

Risk, biotechnology and political rationality:
Lessons from women's accounts of breast cancer risks

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About the Author

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About the Article

Ann Robertson considers the issues for women of increasingly available genetic tests. Drawing on social theory, Robertson analyses how women make sense of their personal risks for breast cancer, and what control they feel able to exert over the disease, as individuals or as members of a group. From this vantage point, Robertson understands the CBS's goal of balancing dangers and opportunities as a valid one, and she hopes, through her work, to contribute to achieving that balance.

The ... point is not that everything is bad, but that everything is dangerous ... If everything is dangerous, then we always have something to do. (Foucault 1984:343)

Introduction

The purpose of this discussion paper is to explore the personal and political implications of current discourses on health and risk, and to suggest some of the ways in which these discourses are produced and shaped, in part, by existing and emerging biotechnologies, specifically diagnostic and screening technologies. I use the term “discourse” in the sense that Michel Foucault used it to refer to ways of thinking, speaking and writing about a particular area of knowledge, as well as the actual practices associated with those ways of thinking, speaking and writing. Biomedicine, for example, continues to be one of the major discourses on health, tending to dominate over alternative perspectives on health and healing such as holistic or traditional medicine. This paper is based on the premise that discourses on health are never just about health. Particular discourses on health emerge at particular historical moments and gain widespread acceptance primarily because they are more or less congruent with the prevailing social, political and economic order within which they are produced, maintained and reproduced. That is, discourses on health are always contingent. Moreover, because they are always attached to other interests and agendas – professional, economic, political, cultural, ideological – discourses on health, including discourses on health risks, also function as repositories and mirrors of our ideas and beliefs about, among other things, what it means to be human and the kind of society we can imagine creating and how best to achieve it. In this sense, discourses on health are fundamentally prescriptive.

This paper is informed, in part, by

empirical research that I have conducted on women’s accounts of breast cancer risks. While the study discussed in this paper has a phenomenological focus, in focussing on women’s experiences in the context of their everyday lives, it also is based on the assumption that women’s health experiences – specifically, the ways in which they talk about their own personal risks for breast cancer – are located within the broader social, political and cultural context which produces and shapes those experiences. In other words, a “phenomenology of risk” is a *situated* phenomenology. This paper argues that diagnostic/screening technologies are not only part of the context that shapes women’s health experiences, they are also produced and implemented within that same context. In addition, particular diagnostic/screening technologies both make possible and are made possible by particular discourses on risk, which themselves are produced within a particular context. In other words, there is a dialectical relationship between women’s health experiences, prevailing discourses on health risks and emerging diagnostic/screening technologies. This means that they must all be analysed within the same social, political, moral, cultural and ideological context.

It should be made clear at the outset that this paper is not intended as a neo-Luddite diatribe against biotechnology in general. Some biotechnologies clearly have enormous potential to improve health overall – and women’s health, in particular. However, it was clear from the CBS documents that there exists a tension between, on the one hand, the consideration of social and ethical issues related to the development and deployment of biotechnology (Canada 1998a) and, on the other hand, the belief that “industrial growth should be the primary objective of the CBS renewal, along with “provision for ‘unencumbered’

basic research", (Canada 1998b). As noted in the CBS Health Sector Consultation Document (Canada 1998c:8), "the health sector bears a particular responsibility to provide leadership to society in imagining creative solutions that articulate and *balance* emerging social values with expanding technological capabilities within regulatory policy development" (emphasis added). This paper seeks to contribute to achieving this balance. Moreover, I will argue that in addition to considering the social and ethical implications of biotechnology as the CBS documents call for, the dialectical relationship between prevailing discourses on risk and emerging diagnostic/screening technologies also has significant personal and political implications which must be considered.

This paper consists of three parts: first, a brief overview of my empirical study of women's accounts of breast cancer risks; second, a discussion more broadly about what this study indicates about the personal and political implications of prevailing discourses on health risks, and some speculation about how these results relate to current and emerging diagnostic/screening technologies; and finally, a consideration of questions – empirical, policy, moral – which a critical social science research agenda might address with respect to the social management of biotechnology.

