Published in final edited form as:

Biosocieties. 2010 December 01; 5(4): 440–466. doi:10.1057/biosoc.2010.28.

BRCA patients in Cuba, Greece and Germany: Comparative perspectives on public health, the state and the partial reproduction of ‘neoliberal’ subjects

Sahra Gibbon^{a,*}, Eirini Kampriani^a, Andrea zur Nieden^b

Eirini Kampriani: e.kampriani@ucl.ac.uk; Andrea zur Nieden: andrea.zurnieden@uni-duesseldorf.de

^aDepartment of Anthropology, University College London, 14 Taviton Street, London WC1H 0BW, UK

^bInstitut für Geschichte der Medizin, Heinrich-Heine-Universität Düsseldorf, Postfach 10 10 07, Düsseldorf D-40001, Germany

Abstract

The relationship among genetic technologies, biosocial identity and patient subjectivity has been the focus of an increasing range of social science literature. Examining mainly European and North American contexts this work has demonstrated the variable configurations of genetic knowledge-practices and the diverse implications for at-risk individuals and populations. This article brings together ethnographic research on genomic medicine, public health and breast cancer in Cuba, Greece and Germany. Although each case study addresses different publics/patients, institutional settings and risk-related practices, they all critically examine ‘neoliberal’ subjectivity and BRCA patienthood, at the intersection of political rationalities, medical discourses, social conditions and moral codes. In the Cuban case, cultural articulations of inherited and other embodied risks relating to breast cancer are analysed in relation to state provision of ‘community genetics’, and the shifting dynamics of public health in response to global social processes. The Greek case explores how culturally embedded values, notions of inherited risk and care inform or are re-articulated through institutional practices and ambivalent subject positions, at the meeting point between individualised medicine, religious philanthropy and the particularities of public health. In the German context, diverging patient subjectivities are examined against the background of prevailing social discourses and institutionalised risk management practices that promote proactive individuality. Drawing on deconstructive and feminist analyses, these case studies reveal how normative ‘neoliberal’ patient subjects are only ‘partially reproduced’ in situated contexts, neither stable nor homogeneous, as different actors and publics variously articulate, embrace or engage with transnational as well as culturally embedded discourses and health practices.

Keywords

BRCA; patienthood; neoliberal subjectivity; Cuba; Greece; Germany

*Corresponding author. s.gibbon@ucl.ac.uk.

Introduction

The relationship between the ‘new genetics’ and identity has been critically addressed by a number of social scientists examining a wide, varied and evolving field of genomic healthcare interventions (Rapp, 1999; Finkler, 2000; Franklin and Roberts, 2006; Konrad, 2005; Gibbon, 2007). The way that genetic knowledge relates to questions of personhood, gender, patient subjectivity, the dynamics within the family and issues of kinship, as well as wider social/community or religious networks or practices, has provided an important focus and context for such studies. At the same time many have argued that the increasing presence of a culture of patient activism, in specific cultural contexts and in relation to certain health conditions, as well as the growing individualisation of public health, have consequences for articulations of citizenship (Rabinow, 1996; Rose, 2001; Gibbon and Novas, 2008). Such forms of informed ‘active’ patient subjectivity have been termed ‘neoliberal’ (Petersen, 1996; Lemke, 2000; Polzer, 2000; Robertson, 2000, among others). This orientation is, for instance, defined in the work of Novas and Rose (2000) who, drawing on Michel Foucault’s studies in governmentality, suggest that:

medicine, including medical genetics, notwithstanding its resolutely somatic understanding of the mechanisms of disease, has been one of the key sites for the fabrication of the contemporary self – free yet responsible, enterprising, prudent, encouraging the conduct of life in a calculative manner by acts of choice with an eye to the future and to increasing self well-being and that of the family. (Novas and Rose, 2000, p. 490)

The potential for developments in the life and medical sciences to generate and inform new modes of identity, sociality and subjectivity, and the transnational effects of scientific developments and associated health discourses, have fuelled and continue to fuel a broad field of social science engagement. Contributing to the empirical exploration of these formulations, this article brings together ethnographic accounts from Cuba, Greece and Germany that focus on breast cancer and health care interventions associated with the ‘BRCA genes’. This comparative reading illustrates aspects of the cultural shaping and the constitutive forms of a variety of patient subjectivities within specific national contexts. In these arenas, BRCA patient subjects may at times and in certain contexts appear to sustain, reflect and contribute to a homogenisation that reproduces ‘neoliberal’ norms. At other times, or in different contexts, such subjectivities may be the product of cultural and socio-political dynamics that would appear to run counter to any normalising trajectory. That is to say, BRCA subjectivities are neither stable nor homogenous and are always the consequence of highly specific historical processes, which are themselves the outcome of varying political, cultural and social practices.

Particular deconstructive and feminist analyses inform the approaches developed in this article. Derrida’s notion of ‘iterability’ aims to capture the fluidity of social meanings generated through reproduction (Derrida, 1982; see also Morris, 2007). Focusing on the capacity of a sign or form to be resignified through repetition, he suggests inherent in a sign’s constitutive structure is that it always entails both a degree of sameness with previous configurations and a degree of difference. In that sense ‘iterability alters’, as any attempt to reproduce a recognisable and repeatable form in new contexts simultaneously creates the

possibility of new/multiple meanings. At the same time it also incorporates the absence or deferral of an imaginary original form or intentions that never appear as stable or explicit. In the context of the discussion outlined here this indeterminacy makes impossible the unconditional or programmatic reproduction of practices, identities and subjectivities that have come to be defined under the term 'neoliberal'. They produce a '*différance*',¹ to use Derrida's proposed term, which exemplifies the notion of a difference with a difference, such that it is not reducible to opposition but implies innate difference based on definite qualities.² That is, as BRCA-related technologies are introduced in new social contexts and cultures, they produce or engage with alternate or conflicting meanings and practices that simultaneously differ while also sometimes appealing to or repeating previous articulations or primary intended effects.

The question of iterability against the failure of pure reproduction is further developed in Butler's work (1999, 1993) on the performativity of gender categories in relation to regulatory power and discourses. She shows both that identity categories are not self-evident or natural and neither are subject positions fixed in meaning or expression. Rather, they are retroactively constituted and performatively appropriated by subjects that assume their social identity, in multiple forms, with reference to core values, dominant discourses and existing power structures. Thus, subjects may seemingly repeat an imposed order through a 'stylised repetition' (1999) of identity acts and bodily practices, yet it is through the agency of their use, as a re-articulatory practice, that they create the possibility of alternative modes of subjectivity – or re-signify the interplay between sameness and difference in unexpected ways, in Derrida's terms. According to Butler, the task at hand would be to unravel the contexts and conditions within which hegemonic norms emerge and, thus, explore the 'matrix of relations' (1993) that operates in the construction of various subject positions. How do culturally embedded values of health and caring, public health ideologies and political rationalities come to matter in the establishment of 'neoliberal' discourses and the performative making of BRCA patient subjectivities? In what ways do the different expressions of the subjects' agency forge a re-articulation of the meanings, assumptions and conventions that are integral, and yet also concealed, within these norms?

Equally informative to this discussion is Donna Haraway's approach to the 'situated' nature of scientific knowledge (1997), which precludes any objective or neutral positioning (what she terms 'the gaze from nowhere'). The perspectival view privileges an acknowledgement of the inevitable partiality of knowledges/practices. This is also demonstrated in the work of Marilyn Strathern in her re-reading of relationality, in which replication is only achieved through (sometimes unexpected) 'fractal' alignments of 'parts and wholes' (2004). It is this sense of 'partial' that we apply in our discussion of the reproduction of 'neoliberal' identities. In this way, tracing the reproduction of patient subjectivities entails exploring how 'neoliberal' discourses are situated in webs of relations and structural conditions as genetic

¹In his lecture presented to a French audience in 1968, Derrida intentionally misspelled the word to show that although the pronunciation does not change in French, the meaning integrates a difference which is not initially obvious but suspended for later (until read) (1982).

²In a recent work Derrida (2005) refers to the challenges of technoscientific developments with respect to the workings of power in modern democracies. He contends that genetic technologies promote the rhetoric of reproduction, as in the case of genetic engineering, despite the impossibility of such iteration and calls for critical examination of the invested moral orders and political ideologies.

knowledge-practices are incompletely connected to social, religious or political projects. Similarly propositions for proactive patienthood and autonomous individuality are re-appropriated by actors and subjects in relation to the array of expressions and possibilities that they both create and are variously informed by. In effect it is this inherent fluidity and interpretative variance of the concept of inherited risk, as well as strategies for risk management and differing formulations of patient subjects, that are the focus of this article.

BRCA Genetics and Patient Subjectivities in Local, National and Comparative Perspectives

Studies in the anthropology and the sociology of breast cancer genetics have shown how the very notion of inherited risk and the possibility of knowing one's genetic susceptibility entails a tentative positioning of persons in relation to risk categories (as pre-symptomatic, high-risk and/or potential patients). This allows for different configurations of identity and subject positions. The visibility of a highly feminised disease, the transnational appeal of the breast cancer movement and the growing socio-political imperative within health promotion discourse that emphasises the proactive individual (Press *et al*, 2000; Klawiter, 2008) are some of the forces that shape identities and subjectivities.

As the globalised narrative about hope and control of one's health and future gets translated through the language of individual 'rights', 'choices' and 'responsibilities' (Kerr, 2003), predictive knowledge becomes subject to different investments and claims by female patients, practitioners, activist groups and social networks. Ethnographic accounts, in different national contexts, reveal the tensions and possibilities inherent in variable perceptions of BRCA technologies and the making-up of 'patient' subjectivities. As Konrad and others argue (2005), the figure of the 'patient' in the context of genetic risk information is itself not straightforward. This is particularly so when genetic health interventions about future disease risk require the involvement of related family members or when 'patients' are 'pre-symptomatic'. We refer to those who are subject to and engaged with risk assessment linked to BRCA-related technologies as 'patients' in this article with an awareness of these complexities.

