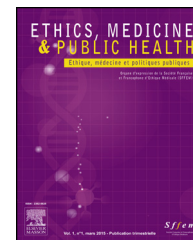




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## THOUGHTS

# The subject and power of bioethics



## *Le sujet et le pouvoir de la bioéthique*

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**Summary** The present paper argues that late work of Michel Foucault is helpful in understanding contemporary bioethics. Specifically, Foucault's writings on biopower and subjectivity are increasingly relevant as we consider the intersection of public policy and clinical ethics in a socio-political context increasingly structured by the demands of neoliberalism. Although Foucault's earlier work on the clinical gaze has been important to bioethics, that is no longer as important as his later, incomplete research into power and subjectivity. The paper develops this argument in four steps. In the first, I look at a classic phenomenological approach to clinical bioethics by Richard Zaner, starting from which I develop a Foucauldian perspective. In that section, I also offer a basic outline of what I take Foucault's primary theoretical contributions to be by way of an initial explication of the biopower-subjectification nexus. The following two sections of the paper present exemplary applications of Foucauldian theory to two areas at the intersection of public policy and clinical bioethics. The first is the procedure for testing women for the BRCA1/2 mutations, mutations that impose on carriers a significant risk of developing breast and ovarian cancer. A comparison between American and Dutch practices underscores not only the new ways that genetic testing interprets the body, but also the importance of local political and cultural contexts for understanding how the test is presented, administered and managed. The second is a consideration of the intersection of employee wellness programs and wearable technologies. In it, I develop Foucault's thought that subjects in the Christian West have long been encouraged to understand themselves confessionally, offering to authority figures the "truth" about themselves. I then interpret the compulsory use of wearables as a verification strategy for compliance with wellness programs as exemplary of such confessional strategies. The final section ties the discussion back to the clinical encounter as Zaner formulates it as an inherently moral encounter structured by vulnerabilities that matter for

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understanding the selfhood of patients. Based on the preceding examples, I make the case that American understandings of selfhood are increasingly separated from any sense of publicness and that this structuring of selfhood is of increasing importance in framing and adequately understanding bioethics today.

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## MOTS CLÉS

Biopouvoir ;  
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Subjectivité

**Résumé** Cet article soutient que les travaux tardifs de Foucault nous aident à comprendre la bioéthique contemporaine. Notamment, les écrits de celui-ci sur le biopouvoir et la subjectivité s'avèrent pertinents alors que l'on s'interroge sur l'intersection entre la politique publique et l'éthique clinique dans un climat socio-politique de plus en plus organisé selon les exigences du néolibéralisme. Bien que les travaux antérieurs de Foucault sur le regard médical aient été important pour la bioéthique, ce travail n'est plus aussi important que son travail plus tardif sur le pouvoir et la subjectivité. Cet article développe cet argument en quatre parties. Premièrement, je me pencherai sur les travaux de Richard Zaner en phénoménologie classique relatifs à la bioéthique clinique, que j'utiliserai comme point de départ afin de développer une perspective foucauldienne. Dans cette section, je propose également un bref résumé de ce que je considère comme étant la principale contribution théorique de Foucault en expliquant d'abord la relation entre le biopouvoir et la subjectification. Les deux sections subséquentes illustrent le travail de Foucault à travers deux exemples appliqués dans deux domaines à l'intersection entre la politique publique et la bioéthique clinique. Le premier exemple est celui de la procédure employée pour dépister les femmes porteuses de mutations BRCA 1/2, mutations qui exposent ces porteuses à un risque important de développer un cancer du sein ou des ovaires. Une comparaison entre les pratiques américaines et néerlandaises démontre non seulement la façon dont les tests génétiques interprètent le corps dans le travail clinique antérieur, mais également le rôle que jouent les politiques locales ainsi que les contextes culturels dans la compréhension de comment un test est présenté, administré et géré. Le deuxième exemple consiste en l'intersection entre les programmes de bien-être pour les employés et les technologies portables. À travers cet exemple, j'élaborerai sur la pensée foucauldienne selon laquelle les sujets en occident chrétien ont longtemps été encouragés à se comprendre de façon confessionnelle, offrant aux figures d'autorité des « vérités » sur eux-mêmes. Ensuite, j'interprète l'utilisation obligatoire de portables comme d'une méthode de vérification de la conformité aux programmes de bien-être reflétant ces stratégies confessionnelles. La dernière partie ramène cette discussion à la rencontre clinique telle que conçue par Zaner, c'est-à-dire une rencontre morale inhérente organisée autour des vulnérabilités qui importent à la compréhension de l'individualité des patients. À partir des exemples précédents, je soutiens que les conceptions américaines de l'individualité sont de plus en plus séparées de tout caractère public et que cette façon de structurer la notion du soi est de plus en plus importante dans l'élaboration et la compréhension adéquate de la bioéthique d'aujourd'hui.