I. Our Bodies, Our Enemies: Women's Accounts of Breast Cancer Risk

There have been a number of studies, recently, specifically investigating women's perceptions of risk for breast cancer (Black, et al. 1995; Breast Cancer Bulletin 1995; National Forum on Breast Cancer 1993; Hallowell 1999; Kavanagh and Broom 1998; Koenig and Stockdale forthcoming; Lipkus, et al. 1999; Lloyd, et

al. 1996; Mannheimer 1992; Potts 1999). However, with a few exceptions, most of the studies of women's perceptions of breast cancer risk have employed a number of psychosocial measurement instruments and structured interviews with, until recently (Hallowell 1999; Koenig and Stockdale forthcoming), very few phenomenological investigations of women's accounts of risks for breast cancer.

According to Sandra Gifford (1986), one of the few researchers who has conducted phenomenological research on women's perceptions of risk for breast cancer, risk for breast cancer becomes internalised and is experienced as a state of being, which leads to an ambiguous relationship between health and ill-health: "This ambiguity results in the creation of a new state of being healthy *and* ill; a state that is somewhere between health and disease ..." (215). As with illness narratives, personal narratives of risk may help women make sense of breast cancer risk by providing an "arena for the negotiation of reality" (Early 1982:1491). At the same time, by leaving women feeling "precariously perched between illness and health" (Garro 1994:784), awareness of risk "forces an awareness of the body as separate from self" (782). As Baines says: "For women with breast cancer, it is a chronic disease; for women generally, it can be a chronic problem" (Baines 1990:20).

In order to investigate the extent to which this was the case, I undertook a study of women's accounts of breast cancer risks. Focus groups and in-depth interviews were conducted with 20 women recruited from a pool of women who had attended a Breast Health Clinic at a metropolitan teaching hospital and had not been diagnosed with breast cancer. Participants were divided into 3 clinically-designated risk groups – low, medium and high – based on certain clinical criteria. Focus

groups and interviews were tape-recorded and transcribed. The transcripts were then subjected to a standard qualitative data analysis to elicit common themes that emerged from the women's accounts of risks for breast cancer.

The following analysis focuses, in particular, on what study participants said about two issues with respect to breast cancer risk: firstly, their perceptions of their own personal vulnerability to breast cancer; and, secondly, how much control they felt they, personally, and women in general have over whether or not they ultimately develop breast cancer. For the sake of brevity, the three major themes which emerged from analysis of the data are briefly outlined below. Data, in the form of direct quotes from the study participants, supporting these themes is provided in a longer paper based on this study (Robertson 1999)

Breast worry: vulnerable and flawed – All the participants expressed varying degrees of “breast worry”. This worry had three essential components: the inevitability of breast cancer, the constancy of this worry about breast cancer, and the sense of the breasts as flawed body parts (employing terms like “time bombs” and “Achilles heel”).

Managing uncertainty: numbers and risk status – Linked to the constant awareness of vulnerability to breast cancer that these women felt was the theme of uncertainty. For some women this was expressed as an awareness that uncertainty was something they simply had to live with. For others, it was expressed as a desire for more certainty. One of the most common strategies that women in this study used for managing this uncertainty was to figure out their own breast cancer risk status. Many women appeared to be continually adjusting their sense of their own risk status over time as a result of incorporating additional information or

making changes in their own health behaviour.

Playing the odds: individual responsibility/no control – Nearly every woman in this study talked about the individual responsibility that she and all women have for reducing their personal risks for breast cancer. This was always framed in terms of individual responsibility at the level of lifestyle behaviours such as diet, smoking and alcohol consumption, behaviours which they were well aware of as “risk factors” for breast cancer.

While there was a general emphasis on this kind of individual responsibility, at the same time, many of these same women recognised that there were many risks for breast cancer that they had no real control over. Significantly, even though most women spoke about environmental issues like polluted air, water and soil and food additives, which they all considered to be major contributors to increasing risks for breast cancer, not one of the women in this study talked in terms of collective action at the social, political and economic levels for reducing breast cancer risks, such as lobbying for stricter environmental controls or food regulation.

What appeared to happen was that women tried to reconcile these two conflicting issues – individual responsibility in the face of limited or no control – with the notion of “playing the odds”. One participant expressed how going back and forth between these two poles of responsibility and control kept her poised on the edge of uncertainty. The result was a fundamental bifurcation of body and self. While this is a particularly eloquent and poignant expression of this, every woman in this study expressed some degree of this bifurcation of body and self.