From a comparative perspective, Parthasarathy (2007) suggests that the institutionalisation of genetic testing in the health care cultures of the United States and the United Kingdom has contributed to the construction of women as consumers, citizens or patients. Institutional structures and science policies have helped produce certain patient subjectivities in attempts to define individualised risk and in relation to variable access to predictive technology. In more experience-near accounts, technologies of genetic testing and risk management have been seen as imposing a medicalised embodiment of risk on women (Finkler, 2000). Although this imposition has the potential to be linked to individual and collective empowerment practices, in other cases genetic interventions reveal the very limits of medical control over biology (Finkler, 2003; Gibbon, 2007; zur Nieden, 2010). As a prevailing health risk narrative is infused through personal experiences and gendered identity politics, women may at times embody these discourses and portray themselves as the model autonomous individual, as 'entrepreneurial subjects' (Robertson, 2000). Yet we contend that

unproblematically terming such forms of subjectivity ‘neoliberal’ and linking them directly to new forms of governance in ‘advanced liberal societies’ (Novas and Rose, 2000) may be too generalising and simplistic. This may neglect social and cultural differences both among and within societies and fail to recognise the way that ‘neoliberal’ forms are themselves forged through the dynamics of state organised public health, national histories, gendered moralities and community or religious practices.

Looking at the intersections of BRCA knowledge and technologies in the United Kingdom, drawing empirically from practices within clinical arenas and the context of cancer charities, Gibbon (2007) has described how individuals relate to the ideals of health awareness and proactive patienthood in more nuanced and gendered ways. Women are shown to negotiate the unstable aspects of the disease, as notions of female nurturance and caring are reworked to account for the benefits of predictive knowledge and particular forms of activism. As other case studies have demonstrated, issues of gendered responsibility and women’s familial obligation (d’Agincourt-Canning, 2001) are central to BRCA medical practices. Confronted with genetic risk, women may identify themselves as ‘selves-in-relation’ (Hallowell, 1999). They filter their choices and practices through questions that appeal not only to responsible citizens and rational individuals, but also in ways that highlight relational identities and the imperatives of caring or being cared for by others, of being ‘ordinary’ mothers (Rowley, 2007), moral persons, patients and women. Furthermore, Gibbon and Scott *et al* have shown that, besides a notion of responsibility for one’s health, ‘patient-clients’ in the United Kingdom articulate a *right* ‘to be monitored’ and desire ‘to be cared for’ (Scott *et al*, 2005; Gibbon, 2007). Similar indirect forms of women’s agency have been described in a German case study by one of the co-authors of this article; in this case, being ‘proactive’ involves actively delegating responsibility to doctors (zur Nieden, 2008). Such dynamics reflect the importance, when considering patient subjectivities, of examining how state sanctioned models of public health (where they exist) intersect with health promotion discourses and individual or collective health activism around the disease in considering patient subjectivities. Studies of community interventions and BRCA genetics by two of the co-authors of this article in the Cuban (Gibbon, 2009) and the Greek contexts (Kampriani, 2009) have already begun to illuminate the different ways that risk and citizenship are linked to collective, political ideologies or religious and gendered moral values.

The importance of re-examining the biopolitical role of state institutional practices in arenas where issues of citizenship, rights and public health are being actively negotiated is now becoming evident in studies of genetic technologies both in the context of Europe and the United States. As Raman and Tutton point out, there is in fact a ‘multiple not singular politics of life’ at stake in the expansion of genomics in these domains where ongoing concerns with ‘public health, environment, migration and border control’ reference a ‘more complex cluster of relationships between the molecular and the population’ (2010, p. 711). Recent ethnographic studies examining the globalising terrain of genomic medicine, particularly in Asia, are now revealing the limits of tracing any linear or straightforward process in the emergence of a model enterprising and self-regulating individual (see for instance Gammeltoft, 2007, 2008; Gottweis, 2009; Greenhalgh, 2009; Sleeboom-Faulkner, 2009, 2010). But as Aiwā Ong’s work illustrates, the ‘zones of exception’ to a ‘neoliberal’

norm, seemingly being constituted in these contexts, are often fluid and themselves subject to unexpected or experimental ‘mutations’ in response to global economic processes (2006).

The ‘co-production’ of medical technologies, socio-political rationalities and persons, in particular comparative contexts (Lock *et al*, 2000; Jasanoff, 2006; Gibbon and Novas, 2008), provides the entry-point for understanding notions of patienthood and subjectivity that are the focus of this article. The ethnographic cases of Cuba, Greece and Germany presented here illustrate how definitions of inherited risk, technologies of screening and practices of risk management linked to breast cancer genetics are shaped, appropriated and negotiated in the context of highly specific institutional cultures and social settings. Each of these studies addresses different facets of BRCA-related medicine that vary from institutionalised predictive genetic testing to practices of identification of ‘at-risk’ persons through family history alone, depending on the particular national system of health care infrastructure in place. Collectively they reveal how patient subjects, at the intersection of particular political rationalities, medical discourses, social conditions and moral codes, sometimes resist but also variously and partially embrace or express ‘neoliberal’ identities.

Breast Cancer Genetics in Cuba as a ‘Zone of Exception’; (dis)Embodied Risk, Community Genetics and Public Health

Cuba, with its unique political history of state socialism and long-standing goals of equitable access and universal public health care, provides an important arena for examining how identity and citizenship are being co-produced at the interface with novel genetic knowledge. The data discussed here, examining the narratives of Cuban women, focuses on the variety of ways that health ‘risks’ linked to breast cancer are articulated. This research points to very particular configurations of embodied health risk that must be understood against the changing dynamics of Cuban medical practice and the expansion of what is described as ‘community genetics’. Although ‘citizenship’ and subjectivity are involved in the interface with genetic medicine, in Cuba the trajectories that link these developments to what might be seen as the ‘neoliberal’ goal of genomic research, ‘personalised medicine’, are neither straightforward nor obvious.

A commitment to universal public health care has been one of the cornerstones of the Cuban ‘socialist’ project. The notable achievements over 40 years in maternal and infant health in a context of reduced economic and material resources (brought about both by the collapse of the Soviet subsidies in the early 1990s and the ongoing US trade embargo) have been widely recognised by the international community, as well as promoted by the Cuban state (Feinsilver, 1993; Eckstein, 1994; Brotherton, 2005). The specific arena of ‘Community Genetics’ or ‘*Genetic Comunitaria*’, as it is described in Cuba, has emerged directly from that programme of maternal and infant health care, and the long-standing project of family or community medicine (Nayeri, 1995; Spiegel and Yassi, 2004). Aiming to extend the ‘success’ of these public health care initiatives, genetic medicine has been consolidated over the last 10 years with regional and inter-regional community genetic clinics established throughout the country. Thousands of health practitioners have been and are being especially trained to work (like Cuban family physicians) within the local communities in which they

also live. This embeddedness within localised settings enables genetic health professionals to pay close attention to and have good working knowledge of family medical history and the social well-being of related individuals. Traditionally more concerned with ante- and pre-natal screening and testing for diseases such as sickle cell or rare chromosomal disorders, the collection of family history data linked to common complex conditions such as breast cancer currently constitutes a minor aspect of the work undertaken in these centres. Yet importantly this is taking place despite the fact that there are currently little or no economic and material resources for providing routine predictive genetic testing for the two BRCA genes. Expanding on the broad findings of this research, aspects of which have also been discussed elsewhere (Gibbon, 2009, 2010 forthcoming), the discussion outlined here examines how patient subjectivity and embodied risk are articulated by Cuban participants. It situates these data in the context of the changing and dynamic arena of community genetics and public health in Cuba, drawing some conclusions about the variety of subjectivities at stake in the global spread of what has been described as ‘predictive’ medicine.³

In comparison with previous work undertaken in the United Kingdom (Gibbon, 2007), most notable in the Cuban context was the very different response to open-ended questions relating to perceived risk factors for breast cancer. While family history and ‘*factores hereditarios*’ did constitute a point of reference for some of the interviewed women, a notion of ‘genetic’ risk was not widely recognised or always acknowledged as important. As discussed elsewhere this contradictory finding must be read against the background of ongoing efforts within the space of Cuban public health, which now includes community genetics, to address family well-being. While such practices reinforce an understanding that medical family history is important to a range of conditions, including breast cancer (Gibbon, 2009; Gibbon, forthcoming), there was little evidence that ‘genetic risk’ *per se* was articulated through an idiom of individual health awareness.

More generally, attention seemed not, as it had been in the United Kingdom, focused on individual lifestyle or genetic factors that reflected a moral discourse about the value of what was perceived as preventative monitoring of personal health (Gibbon, 2007; Parthasarathy, 2007; also Klawiter, 2008). Rather, in the Cuban context risk factors that were to a large extent outside of the individual control of persons were often emphasised. Environmental factors, ozone depletion, the effects of pollution arising from the west, including the effects of ‘*guerras*’ [wars] such as that in Iraq, were all readily offered by many women as the primary or most important explanations about what they believed to be the causes of breast cancer (see Gibbon, 2009). Elsewhere these perceptions have been explored in relation to the predominance of causal explanations for the disease relating to a ‘*golpe*’ or physical blow to the body and gendered ideas about the dangers of excessive physical exertion for women that reflect the dramatic changes in the role of women in Cuban society (Gibbon,

³The data explored here are drawn from research working with community genetic health professionals exploring perceptions of disease risk (including genetic risk) linked to breast cancer among Cuban publics. Alongside ethnographic research, a questionnaire was undertaken with healthy women and those affected by breast cancer in three regions of the country, all outside of Havana. Healthy women and those with breast cancer were invited to participate by Cuban health professionals in the areas where the research was undertaken. Using open and closed questions participants were asked about their health beliefs regarding the causes of breast cancer, including genetic and non-genetic risk factors.

forthcoming). The case study material discussed here focuses on Cuban women's narratives about cancer risk relating to food and 'stress'.