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Although the term has expanded to cover such topics as agricultural bioethics, the core of bioethics is often taken to be medical. The most obviously ethical moment in medicine is the clinical encounter itself. Indeed, as Richard Zaner demonstrated over a career of careful phenomenological work, clinical encounters involve very socially complex interactions between clinicians and patients. These interactions are informed and structured by a variety of factors inherent to the human experience of sociality. In what follows, I want to make the case that we also need to be very attentive to political factors. In other words, we need to understand bioethics, particularly when we think of health policy, as the study of a form of power. As such, it is

invariably involved with the techniques by which we become subjects, that is, the techniques, both social and personal, by which we become who we are.

The theoretical support for this position comes from Michel Foucault and the first part of the paper draws a line from Zaner's work in clinical ethics to the "biopolitical" theories of Foucault. The following two sections exemplify the sorts of analysis I think are important, and the interaction between strategies for care, on the one hand, and the functioning of power, on the other. Accordingly, section 2 compares American and Dutch strategies for using the test for the so-called breast cancer mutation (BRCA1/2), and section 3 attempts to tease out the confessional logic at work

behind the rise of wearable technologies as an aspect of wellness. Both cases suggest the extent to which health in the U.S. is being pushed in the direction of individualized lifestyle choices and away from any sort of broad-based public policy. The final section returns briefly to this move as exemplary of current, neoliberal biopower.

## From the ethical encounter to the political one

Zaner characterizes the moral valences of the clinical encounter as follows, which I quote at length because of its importance in framing what follows:

*The therapeutic dyad of trust and care has its basis, on the one hand, in the 'moral chance' of illness and in the scientifically and linguistically informed clinical act of affiliative feeling, on the other. Because of the uniqueness of this relationship and the conversations and actions by which it is carried out as a process, it is an essentially moral relationship showing all the characteristics of being fundamental to moral life. On the one side, the vulnerability and appeal of the ill person; on the other, the response from the would-be healer. Their relationship, deeply textured in our times by complex forms of social norms and institutions, complicated by strangers engaging in multiple forms of intimacy, is an essentially tenuous, unequal, and asymmetrical one, the very fact of which constitutes a complex and altogether special set of occasions for awakening our sense of morality in its core form [1 p.319].*

Of the many things that invite comment in this summative paragraph, I want to highlight three here that will constitute the core of my discussion.

First is the fundamental asymmetry of the clinical encounter. This is an asymmetry of vulnerability and of knowledge; in short, it is a relationship of power. Because it is a relation of power, it is at least equally fundamentally a political one (in a broad sense I will specify), a point to which Zaner gestures in noting the "complex forms of social norms and institutions" that texture it. Second, and consequently, we need to understand those social norms and institutions and how they operate to directly shape the clinical encounter. Demonstrating this point is the burden of the BRCA section. Finally, and as a further consequence, we need to be attentive to broader and more diffuse social norms, because they have implications for how we understand medicine and health, and those understandings find their way to the clinical encounter. This point emerges in the discussion of wearables and health. In particular, social norms and understandings of wellness have effected a fundamental transformation in the social meaning of many kinds of illness over the last two or three decades: where once it was unproblematic to characterize illness as a matter of "moral chance," illness today is very often seen as a matter of moral desert.

All of that is to say that the study of bioethics, even if one understands it in the somewhat narrow sense of clinical encounters, requires the study of processes of power and of subjectification, which is to say that it is involved in several

socio-political processes concerning the meaning of illness and health, the ways that moral responsibility for health is understood, and the political power structures through which those social understandings operate. Foucault is most often brought into the context of bioethics through his early *Birth of the Clinic*, which talked generally about the development of the "clinical gaze" and ways that the medical technique, from the eighteenth century onward, renders both the body and disease visible. This text has been important in our understanding of the operations of medicine and continues to inspire valuable work<sup>1</sup>.

Foucault's later work has been applied to medical bioethics much less often<sup>2</sup>. This work, taken broadly, investigates the way that power operates in societies, and the ways that individuals develop as subjects within those societies. Regarding power, Foucault's thesis is that power today is best understood as "biopower," which operates directly on life processes, to discipline individuals and to optimize the productivity of population. This is a change: power used to be subtractive, measured by prohibitions and the sovereign right to kill. Biopower, by contrast, is about optimizing a population's capacities, with focus on the "administration of bodies and the calculated management of life" and the emergence of "problems of birthrate, longevity, public health, housing and migration" [10 p.140]<sup>3</sup>. His most famous discussion of the processes of subject formation is his discussion of ancient Greek practices of selfhood in *Care for the Self*<sup>4</sup>.

<sup>1</sup> See, for example, [2]. As Foucault puts it, "the structure, at once perceptual and epistemological, that commands clinical anatomy, and all medicine that derives from it, is that of invisible visibility. Truth, which, by right of nature, is made for the eye, is taken from her, but at once surreptitiously revealed by that which tries to evade it" [3 p.165–6].

