	Epidemiologist
Chingos	Reviewer/advocate	Advocate/Entertainment
Rudel	Reviewer/working group	Toxicologist, chemist
Van Olesen	Reviewer/evaluator	Public Health Researcher
Winn	Official (NCI)	Epidemiologist
Brody	Reviewer/working group	Public Health (epi focus)
Olden	NIEHS official (stepped down)	Cell biologist
Trock	Reviewer/working group	Epidemiologist
Kushi	Epidemiologist (Cygnet)	Nutritional Epidemiologist
Yaswen	Basic Scientist	Cell Biologist
Reinlib	NIEHS official	Neurobiologist
Koblick	COTC/advocate	MPH (epi focus)
Werb	Basic Scientist	Cell biologist
Barlow	COTC/advocate	Advocate/Nursing
Collman	NIEHS official	Epidemiologist
Haslam	Basic Scientist	Mammary Gland Biologist
Biro	Epidemiologist	Pediatrician
Anonymous	COTC/advocate	-
Anonymous	COTC/advocate	-
Karen Miller	Reviewer/advocate	Advocate/interior decorator
Brynn Taylor	COTC/advocate	Advocate/public health
Anonymous	Community Member	-

APPENDIX D: MAPPING ARGUMENTS ABOUT THE IMPORTANCE OF STUDYING PUBERTY ACCORDING TO BCERC AND PUBLIC VENUES



APPENDIX E: CONTENT OF NEWSPAPER ARTICLES

Los Angeles Times

Szegedy-Maszak, M. (2005, May 9). A distinct science; The female body is more complex than once thought. Hormones, genetics and environment all play a role.

Cone, M. (2006, June 1). Chemical in plastics is tied to prostate cancer; Bisphenol A, found in baby bottles and microwave cookware, permanently altered genes in newborn lab rats, a study finds.

Early puberty not cause of obesity. (2005, August 15).

Love, S., and S. Rochman. (2006, November 27). The cure for what we don't know; Breast cancer can't be prevented. That makes us suckers for rumors and anxious about the facts.

Beckman, M. (2006, December 4). Breast Cancer; Pounds may lower risk but only for the young.

The Dark Side of Lavender Oils. (2007, February 5).

Cone, M. (2007, March 4). Agency linked to chemical industry; The work of a federal

risk-assessment center is guided by a company with manufacturing ties. Some scientists see bias.

Beckman, M. (2007, March 12). First, weight; next, puberty; Heavier girls tend to develop earlier, but obesity is the real problem, experts say.

Maugh, T. (2007, March 28). Mom's beef puts son's sperm count at stake.

Meyerhoff, A. (2007, May 18). Who's tracking the chemicals?

Beckman, M. (2007, May 21). Chemicals and breast cancer; Suspects, but not all perps; A report has linked chemicals to tumors in animals. But the risks to women are less clear.

Cone, M. (2007, August 9). Panel finds some risk linked to plastic chemical.

Conis, E. (2007, September 10). Are plastics safe? Some chemicals may affect the reproductive system, growing research suggests. But as consumers seek alternatives, scientists point out that human studies are few.

Karp, H. (2007, September 20). Phthalates? Phtooey! Toxic chemical softening agents do not belong in kids' rattles, teethers and toys.

Cone, M. (2007, September 30). Study finds DDT, breast cancer link. Exposure in childhood is key, quintupling the risk among women with high levels of the pesticide, scientists say.

Balbus, J. (2007, October 7). We’re safer without DDT.

Wilson, S. (2007, October 22). Chemical stirs up controversy; Phthalates, compounds used in toys and many other plastic items, have raised health concerns.

Roan, S. (2007, November 12). Living for two: Mounting evidence suggests that fetuses are surprisingly susceptible to outside influences such as food, environmental pollutants, even stress.

Brink, S. (2008, January 21). Girl, you’ll be a woman sooner than expected: Puberty is arriving ever younger in American females - - 8 is no longer considered abnormal.