Discussions of dietary factors relating to health risk have often served to illustrate the way that the moral discourse of individual health awareness has become central to the practices of health promotion in 'western' societies (see for instance Lupton, 1996). By contrast, the way that these factors were raised by many Cuban women revealed a rather different reading of personal embodied risk. Rather than a particular lifestyle practice relating to an excess of food consumption being the perceived cause of the disease, more prominent was the idea that there was a deficit in the diet – most often associated with lack of vitamins, protein or milk. These two examples illustrate this type of reading:

There are so many cases [of cancer] now I think that it must be something missing in the diet, a vitamin that the body needs, because everyday there are more cases.

It could be some food that you don't eat which produces your cancer, some fruit or vegetable that we don't have the habit of eating, perhaps because there aren't any.

These comments relating to a lack or deficit in the diet reflected a general sense that health risks associated with risk of breast cancer were not always within the control of individuals but rather were linked to collective contexts and the wider shared challenges of daily life in Cuba.

Discussion of 'soya' consumption among research participants appeared initially to have been the exception to this perceived tendency to see lack (rather than excess) of appropriate food in the diet as the cause of breast cancer. However 'soya' consumption was also for some linked to suspicions regarding the long-standing state practice of including this product across a wide variety of food products, as a replacement for milk, cheese and meat, as these comments illustrate:

I think that the use of soya could be the cause [of breast cancer] because everything contains soya and the cases of cancer have risen.

Since the Special Period they have incorporated soya [into the diet] and there are a large number of persons with cancer.

As the comments of Cuban women relating to perceived risks for breast cancer associated with genetic and dietary factors illustrate it would seem that the morality of a discourse of individual health awareness does not have the same resonance in Cuba as it does in the United Kingdom and elsewhere. This was not a context in which there was an active desire to be part of a programme of genomic health interventions linked to individualised rights to health care monitoring and preventative interventions, such as mammography screening, as it seemed to have been for many patients in the United Kingdom (Gibbon, 2007). Yet the articulations in Cuba of a somewhat 'disembodied' sense of health risks or dangers must in part be read in the light of very specific structural conditions. Not only is there no significant culture of health activism around breast cancer, but, additionally, there is no public health basis for routine clinical genetic testing and often little resources for 'pre-emptive' mammography screening for those identified at increased genetic risk on the basis of family history.

It would seem that, at least in part, the biosocial identities at stake in Cuba link subjectivity and citizenship to public health, through state sanctioned concern with collective well-being. From one perspective, it is a situation that poses significant challenges to the translation of personalised medicine in Cuba (Gibbon, 2009; Gibbon, forthcoming). In considering the obstacles to the transnational spread or limits to the application of genomic technologies, the tentative translation of BRCA genomics into health care practice in Cuba would appear, in Aiwa Ong's sense, to present a clear cut 'zone of exception' (2006). Yet as Ong's work attests to, and other recent studies emerging from Asia and China also illustrate (see for instance Gottweis, 2009), there are a variety of biopolitical processes at stake in the transnational spread of 'neoliberal' practices, including those associated with genomic medicine. These are often spaces where commitments to and expressions of collective *and* individual health are being negotiated in relation to changing national and global dynamics. 'Exception' is in this sense also subject to the conditions of 'iterability', as outlined in the introduction to this article. That is, the articulation of biosocial subjectivity may both include traces of an *imagined* original while also generating the possibility of new or diversely articulated meanings and values. The concluding sections of this discussion explore these conflicting and contradictory processes within Cuba as they emerged within the context of research on publics' health beliefs related to the causes of breast cancer. Here the difficulty of articulating a generalised 'Cuban' response to these developments is foregrounded in ways that highlight the need to understand the expanding field of 'community genetics' in relation to the changing geo-political and economic dynamics around public health within Cuba. Some significantly less common yet important differences in Cuban women's responses to questions about their health beliefs pointed to these shifting social and cultural dynamics.

For a few women there was a sense that individual responsibility for one's health was important and '*no se cuidar*' (not to look after one's health) or '*se abandone*' (to neglect oneself), with respect to having a bad diet or not exercising, was detrimental to health. Importantly these commentaries came from individuals who often lived closer to tourist or metropolitan centres who had direct access themselves or through kin networks to the so-called 'dollar' economies in some way, as their frequently well-kept homes displaying the very latest consumer products often made evident. Reflecting this difference it was notable that discussions of 'stress' as a disease risk factor was *less* likely to be discussed in the eastern regions of the country. This points to the possibility of a regional variation in the way ideas of 'self-responsibility' for health are expressed in Cuba. A number of regional differences have long been noted with distance from the metropole of Havana generally seen to constitute the axis along which more openly expressed loyalty to socialist ideals can be mapped (Rosendahl, 1997). Yet importantly, even when 'stress' was seen as possibly prejudicial to health, regardless of regional location, there was often an explicit sense that this was only related to diseases of the 'mind' not to conditions such as cancer. This suggests that there are ongoing limits in Cuba to a reading of cancer as a disease in which the 'self' is causally implicated.

The particular comments of one female participant provide further evidence of some of these contradictory dynamics. This example illustrates how the articulation of active individualism in the context of an explicit discussion of genetic testing is not simply or only an articulation

of emerging consumerism or health care activism but is cross-cut and referenced through other collective cultural meanings that have particular resonance in Cuba.

Living close to a tourist region in a central province of the country in a home that reflected her access to extra non-state financial resources it was in many ways not surprising to find that Mayra talked at length about her careful dietary regime and the need to monitor her own health. Of particular note however was her statement:

I hope that there is a test to prevent it [breast cancer] – I want to do it, to know, for my daughter.

Mayra's comments about a need and desire to take a 'test' referred in this instance to the possibility of a genetic test for her to 'know', in order to care for her daughter. From relatives in Miami, she had heard about the possibility of having a predictive genetic test.⁴ Her comments therefore would seem to reflect a rare instance of 'neoliberal' activism and awareness directly linked to the equally rare interest in and knowledge of the possibility of predictive genetic testing. But at the same time Mayra's 'hope that there is a test to prevent it' also demands another reading. Such remarks must also be seen in the light of high-profile efforts in Cuba linked to investment in science and biotechnology to develop 'cancer vaccines'. Importantly it is a programme of investment that state rhetoric positions as an integral aspect of Cuba's 'modern' socialist state, explicitly orientated to broad public health interventions (Thorsteinsdóttir *et al*, 2004).

These examples shed light on the complex and often unexpected ways that 'neoliberal' subjectivities are being expressed in the Cuban arena, often emerging through and within state practices and collective political rationalities. These findings reflect the work of others, such as Sean Brotherton, who has pointed to the way informal economy practices in the fields of Cuban health care are producing and requiring enterprising individuals who paradoxically are helping to sustain a weakened public health infrastructure (2005, 2008, see also Andaya, 2009).

The expansion of community genetics in Cuba to include the collection of family history information linked to breast cancer can therefore not simply be seen as an expression or an extension of state control over health. Instead, it must be read in relation to the shifting space of Cuban socialist governance that is an arena where informal and 'entrepreneurial' economic practices operate alongside state health care interventions. It is also a context where government efforts to expand community genetics reflect an ability to participate in 'modern' global and transnational expansion of novel health care techniques. In the changing political context of Cuba it is also possible that such practices may even represent tentative moves by the state towards the incorporation of neoliberal health practices.

Nevertheless it is also clear in Cuba that the work of translating genomic interventions linked to the management of breast cancer risk is neither straightforward nor obvious. As the work of Elise Andaya illustrates in her examination of reproductive health consultations in

⁴In fact explicit discussion of this possibility arose a number of times whilst completing the questionnaire when the woman mentioned seeing foreign news reports about genetic testing in families for breast cancer.

Cuba, the emphasis on being ‘*disciplinaria*’ or ‘self-disciplined’ must be always read in terms of a dual emphasis (2009). Here ideas of individual responsibility co-exist with an ongoing emphasis and intervention in health at the level of the family, community and state.

The work of the other co-authors in this article powerfully illustrate how the conflicting dynamics around predictive medicine as public or state provision of health care, as well as a variety of biopolitical subjectivities that this entails and reproduces, require much further research in diverse global and national arenas. ‘BRCA’ medicine clearly does not yet appear to exist in quite the same way in Cuba as it does in the other national arenas explored in this article. Yet moves to incorporate genetic risk assessment linked to breast cancer as part of the growing provision of community genetics as public health demonstrate the vital importance of understanding what is at stake for patients and professionals (see Gibbon, forthcoming) in this contrasting cultural and political arena. This is particularly true when limited economic and technological resources severely hamper the translation of predictive interventions into meaningful public health care and when the well-being of the population still constitutes a powerful tool of governance and source of political rhetoric with national and international ramifications. While the expansion of Cuban community genetics to include the collation of family history data linked to breast cancer illustrates the transnational power of the quest for ‘personalised’ medicine, this endeavour works in tension with socialist political ideologies, the local organisation of health care and highly specific renderings of individual embodied risk.

