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June 2001

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### Recommended Citation

Potts, Laura (2001). Lies, Damn Lies and Public Protection: Corporate Responsibility and Breast Cancer Activism. *Journal of International Women's Studies*, 2(3), 1-11.

Available at: <https://vc.bridgew.edu/jiws/vol2/iss3/1>

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## Lies, Damn Lies and Public Protection: Corporate Responsibility and Breast Cancer Activism.

Laura Potts<sup>i</sup>

### Introduction

The first world conference on breast cancer, held in Kingston, Ontario, in July 1997, provided a unique opportunity for activists, concerned about the possible links between breast cancer and the environment, to share their concerns in an international forum, with oncologists, radiologists, epidemiologists, survivors and alternative therapists. It also clearly exposed the fracture lines between competing discourses of risk and responsibility, between groups charged with a duty to protect and to care - health professionals, epidemiologists, statutory bodies, and those taking on those duties - generally activists, from environmental, feminist and survivor groups. These lines were even more clearly drawn at the second world conference in summer 1999 in Ottawa, particularly by the popular and medical media, which chose to stress the 'radical' (ie. 'dubious') claims of many of the papers which considered breast cancer risks from the environment.

The fundamental question that concerns me here is an explicitly ethical one: if we must act to prevent harm (and presuming for the moment the not uncontroversial assumption that disease is a harm), that is to say, if we are to act morally, then what counts as necessary and sufficient evidence to act? This, I think, is the ethical dimension to activism neglected or hidden in other formulations; Cuomo, for instance, defines activism as "conscious, purposeful, political activity" (1996:43), which seems



Photo 1.



Photo 2.

to ignore the sense of moral duty and responsibility that characterises confrontational activity from the margins and which I want to consider here.

### The social, political and cultural contexts of breast cancer activism

Several features of our 'late modern times', and changing patterns of social movements, shape the context in which such moral and political activity to prevent breast cancer is undertaken. The first of these is a public scepticism about science and technology, informed by mishaps and blunders on the one hand (Yearley 1991), and on the other by an ideological shift as positivist methodologies have been questioned and found wanting (Harding 1986 and 1991). (While there is a clear differentiation between health/medical science and environmental/agricultural science, in the public mind it is the overarching, generic nature of science that prevails, whether it relates to rail safety, BSE or breast cancer.) A second feature is the emergence of consumer rights movements, and patient advocacy groups within health care, informed by a neo-liberalism which likes to pay at least some lip service to values of participatory democracy; this is the 'normative rationale' for public input to risk assessment, a pragmatic approach "predicated on an appeal to democratic principles" as advocated by Perhac (1998:237). A third feature is the recent history of highly effective feminist campaigns from the 1970s on, in which women's skills and strategies have been honed, and public visibility and credibility earned (Klawiter 2000) [see photos 1 and 2]. And fourthly, breast cancer activists have learned lessons from those working with HIV and AIDS in the 1980s (Epstein 1996:348; Anglin 1997:1404), whereby scientific knowledge and expertise were acquired and campaigning tactics refined and transformed. Each of these features contributes to the positioning of breast cancer activism as a social movement confident in making knowledge and value claims, in contesting the scientific establishment, and in demanding, above all, changes in policy to protect the public health. In this last respect I argue that breast cancer activists have claimed a moral authority and responsibility which remains legally invested in statutory and regulatory bodies - thus, incidentally, exposing a critical limitation of both Beck and Lupton's formulations of the 'risk society', in which 'lay' responsibility is legitimated only in terms of individual health behaviours.

In his discussion of AIDS activism in the USA, Epstein (1996) notes that many of those involved were already socially positioned as 'outside' the dominant norms of society, by virtue of their sexuality, and familiar with campaigning, lobbying, organising and protesting within the gay rights movement. The story of breast cancer activism is not so clear cut: while some of those involved have a history of campaigning work, as feminists, lesbians and/or environmentalists, many 'lay' women



Photo 3.