Brink, S. (2008, January 21). Modern puberty; For American girls, womanhood’s first signs are appearing at ever-younger ages, effectively shortening childhood. While scientists look for causes, parents must rethink what’s ‘normal’.

Chapin, J. (2008, January 28). What’s ‘normal’ for puberty? [Letter to the editor].

Mood, M. (2008, January 28). What’s ‘normal’ for puberty? [Letter to the editor].

Williams, R. (2008, January 28). What's 'normal' for puberty? [Letter to the editor].

Ross, G. (2008, January 28). What's 'normal' for puberty? [Letter to the editor].

New York Times

Belkin, L. (2000, April 29). The making of an 8-year-old woman.

Kolata, G. (2001, February 1). Doubters fault theory finding earlier puberty.

Kolata, G. (2005, December 13). Environment and cancer: The links are elusive; Preventing cancer, a matter of risk.

Fischler, M. (2006, January 1). After breast cancer, changing the world one house at a time.

Nestor, J. (2006, August 13). Too much of a good thing? Controversy rages over the worlds's most regaled legume. San Francisco Chronicle.

Sanghavi, D. (2006, October 17). Preschool puberty and a search for the causes.

Ross, G. (2006, October 24). Chemicals and pubescence. [Letter to editor].

Tawil, C. (2006, October 24). Chemicals and pubescence. [Letter to editor].

Kolata, G. (2006, December 26). Hormones and cancer: Assessing the risks.

Singer, N. (2007, February 15). Should you trust your makeup?

Kuczynski, A. (2007, June 14). A sense of anxiety a shirt won't cover.

Angier, N. (2007, August 7). Its poor reputation aside, our fat is doing us a favor.

Brown, P. (2008, February 16). For 'Eco Moms,' saving earth begins at home.

Pacific Sun

Kramer, J. (2006, March 31). Preventing cancer: Breast cancer activist Jeanne Rizzo keeps pushing the precautionary principle – if a chemical appears harmful, stop using it.

Cohen, R. (2006, October 27). Their breast guess: New Marin Women's Study seeks the breast cancer answer.

Cohen, R. (2007, February 2). Breast cancer reduction: Plunge in county rates linked to plunge in hormone therapy, say medical experts.

Cohen, R. (2007, February 16). Girl, you'll be a woman soon: Environmental factors are herding girls into womanhood sooner than ever.

Keen, C. (2007, March 31). Girls who start puberty earlier are less able to cope with stress.

Lanzendorfer, J. (2008, June 6). Powder-puff girls: Teens for safe cosmetics are applying their exfoliating pads to the makeup industry.

Other

Breast Cancer Fund Report examines causes, effects of early puberty. (2007, September 20). Medical News Today. Accessed February 17, 2009 from http://www.medicalnewstoday.com/articles/82901.php

Dungjen, T. (2007, October 31). Cincy girls at high risk for breast cancer. The News Record.

Wadia-Ells, S. (2007, December 22). High breast cancer rates found in Essex, Manchester – Is it the water? Gloucester Daily Times. Accessed February 6, 2008 from http://www.gloucestertimes.com

Priesnitz, W. (2008, February 5). Environmental problems hurt kids the most. Natural Life Magazine. Retrieved February 6, 2008 from http://www.naturallifemagazine.com/0802/NaturalLifeJanFeb08.pdf.