<sup>2</sup> The most notable exception is in the work of Nikolas Rose: see especially [4]. For other recent examples, see [5] (treating pharmacological practice as a form of biopower); [6] (on how governing understandings of autonomy and selfhood determine the construction of dementia); and [7] (on how exercise culture has pushed "healthy" to mean "fit"). It should be stressed that a variety of approaches can be considered "biopolitical": see the contrasting discussions of the Terry Schiavo case in [8] and [9].

<sup>3</sup> Disciplinary power is the subject of *Discipline and punish*. His most sustained discussions of biopower are in the final chapter of *History of sexuality vol. 1* and the last lecture (17 March 1976) of *Society must be defended*. There is a large literature explicating what the precise contours of biopower are and how they should be understood. A good introduction is [11]. I am going to assume without extensive argument that contemporary neoliberalism is a specific way that modern biopower functions. Foucault's discussion of neoliberalism is in his *Birth of biopolitics* lectures. For accessible work explaining the neoliberal-biopower connection, see, e.g., [12,13].

<sup>4</sup> For some time, those bodies of work were considered separate, with Foucault making an abrupt shift from power to subjectification in the late 1970s. As will become apparent, I see no incompatibility between the approaches: Foucault's mature understanding of power understands it as productive of subjectivity, and vice versa. See, for example, his 1973 Rio lectures [14], in which he sets up the argument that will become *Discipline and punish* as a question of truth and power. Even a casual reading of *Discipline and punish* shows the importance of subject-formation to the exercise of disciplinary power: the entire point is to use micro-regulations to get

Foucault understands the two as aspects of the same research program. In a 1982 interview, he proposes that the goal of his work over the past twenty years had not been an analysis of power, but “to create a history of the different modes by which, in our culture, human beings are made subjects” and emphasizes that “it is not power, but the subject, which is the general theme of my research” [17 p.208–9]. In a 1984 interview, he adds that “I have always been interested in the problem, of the relationship between subject and truth. I mean, how does the subject fit into a certain game of truth?” This question framed his research into current political struggles, and “the widespread use of incarceration . . . sent me back to the problem of institutions of power,” which led him to “pose the problem of knowledge and power, which for me is not the fundamental problem but an instrument that makes it possible to analyze the problem of the relationship between subject and truth in what seems to me to be the most precise way.” In other words, “what I wanted to try to show was how the subject constituted itself, in one specific form or another, as a mad or a healthy subject, as a delinquent or non-delinquent subject, through certain practices that were also games of truth, practices of power, and so on” [18 p.289–90]. He gestures to how such an endeavor might proceed:

*I would say that if I am now interested in how the subject constitutes itself in an active fashion through practices of the self, these practices are nevertheless not something invented by the individual himself. They are models that he finds in his culture and are proposed, suggested, imposed upon him by his culture, his society, and his social group [18 p.291].*

It is this logic I will trace here.

Foucault proposed that his work offered a toolbox of concepts to assist people in their struggles [19,20] and his late lectures mark with apparent approval a distinction in the context of the Greece of Plato and Socrates that philosophy should be a matter of work (*ergon*), not “mere *logos*.”<sup>5</sup> In the 1984 interview cited above, he closes with the admonition that “in its critical aspect, philosophy – and I mean critical in a broad sense – philosophy is that which calls into question domination at every level and in every form in which it exists” [18 p.300]. The following two extended

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individuals to internalize certain behaviors. The connection is also clear in the discussion of morality in *Use of pleasure*, which ties codes of moral conduct with subject formation [15 p.25, 8]. For a discussion emphasizing that power involves subjectification, see [16]. Recent work often assumes the connection; see e.g. [5].

<sup>5</sup> For Plato and his contemporaries, “the reality of philosophy will not be its practice as discourse, or even as dialogue. It will be the practice of philosophy as ‘practices’, in the plural; the practice of philosophy in its practices, its exercises” [21 p.242]. Or, “what is it to put one’s hand to *ergon*? It is to be the real counselor of a real politician in the field of political decisions he really has to take” and “*logos* is complete only if it can lead to *ergon* and organize it according to the necessary principles of rationality” [21 p.219]. See also his discussion with Deleuze [22] (in which he emphasizes that theory is a form of practice and intellectuals need to resist being mere agents of power); and [23] (emphasizing that his own work is political intervention and praxis).

examples attempt to make good both on the injunction to relevance and on the promise of productive engagement with Foucault’s late work by showing the relevance of the constitution of subjects, of the functioning of power, and the ways that social truths are formed, as matters of central concern to contemporary bioethics.