... I think that there's – say there's two of me and one of me goes low-fat [diet], doesn't drink or has the odd

drink, doesn't smoke, exercises, and the other one smokes and drinks and eats so that they're out like this, yeah, I think I'm gonna – this one over here [indicating the “healthy lifestyle” self] is going to have a lot better chance of not developing cancer than this one over here [indicating the “unhealthy lifestyle” self]. I would say this one over here will develop it if she has ... the propensity. But then the thing is both these two people have the genes. They both have an eighty-five per cent chance. Yeah, and I would say this one over here, the fat one, the smoking, alcoholic fat one, will develop it. And this one over here, the exercising obsessive, maybe she won't get it; but there's a good chance she will. But she seems to be smart enough that she looks after her body and she takes care of herself that she'll get the proper help to deal with it better emotionally, *she'll nip it in the bud because she's aware of it and she's doing things about it, and she won't die*; whereas this one over here may not realise she has it until it's too late. (Donna, HR:29 - 31).

Donna, like all the women in this study, have literally embodied prevailing discourses on breast cancer risk, and along with them, a particular political rationality.

II. Embodying Risk, Embodying Political Rationality

“Risk” has become one of the defining cultural characteristics of Western society at the end of the twentieth century (Beck 1992b; Douglas 1994; Douglas and Calvez 1990; Douglas and Wildavsky 1982; Giddens 1991; Nelkin 1985; Renn 1992; Scott, et al. 1992). Perhaps, most significant is that, in the current context, the meaning of risk has shifted away from being a neutral mathematical probability, and has come to signify impending danger

(Douglas 1990; Lupton 1994b). A common theme in much of this literature is that risk consciousness reflects a new social, political and moral order: “[the] risk debates around which much of modern politics has been shaped are quintessentially tied up with ... the search for new forms of legitimate order and authority” (Wynne 1996:78).

As in other areas of life, “risk” has become has become central to discourses related to individual health; that is, risk has become a common construct around which health in Western society is described, organised, and practiced, both personally and professionally (Bunton 1992; Hayes 1991; Hayes 1992; Lupton 1995; Petersen 1996). The results of this study demonstrate the extent to which the participants embody discourses on risk, in general and discourses on breast cancer risk, in particular. This embodiment of risk is expressed by the women in this study in terms of a phenomenological experience of “being at-risk” for breast cancer. There has been much recent discussion about the implications of this “at-risk” consciousness (Castel 1991; Crawford 1994; Greco 1993; Lupton 1994a; Petersen 1998; Petersen 1996).

Firstly, and as indicated by the results of the present study, such consciousness contributes to the emergence of a particular form of subjectivity – that is, a particular way of thinking about, relating to the self in terms of the broader social and political context within which the self is embedded/located. The particular subjectivity made possible by current discourses on health and risk and the resulting “at-risk” consciousness has been described as the “entrepreneurial subject” (Petersen 1996; Rose 1990; Rose 1993). This captures the notion that “life should be an enterprise of oneself” (Petersen 1996:48), a personal project, to be continually and actively assessed, managed, worked and improved upon

(Greco 1993; Lupton 1995; Petersen 1997; Petersen 1996; Rose 1993; Rose 1990); in turn, "this requires the individual to adopt a calculative and prudent attitude with respect to risk and danger" (Petersen 1996:51).

For the women in this study, this enterprise is essentially an embodied one: they manage their anxiety about being "at-risk" for breast cancer by managing their bodies, that is, by adhering to particular lifestyle behaviours such as low-fat diets, not smoking, controlling their alcohol consumption, practising stress management strategies and managing of their reproductive options in particular ways. Where they are not actually engaged in such "healthy" lifestyle choices, they exhort themselves to become so. Other investigators have talked about "panic bodies" (Lupton, et al. 1995b; Lupton, McCarthy et al. 1995), "risky bodies" or "risky selves" (Nettleton 1997), and even "dangerous bodies" (Hallowell 1998) and "malignant bodies" (Williams and Bendelow 1998). The women in the present study appear to manage their uncertainty and anxiety about breast cancer by negotiating an uneasy pact with their "treacherous bodies".