Tracing Breast Cancer Genetics in Greece; Cultural Engagements with Inherited Risk and the Making of Ambivalent Patient Subjectivities

In Greece, developments in preventive and genetic medicine have been forged on the rhetoric of ‘progress’ and ‘hope’ as individuals and groups make different investments in new knowledge/practices. As a result, this is an arena where multiple, sometimes juxtaposing, appropriations and negotiations take place. This ethnographic case exemplifies how cultural articulations of the globalising ideals of self-actualising individuality linked with genetic technologies are implicated in socio-political processes and medical and moral discourses that appeal to notions of the collective (Raman and Tutton, 2010). Of particular interest is how individual patient subjectivities are informed by or engage with the collective management of risk by social networks or medical and non-medical institutions and the relational dimensions of being a person at-risk in the context of BRCA-related knowledge. The ethnographic material presented here draws on research in the cultural context of breast cancer genetics in Greece,⁵ focusing on the ways in which inherited risk and related health practices are configured by various actors and in different social fields.⁶

⁵This study was conducted by Eirini Kampriani for the purposes of her PhD, Department of Anthropology UCL. Fieldwork research was funded by the Wenner-Gren Foundation for Anthropological Research (Dissertation Fieldwork Grant No: 7411); financial support was also provided at an initial stage by the UCL Graduate School (Research Fund).

⁶Fieldwork research was conducted mainly in the broader area of Halkidiki, in Northern Greece, and a shorter part in the urban setting of Athens. Anthropological research methods included both observations and daily interactions in different settings (clinical, social, charity) and interviews with women with family histories of breast cancer, scientists and practitioners.

Genetic ideology and applications of genetic medicine have been welcomed in Greek society, particularly those connected to reproductive technologies and pre-natal testing. Breast cancer genetics, on the other hand, has been embedded within the recently evolving context of health promotion and linked with the biopolitical anxieties concerning the spread of the disease. Mobilising women to attend mammography screening is associated with controlling the high frequency of advanced breast cancer diagnoses and the estimated increase in death and incidence rates. To this end, health campaigns and media coverage of the topic aim to inform women of the biological and lifestyle factors that account for the medically defined risks for the disease and enhance the feeling that ‘breast cancer concerns us all’. In this context, individual women’s choices and practices are projected as national attributes in a country where the dissemination and widespread use of new medical technologies has served to symbolise an advanced state, the modernisation of society and its citizens’ participation in a globalised order (Trakas, 2007; Georges, 2008). However, this rationality is rendered against the public health system’s own shortcomings and inequities (geographic and socio-economic). Seeking care, women are faced with the expansion of the private sector and challenges within the public health system of providing accessible and quality services for breast care for all. As there is no structured national population screening programme for breast cancer, this affects mainly populations in the periphery who often have to rely on occasional interventions or initiatives by medical associations, religious groups or charities.

The particularities of the establishment of BRCA-related technologies, largely dependent on individual or institutional initiatives and opportunities for the profit sector, have contributed to shaping clinical practices (Löwy and Gaudillière, 2008) and creating inclusions and exclusions of certain types of consumers or populations (as discussed by Mozersky and Joseph, this issue). Currently, BRCA genetic services are provided in research centres or departments (not exclusive to breast cancer) of a few leading public and private hospitals, concentrated in the dense urban spaces of the country. The standardisation of practices and services offered (genetic counselling, genetic testing, prophylactic surgeries) in this field of medical care is also variable, depending on material and human resources as well as funding sources, especially as there is as yet no officially agreed national practice and quality control guidelines. These services connect to genetic labs (in Greece and abroad) and offer genetic testing either at a (highly variable) private cost or through the funding schemes of international projects and occasional donations from medical associations for research purposes. It has only recently been possible to (partially) cover these costs through social insurance (mainly provisions for the higher status occupational sectors); this involves a doctor making the case for the ‘clinical need’ for genetic testing, either for preventive or therapeutic purposes.

Within this uneven terrain, of particular focus is the prevention centre for breast and cervical cancer, in Northern Greece, organised by an Orthodox Christian Convent in the spirit of religious philanthropy.⁷ Services provided include mammography screening, clinical examination and hereditary breast cancer detection through an assessment of family history,

⁷See Kampriani (2009) for a discussion of the interfaces between religious philanthropy and breast cancer genetics in Greece, with reference to institutional practices and the social dynamics within which they are embedded.

in collaboration with health practitioners, medical scientists and geneticists, all offered free of charge to healthy or non-diagnosed women.⁸ Positioned in the periphery of the rigid public health structures, the centre reaches out to women and local communities providing medical care, psychosocial support and at times spiritual guidance. This religious institution assumes responsibility to mobilise women in rural and semi-urban areas (populations facing health inequities and who are categorised as ‘traditional’ in public health literature) and introduce them to the norms and practices of health awareness. At the same time, religious intervention in the application of secular tests, as other studies have also shown, is responsive to the ‘social truths’ of collective risk management and people’s perceptions of risk that relate to culturally embedded values and anxieties (Prainsack and Siegal, 2006).

This case study reflects on narratives of women with a family history of breast cancer attending the religious prevention centre’s screening programme and others following different paths to biomedical departments. Among women interviewed, notions of disease risk that draw on the biological makeup of the individual/family body and embodied or affective states were vividly described. Women referred to predisposition to the disease (*prodiathesi*) as rooted in the family history, connected to notions of nature (*einai sti fysi mas*), genes (*einai sta gonidia mas*) and heredity (*einai klironomiko*). These articulations emphasise the biosocial aspects of inherited risk, which can be related to experiences of the disease in the family, cultural understandings of kinship and inherited traits and also ways of individual engagement with risk as inherently linked with social relations (Malaby, 2002). Thus, embodied risk appears as a key factor which supplements or underlies other causes (such as diet, smoking, and so on) that contribute to the onset of the disease and may overshadow factors such as environmental pollution or excessive/unprotected use of chemicals for agricultural purposes. In fact, such forms of external risk at times seem to be ‘naturalised’ in the name of social progress, as agrarian populations in rural areas engage with modern technologies of agriculture, suffering in effect high rates of cancer affliction (Karakasidou, 2008).

The following discussion traces the ways individuals and institutions engage with facets of inherited risk and genetics and articulate ‘neoliberal’ ideologies or perform different positions. Medical and scientific efforts to educate the public on the disease risk and factors often also draw on the global imaginaries of genetics. In public health conferences, seminars and popular magazines, notions of empowerment are utilised in phrases like ‘knowledge is power and hope’ and ‘genetic testing can help us save lives’. Women’s and patients’ organisations, on the other hand, contribute to the discourse on the value of health awareness, for the individual, the family and the female population at large. Their efforts concentrate mainly on the suffering cancer patients. Activist groups, such as the first initiative on advocating cancer patient rights, prioritise care and welfare provisions to the afflicted. The issue of predictive knowledge, when raised, is mainly related to possible ‘benefits’ for patients with breast cancer and future hopes of therapeutic genetics.

⁸Screening programmes implemented by the centre follow the guidelines of the European and international funding projects. The programme on hereditary breast cancer detection, in particular, was initiated as the first stage of a broader project aiming to provide BRCA genetic testing free of charge to women identified as high-risk, in its full implementation.

The divergent focus of interest in these discourses, promoting biological notions of *heredity* and the promise of control, against the social demand for *care* create an uneven and ambivalent space within which technologies of risk management are introduced and articulated. The religious centre, on the other hand, frames its activities as a 'moral obligation' and social contribution motivated by notions of humanism and *protection* of the population. In this context, one can observe a plurality of responses to predictive knowledge and practices related to control of breast cancer. A common thread is the inherent ambiguity in the use of the concept of 'high-risk' and women's negotiations between proposed notions of informed action and demands for different kinds of protections.

Despite the fact that a community of geneticists is building up, the initial assessment of inherited breast cancer risk is made mostly by gynaecologists, upon a woman's regular clinical examination, or by oncologists, usually on the occasion of a relative's affliction with the disease. In these clinical interactions, women reporting family history of the disease are often directly positioned within a generalised high-risk category. From the doctors' perspective, this attitude is part of what they consider as 'our social obligation to mobilise women to go for screening', as a gynaecologist explained. Through this harsh attribution, notions of fear and danger come to be invested in the promise of control, for women's own good. However, women do not directly become what Finkler (2000) has termed 'perpetual patients'; that is when being confronted with their family history they 'change their persona from healthy to sick' (p. 197), despite the fact that they are healthy. Instead, it is exactly this identification that many women may actively try to avoid.

A lot of women described an uneasy confrontation with a medically defined risk category and prescriptions for risk management, while being the informal caregivers for close family members with the disease and decision-makers for their treatment. Ioannidou and Galanakis (2008) have suggested the limits of individual autonomy in relation to a revised code of medical deontology on the disclosure of cancer diagnosis. They show how in Greece the decision-making unit is not the patient alone but the family, which participates as a third key-actor in the clinical encounter, mediating between the doctor and the patient.

In the following interview quotes, these women describe how, in such clinical encounters, they were confronted with the medical category and passed from a state of caring for others to caring for oneself. As pointed out in other studies (Hallowell, 1999, 2006), the inter-subjective and relational aspects of risk and suffering of the disease come to frame women's responses in ways that do not necessarily fit into the model of rational calculation or management of risk. Here, the concept of inherited risk seems also to become the grounds for re-articulation of gendered moral codes. This requires women to reconcile social expectations for their caring role and individual fulfilment, as part of their 'gender proficiency' (Paxson, 2004).

The doctor told us, me and my sister, we are in a high-risk group now with my mother's case and we have to do mammography every year. And you follow that, I mean, for your own health. You leave yourself to the doctor's hands to take care of the problem, to a certain degree, and do what he tells you, and turn to religion for support and relief, then you can say ok, I can handle this.

You will do what your doctor says and you do it either because of ignorance or fear of taking responsibility, because he knows, you cannot judge what science says, you only do it because you have to, you do what's for humans, and then it's God.

Ethnographic accounts of experiences of cancer suggest that the Greeks do not usually become 'proactive' or expert patients, partly because medicine retains its 'authority over the biological body' (Karakasidou, 2007, p. 59). In a similar vein, Seremetakis (2001) has argued that increasing medicalisation is characterised by a concern with bodily deficits whereas the theological perspective serves to inform the moral-symbolic aspects of embodiment. The coexistence of medical and religious rationalities in health care and public responses to biotechnologies is a common reality in this context. In Greece, negotiating between medical categories of risk or failure of the biological potential, and religious notions of nature and divine power helps shape the experiences of consumers of new reproductive technologies (Paxson, 2006); a situation which is reflected in other countries where religion retains significant social power (Bharadwaj, 2006).