researching the links between the environment and breast cancer and working for primary prevention, were politicised by their personal experience of the disease, by an urgent need to know why they had it, and by a growing concern about the potential

hazards in their own local communities [see photos 3 and 4]. As the photographic artist Matuschka asserts: “I lost a breast and the world gained an activist” (Exposure 1997; see also Rachel’s Daughters 1998). In this respect, then, such activists, new to this identity, are ironically positioned as “hysterical housewives’ and other mad women”, as Seager labels those working in grassroots environmental campaigns in the USA (1996). As she says, “many women who are now environmental leaders were, initially, reluctant activists; most grassroots women report little prior community activism, little environmental knowledge, almost no experience in public speaking or organising; many describe themselves modestly as ‘mere housewives’” (*ibid*). The process of politicisation is an uncomfortable one: a growing distrust of government and corporations; anger that their health has not been protected as they might reasonably have assumed, but has in fact been jeopardised by environmental hazards; fear that this epidemic of breast cancer is not controllable [see photos 5 and 6].



Photo 4.

Several meetings were held in Canada and the USA in the early 90s on, bringing together women who saw a need, often prompted by their own experience of breast cancer, to shift the policy agenda towards more primary prevention (see Batt 1994:187-209). Enquiry and analysis undertaken by these groups of women uncovered a particular concern about possible environmental causes of the breast cancer epidemic, and inevitably, then, women making those connections, and making them publicly, became identified as activists (Read 1995:67-77). Of course, this was no new story: Rachel Carson’s work (1962/1999) in the early 1960s had already alerted us to the hazards of industrialised agricultural development, with its use of toxic pesticides such as DDT causing the ‘silent spring’ of which she warned. In the last ten years a great deal of other work has been done, most notably and eloquently perhaps by Sandra Steingraber in *Living Downstream: an ecologist looks at cancer and the environment* (1997), and specifically on breast cancer by the epidemiologist and campaigner Devra Lee Davis (1995; Second World Conference on Breast Cancer). In the UK, much of the available evidence on the links between breast cancer and the environment was



Photo 5.

collated in the Women's Environmental Network's reference pack for the project *Putting Breast Cancer on the Map* (1998). Many aspects of our lived environment are implicated: I want here briefly to focus particularly on organo-chlorine pesticides, which have oestrogen mimicking properties as they metabolise in the body<sup>ii</sup> (see *Rachel's Environment and Health Weekly* #571-5, 1997, for a comprehensive summary of environmental factors implicated in breast cancer).

### Regulation and the public health

In England the Pesticides Safety Directorate of the Ministry of Agriculture Fisheries and Food has the statutory responsibility for the regulation and licensing of all pesticides, following recommendations from the 'independent' Advisory Committee on Pesticides (November 24<sup>th</sup> 1998). The ACP states that its overriding aim is that "pesticides should be used for the public good" (minutes of meeting with ACP chair, April 5<sup>th</sup> 2000), from which we may infer a utilitarian approach



Photo 6.

emphasising the greatest good for the greatest number, not absolute protection of any citizen at risk. Other aims are that "nobody should be made ill by exposure to pesticides" and that "nobody should be made seriously ill by use of pesticides"; the committee does not, however, have "the legal basis to ban a particular pesticide on the basis that there are less toxic alternatives" (*ibid*). "The Directorate's specific responsibilities relate to ensuring that the use of agricultural pesticides does not have unacceptable implications for people and the environment" (correspondence 1998). Clearly here, then, is an expression of a statutory remit that is congruent with what a common sense – or lay? – approach might assume: as an expert government body, the PSD has a responsibility to protect the public health, on expert advice from the ACP.

The procedures by which the ACP attempts to ensure pesticides are used for the public good and without causing harm (classic ethical principles of beneficence and non-maleficence) involve risk assessment measures designed to calculate acceptable levels of toxicity, exposure levels and daily intake, based largely on tests in animals. They neglect certain other factors which may be regarded as significant – synergistic effects, bio-accumulation, multiple exposures, public reporting of symptoms thought to be linked to pesticide exposure, and global environmental implications. Demanding a more holistic assessment that includes such considerations is a key feature of environmentalists' scientific method, one which does not challenge the ideological basis of that approach, but rather extends it, as we shall see below. In addition, most epidemiological studies relate to men, as they are assumed to be the primary workers with pesticides; this may be the case in the over-developed world, but is certainly not so in less developed countries (ed. Barrientos et al 1999). The emphasis on risk from operator exposure is a testament to the trade union and health and safety movements, and their long battles for worker protection; it may, however, preclude recognition of