The phenomenological experience of the women in this study does not, of course, occur in a vacuum; such experience is always situated and located – socially, politically, historically. In analysing the portrayal of risks for breast cancer in popular media, Deborah Lupton (1994a:73) found that the Australian press drew upon "dominant cultural metaphors and discourses concerning femininity, the individual's responsibility for illness, and medical and technological dominance". These same themes were reflected in the accounts the women in this study give of their vulnerability to breast cancer.

Many scholars have written about how the

role of public health is central to the reproduction of this risk consciousness. (Bunton, et al. 1994; Bunton 1992; Lupton 1995; Nettleton 1997; Petersen and Lupton 1996). For example, the phenomenological consequences of the public health practice of "risk assessment" for the entrepreneurial subject are clear.

Preventive medicine and statistical calculations in the context of epidemiology are part of a *moral technology*; by being made aware of risks, the individual is told to provide for and discipline the future, to calculate future actions and dealings. (Adelswards and Sachs 1998:207; emphasis added)

The scope of public health would appear to be almost limitless, for as Castel observes, "for what situation is there for which one can be certain that it harbours no risk, no controllable or unpredictable chance feature" (Castel 1991:289). And it is diagnostic/screening technologies – such as mammography and genetic testing for breast cancer – which, in part, have provided the means for public health and preventive medicine to cast an ever-widening "clinical gaze" – or more specifically, a "technological gaze" – over the health and lives of women, such that "to be suspected, it is no longer necessary to manifest symptoms ... it is enough to display whatever characteristics the specialists responsible for the definition of preventive policy have constituted as risks" (Castel 1991:287).

Diagnostic/screening technologies are instrumental in defining and assessing these "characteristics", resulting in a "technologization" of risk. To date, these have been largely imaging technologies – such as mammography, ultra sound, bone-density testing – but with the enormous global effort being put into the Human Genome Project, these "characteristics" are becoming

increasingly genetic, surely confirming Lippman's (1992) early insights into the "geneticization" of risk. With the current push to make genes the ultimate "risk factors", the individualization of health, and health risks, is complete. Health risks are in the very "building blocks" that make up the person and not in the social, physical or political environment.

Prevailing discourses on risk, and the biotechnologies which both make them possible and are made possible by them, also have implications at a social and political level. It could be argued that the phenomenological experience of the women in this study represents an embodiment of a currently prevailing neo-liberal rationality (Burchell 1993; Castel 1991; Greco 1993; Petersen 1997; Rose 1993; Rose 1990). The argument here is that neo-liberal notions of individual autonomy, the free market and limited government are related, in a mutually producing and sustaining way, to the imperatives to "self-care" (Greco 1993) – in the form of self-surveillance and self-regulation – which themselves are a consequence of the phenomenological experience of being "at-risk". Petersen makes this link between risk consciousness and the prevailing political order, characterised, in part, by the rapid retreat of the welfare state.

Neo-liberalism calls upon the individual to enter into the process of their own self-governance through the processes of endless self-examination, self-care, and self-improvement. Given that the care of the self is bound up with the project of moderating individual burden on society, it is not surprising ... that since the mid-1970s there has been a clear ideological shift away from the notion that the state should protect the health of individuals to the idea that the individuals should take responsibility to protect themselves from risk. (Petersen 1996:48-49)

In other words, the entrepreneurial subject is reconceived – and reproduced – as a new kind of citizen: a neo-liberal citizen who is autonomous, responsible and self-governing. Within this kind of rationality, health and health risks are individualized and, thus, depoliticized. It should, therefore, not be surprising that the women in the study discussed here readily took up prevailing discourses on breast cancer risk, assigned themselves a "risk status" and talked about the management of breast cancer risk only at an individual level and not at a collective or political level.

It is to this extent that it could be argued that, for the women in this study, embodying risk represents the embodiment of a neo-liberal rationality. Diagnostic/screening technologies are firstly imagined, and then developed and deployed, within that same political rationality which they, in turn, reinforce and reproduce.