Following doctors' advice and reaching out to religious values of relational identification and protection can be seen as a strategic management of the ambiguities or danger of being at-risk, against the possibilities for informed action. As McMullin and Weiner (2008) have suggested, once people are exposed to 'neoliberal' orders that promote informed individual responsibility, the supporting social or structural elements to perform such norms may be lacking. In this context, aspects of health awareness are addressed in relation to monitoring one's health and going for mammography screening, phrased by some in terms of 'a woman's duties' for self-care and attending to medical prescriptions. For others, their difficulty or uneasiness with attending to their health does not always refer to lack of knowledge or information on health. Rather it is lack of support within the health system's structures and the emotional difficulties of performing the proposed health orders or bodily practices that come to matter. As one woman put it,

It is not that we don't know nowadays. You know there is heredity and the doctors tell you what you have to do, ok you choose to do it or not, but it would have been much easier if you had support through that, different kinds of help, you know, being close to you, so that you feel stronger and say now I can face that and take care of myself. [...] I mean if I want, I will find a way to go to a specialist doctor and then manage through all these, won't I? But you don't want to be alone in this.

Against these concerns, practices of health promotion and risk management vary. Among the 'underserved' women in Northern Greece, genetic testing is largely not pursued and for some not even considered an option, especially from the standpoint of 'healthy' women. It is not that there is no desire to know about one's genetic risk or embrace this kind of technology. On the contrary, they are willing to follow the opportunities of genetic medicine, especially if 'offered' by a trusted institution, but are concerned with having to become active consumers of an uneasy knowledge that does not provide any reassurance for their health or social well-being.

Other women express a desire for information and access to health services or specialised counselling/care: in these cases being informed and proactive means going to private

(preferably) doctors' offices and receiving quality care. A woman, confronted with her mother's and first cousin's experiences of breast cancer at more or less the same age as hers, describes how she chose a private oncologist specialising in breast care, in Athens. Following her active quest for information she was faced with the doctor's suggestion that she may have genetic testing for BRCA mutations. However thinking of the possibility of getting a positive test result, she felt quite disempowered, as she said,

If then he decides I should have a prophylactic mastectomy, what will I do? I don't feel ready for something like that, I cannot do that, we are discussing it with my husband, it is not even a matter of our own decision.

For her and other women who voiced similar concerns in this ethnographic context, engaging with new health practices associated with breast cancer genetics does not automatically render them autonomous individualised consumers of biomedicine (Kampriani, 2009). Instead, their fluctuation between aspects of health awareness and a reluctance or inability to fully embrace risk assessment technologies or individualised interventions reflects how notions of informed patienthood and individual responsibility are negotiated or compromised through the agency of their appropriation (Butler, 1993). In this sense, such ambivalence may also be seen as a way of exercising choice or be itself one possible expression of an 'enterprising self', in certain contexts.

The Greek arena of preventive and predictive technologies related to breast cancer can be seen as one where, in Derrida's reading, the dynamics of different iterating forms engender multiple possibilities of meaning and engagements. It is possible to see how globalising discourses and practices mobilise different institutional actors and rationalities that come to embrace aspects of modern science and biotechnology, in situated contexts (see also Wahlberg, 2009). In this ethnographic case, the cultural context of breast cancer preventive and genetic medicine is shaped by diverse values and practices of medical paternalism, collective management of risk and modern bioethics. Here scientific and social knowledges are articulated through narratives of heredity, care and protection, which inform health discourses and women's perceptions of embodied risk. This conjoins the biological and social or affective dimensions and produces certain multi-layered trajectories. In the Greek context these speak both of the individual body and the collective and allow for a variety of engagements in the field of BRCA medicine, among and within different populations.

BRCA Discourses in a 'Neoliberalised' Health System and Diverging Patient Subjectivities in Germany

In Germany, BRCA diagnostics have become part of institutional health care practices since 1997. The 'German Consortium for Hereditary Breast and Ovarian Cancer' established 12 specialised centres for familial breast and ovarian cancer located at public clinics distributed all over Germany, which like other countries in Europe and North America, offer genetic testing in combination with genetic and gynaecological consultation and follow-up measures for the so-called 'high-risk families'. In the beginning, the costs were paid in the context of a multi-centre clinical trial financed by the German Cancer Aid. Approximately 2500 families were tested. Since 2005, testing and follow-up have become part of regular health care

covered by statutory insurance, encouraging women considered to be ‘at risk’, because of their family history, to take part in the programme.

This discussion, drawing on ethnographic fieldwork in some of these specialised BRCA centres in Western Germany,⁹ first describes the discursive and institutional practices that informed the development of BRCA medicine in Germany before concentrating on the narratives of women who have undergone BRCA genetic testing. This article illustrates how despite the German BRCA health discourse following globalising ‘neoliberal’ rhetorics, individual patients may in their rearticulations only partially reproduce or even subvert these dominant norms.¹⁰

Women contact one of the 12 specialised German breast cancer centres through their own initiative or through referral by their gynaecologist.¹¹ If they meet the high-risk criteria, they will be invited to three consultations: a gynaecological, a psychological and a genetic consultation. The genetic and gynaecological counselling sessions inform women about the genetics of cancer in general and the BRCA genes in particular, explaining the possibility of further interventions in case the result is positive. These options range from intensified screening (basically mammography and ultrasound, in some cases also magnetic resonance imaging), to taking part in other clinical trials with hormonal therapy (for example, Tamoxifen), to prophylactic surgeries, including the removal of healthy breasts and ovaries. Additionally, general lifestyle advice thought to be protective against cancer is given to those attending the centres. This includes advice such as ‘eat five portions of fruit and vegetables every day’, ‘do modest sports and avoid smoking’, and above all ‘try to maintain the joy of life’.¹² The counselling sessions stress that because all the options have (sometimes extensive) side effects and none of the options will completely remove the risk, the woman herself has to make the choice which is right for *her*: not just regarding her decision to take a test, but also concerning any follow-up measures, which may or may not be linked to taking a test.¹³

In relation to the discursive practices of the Consortium, it is possible to identify what might be seen as a ‘neoliberal’ health promotion discourse that emphasises the proactive, responsible individual. Women are encouraged to become active patient-subjects, to inform themselves, to find out about their so-called risk-status and to get involved in practices of risk management, of which genetic testing is just one that may be followed by others. Moreover, they are encouraged to take responsibility for these choices; the importance of the

⁹Research was funded by the DFG post-graduate college ‘Technology and Society’ and conducted by Andrea zur Nieden. The study included analysis of medical publications and guidelines, hand-outs of the German Consortium, genetic counselling sessions and also in-depth interviews with genetic counsellors and other staff as well as with women who had undergone genetic testing (see zur Nieden, 2008). Latter interviews were held at least one year after women received the test result. Women had different test results: positive (mutation was found), negative (mutation was found in the family, but they were non-carriers) or inconclusive results. None of the women had cancer themselves.

¹⁰Some of these research results have already been discussed elsewhere with a different focus (zur Nieden, 2009, 2010).

¹¹In Germany, annual gynaecological check-ups are recommended to all women, with gynaecologists being the specialists for specific ‘female’ health problems and questions of female sexuality and reproduction. This form of gendered medicine and health service in which the male appears as the norm model and the female as the deviation that needs additional treatment has only recently been supplemented by the discipline of ‘andrology’ (Wöllmann, 2007), and services of urology for men are still far from being routine.

¹²For a more detailed evaluation of the informative material and account of the counselling sessions, see zur Nieden (2005, 2007).

¹³The payment for follow-up measures like intensified screening are always a means of negotiation if women from ‘high-risk-families’ decide not to take a test.

‘woman’s own decision’ is emphasised many times during the counselling sessions and informative material given to the patient. Nevertheless, more paternalistic medical practices can also be identified. For example, psychological consultation aims to empower women to make a choice by imagining the possible consequences of the test and, at the same time, assesses their psychological competence to see if testing may be contraindicated because of particular psychological problems. Another example is the fact that women who do not regularly participate in follow-up measures are excluded from the programme, pointing to aspects of disciplinary power and pressure at work in the institutionalised BRCA services (Palfner, 2009). Yet, these practices co-exist with an overwhelming rhetoric of ‘non-directiveness’ and an emphasis on ‘personal choice’. Consequently, it is not surprising to find that the risk-factors for breast cancer addressed in the counselling sessions are factors that can be individualised, such as genetic or life-style factors, rather than environmental factors (for example, pollution or dangerous substances in workplaces).

These social practices and discourses reflect a process of generating ‘a responsible self’ which is in line with a ‘neoliberal’ transformation of the German health system. Traditionally, Germany had a system of statutory health insurance mandatory for all employees, students and unemployed and covering the greatest part of costs for health. During the ‘Health Reform’ of the last decades aiming at cutting health expenses, this system was de-regulated in several respects. It is now possible to choose between statutory and private insurance companies whose rates vary in relation to age, sex, state of health, participation in preventive measures and so on. The latter also have the power to deny health insurance to some people. Some of these initiatives have been taken up in the provision of statutory insurances such as the chance to get reduced rates or bonuses for ‘proactive’ behaviour such as taking part in programmes of ‘early detection’ for cancer or joining a fitness centre. Also many costs that were previously paid by insurance now must be covered by patients. The whole reform process was accompanied by a discourse that stressed the responsibility of the patient for his or her own health of which the prevention or early detection of breast cancer is just one illustration.