other health risks to different populations from the same substances. There is a clear gendered and racial bias in such a limited approach, as those active in the environmental justice movement have demonstrated (Fishman 2000). By focussing on women's risk of breast cancer from the consumption of dairy products contaminated with Lindane, an OC pesticide, alongside the ignorance about its safe usage among agricultural workers, a Dispatches documentary (Channel 4 1996) brought these two conventionally divergent perspectives together, gave public prominence to the concerns of women with breast cancer, and called for Lindane to be banned.<sup>iii</sup> This approach demonstrates, I think, a popularist paradigm of risk assessment, and also challenges the dominant positivist basis to scientific enquiry exemplified by the methods adopted by the ACP, by demanding action on the basis of existing knowledge and compatibility with regulations in place elsewhere in the world.

### The uncertainty of scientific knowledge and the moral imperative

A defining feature of this paradigm, and of the demands of environmental activists more broadly, is the 'precautionary principle', articulated by Davis (1995), Batt (1994), Read (1995), Simpson (2000), Steingraber (1997), Epstein (1997), *inter alia*, and heartily endorsed by the International Global Action Plan (First World Conference on Breast Cancer 1997) that came out of the first world conference. As Steingraber states, "the precautionary principle...dictates that indication of harm, rather than proof of harm, should be the trigger for action – especially if delay may cause irreparable harm" (1997). The frustration of many activists, expressed at the conference and in the British campaign to ban Lindane, is with the reluctance of policy makers to acknowledge that we know enough, that the "weight of evidence is sufficient" (Second World conference on breast cancer 1999). The precautionary principle demands that policy makers act *as though* they were certain. In terms of the tradition of public health policy, this is nothing new: "we must act on facts, and on the most accurate interpretation of them, using the best scientific information. That does not mean we must sit back until we have 100% evidence about everything. Where the state of the health of the people is at stake, the risks can be so high and the costs of corrective action so great, that prevention is better than cure" (Horton 1998:251). In the case of tobacco use, they sat back too long; in the case of preventing the 19<sup>th</sup> century epidemic of cholera in London, action was taken on the available, limited evidence, and the understanding of the spread and prevention of the disease greatly enhanced – as well as lives saved.

The moral imperative of the precautionary principle in risk assessment thus manifests an explicitly deontological principle that *requires* action to prevent harm, rather than the consequentialist position adopted by the statutory 'protection' agencies. The precautionary principle is a response to the explicitly ethical issues that activists identify: a perceived injustice in terms of the moral failure of government and industry to protect health, a sense of the equal human worth of all those 'at risk', and a conviction of the moral responsibility to act to change the conditions which are believed to threaten the health of our communities.

In asserting that "we never have enough proof", but that "dead bodies should not be the requirement to act to prevent breast cancer" (Davis in *Exposure* 1997), the precautionary principle emphasises the "*inherent* uncertainty of science" (*ibid*). While subverting a fundamental tenet of the scientific paradigm, such an approach is not,

however, a challenge to science *per se*, as activism may be caricatured, for still we need scientific enquiry and the resultant evidence in order to test hypotheses and to shape conclusions and policy action. As Evelleen Richards is quoted as saying (in Epstein 1996:343), we need “‘to learn to live with the reality of uncertainty’ and to introduce political, ethical and subjective criteria” into scientific processes. Of course the critique of the dominant positivist method shows clearly just how such criteria are implicit in so-called objective, unbiased and value-free science<sup>iv</sup>; Richards’ proposal is for the legitimation of such criteria as the basis for policy making for the public good. The political criteria employed by activists’ analysis of the environmental risks of breast cancer are crucial to the understanding of the broad picture of disease they advocate. This includes, for instance, a powerful critique of the vested interests of ‘the cancer industry’ – characterised by corporations such as Zeneca (Klawiter 2000), a \$8.6 billion international biosciences business, involved in the complete cycle of breast cancer through a pesticide and herbicide division, ownership of a chain of cancer care centres in the US, and the manufacture of the world's largest selling breast cancer drug tamoxifen. Many other examples might be cited, but not in a paper of this length and focus.