## Family values

DNA repair is important for overall health and accurate DNA repair is essential for avoiding potentially cancerous mutations. Those who inherit mutations in the BRCA1/2 lack proteins that increase accurate gene repair and the absence of these proteins forces the body to engage in less accurate means of gene repair. Accordingly, those who inherit the mutation are at increased risk for breast and ovarian cancers due to inaccurate gene repair. BRCA1/2 carriers have a cumulative breast cancer risk of roughly 72% to age 80, and BRCA1 carriers have a 44% cumulative ovarian cancer risk by that age (17% for BRCA2) [24]<sup>6</sup>. Both are orders of magnitude higher than population baselines, and present patients with significant clinical management questions, especially around ovarian cancer, for which detection is very difficult but for which prophylactic surgery causes infertility.

Although there are beginning to be clinical implications for treatment of BRCA1/2-induced cancers, the primary emphasis has been on risk stratification and presenting opportunities for risk management. Particularly after Angelina Jolie’s high profile decision to undergo a prophylactic double mastectomy after discovering that she carried the BRCA mutation, discovery of one’s genetic status and the resulting availability of risk management strategies have been presented as empowering to patients. The most significant decision a carrier faces is whether to undergo prophylactic mastectomy (associated with lower breast cancer risk) or salpingo-oophorectomy (associated with lower breast and ovarian cancer risk, as well as lower mortality from either form of cancer) [26]. This is only the beginning of a woman’s decisions, however: armed with knowledge of her mutation, she can proceed to analyze other risk management strategies, as for example when to start screening, what kind of screening to undergo and how to factor the risks of false-positive results [27].

There are two points to be made here, one about the underlying understanding of disease and the other about how different social and political structures alter how patients interact with genetic testing regimes. First, that the genetic test produces a risk (and not a diagnosis) and generates a series of risk reduction strategies, should signal that the underlying concept of disease is very different from a clinical model where patients would arrive at the doctor’s office presenting symptoms. In terms used by both Nikolas Rose [4] and Marianne Boenink [28], the move is toward a “molecular” understanding of the body and clinical practices. The understanding of life in terms of risk management

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<sup>6</sup> This is consistent with earlier work finding that, depending on how one analyzes the data, BRCA1/2 mutation carriers are at a cumulative breast cancer risk in the 50–60% range by age 70, and an ovarian cancer risk in the 18–50% range [25].



is central to biopower, which developed historically with the rise of statistics as a tool of population management<sup>7</sup>. This means we need to look at Foucault's later work for help, not the earlier *Birth of the Clinic*. The body of clinical medicine as described there is understood in terms of what it presents, both symptomatically and phenotypically. The molecular body treats the clinical body as the collection of the parts which compose it and conceptualizes those parts as separately manipulable. The shift to a molecular body, then, while it still involves imaging, involves a disaggregation of the body into its components and a devaluation of both phenotypical and symptomatic evidence: the "truth" of the body's condition is to be understood at the molecular level. There are direct clinical implications; for example cancers are coming to be understood not just by where they present, but by commonalities in tumor structure. Embedded in the move to a molecular understanding of the body, it seems to me, is a potentially more significant shift. Increasingly, the body is not thought of as a collection of parts at all; rather, it is understood in terms of informational content: not the parts per se, but what the parts or their arrangement can be said to signify. As Eugene Thacker proposes, "the point is that the material biological body — 'life itself' — is also the informatic body. The body materially counts only inasmuch as it is understood as information and as genetic information" [30 p.86].

All of this presents a very different way of understanding one's clinical situation. For one thing, it tends to focus attention on very technologically intensive diagnoses and interventions, often at the expense of less technological but potentially more cost-effective and broadly defined measures [31]<sup>8</sup>. More theoretically, on the one hand, an increasingly prominent underlying conception of disease is that of a "cascade," in which "one step leads to another, in a stream that with each subsequent step becomes more difficult to stop," even as that understanding of an inexorable process is limited both by its own assumptions of linearity and the fact that testing routines are only predictive [28]. On the other hand, precisely because information is presented in terms of one's risk profile, the presentation of symptoms becomes less important. Rather, genetic features of one's body are read as points of information, which then construct a risk profile; this risk profile is then used to make strategic investments in one's future health. Those at high risk for particular conditions are "presymptomatically ill," as Rose [4] puts it, or can be viewed as "previvors" [33]. In other words, the cascade model translates into a risk model and the risk model is taken to the recommend specific preventative courses of action.

Second, the risk modeling has a particular valence in the context of a neoliberal U.S. ideology that emphasizes individualizing risk more generally and which tends to assign less value to larger social units. The model neoliberal citizen is, as Foucault [34] puts it, an "entrepreneur" of himself or herself, an understanding abetted by Gary Becker's human capital theory and any number of social institutions and norms that push this kind of self-conception<sup>9</sup>. Family also changes its meaning to accord with this model (see, e.g., [38]). In the case of BRCA, genetic testing is presented as empowering individual women to take charge of their health. In other words, not just the meaning of "breast cancer," but the meaning of "BRCA test" is not the same in different socio-cultural environments, and the U.S. system of individualizing medicine both rewards and helps to create the sorts of actuarial patients encouraged by the previvor and cascade models.