However, in examining interviews with Western German women, patient subjectivities do not automatically perform this ‘neoliberal’ discourse of personal responsibility and health activism. In fact, all women interviewed *did* feel responsible to inform themselves drawing on different sources and they *did* have a genetic test. They also got engaged in different practices of risk management that seemed personally appropriate to them, such as intensive screening, prophylactic surgeries of breast or ovaries or paying attention to diet and lifestyle, which also involved ‘positive thinking’. But only one part of the sample described themselves in terms that suggested they were ‘free, enterprising’ subjects, ‘calculating their choices’, becoming ‘lay experts’ and/or active partners of the doctors, as Novas and Rose (2000) described in their study (see also Robertson, 2000). In the following discussion this first type of patient is described as an ‘informed risk-manager’. The second type of patient emerging from the data appears to relate to what is characterised here as a ‘care-seeking client’. In this second case, agency during the process of testing and treatment is narrated through the activities of doctors, and patient’s self-responsibility is less important and sometimes even rejected.¹⁴

Similar to women observed in other studies (for example, Foster *et al* (2002), Hopwood (2005), for quantitative studies; Hallowell (1999); Robertson (2000); Scott *et al* (2005); Gibbon (2007), for qualitative studies) the ‘informed risk-managers’ are very alarmed before the test and have extensive cancer worries because they see the cancer cases in their family as being connected to genetic factors. The discourse on genetically informed prevention is so self-evident to them that they perceive themselves as at-risk persons already and act as active decision-makers, informing themselves and calculating the costs and benefits of the knowledge being provided as well as the different options. The risk figures given to them in the clinic about the chance of developing cancer make sense to them and serve as a rule for making decisions, as may be seen in the following quote:

I would recommend everybody who belongs to the risk population, to take the test, (...) simply because I appreciate *knowing* about the things that are inside of me, and if there is a risk inside of me, then I am really the first person who should know about this, so that I can deal with it, no matter *how* I deal with it. Well, basically it is *my* problem how I deal with such a matter, (...) And I think the risk *not* to know and to be unnecessarily anxious is so high.¹⁵

Genetic risk is obviously perceived by this woman as something you can deal with and calculate; she can even weigh the costs and benefits of the test against the emotional risk *not* to know. It is also striking how she represents herself as the responsible subject for whom it is important to know and to act.

A similar strong sense of agency and empowerment through predictive risk figures can be found in the following quote where a woman discussed the possibility of having prophylactic breast surgery (mastectomy) in the event of her having a positive result:

Because if I know I have a risk of maximum eighty percent, that is really high; then it doesn't make sense to have a check-up every three months. It makes much more sense if I take a really serious step.

This group of patients also appear very self-confident in their relationship to doctors; they actively ask for information and often decide against recommendations.

In the narratives of the second group, women typified as ‘care-seeking clients’, patients do not appear as active subjects informing themselves and then *deciding* what to do. When being asked how it came about that they had a genetic test, they would say for example, ‘that was completely by chance’ or ‘I didn't think much about it’ or describe only what the doctors suggested without talking about their own actions. Getting in touch with the clinic seems more like an automatic process than a conscious decision. Most frequently women are informed about the test when visiting a near relative with cancer in hospital. The exact motives for the test remain unclear in their accounts and the decisions for the genetic test or for measures of risk management are not always narrated as such. Instead of an ideal process

¹⁴The described types emerged from the data through a grounded theory process of analysing and comparing the individual cases along certain dimensions such as ‘relationship to doctors’ and so on, as suggested by Kelle and Kluge (1999). The types can be seen as empirical and not ‘ideal’ types, as all interviewed women fell into these categories, although there were certainly many individual nuances.

¹⁵All interview quotes are translated by the author from the German original.

of will, plan and action, the agency of these women is often indirect, as they delegate it to the doctors who thus appear to be the only persons acting in the process. The concept of 'informed decision-making' seems to be too simple a description for what is taking place in this context. Instead of a clear decision based on sound information, other forms of agency are involved which cannot merely be seen in terms of passivity. Although the doctors act, women at least decide to either follow their recommendations or not attend the clinic when they do not trust the doctors. Unlike in the classic paternalistic authority relationship, these patients insist on being taken seriously as a *person*; doctors who treat people 'only as a number' are criticised. These women do not see themselves as well-informed patients or lay experts having an equal partnership with the medical expert like the first type of patients, but seek a 'good doctor' that they can trust. A central topic is 'being in good hands'. A notion similar to a desire to be 'monitored' or 'cared for', as in the mentioned British studies mentioned by Gibbon (2007) and Scott *et al* (2005) is apparent, here accompanied by the desire to know a doctor personally and a rejection of the anonymous atmosphere in some of the breast cancer centres.

In a similar way, one woman explicitly rejects the position of being an informed decision-maker, narrating an anecdote where she was told about some changes found in her breast radiographs (X-rays):

Then, you see, I ask a *doctor*, I *am* not a doctor myself: 'so, what do you recommend' or 'what shall I do now', and then he tells me: 'in my eight-month experience, women mostly react by doing this or that'. And then I looked at him, and I said, 'ok, (...) I go back to my gynaecologist'.

In this case clearly the doctor's statement referring to a percentage of actions taken by others and leaving the decision to her, makes no sense to her, and she relies on her trusted gynaecologist's advice. The call to be a self-determined subject of one's health is partially rejected, transformed into the *choice of the right doctor*, who then must, from the point of view of this type of patient, make decisions.

This discussion has illustrated how a 'neoliberal' subjectivity as evoked in the German discourse on health prevention is not performed by all patients. There seem to be differences in the extent to which people perceive themselves as 'enterprising subjects' (Novas and Rose, 2000). This may be related to the ambivalent practices of the German medical system itself that point to the persistence of disciplinary aspects in interplay with new technologies of the self (see also Raman and Tutton, 2010). It could be assumed that the shifts in the German health system are not yet but soon will be incorporated by everybody, interpreting the first type as 'already neoliberalised', and the second type as a residue of 'soon-to-be outdated patient-doctor-paternalism'. Gender perceptions could also explain the way that 'care-seeking clients' rather recount actions of doctors than planned and calculated decisions in the process of testing and follow-up measures: it is a classical pattern of female biographical narration to present events in their life as 'happening to them' rather than as an outcome of their own decisions. A reason that is often suggested for the presented differences *within* gender or national contexts is class or education, with an assumption that more educated women feel more responsible for health prevention practices. This is not confirmed by the data analysed here: for example, in the group of 'informed risk-managers'

there were working-class women with low education from a rural area.¹⁶ Besides these possible cultural and social contexts involved in the making of BRCA patient subjectivities in Germany, the observed diverging re-articulatory practices may also point to the necessary *failure* every performance entails (Butler, 1993).

This is more obvious in the case of the care-seeking clients who, far from being able to transgress discourses or ‘interpellations’ (Butler, 1997) of personal responsibility for health, articulate the perceived impossibility to control cancer, as this comment illustrates:

Well, I have that *gene*, it is true, but what is it that happens in order that the gene becomes *cancer*?

It seems in this case that the gene mutation is not perceived as a calculable risk, but as an unpredictable danger (Luhmann, 1990), and a direct connection between knowledge and actions cannot be drawn. Nevertheless similar to some women in other studies (Robertson, 2000; Finkler, 2003), this group of women still feels obliged to ‘do something’ about their health or feel guilty if they do not act, and address their sense of being responsible for the supposed consequences of their behaviour, although they cannot solely trace them back to themselves. There is however also ambivalence about the notion of control evident in the women described as ‘informed risk-managers’. In the subtext of some narratives it becomes obvious that they are very preoccupied with thoughts of cancer and not totally relieved after a negative test result. Even in this case it seems that the fear of cancer, the fear of suffering, of illness and death cannot totally be rationalised and integrated into a simple assessment and management of risk.¹⁷

Conclusion

The three case studies presented in this article critically address the extent to which the global expansion of genomics and specifically the translation of BRCA genetics in different medical arenas necessarily or always entails the identical reproduction of ‘neoliberal’ subjects.

Starting in what would seem to be an obviously ‘other’ cultural arena to a ‘neoliberal’ norm, Sahra Gibbon’s case study explores the tensions inherent in the shifting relationship between the state and publics in Cuba as fledgling attempts are made to incorporate predictive medicine linked to breast cancer as part of the state public health provision of ‘community genetics’. She shows how patient subjectivity in this context is not generally articulated through idioms of individual health activism, responsibility and awareness; a situation which reflects the institutional culture of public health in Cuba while also posing significant challenges to the translation of BRCA genetics in this context. Yet ‘neoliberal’ patienthood is not entirely absent and emerges in the interstices of collective state rationalities and shifting political dynamics within and beyond Cuba. In sum, the space of predictive medicine seemingly being constituted here is neither clear-cut nor static but in fact evolving in ways that situate Cuba within rather than outside global social processes.

¹⁶Certainly, because of the qualitative approach and small number of interviews it is not possible to draw significant correlations between social variables and outcome.

¹⁷For more elaboration on this point, see zur Nieden (2010).

Eirini Kampriani's contribution explores the cultural shaping of biosocial subjectivities around developments associated with breast cancer prevention and predictive genetics in Greece. Drawing on the meeting point between religious philanthropy and individualised medicine against state attempts to meet the social demand for breast cancer control, she shows the inherent 'partiality' of 'neoliberal' forms and practices related to inherited risk. As different institutional and social actors intervene in the establishment of breast cancer genetics and the articulation of discourses on health awareness and risk management, they create an uneven field, informed by diverse values and intentions.

Andrea zur Nieden's case study reconstructs the discrepancies between interpellations of health activism present in the German discourse on predictive medicine and actual subjectivities of women. She refers to two types of patients differing in how they deal with genetic information, drawing on narrative interviews of women who took the genetic test. Against the background of a discursive model that propagates proactive behaviour and personal responsibility for one's health, connected to the ideal of 'informed decision-making', she shows how even in a European, supposedly 'neoliberalised' country and health system like Germany, there are re-articulations of patient subjectivities that cannot be described in terms of 'enterprising subjects'.

