

# Caring for the Self, Caring for Others

## The Politics and Ethics of Genetic Risk for Breast Cancer

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*Ce texte avertit les femmes qui ont subi le test de génétique prédictive (PGT) des risques de cancer du sein. Je m'inspire des écrits de Foucault sur l'éthique et je mets de l'avant la sexualisation des relations éthiques et subjectives entretenue par le discours sur les risques génétiques du cancer du sein.*

*... [genetic testing] just gives me a sense of accomplishment that I am doing everything I can. ... That I am being proactive in preventing it [breast cancer] from coming back. And plus it's a good feeling ... maybe I'm not in control but I feel like I do have control to a certain degree or that I'm doing the best I can ... and it makes me very hopeful. You know? Because of all the other things I went through and the negative prognosis that I got from doctors. Like I don't have to take their word ... things can be different.*

—Annie<sup>1</sup> (45 years old, underwent single mastectomy plus radiation and chemotherapy for breast cancer diagnosed one year before interview)

This passage is taken from an interview I conducted as part of my doctoral research which explored women's experiences and understandings of their susceptibility to breast cancer, and how these were shaped by their involvement in predictive

genetic testing (PGT) for mutations in the BRCA1/2 genes.<sup>2</sup> I begin with this quote because it illuminates the central argument developed in this paper: that participation in predictive genetic testing for hereditary breast cancer risk constitutes part of an ongoing process of risk management through which women constitute themselves as active participants in their health. Furthermore, I suggest that these technologies are transformative in the sense that they help to effect shifts in how women relate to themselves and others (in particular their genetically-related female family members) as individuals who are “at risk” for developing cancer, and who strive for health in light of their at-risk status.

In this paper, I combine my theoretical interest in risk governmentality with Michel Foucault's work on ethics and care of the self in order to consider critically the forms of subjectivity and ethical relations that are cultivated by discourses on genetic risk for breast cancer. I illustrate and give life to these theoretical insights by drawing on interview data I collected for my doctoral research, with a particular focus on Annie, one of my study participants whose commentary opens this paper. Before turning to the interview data, it is first necessary to situate predictive genetic testing within the broader neoliberal politics of health risk.

### **Risk, Biotechnology and Neoliberalism**

From the perspective of governmentality, neoliberalism is seen as a political rationality that involves the shifting of power away from State intervention toward generating conditions that facilitate self-regulation. Neoliberal programmes of governance include multiple practices and techniques that specify active citizen-subjects who are incited to “enterprise themselves, to maximize their quality of life through acts of choice” (Rose 57) and who are encouraged to make responsible choices for themselves and for those to whom they are connected. As Nikolas Rose suggests:

Within this new regime of the actively responsible self, individuals are to fulfil their national obligations ... through seeking to fulfil themselves within a variety of micro-moral domains or “communities”—families, workplaces, schools, leisure associations, neighbourhoods. Hence the problem [for government] is to find means by which individuals may be made responsible through their individual choices for themselves and those to whom they owe allegiance... (57)

Discourses on health risk are central to neoliberal modes of governance since their prevailing focus on individual behaviours and lifestyle modifications have helped to solidify a shift in responsibility for health from the State to individuals and their families. The proliferation of discourses on *genetic* risk further individualizes health risks, and responsibility for the management of health risks, within the context of (geneticized) familial relations. The practice of PGT for breast cancer provides a contemporary *gendered* example of geneticization (Lippman 19) of cancer risk, where geneticization refers to the increasing reliance on genetic technologies to manage health problems (Lippman 19). By focusing on the detection of genetic mutations that increase a woman's probability of getting breast cancer, PGT privileges the *female* body as the appropriate site for technologically-mediated risk identification, surveillance, and management, and thus deflects attention from cancer risks that are produced in the physical environment and that are exacerbated by broader social structures and the social determinants of health.

Furthermore, discourses on genetically-transmitted health risks imply that individuals must acquire knowledge about their genetic risks in order to make "informed choices" about their health (Petersen and Bunton 57-8). This emphasis on informed choices links the exercise of agency in gaining knowledge about one's genetic risks with that of demonstrating personal responsibility for health through the adoption of individualized risk management strategies (e.g. monitoring and modifying one's diet). This is a particularly seductive strategy of governing women's health since, in taking active measures to become knowledgeable about health risks, women must necessarily rely on medical authorities and other health-related professions and disciplines (e.g. genetic counselling, epidemiology) that are invested in constructing and framing knowledge of breast cancer risk.