Since the BRCA1/2 mutation is hereditary, clinical practices are profoundly implicated by normative and social understandings of family. Recent work [39] comparing American and Dutch testing practices underscores this point<sup>10</sup>. A healthy woman in the Netherlands who wishes to be tested for the BRCA mutation must, among other things, complete a detailed questionnaire that includes considerable medical information about all of her first and second-degree relatives. Since privacy laws prevent geneticists' contacting these family members, the woman must do so herself. If she is unable to do so, the geneticist will generally refuse to offer the test, offering instead more frequent breast and ovarian screening. As Boenink notes, this practice is normatively significant in two ways. On the one hand, it both presupposes and works to create an ideal of "intensive, open, communicative, harmonious and cooperative relations," to the point that women who do not already have such family contacts "are actively counseled to restore contact and advised how to approach their relatives" [39 p.1797]. On the other hand, it assigns a high value to accuracy in testing and attempts to eliminate ambiguity in interpreting test results. Boenink quotes one clinician explaining why the BRCA test by itself, absent the context of detailed family medical histories, is not useful:

*We do not ... find the defect in all families with HOB [hereditary breast and ovarian cancer]. If we would not find it in you, this does not mean that it is not hereditary. It may mean that in your mother it is hereditary, but you did not inherit it. Or it may mean that everyone inherited the defect, but we can't find it. Or everything is coincidental [qt. 39 p.1796]<sup>11</sup>.*

<sup>7</sup> The emphasis on statistics is not uncontroversial; for a defense see [29]. As is obvious, I draw from that paper's discussion of the BRCA mutation here.

<sup>8</sup> It can also mask structural inequalities. For example, in the U.S., focus on individuals and their choices routinely obscures systemic and structural racial disparities; in the BRCA case, recent research suggests that black women both get genetically tested at lower rates than non-Hispanic white women, and are much less likely to have meaningful provider discussions [32].

<sup>9</sup> For three different but informative and fundamental introductions to neoliberal theory, see, in addition to the exegesis in Foucault [34–37].

<sup>10</sup> The rapid development of clinical practices in oncology, in genetic screening, and around the BRCA1/2 mutations mean that the picture sketched here should be considered a snapshot, specific to a particular historical moment. However, even as such, it indicates the point. As I note below, Myriad's online promotional materials are considerably more accurate and informative than the first time I looked at them, in 2011.

<sup>11</sup> Even here, the test may be of limited value. For example, although BRCA1/2 mutations appear to be uncommon in HER+

In other words, on this analysis, detailed family history information, both for affected and non-affected relatives, is essential for accurately deciding whether to administer the test such that its specificity can be reasonably high. Myriad's advertising emphasizes the test's high sensitivity, but it is important to underscore that not just the test, but the selection criteria for getting the test needs to be accurate<sup>12</sup>.

This is a near-perfect description of the epistemic situation faced by the actuarial agent of genomic medicine: her clinical condition is not clarified, but there is some difficult-to-interpret information about her risk profile, information that might or might not warrant further medical intervention. What is significant in the Dutch context is the extent to which the medical system attempts to avoid this result by first testing relatives with breast cancer for the mutation, and then determining if they passed it on to the woman seeking testing for herself.

The Dutch effort to contextualize test results and minimize ambiguity emerges clearly in comparison to the American system. Most women who receive BRCA1/2 testing in the U.S. do not have breast cancer, a figure that represents a reversal of the situation in 2000, when a majority who received the test were cancer patients [42]. Women in the U.S. who are concerned about their hereditary cancer risk can receive direct-to-consumer advertising and are invited by testing companies like Myriad to press their doctors to push for testing. Myriad maintains a complex website that aims to help patients determine whether they are at risk for hereditary cancers associated with the BRCA1/2 mutation (which includes hereditary pancreatic cancer, for example). As of this writing, Myriad's website claims to integrate family history into risk assessment, but there is no evidence that family history serves the same gatekeeping function it does in The Netherlands. The site also repeatedly emphasizes that those with positive test results can do a range of potentially beneficial things ranging from increased monitoring to "risk-reducing medicines and surgeries"<sup>13</sup>.