In the German context as well as in the Greek and Cuban cultural arenas, we can see that there are many nuances between proactive responsible patienthood and patient sanctioned desire for or expectations of paternalistic authority over the body, linked to the cultural practices of different medical institutions and public health practices. The differences in these dynamics partly reflect the variability of the relationship between different publics and/or patients, doctors and medical institutions. Forms of indirect agency that delegate responsibility to doctors, as found in the 'care-seeking client' type described for Germany, are linked to a long-standing system of state organised health care as it partly still exists in Germany. This has also been identified by others in the United Kingdom as influential in configuring the social and cultural context of BRCA genetics (Parathsarthy, 2007; Gibbon, 2007). In these two contexts it seems that 'neoliberal' practices which speak to the rationalisation of health care services and which require 'informed risk-managers', evolve alongside and do not totally remove the desire 'to be cared for' or the expressed need to 'be in good hands'. In Greece, the introduction of breast cancer genetics is challenged by the difficulties the public health system confronts in facilitating the practices of 'personalised' medicine and providing equal access to the population. The co-existence of facets of medical paternalism, collective management of risk and illness and modern bioethics inform the shaping of BRCA-related discourses and practices and the expressions of patient subjectivity in crucial ways. In this case, the globalising ideals of autonomous individuality are crafted on concepts of heredity, embodied relationality and notions of care. For Greek women with a family history of breast cancer, confrontation with the ideals of 'modern', informed and active patienthood leads to a sense of ambivalence, resulting in forms of patient engagement that entail reaching a sometimes uneasy compromise among different possibilities. Patienthood in Cuba, as this relates to a discourse of risk linked to breast cancer while also reflecting expectations related to state provision of health services, seems to be rooted in a very particular set of social and historical dynamics. Here, for the majority, the value of disease prevention is not the sole responsibility of the individual or strongly linked to a

moral discourse about health activism. Yet there are subtle shifts happening around what constitutes preventative health care for oneself and others in certain regions of the country, as the discussion of 'stress' in this context also illustrates. While Cuba would seem initially to constitute a clear-cut 'zone of exception' to expanding 'neoliberal' ideology, efforts to incorporate BRCA genetics into a broader programme of Cuban Community Genetics suggest that such developments and state, professional and public responses constitute a highly mutable arena that is neither uniform nor static.

Together, the ethnographic sections in this article support the need to examine the social and cultural dynamics of BRCA genetics and patient subjectivity and identity in situated contexts. This requires due attention to local biopolitics, structural factors, social norms and embodied daily practices that shape these developments, and to problematise what is assumed to be a necessarily 'programmatic' emergence of 'neoliberal' formations (Reynolds Whyte, 2009). Drawing on the work of feminist and deconstructive analysis, we have argued that tracing the 'partial reproduction' of forms of genetic individuality and patienthood related to inherited risk entails exploring genetic medicine and 'neoliberal' rationalities as products of trans-national dynamics and global social processes. At the same time, such forms are by no means mimetically practiced. Rather, they are only ever the outcomes of, while also themselves producing, in Derrida's sense, *différance*. In other words, diverse 'neoliberal' identities may express or conform to particular political rationalities, medical discourses, social conditions, moral and gendered codes, yet also problematise or subvert these in the necessary 'failure' (Butler, 1993) to reproduce identical subject positions. The case studies presented suggest that responses to BRCA knowledge-practices may be seen as revealing both a desire for and the impossibility of exactly reproducing globalising ideals in specific cultural contexts. In using ethnographic approaches that seek to constitute and reflect 'partial connections' (Strathern, 2004), this article highlights the impossibility of any examination that rests on an inevitable, hegemonic or uniform spread of 'neoliberal' ideology. Rather we hope we have illustrated how making visible the paradoxes and sociocultural complexities within and among different national contexts becomes vital to the task at hand.

Acknowledgements

We are grateful for the insightful comments on earlier versions of this article from Galen Joseph, Ute Kalender, Jessica Mozersky and Sonja Palfner, as well as the anonymous reviewers who provided helpful critique and constructive commentary.

About the Authors

Sahra Gibbon is a Wellcome Trust University Award Research Fellow in the Anthropology Department at UCL in London. She has carried out research in the United Kingdom and Cuba examining the social and cultural context of developments surrounding the knowledge and technologies associated with the BRCA genes. She is currently completing research in Brazil examining the relationship between ancestry, identity and breast cancer genetics.

Eirini Kampriani has studied social and medical anthropology in Greece and the United Kingdom, in the Department of Anthropology at UCL MSc, PhD. Her ethnographic

research, funded by the Wenner-Gren Foundation for Anthropological Research, explores the cultural context of inherited breast cancer risk in Greece. She has also conducted research and teaching in public health.

Andrea zur Nieden is a research assistant at the Institute for the History of Medicine, Heinrich-Heine-University, Düsseldorf, Germany and currently interested in issues of race and genetics and post-war history of psychiatry. Funded by the DFG Post-Graduate College 'Technology and Society', TU Darmstadt, she has carried out ethnographic fieldwork in German BRCA centres and completed her PhD in sociology focusing on subjectivities in the context of geneticisation of breast cancer.

References

- d'Agincourt-Canning L. Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics*. 2001; 15:231–247. [PubMed: 11700677]
- Andaya E. The gift of health: Socialist medical practice and shifting material and moral economies in post-soviet Cuba. *Medical Anthropology Quarterly*. 2009; 23:357–374. [PubMed: 20092049]
- Bharadwaj A. Sacred conceptions: Clinical theodicies, uncertain science and technologies of procreation in India. *Culture Medicine and Psychiatry Special Issue: Sacred Conceptions: Religion and the Global Practice of IVF*. 2006; 30:451–465.
- Brotherton S. Macroeconomic change and the biopolitics of health. *Journal of Latin American Anthropology*. 2005; 10:339–369.
- Brotherton S. We have to think like capitalists but continue being socialists: Medicalised subjectivities, emergent capital and socialist entrepreneurs in post-soviet Cuba. *American Ethnologist*. 2008; 35:259–274.
- Butler, J. *Bodies that Matter: On the Discursive Limits of 'Sex'*. New York, London: Routledge; 1993.
- Butler, J. *The Psychic Life of Power: Theories in Subjection*. Stanford, CA: Stanford University Press; 1997.
- Butler, J. *Gender Trouble*. New York and London: Routledge; 1999 [1990].
- Derrida, J. *Margins of Philosophy*. Bass, A, translator Chicago, IL: University of Chicago Press; 1982 [1968].
- Derrida, J. *Rogues: Two Essays on Reason*. Brault, PA, Naas, M, translators Stanford, CA: Stanford University Press; 2005 [2003].
- Eckstein, S. *Back From the Future: Cuba under Castro*. Princeton, NJ: Princeton University Press; 1994.
- Feinsilver, J. *Healing the Masses: Cuban Politics at Home and Abroad*. Berkeley, CA: University of California Press; 1993.
- Finkler, K. *Experiencing the New Genetics: Family and Kinship on the Medical Frontier*. Philadelphia, PA: University of Pennsylvania Press; 2000.
- Finkler K. Illusions of controlling the future: Risk and genetic inheritance. *Anthropology & Medicine*. 2003; 10:52–70.
- Foster CG, et al. Predictive testing for BRCA1/2: Attributes, risk perception and management in a multi-centre clinical cohort. *British Journal of Cancer*. 2002; 86:1209–1216. [PubMed: 11953874]
- Franklin, S, Roberts, C. *Born and Made: An Ethnography of Preimplantation Diagnosis*. Princeton: Princeton University Press; 2006.
- Gammeltoft T. Prenatal diagnosis in postwar Vietnam: Power, subjectivity, and citizenship. *American Anthropologist*. 2007; 109:153–163.
- Gammeltoft T. Sonography and sociality: Obstetrical ultrasound imaging in urban Vietnam. *Medical Anthropology Quarterly*. 2008; 21:133–153.
- Georges, E. *Bodies of Knowledge: The Medicalization of Reproduction in Greece*. Nashville, TN: Vanderbilt University Press; 2008.