III. Implications for a Canadian Biotechnology Strategy

The preceding discussion is offered as some preliminary thoughts about the dialectical relationships between prevailing discourses on health risks, emerging biotechnologies (specifically, diagnostic/screening technologies) and the prevailing social, political, moral, cultural and ideological order (more specifically, the current neo-liberal rationality). This raises a number of questions at several levels – social, political, ethical. What I will attempt to do in this final section is to raise two fundamental questions, to begin with, which a critical social science research agenda might address in relation to the current Canadian Biotechnology Strategy.

Firstly, at a phenomenological level, I think

we need to understand more about how women take up prevailing discourses on health risks. It would appear that women, generally, have willingly taken up certain practices of self-surveillance and self-governance (eg. breast self exam, annual mammograms, lifestyle management). It is poignant to reflect on the extent to which the notion of “Our Bodies, Our Selves” (reflecting a political intention, on the part of the women’s health movement, for women to “re-own” their bodies – i.e. to remove them from the clinical gaze) has, within 30 years shifted to “Our Bodies, Our Enemies” (reflecting a turning back of the clinical gaze on oneself). But is this what is actually happening? Do women take up prevailing discourses on risk – and submit themselves to the diagnostic/screening technologies – wholly, uncritically? Or are there pockets of resistance to these risk discourses? What do these discourses of resistance look like and, remembering Foucault’s injunction to “look to the margins”, where are they located?

In this respect, there are clear limitations to the study reported here because of the selective nature of the study sample. The participants were all English-speaking women of European – mostly northern European – descent, middle-class, mostly working and largely professional. More significantly, they were all either self-referred or referred by their family physicians to the Breast Health Centre of a major downtown teaching hospital in a large urban centre. This in itself speaks to a certain pre-selection in terms of class, education, and other social locations of these women. Because of this limitation, the investigation of potential differences in terms of a variety of social locations – class, race/ethnicity, mother tongue, sexual orientation – representing different experiences of embodiment, was not possible. For theoretical reasons, one might expect very different results from women who attend a Community Health Centre in a low-income neighbourhood,

women who are recent immigrants, women who live in rural settings or women who have some other racial/ethnic/cultural origin besides northern European. Further research would illuminate how differently embodied subjects take up, interact with and transform prevailing discourses on health risks in general and breast cancer risks in particular.

In addition, remembering that phenomenological experience is always situated, comparative research would indicate what and how different discourses on health risks emerge within different professional, political, legislative and regulatory contexts (e.g., UK, USA and Canada). For example, is there now a global discourse of breast cancer risks or are there jurisdictional variations? And how does this impact on women’s health experiences within these contexts?

Secondly, and related to the above question (in ways which remain to be explored) is the question of public participation in the setting of the Canadian public policy agenda for the development and deployment of emerging biotechnologies. The CBS documents appear to address this issue, but the nature of the suggestions and recommendations makes it clear that this represents a kind of “tokenism”, referring to the “information needs” of the public and strategies for “increasing public awareness and understanding of biotechnology products and processes” (Canada 1998d:15). The assumption here is that the public somehow doesn’t “get it” with respect to biotechnology, and that public knowledge is somehow a “degenerate” form of knowledge. This is often reflected in the reference to “scientific evidence” and “lay beliefs”, as if science, itself, were not a belief system. The solution, according to the CBS, is to make scientific knowledge more “accessible” to the public.

Research points to gaps in consumer awareness and understanding of biotechnology ... The attributes of biotechnology applications often are not directly evident to citizens. More work is needed to determine the best way to inform them about such technologies. (Canada 1998d:14)

In other words, the suggestion here seems to be that the biotechnology sector needs to engage in a public relations campaign. Note, also, that not only understanding, but also accepting, scientific knowledge has become an attribute of citizenship. An alternative view is to regard public (or “lay”) knowledge as a legitimate, competing knowledge system alongside scientific knowledge (Brown; Balshem 1991), albeit less systematically articulated. Further research into public knowledges about health risks and what happens to them as they enter the public policy arena would be illuminating. Again, comparative research would indicate how different jurisdictions have addressed the issue of ensuring (or, alternatively, limiting) public participation in setting the public policy agenda with respect to the development and deployment of biotechnology.

This Discussion Paper is offered in the spirit of David Suzuki’s caution that “science is too important to leave to the scientists”. What this means for social scientists is that, as Foucault said, “we always have something to do”.

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