#### ‘Lay’ and ‘expert’ knowledge claims

Such considerations provoke a lack of trust in ‘experts’, which, according to Beck (1995:126), is in the nature of the ‘risk society’ we inhabit; he seems, however, to overlook the mutual and reciprocated nature of that mistrust. In order to challenge the status quo of the breast cancer industry’s priorities, activists have learned fluency in the languages of science: of epidemiology, biochemistry, human biology (see Klawiter 2000; WEN 1998 and 1999; Second World Conference on breast cancer 1999). Their appraisal of the published data on pesticides and breast cancer uses the same skills of critical analysis of the evidence presented as any ‘good’ scientist, but the legitimacy of ‘non-experts’, and ‘lay’ knowledge claims are perceived as biased and devalued by the political, ethical and subjective criteria implicit in their conclusions. Lupton observes (1999:86) that “Foucault, like Beck and Giddens, emphasises the role of expert knowledges in the constitution of late modern subjectivity...[which] are seen as pivotal to governmentality, providing the guidelines and advice by which populations are surveyed”. What actually seems to be the case is that the subjectivity of the experts is the key factor here, rather than the status of their knowledge. By virtue of their proximity to science, and thus to that hierarchical esteem invested in science since the post-Enlightenment modernisation of the world, their knowledge is imbued with more status than that of equally knowledgeable activists or lay people. Thus it is that authority, not the facts – the knowledge claims – and, by extension, the legitimated basis of regulatory policies and practices, that are challenged when ‘lay expertise’ contests the evidence and conclusions cited by the institutions of power and government (see also Wynne 1997; Abraham and Sheppard 1997).

Some campaigners clearly think that such legitimacy may be granted to all and any lay persons, as evidenced by the WEN information pack given to all women who might participate in *Putting breast cancer on the map* (1998): “To make this project work we are asking you to be the researcher. You already possess all the skills, knowledge, experience, enthusiasm and local knowledge (*sic*) necessary to achieve

this. You also have a vested interest in yourself, your community and your environment.” The basis of these claims is a wholly different discursive position, one which derives from a particular feminist epistemology: the authority of women as good-enough experts, and the validation of a ‘vested interest’ (Harding 1991). While many breast cancer activists clearly have an acquired expert status within a traditional scientific paradigm,<sup>v</sup> their knowledge claims derive not solely from their assessment of those ‘facts’ of potential hazards, but from a differently constructed subjectivity, as women at risk of breast cancer (Potts 2000:123-4; Epstein 1996:347). Thus while, as we saw, the legitimacy of the knowledge claims of the ‘scientific experts’ is invested in their identity *qua* scientists, the moral legitimacy of ‘lay experts’ or breast cancer activists may be understood to be invested in their identity based on an embodied knowledge, which rests in the personal risk to the self of breast cancer.

Such ‘subjective’ criteria beg the whole vexed question of the relationship between emotion and science, a polarity of positions that on the one hand still characterises activists as ‘too involved’ and therefore too partial, in every sense ( see Harding 1991:109 for a full discussion of this point), and on the other hand expressly legitimates that local, intimate, first hand embodied knowledge that women may have: as Nancy Evans, a breast cancer activist in the Bay Area of California states, “we *are* the body of evidence” (Second World Conference on Breast Cancer 1999). Such acquired and embodied ‘expert’ knowledge is based in opposition to the established claims of risk assessment made by statutory and regulatory bodies; it is grounded in a discourse which acknowledges the validity of the explicit inclusion of the personal and ethical. Activists, then, move between these discursive positions, learning scientific method and analysis while also asserting an personal/embodied/ethical standpoint. The ‘cognitive praxis’ (Eyerman and Jamison 1991) of the breast cancer and the environment movement thus also reflects this ‘bifurcated consciousness’ (Smith 1988). A similar effect has been identified by Fosket in relation to women’s knowledge claims about the treatment of breast cancer; as she states, “women can be seen as occupying this critical position of bifurcation and constructing knowledges that reveal the spaces that exist between...biomedicine...and those knowledges that are meaningful to the lives of women” (Fosket 2000:31). I do not wish to ascribe an enhanced or special status to these experience based knowledge claims; they are not, as Gruen states (1994:129), transparent; they “...give no direct or immediate access to ‘facts’”, and nor do they have an intrinsic authority or legitimacy, as Fuss (1989) has shown. But their inclusion in risk assessment would make for stronger science, not ‘bad’ science.