The juxtaposition with the Dutch model is striking. The ambiguity presented in the Dutch situation, ambiguity sufficient for geneticists to refuse to provide the test, is here presented as a form of empowerment. The ambiguity in a negative result against which Dutch clinical practice warns is missing from the general testing FAQ page, buried in a

"negative results" brochure, which says that "your test has given you some helpful information but it is still best to manage your cancer risks based on your personal and family history"<sup>14</sup>. Boenink notes that family members are conspicuously absent from the American version she studied, at two levels. First, "the American client is supposed to be able to handle test results on her own, independently from her family" [39 p.1798]. That is, the American client is constructed as an "independent, autonomous individual who is capable of finding and making sense of information about genetic risk and predictive testing" (ibid.). Second, the American family is constructed "as a set of biologically related individuals (figuring in the pedigree), rather than as an active social unit" (ibid.)<sup>15</sup>. Evidence of this is that women who had received genetic counseling and who tested positive for the mutation generally reported that result to parents and sisters. On the other hand, they were much less likely to report positive results to male relatives, or to report uninformative results to anyone [44].

The result is a medicalization of post-test social support. Recent work suggests that American women rely heavily on clinicians (whom they often find uninformed, and who can be sources of great frustration) and genetic counselors, but less on families, friends or social networks, for help in managing a positive test result [33]. At the core of managing this risk is a feeling of inevitability: as the linearity of the cascade model suggests they would, patients tend to receive evidence that they carry the mutation as indicating that they will develop cancer, not that they have an elevated risk of doing so; most of those interviewed in one study elected prophylactic surgery [45]. Social support networks broaden onto the Internet. Both Rose and Paul Rabinow suggest that the socially isolated American patient is part of what gives rise to support and advocacy groups for certain diseases, such as "Facing our risk of cancer empowered" (FORCE), from which the subjects of the previous two studies were recruited, or through Facebook. Rabinow's suggestion of a decade ago was prescient, as he noted that the situation will likely lead to:

*The formation of new group and individual identities and practices arising out of these new truths. There already are, for example, neurofibromatosis groups whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on . . . It is not hard to imagine groups formed around the chromosome 17, locus 16,256, site*

tumors, testing of those tumors appears to be unlikely to detect the presence of the mutation. In other words, in the case of someone whose mother developed HER+ breast cancer, a negative BRCA1/2 result for the mother may not be particularly informative. For some of the complexities around this case and of assigning risk status, see [40].

<sup>12</sup> One analysis roughly contemporaneous with Boenink's research found that the best process for selecting families for testing used a combination of probabilistic models and information on the pathology of breast cancers; models using clinical criteria (like family history checklists) or scoring methods did considerably worse, especially at excluding those that did not need testing. None of the tested models successfully selected all carrier families [41]. In short, better to include family history, but even that potentially leaves considerable uncertainty.

<sup>13</sup> The site aimed at clinicians includes brochures and educational materials that can be provided to patients. See [www.myriadpro.com](http://www.myriadpro.com) (accessed 6/17).

<sup>14</sup> At <https://mysupport360.com/genetic-testing/testing-results/> (visited 6/17; brochure on file with author). The current Myriad site is considerably more sophisticated than it was in 2011, as well as being more accurate. The 2011 version, for example, said of a negative result that "a negative result does not mean that you have no risk for developing cancer," while the website as a whole made it difficult to find the information that only about 10% of breast cancer risk is hereditary (on file with author). This information is on the front of the current website, which also includes a quiz that will advise whether an individual should consider testing.

<sup>15</sup> This construction may be warranted: a 2004 CDC study found that 96% of respondents thought that family history was important to their personal health, but only 30% had collected information to construct such a family history. See [43].

654,376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and 'understand' their fate [46 p.102].

In the same manner, Rose refers to examples such as Parkinson's disease advocacy, which received a considerable boost when Michael J. Fox developed the disease.

None of this is necessarily to endorse the apparent Dutch model of the family, but it is to note the stark contrast. That contrast can be demonstrated concretely here in the tradeoff between autonomy and uncertainty. An American woman, presumed to be an autonomous instance of *homo economicus*, wishing to maximize investments in her health, is portrayed as a rational consumer and calculator of radically indeterminate information<sup>16</sup>. As Boenink puts it:

*American practice is prone to present clients with ambiguous test results that are difficult to interpret. However, Myriad hardly provides support to make sense of such results, nor does it inform clients of ways to improve the quality of the test result (for example by testing diseased relatives first). So, even though American practice does not confront the client with difficult requests with regard to her family, it is likely to increase rather than decrease uncertainty regarding the future [39 p.1798].*

In other words, the differences in individual patient experience and in the construction of patients as actuarial agents is also reflected in the larger social policies of different countries.

## Bless me Fitbit, for I have sinned...

According to Foucault, biopower traces its roots back to pastoral power – the power of a minister over his flock – under medieval Christianity. As he puts it, pastoral power “gave rise to an art of conducting, directing, leading, guiding, taking in hand, and manipulating men, an art of monitoring them and urging them on step by step, an art with the function of taking charge of men collectively and individually throughout their life and every moment of their existence” [48 p.165]. The pastorate does not disappear with the rise of modern power forms, as he emphasizes more than once [48 p.148, 50]<sup>17</sup>. Indeed, he makes a much stronger claim: “I think this is where we should look for the origin, the point of formation, of crystallization, the embryonic point

of the governmentality whose entry into politics ... marks the threshold of the modern state” [48 p.165].