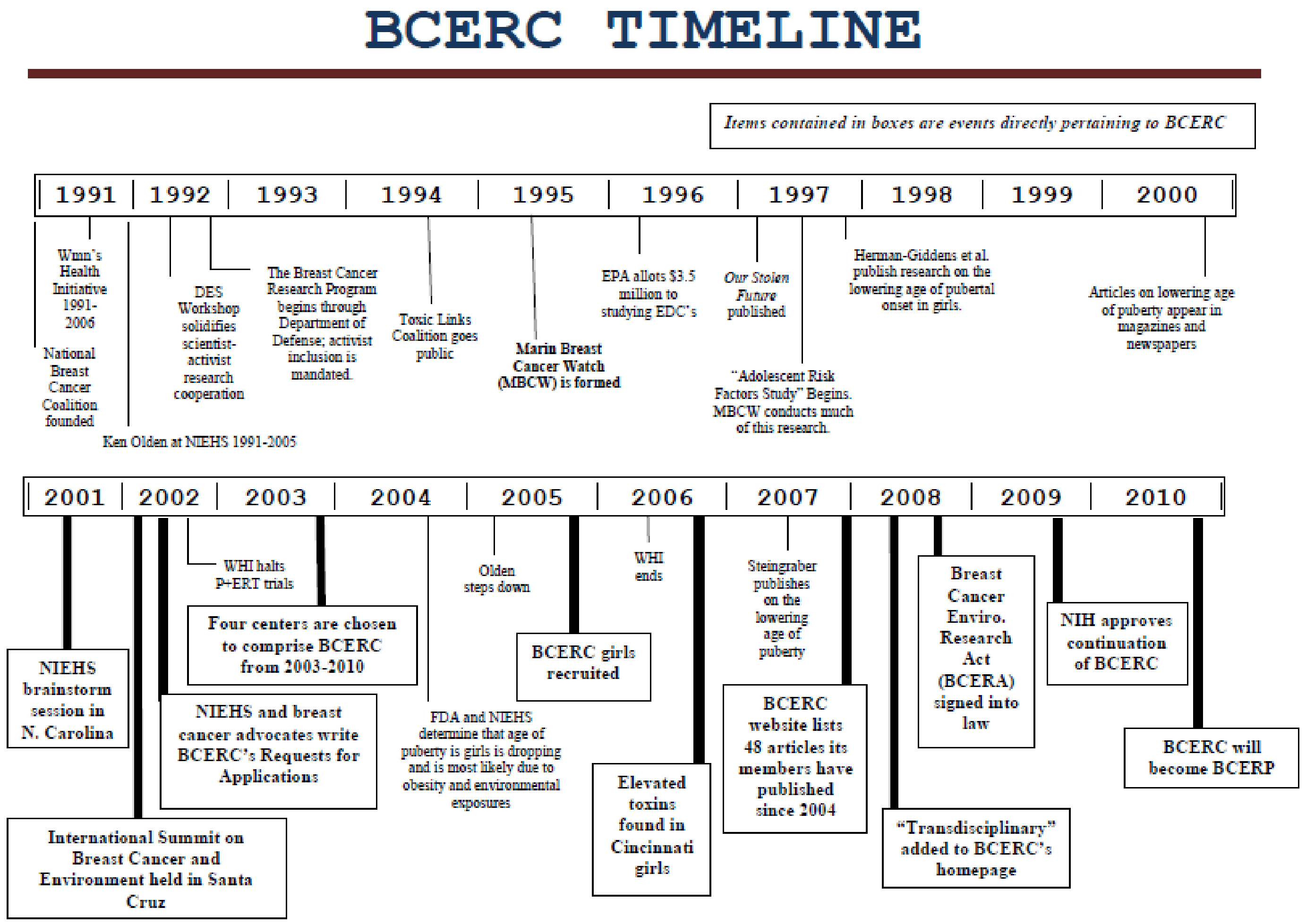
Johnson, L. (2008, February 11). “Early Puberty” in girls: Home life, toxins may be cause. The National Ledger. Accessed February 11, 2008 from http://www.nationalledger.com.

Enersen, Jean. (2008, February 23). Many girls experiencing early puberty. King 5 News (Seattle-based). Accessed February 23, 2008 from http://www.nwcn.com/health/children.

Blues of Puberty too soon. (2008, February 28). Sydney Morning Herald. Accessed March 20, 2008 from http://www.smh.com.au/lifestyle/wellbeing/blues-of-puberty-too-soon-20090407-9y8o.html.

Song, V. (2008, March 16). Growing up too fast? The Calgary News. Accessed March 20, 2008 from http://calsun.canoe.ca/News/Features/2008/03/15/5015841.html.

APPENDIX F: TIMELINE OF KEY EVENTS



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