### Alliance for change

What, then, might be ‘good enough’ science in this context? An oral claim by Friends of the Earth that the WEN report (1999) on the perceived environmental risk of breast cancer is ‘bad science’ because its conclusions are loose, woolly and unspecific, is premised on a positivistic “cognitive science perspective” (Lupton 1999), embraced by many environmental organisations in the quest for legitimacy and recognition. Such criticism echoes Mulkey’s review of *Misunderstanding Science* (1997:257), in which he implies ‘lay experts’ are doing ‘bad’ science by not being immune to bias – a statement of the obvious, but not, as I hope I have shown, necessarily one that should be blameworthy. For if we acknowledge with Harding (1991:145) that any

objectivity in science is a myth, that all knowledge is situated and all knowers are different (Cheney 1994:168), then we can validate as a 'stronger objectivity' a scientific paradigm that expressly locates the (moral) agents in the making of knowledge claims about risk. Such an approach evokes Gruen's notion of "an ecofeminist moral epistemology ... (that) results from the recognition of the interdependent nature of science and society, reason and emotion, facts and values" (1994:134). This would be a process of risk assessment informed on the one hand by standpoint theory and nicely incorporating Lupton's synthesis (1999a; 1999b) of existing approaches, while legitimating the value claims of activists too, made as moral agents with relevant embodied knowledge. In this way a changed paradigm of risk assessment and regulation could provide Harding's "possibilities for a transformed, socially just science"( Rocheleau 1996:3).

In order to 'stop breast cancer before it starts', a slogan adopted by the UK campaigning group 'free rradicals', to protect future generations of women from environmental risks, we need urgently to establish a different basis for regulatory practices; as Cheney suggests, "our real concern ... is with the relationship of people *variously* positioned, those *not* socialised to the same set of theoretical vocabularies. Under what conditions would *they* agree on a world-story?" (1994:168; *emphasis in the original*). The work of breast cancer activists is informed by such considerations, and thus has the potential to *transform*, rather than overthrow, professional scientific endeavour, and to invest it with appropriate ethical concern, for the health of women and the health of the planet. The ACP would likely be astonished by demands for a 'stronger objectivity' in their risk assessment procedures, but as Cheney (1994:168) makes clear, the "matter of negotiating reality, and with it, values", is a logical outcome of such an alternative position. Peggy Reynolds, a formidable breast cancer activist and environmentalist from the Bay Area in California articulated this position with characteristic verve: "We are not waiting for these studies to be complete; we need these studies, yes, but they're not going to be done in my life time...or even in my grand-daughter's...we're not waiting any more; we're going for action. 'Do no harm', that's what it really translates to, the Hebrew phrase to 'repair the world' – that's what we're trying to do...We were given a place that's got a little messed up. We have a responsibility to work to clean it up. As Bella (Abzug, erstwhile president of WEDO) said, 'we are the ones we've been waiting for (Second World Conference on breast cancer, 1999).

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<sup>ii</sup> In recent years I have personally been involved in campaigning to ban Lindane in the UK; this has involved direct action, lobbying and participation in public forums. As an organic gardener I have been committed to non-harmful cultivation for twenty years, and first undertook research in this area when I worked in health promotion from 1984.

<sup>iii</sup> In the UK, a network of groups actively campaigns has been very successful in campaigning for a ban on Lindane, in line with European Union directives; UNISON, a public sector trade union, Pesticides Action Network UK, Women's Environmental Network, Breast UK, Green Network, and free radicals are all involved. Current activity focuses on Lindane in chocolate (from cocoa grown mainly in Africa), and extending the ban to cover all domestic use products.

<sup>iv</sup> Concern remains about the outside interests of members of the ACP; several hold academic/research positions funded by pharmaceutical companies.

<sup>v</sup> But as Epstein makes clear, while the democratisation of biomedical knowledge-making is clearly a good for society, it is not without problems (1996:351). The problem of 'expertification' within social movements certainly bedevilled the Women's Health Movement, causing what Epstein calls "knowledge hierarchies" that "build upon and reinforce social cleavages based on other markers of difference – class, formal education, race, gender, sexuality, and nationality" (*ibid*:352).