By situating the body as neither healthy nor diseased but somewhere in-between, discourses on health risk provoke a constant awareness of the body and thus recruit individuals into multiple "processes of endless self-examination, self-care and self-improvement" in order to maintain their health and wellbeing (Petersen 194). With specific reference to breast cancer, Sandra Gifford suggests that the ambiguity engendered by discourses on risk "results in the creation of a new state of being healthy and ill; a state that is somewhere between health and disease and that results in the medicalization of a woman's life" (215). Feminist analysis that focuses on the links between discourses on genetic risk for breast cancer and women's experiences of their risks in the context of their participation in predictive genetic technologies is particularly important given the history of the medicalization of women's bodies and current trends in what Batt and Lippman call "neomedicalization" (50). Neomedicalization is a by-product of neoliberal policies which aim to minimize social spending while expanding women's "choices" in health through the promotion of technologies, drugs and devices that capitalize on (the construction of) risks for future disease in order to stimulate economic growth (Batt and Lippman 50-1).

Michel Foucault's later work on ethics and care of self is particularly useful as a frame to understand women's experiences of their genetic risks for breast cancer in relation to their participation in PGT. In particular, and as I will illustrate, his elaboration of *askesis*, which he describes as the work that one performs on oneself in order to transform oneself into the ethical subject of one's behaviour (Rabinow xxxiii; Foucault, "On the Genealogy of Ethics" 265), is useful to understand how women's experiences of their genetic risks for breast cancer are informed by their already existing commitments to be active participants in their health. Related to the concept of ethical work is

Foucault's notion of the "care of the self" which he conceived as a practice, an activity in which one, by paying attention to oneself, produces one's self as an object and lifelong project (Foucault, "The Ethics of the Concern for Self" 285). Foucault suggests that, in modernity, the principle of caring for oneself was supplanted by the imperative to "know oneself", to equip oneself with the truth about one's self (Foucault, "Technologies of the Self" 228). Trent Hamann points out that, in contemporary forms of health care, knowledge of the self is largely mediated by disciplines such as biology, epidemiology, and genomics:

These forms of knowledge ... become crucial to the emerging biopolitical forms of governmentality. Whereas individuals were once urged to take care of themselves by using self-reflexive ethical techniques to give form to their freedom, modern biopolitics ensures that individuals are already taken care of in terms of biological and economic forms of knowledge and practices (Hamann 56)

Cressida Heyes extends the thinking of other Foucauldian feminists (in particular, Sandra Bartky and Susan Bordo) to consider the ethical practices and processes of self-transformation that gendered technologies of discipline invite. While Heyes commends these scholars for illuminating how patriarchy operates through disciplinary power (72-3), she extends their arguments to consider how processes of discipline enhance certain capacities and skills and create possibilities for women to reflect on and consider the forms of the 'care of the self' that underwrite their art of living (8). Focusing specifically on dieting as a disciplinary technology, Heyes suggests that by focusing only on the *ends* sought by such technologies (the privileging of the ideal, slender feminine body), feminist analysis runs the risk of

overlooking how such technologies are implicated in *processes* of ethical, self-transformation. Such a shift in focus can provide further insight into the micro-operations of power and instances when such technologies generate non-normative, creative responses that have the potential to disturb the logic of discipline. While Heyes concedes that disciplinary technologies have the potential to

shift was significant and involved a change in subjectivity from what I called being an “active participant in health” to becoming a “(pro)active manager of genetic risk.”

Far from being passive recipients of a diagnosis of genetic risk, the women in my study pursued genetic testing as part of an overall strategy to be “active participants” in their health. Learning about their risk

subjects of risk. While the women did not feel that they had control over breast cancer, or that they could fully prevent *disease*, they felt that, through their participation in risk management activities, they could, and therefore *should*, exert control over certain aspects of their *health* in light of their family histories of disease. It was this *control over health*, and not the prevention of disease,

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build women’s capacities in multiple directions, she also acknowledges the seductive qualities of such technologies which, in usurping the language of empowerment and care of the self, govern women through the intensification of power relations (Heyes 85-6).

In light of these theoretical formulations and critiques, I now turn to my case study to explore further women’s understandings and experiences of their susceptibility to breast cancer as they went through the process of PGT, and to consider specifically how discourses on genetic risk for breast cancer target and transform ethical relations as objects of governance.

### **Genetic Testing as Risk Management and Ethical Practice**

In my analysis of women’s experiences of their genetic risks for breast cancer, I argue that the process of PGT effects a transformation both in how the women in my study came to understand their susceptibility to breast cancer, and how they came to understand and act on themselves as women who were particularly vulnerable to the threat of breast cancer given their family histories of the disease (Polzer 133; Polzer and Robertson 37-8). Though subtle, this

genetically did not suddenly make these women experience themselves as “at risk” for breast cancer, for they already had strong notions of their vulnerability to breast cancer prior to genetic counselling based on their experiences of having witnessed directly or heard stories about women in their families who had suffered with and died from the disease. With this embodied knowledge already in place, the study participants lived, not necessarily in fear, but with the threat of breast cancer firmly lodged “in the back of their minds.”