One of the pastor's responsibilities is surveillant, because to guide the flock, you must know the flock: “the pastor must really take charge of and observe daily life in order to form a never-ending knowledge of the behavior and conduct of the flock he supervises” [48 p.181]. The acquisition of knowledge about subjects is fundamental to the operation of disciplinary power, as Foucault formulates it in *Discipline and punish*. So too, the specific sense in which pastoral power carries with it the logic of its own extension is very similar to what he calls the “swarming of the disciplines” in *Discipline and punish*, where disciplinary institutions extend their data-collecting reach (by talking to the neighbors of truant children, for example, about the prayer habits of the children's parents), as well as through the dissemination of the procedures themselves [50 p.211].

One of the central ways this epistemic function happens is to get the individual members of the flock to produce (and desire to produce) their own truth about themselves. That is, after all, both efficient and probably more efficacious than earlier techniques. Again, in the terms of *Discipline and punish*, the key to the efficiency of disciplinary power is that one never has to actually exercise it: through a process of careful behavioral conditioning, subjects take compliance with regulatory demands upon themselves.

One of the main vehicles for such truth production is the confession, which is a central theme of *History of sexuality I*. In that text, Foucault proposes that confession is, “since the Middle Ages, at least ... one of the main rituals we rely on for the production of truth” [10 p.58]. As he notes:

*One confesses in public and in private, to one's parents, one's educators, one's doctor, to those one loves; one admits to oneself, in pleasure and in pain, things it would be impossible to tell anyone else, the things people write books about. One confesses – or is forced to confess [10 p.59].*

Or, as he puts it in a later lecture course, “the obligation to tell the truth about oneself has never ceased in Christian culture, and probably in Western societies.” He adds that “putting oneself in discourse is ... one of the major driving forces in the organization of subjectivity and truth relationships in the Christian West” [51 p.311]. That is, “we are obliged to produce the truth by the power that demands truth and needs it to function” [52 p.24].

By way of example, consider the intersection between wearable technologies and employee wellness programs in the U.S. Many employers offer some sort of financial incentive to those who are willing to confess their daily habits to the insurance company (or the employer)<sup>18</sup>. Employees should have a primary care physician; swear that they don't smoke; and upload some biometric data (like blood pressure, blood sugar count, weight, BMI, etc.) into insurance databases. Employees who fail to comply can be faced with punitively higher premiums, or even the denial of coverage altogether [54]. The technique produces and teaches a

<sup>16</sup> In this sense, one might complain that the Dutch practice is “paternalistic.” As Bernstein notes, however, the presence of a medical professional as a gatekeeper can equally be said to be autonomy-enhancing by allowing more informed choices [47 p.11 n40].

<sup>17</sup> This claim is important because it indicates clearly that various forms of power can coexist within the same social structures; the point is which ones appear to be more salient either in general, or in specific situations. In other words, Foucault does not think we transition into and out of regimes of power in any straightforward sense. For this reading, see [49].

<sup>18</sup> As of 2013, 80% of those at firms with more than 50 employees were subject to such programs [53].



direct tie between salvation in the form of lower insurance premiums and the confession of one's health habits. As Foucault notes with regard to disciplinary power, the technique is portable and applicable to other contexts. For example, car insurance companies offer lower premiums to drivers willing to have their driving monitored; as Scott Peppet [55] notes, the adoption of this monitoring technology by the best drivers (who have a strong financial incentive to participate) generates an inexorable logic for others to adopt the technology so as to associate with the in-group. Eventually, not consenting to confessing one's driving habits becomes itself the justification for suspicion and higher premiums.

As we know, financial incentives to do things that many people do not like or do not have the time to do (such as exercise) generate all kinds of other incentives — like lying about whether one smokes or exercises. Indeed, people do not seem to be particularly compliant and experience these little exercises in data entry as annoying, intrusive and paternalistic. So, as Bruno Latour [56] observed a long time ago, we outsource a lot of our moral enforcement to devices like automatic door closers and automatic seat belts. Here is where wearable technology intervenes, as a way to compel confession<sup>19</sup>. Imagine a wellness plan that requires employees to wear fitbits or other electronic monitoring devices. The granularity of such surveillance is already high and certain to increase in the future, as insurance companies learn to mine their data (or purchase it cheaply from others) for risk factors and predictors of poor outcomes. Some of this data will not be data users voluntarily provided (or thought they were providing), as data brokers will learn how to associate either seemingly unrelated data (furniture purchasing habits and diabetes risk: do you tend to comfy sofas?) or metadata (do you spend a lot of time on the phone with other couch potatoes? How about playing multiplayer video games?).