- Gibbon, S. *Breast Cancer Genes and the Gendering of Knowledge: Science and Citizenship in the Cultural Context of the 'New' Genetics*. London: Palgrave Macmillan; 2007.
- Gibbon S. Genomics as public health? Community genetics and the challenge of personalised medicine in Cuba. *Anthropology and Medicine Special Issue: Biomedical Technology and Health Inequities in the Global North and South*. 2009; 16:131–147.
- Gibbon S. La herencia, family medicine and the (dis)continuities of genomics as revolutionary health care. *Social Science and Medicine*. 2011
- Gibbon, S, Novas, C, editors. *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*. London: Routledge; 2008.
- Gottweis H. Biopolitics in Asia. *New Genetics and Society*. 2009; 28:201–204.
- Greenhalgh S. The Chinese biopolitical: Facing the 20th century. *New Genetics and Society*. 2009; 28:223–229.
- Hallowell N. Doing the right thing: Genetic risk and responsibility. *Sociology of Health & Illness*. 1999; 21:597–621.
- Hallowell N. Varieties of suffering: Living with the risk of ovarian cancer. *Health Risk & Society*. 2006; 8:9–26.
- Hopwood P. Psychosocial aspects of risk communication and mutation testing in familial breast-ovarian cancer. *Current Opinion in Oncology*. 2005; 17:340–344. [PubMed: 15933464]
- Ioannidou E, Galanakis E. O prosfatos kodikas iatrikis deontologias, i enimerosi tou asthenous me kakoi theia ke i emploki tis ellinikis oikogeneias [The recent code of medical deontology, the cancer patient informing process and the involvement of the Greek family]. *Archives of Hellenic Medicine*. 2008; 25:224–230.
- Jasanoff, S. *States of Knowledge: Science and the Co-production of the Social Order*. London: Routledge; 2006.
- Kampriani E. Between religious philanthropy and individualized medicine: Situating inherited breast cancer in Greece. *Biomedical Technology and Health Inequities in the Global North and South, Anthropology & Medicine Special Issue*. 2009; 16:165–178.
- Karakasidou A. I viopolitiki tou karkinou: empeiria, metaforikes ennoies kai i exousia tis exeidikevmenis gnosis [The biopolitics of cancer: Experience, social metaphor and authoritative knowledge]. *Archaologia & Technes*. 2007; 105:55–62.
- Karakasidou, A. The elusive subversion of order: Cancer in modern Crete, Greece. *Confronting Cancer: Metaphors, Advocacy and Anthropology*. McMullin, J, Weiner, D, editors. Santa Fe, NM: School for Advanced Research Press; 2008. 83–102.
- Kelle, U, Kluge, S. Vom Einzelfall zum Typus [From Case to Type]. Opladen, Germany: Leske & Budrich; 1999. (in German)
- Kerr A. Rights and responsibilities in the new genetics era. *Critical Social Policy*. 2003; 23:208–226.
- Klawiter, M. *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*. Minneapolis, London: University of Minnesota Press; 2008.
- Konrad, M. *Narrating the New Predictive Genetics: Ethics, Ethnography and Science*. Cambridge: Cambridge University Press, UK; 2005.
- Lemke, T. *Die Regierung der Risiken: Von der Eugenik zur genetischen Gouvernementalität*. [The government of risks: From eugenics to genetic governmentality] *Gouvernementalität der Gegenwart Studien zur Ökonomisierung des Sozialen*. Bröckling, U, Lemke, T, Krassmann, S, editors. Frankfurt am Main, Germany: Suhrkamp; 2000. 227–264. (in German)
- Lock, M, Young, A, Cambrosio, A. *New Medical Technologies: Intersections of Inquiry*. Cambridge: Cambridge University Press, UK; 2000.
- Löwy I, Gaudillière JP. Localizing the global: Testing for hereditary risks of breast cancer. *Science, Technology & Human Values*. 2008; 33:299–325.
- Lupton, D. *Food, the Body and the Self*. London: Sage Publications; 1996.
- Luhmann, N. *Risiko und Gefahr [Risk and danger] Aufsätze zur Theorie der Gesellschaft*. Luhmann, N, editor. Opladen, Germany: Westdeutscher Verlag; 1990. 126–162. (in German)
- Malaby, ThM. Odds and ends: Risk, mortality and the politics of contingency. *Culture Medicine & Psychiatry*. 2002; 26:283–312.

- McMullin, J, Weiner, D, editors. *Confronting Cancer: Metaphors, Advocacy and Anthropology*. Santa Fe, NM: School for Advanced Research Press; 2008.
- Morris RC. Legacies of Derrida. *Annual Review of Anthropology*. 2007; 36:355–389.
- Nayeri K. The Cuban health care system and factors currently undermining it. *Journal of Community Health*. 1995; 20:321–335. [PubMed: 7593738]
- zur Nieden, A. Wie werde ich zum Subjekt meiner Gene? [How do I become subject of my genes?] Put on your blue genes. *BioTech-Kunst und die Verheißungen der Biotechnologie*. NGBK. , editor. Berlin, Germany: NGBK Neue Gesellschaft für Bildende Kunst; 2005. 101–110. (in German)
- zur Nieden, A. If there is a risk inside of me, I am the first person who should know about it'. Images of 'genetic risks' as anticipation of the future Tensions and Convergences: Technological and Aesthetic (trans)Formations of Society. Heil, R, Kaminsky, A, Stippak, M, Unger, A, Ziegler, M, editors. Bielefeld, Germany: Transcript; 2007. 163–172.
- zur Nieden, A. Zum Subjekt der Gene werden: Subjektivierungsweisen im Zeichen der Genetisierung von Brustkrebs [Becoming subject of the genes: Ways of subjectification in the age of geneticisation of breast cancer]. Dissertation Freiburg i. Br; 2008. (in German, unpublished)
- zur Nieden, A. Die Verkörperung des genetischen Risikos: Gentests für Brust- und Eierstockkrebs aus der Sicht von, Betroffenen' [The embodiment of genetic risk: Genetic testing for breast and ovarian cancer from the perspective of 'affected' women] *Biotechnologie in Kontexten der Sozial- und Gesundheitsberufe. Professionelle Praxen – Disziplinäre Nachbarschaften – Gesellschaftliche Leitbilder*. Dungs, S, Gerber, U, Mührel, E, editors. Germany: Peter Lang Verlag; 2009. 83–98. Frankfurt a. M., (in German)
- zur Nieden, A. The embodiment of genetic risk: Women's experiences of genetic testing for breast cancer susceptibility mutations Yearbook 2009 of the Institute for Advanced Studies on Science Technology and Society. Bammé, A, Getzinger, G, Wieser, B, editors. Wien, Germany: Profil; 2010. forthcoming
- Novas C, Rose N. Genetic risk and the birth of the somatic individual. *Economy and Society*. 2000; 29:485–513.
- Ong, A. *Neoliberalism as Exception: Mutations in Citizenship and Sovereignty*. Durham, NC: Duke University Press; 2006.
- Palfner, S. Gen-Passagen. Molekularbiologische und medizinische Praktiken im Umgang mit Brustkrebs-Genen. Wissen – Technologie – Diagnostik [Gene-passages: Molecularbiological and medical practices related to breast cancer genes. Knowledge – Technology – Diagnostic]. Bielefeld, Germany: Transcript; 2009. (in German)
- Parthasarathy, S. *Building Genetic Medicine: Breast Cancer, Technology and the Comparative Politics of Health Care*. Cambridge, MA: MIT Press; 2007.
- Paxson, H. *Making Modern Mothers: Ethics and Family Planning in Urban Greece*. Berkeley, CA: University of California Press; 2004.
- Paxson H. Reproduction as spiritual kin work: Orthodoxy, IVF and the moral economy of motherhood in Greece. *Culture Medicine and Psychiatry*, Special issue: Sacred Conceptions: Religion and the Global Practice of IVF. 2006; 30:481–505.
- Petersen A. Risk and the regulated self: The discourse of health promotion as politics of uncertainty. *Australian and New Zealand Journal of Sociology*. 1996; 32:44–57.
- Polzer, J. Genetic testing, citizenship and subjectivity: Implications for women and health The Gender of Genetic Futures: The Canadian Biotechnology Strategy, Women and Health. Miller, F, Weir, L, Mykitiuk, R, Lee, P, Sherwin, S, Tudiver, S, editors. NNEWH Working Paper Series; Toronto, York University: 2000. 55–63.
- Prainsack B, Siegal G. The rise of genetic couplehood? A comparative view of premarital genetic testing. *Biosocieties*. 2006; 1:17–36.
- Press N, Fishman JR, Koenig BA. Collective fear, individualized risk: The social and cultural context of genetic testing for breast cancer. *Nursing Ethics*. 2000; 7:237–248. [PubMed: 10986947]
- Rabinow, P. *Artificially and Enlightenment: From Sociobiology to Biosociality* Essays in the Anthropology of Reason. Princeton: Princeton University Press; 1996. 91–111.
- Raman S, Tutton R. Life, science and biopower. *Science, Technology and Human Values*. 2010; 35:711–734.

- Rapp, R. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis*. New York: Routledge; 1999.
- Reynolds Whyte S. Health identities and subjectivities: The ethnographic challenge. *Medical Anthropology Quarterly*. 2009; 23:6–15. [PubMed: 19449709]
- Robertson A. Embodying risk, embodying political rationality: Women's accounts of risks for breast cancer. *Health, Risk and Society*. 2000; 2:219–235.
- Rosendahl, M. *Inside the Revolution: Everyday Life in Socialist Cuba*. Ithaca, NY: Cornell University Press; 1997.
- Rowley E. On doing 'being ordinary': Women's accounts of BRCA testing and maternal responsibility. *New Genetics & Society*. 2007; 26:241–250.
- Scott S, Prior L, Wood F, Gray J. Repositioning the patient: The implications of being 'at risk. *Social Science & Medicine*. 2005; 60:1869–1879. [PubMed: 15686817]
- Seremetakis N. *Toxic beauties: Medicine, information and body consumption in transnational Europe*. Social Text. 2001; 19:115–129.
- Sleeboom-Faulkner, M, editor. *Human Genetic Biobanks in Asia: Politics of Trust and Scientific Advancement*. London: Routledge; 2009.
- Sleeboom-Faulkner, M. *The Frameworks of Choice: Predictive and Genetic Testing in Asia*. Amsterdam: Amsterdam University Press; 2010.
- Spiegel J, Yassi A. Lessons from the margins of globalization: Appreciating the Cuban health paradox. *Journal of Public Health Policy*. 2004; 25:85–110. [PubMed: 15134135]
- Strathern, M. *Partial Connections*. Lanham, MD: AltaMira Press; 2004 [1991]. (updated edition).
- Thorsteinsdóttir H, Sáenz T, Quach U, Daar AS, Singer P. Cuba – Innovation through synergy. *Nature Biotechnology*. 2004; 22(Suppl):OC 19–24.
- Trakas D. Iatriki sti syghroni Ellada [Medicine in modern Greece]. *Archaiaologia & Tehnes*. 2007; 105:6–10.
- Wahlberg A. Bodies and populations: Life optimization in Vietnam. *New Genetics and Society*. 2009; 28:241–251.
- Wöllmann, T. Andrologie – Wie die Medizin die Männer, entdeckt' [Andrology – How medicine 'discovers' the male] *Männlichkeit und Gesundheit im historischen Wandel ca. 1800 – ca. 2000*. Dinges, A, editor. Stuttgart, Germany: Franz Steiner; 2007. 87–104. (in German)