With the threat of breast cancer firmly in the back of their minds, the women in my study were already engaged in a number of risk management activities before they went to genetic counselling in order to “take charge” of their health. For Annie, knowing that so many women in her family had had breast cancer served as a “wake up call” that she had to make extra efforts to try to prevent cancer. I suggest that the risk management activities that these women adopted (which included making modifications to their eating and exercise habits and participating in various forms of regular breast screening) constituted the *askesis*—that is, the ethical work—through which they constituted themselves as ethical

that constituted the *telos* of their ethical work—that is, the ends sought through the work they performed on themselves through their participation in risk management activities.

Arriving at genetic counselling already as active participants in their health, the women in this study saw genetic testing as a “unique opportunity” to take even further control of their health by expanding their options for risk management. The options they mentioned most frequently included prophylactic medication (Tamoxifen), preventive surgery (mastectomy), and new forms of screening (magnetic resonance imaging or MRI) that were not widely available but were in the process of being evaluated through clinical research. Genetic testing was at times described as a “door opener” to difficult-to-access health services, with MRI screening in particular highlighted as a service one could “qualify” for as a result of their participation in genetic testing. This was the case for Annie, who had already had breast cancer, and who felt that genetic testing would help “direct” her towards new screening options which she felt would help her to keep a “closer look” over her body for signs of a recurrence. As she put it:

*...If I have to summarize my whole experience with genetic testing... [I'd say] I'm glad that it opened doors for me to keep a closer look. To have more screening and it gives me direction of how I should—why I should—do certain things with myself or with my life or with my body. You know? ...It's better to know than not to know.*

their memories of familial disease, as the genetic testing process unfolded, and as they were presented with new options for risk management, their susceptibility to breast cancer was increasingly described as something that could be personally managed and “decreased” through their own individual actions. This transformed understanding of their susceptibility to breast cancer merged with their

knowledge of their vulnerability to breast cancer based on their family histories of the disease. From this perspective, the effects of PGT can be read as simultaneously enabling and constraining. On the one hand, gaining knowledge about their genetic risks can be interpreted as enabling in the sense that it formed the basis of new understandings of their susceptibility and new risk manage-

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The above quote captures eloquently the notion that knowledge of the self is a fundamental element in the care of the self. For Annie, as for the other women in my study, gaining knowledge about genetic risk not only provided her with information about her susceptibility to breast cancer (about which she was already knowledgeable), but also constituted part of a process of learning about how she should direct her activities in her everyday life as someone who was particularly susceptible to breast cancer given her family history of the disease.

By providing women with a number of previously unavailable or restricted risk management options, PGT was not seen by Annie and the other women in my study as limiting what they *could* do. Rather, PGT was envisioned as *enabling* them to choose a particular course of action *for themselves* as part of their ongoing efforts to manage their risks for cancer and take matters of health into their own hands. As the women were presented with these new options for risk management, they came to articulate their susceptibility to breast cancer as something that was amenable to their individual control. Whereas prior to genetic testing the women were called to take charge of their health by

already existing risk management regimes. As suggested below, Annie's positive genetic test result not only widened her selection of risk management opportunities, but also acted as a “constant reminder” that she should be hyper-vigilant in her efforts to “reduce” her risks for cancer:

*I know that I'm more susceptible [to breast cancer] than before but it's not like it's a panic thing ... it's more of an “Okay, I have to do everything I possibly can.” ... I'm trying to do the best I can to decrease my risk factor. ... I'll be more careful about things. I'll be more observant.... It's a constant reminder that I really have to watch out for things. I shouldn't forget my vitamins. I shouldn't forget eating properly ... it just makes me more careful....*

### **Discussion**

As Annie's case suggests, women who pursue PGT for breast cancer do so not to learn about their genetic fates. Rather, the interpretation I offer here suggests that women seek knowledge about their genetic risks for breast cancer in order to engage in particular kinds of self-care practices in light of their already existing

ment directions they could pursue as women who were genuinely concerned about developing breast cancer given their past experiences of cancer in their families. At the same time, by opening up a number of new possibilities for screening and risk management, the practice of PGT inserted the women into an expanded network of surveillance and encouraged them to internalize and embody a technological gaze, a phenomenon Ann Robertson refers to as “swallowing the Panopticon” (Robertson 303).