In doing all this, the intersection of wellness programs and wearable technologies would represent an intensification of the logic of confession, applied to the intersection of health and work. Most generally, the programs represent the nexus of the emergence of "lifestyle medicine" and the consequent medicalization of everyday life since the 1970s [58] and the emergence of steadily more granular and intensive workplace surveillance [59]. This combination aims at nothing less than a reinterpretation of our traditional concept of the employment-health relation. As David McGillivray puts it, "under health promotion logic, workplaces are now recognized as places that can be 'good' for, rather than deleterious to, your health and well-being" [60 p.130]. Put differently, the emphasis on "fitness" is an entirely different way of looking at health: bodies are not at danger from outside, aleatory events, but in a process of continual adjustment to (and preparation for) risks brought about by their own behaviors. "Fitness" becomes a proxy for health because it becomes a marker of adequate risk preparedness [7]<sup>20</sup>.

<sup>19</sup> For a brief, critical introduction to wearable fitness technologies, see [57].

<sup>20</sup> On well-being as a neoliberal desideratum, see [61]. See also [62] (arguing that "a conflation between work and health is being achieved through a reorientation of wellness as within the remit of

All of this is not to say such programs as these are *actually* good; after all, living under a regime of constant surveillance might make one feel less attached to work, and more stressed while there. As Hansen notes:

*In this attention to personal problems—as the source of potential costs to productivity — workplace monitoring practices and other 'stress-inducing' workplace practices are effectively excluded from serious consideration as a credible source of unease, discontent and associated grounds to inefficiency [65 p.163].*

Hansen concludes that the current programs represent a "transition ... from a form of governance characterized by a pastoral mode of control and care to a neoliberal form of discipline, marked by an increasing reliance on the motivation of workers towards self-management, self-monitoring and self-correction" [65 p.160]. Or, as McGillivray put it, "this health promotional logic appears to provide medicalized legitimacy for the organizational governance of an employee's subjectivity" [60 p.132].

## Conclusion: the political is personal

By way of conclusion, I would like to return briefly to the moral sense of a clinical encounter invoked by Zaner. In a later paper, Zaner remarks that "the asymmetry of the clinical relationship harbors the prospect of the healer taking advantage of the multiply vulnerable patient — and just this constitutes the relationship as specifically moral" [66 p.272]. He also comments on selfhood:

*'Self' is not something which everyone acquires at birth, whole and entire. It seems instead a gift and an accomplishment in which I am gradually thrust, entrusted to my care, and is acquired through the course of experience [66 p.270].*

It is by offering an expansive treatment of this sense of selfhood both as an accomplishment and as something into which we are thrust that Foucault seems to me most relevant in understanding bioethics today more broadly.

To be blunt: the current social and political landscape that structures clinical encounters and ultimately produces an understanding of health and selfhood is pushing inexorably toward gutting of any sense of "public." That is, the social truth of medicine is that health is a personal matter of lifestyle and genetics, matters which need to be managed individually through a series of rational cost-benefit

employers and as an issue best tackled through management strategies"); [63] (arguing that Fitbit etc. quantify exercise, making it a part of surplus labor extraction and suggesting that this will change the meaning of exercise to be only what can be appropriated this way); and [64] (noting that wearables are engaged in a form of micronudging. Even absent direct employer coercion, people are scared of their futures, and they're trying to get the machines to help manage the required anticipatory approach to it. In other words, the growth in popularity of wearable technologies as arbiters of fitness is clearly tied to the rise of neoliberal lifestyle approaches to medicine more generally).



calculations. This is the vision of subjectivity behind neoliberalism, and it has been applied specifically to health by leading neoliberal economists [67]<sup>21</sup>. This is not to say that “neoliberalism” can be defined precisely; indeed, part of its political durability lies precisely in its malleability [37]. But one consistent part of its message is the transference of risk to individuals, who are then expected to manage it on their own.

The rise of the “wellness lifestyle” since the 1970s, and the ways that genetic testing is managed in the U.S. both point in that direction. BRCA testing presents a woman as an isolated actor, who is supposed to be empowered by knowledge of her carrier status to make difficult and far-reaching decisions about her own future health. Similarly, when insurance presents health as a lifestyle, it abets not just an unraveling of the risk-pooling that insurance supposedly accomplishes in the first place, it encourages a confessional logic of subjectivity, a logic according to which selfhood is constituted in part by the submission of vast amounts of data about our personal choices and behaviors to authorities who have the power to discipline us for those behaviors. In its neoliberal version, biopower has tremendous implications for health policy; these implications matter because they ultimately provide and texture significant parts of the structure of the asymmetry in clinical encounters, the asymmetry that makes those encounters moral in the first place.

## Disclosure of interest

The author declares that he has no competing interest.

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<sup>21</sup> For Becker’s influence in health economics, see [68].

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