In this sense, the process of PGT had the effect of harnessing women's concerns and energies toward a new spectrum of risk management techniques. As suggested by Annie's account, gaining access to MRI screening has the potential to make women feel as though they can “keep a closer look” over their risky (potentially cancerous) bodies. In turn, this suggests that the new forms of surveillance introduced by PGT may be experienced by women as reassurance that they are being cared for in a cancer care system that is increasingly oriented towards the surveillance of risk factors. This is supported by Scott et al. who argue that participation in genetic testing services has the effect of making those who are eligible for

testing feel as though they are being “looked after”:

references to being monitored, cared for, looked out for, and being supervised ... signify a desire for surveillance and engagement with a health care system that will constantly check and ‘keep an eye on’ the patient-client. In that sense, patient-clients are ... seeking ways of organizing health care resources around their specific and particular needs and life-worlds. (Scott et al. 1876)

At the same time, it should not be forgotten that, while women may be provided with a greater number of options for risk management, and while this may instil in them a sense of self-control and being looked after, they are not in control of deciding the menu of options from which they choose (Batt and Lippman 52).

Although not explored in this paper, PGT also has implications for how women relate to their (genetically related) family members. As discussed elsewhere, individuals undergoing PGT for cancer risk often see themselves as having a “genetic responsibility” (Hallowell) to family members to “pass on” information about their genetic risk and to encourage these relatives to manage their cancer risks accordingly. In this sense, predictive genetic technologies demarcate “the family” as a territory of governance that links the ethic of maintaining personal health with political objectives to optimize the health of the population (Polzer, Mercer and Goel 163). Such responsibilities that emerge in the context of PGT are thus suggestive of the influence of knowledge about biological, genetically-transmitted vulnerabilities on familial relations and obligations (Polzer, Mercer and Goel 163).

The recent introduction of voluntary human papillomavirus (HPV) vaccination programs in Canada is interesting to consider in light of the theoretical frame explored here.

Discourses on HPV (a common, sexually-transmitted virus which can lead to cervical cancer in cases of persistent infection with high-risk strains) are similar to those on genetic risk for breast cancer in the sense that they situate female bodies as carriers of risks for future disease and as appropriate sites for biotechnological intervention. However, unlike PGT for breast cancer, there appears to be a glaring absence of appeals to informed “choices” and decision-making in both industry- and government-sponsored information materials about HPV vaccination. This is, perhaps, unsurprising given that the school-based immunization programs aim to vaccinate girls prior to sexual onset, citizens-in-the-making who are not-yet capable of governing their own freedoms. Rather, HPV vaccination discourse consistently calls upon parents, in particular mothers, to “protect” their daughters by getting them vaccinated and positions the vaccine as marking an important opportunity for parent-child communication about health risks and for general relationship-building.

### Conclusion

In conclusion, I suggest that feminist readings of Foucault’s elaborations on ethics and care of the self provide meaningful insight into how discourses on genetic risk for breast cancer, and the health care practices they engender, are implicated in the cultivation of particular kinds of ethical relations. This theoretical lens can be particularly fruitful to understand how contemporary developments in women’s health technologies govern women’s conduct by channelling their energies, and their ethical freedoms, in particular ways. While, in theory, health risk biotechnologies have the potential to generate multiple responses from women, and while they may facilitate early detection and access to cancer care resources for some women, the potential for such technologies to harness wom-

en’s ethical capacities and freedoms towards technological ends must not be underestimated.

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<sup>1</sup>“Annie” is a pseudonym.

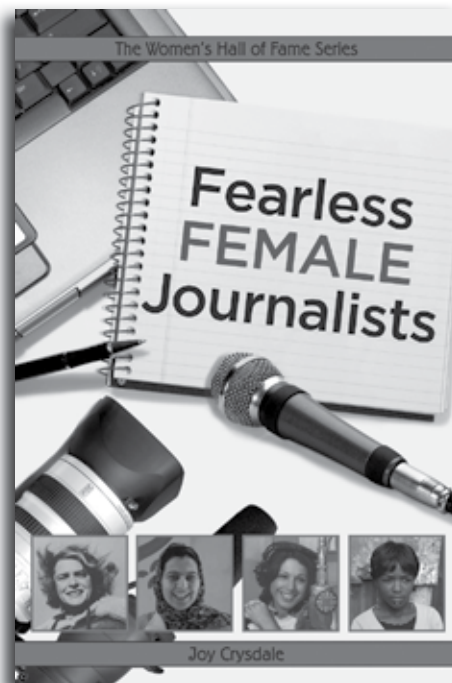
<sup>2</sup>This study was conducted in an urban setting in Ontario where predictive genetic testing (PGT) for hereditary breast, ovarian and colon cancers are included as insured health services for individuals whose family histories indicate a possible genetic predisposition. The process of PGT is complex and involves a number of components, including the completion of family history forms, the construction of a family “pedigree” (family tree), genetic counselling, and mutation testing for those whose family histories suggest a possible genetic predisposition. The BRCA1 and BRCA2 genes are tumour-suppressor genes which normally function to inhibit cell growth. Inherited forms of breast cancer account for a small proportion of all breast cancers; however, and although estimates vary, mutations in either the BRCA1 or BRCA2 genes have been found to significantly increase a woman’s risk of developing breast cancer in comparison to the general population (see Heisey et al.).

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