



Translating genomics: cancer genetics, public health and the making of the (de)molecularised body in Cuba and Brazil

*Convertendo a genômica:
genética do câncer, saúde
pública e a formação do
corpo (des)molecularizado
em Cuba e no Brasil*

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Abstract

This article examines how cancer genetics has emerged as a focus for research and healthcare in Cuba and Brazil. Drawing on ethnographic research undertaken in community genetics clinics and cancer genetics services, the article examines how the knowledge and technologies associated with this novel area of healthcare are translated and put to work by researchers, health professionals, patients and their families in these two contexts. It illuminates the comparative similarities and differences in how cancer genetics is emerging in relation to transnational research priorities, the history and contemporary politics of public health and embodied vulnerability to cancer that reconfigures the scope and meaning of genomics as “personalised” medicine.

Keywords: cancer genetics; biomedicalisation; Cuba; Brazil.

Resumo

O artigo mostra como a genética do câncer, em Cuba e no Brasil, tornou-se matéria de pesquisa, despertando maior interesse da saúde pública. Foram usadas pesquisas etnográficas realizadas em clínicas de genética comunitária e serviços de genética do câncer para averiguar como o conhecimento e as tecnologias associadas à nova área da saúde são convertidos e empregados por pesquisadores, profissionais da saúde, pacientes e familiares nesses dois contextos. Destaca, comparativamente, as semelhanças e diferenças na maneira pela qual a genética do câncer se posiciona em relação às prioridades em pesquisas transnacionais, na história e na política contemporânea da saúde pública e a vulnerabilidade incorporada ao câncer que reconfigura o escopo e o significado da genômica como a medicina “personalizada”.

Palavras-chave: genética do câncer; biomedicalização; Cuba; Brasil.

The growing expansion of genetic medicine beyond an exclusive focus on European-American societies has been particularly notable in the last ten years. In a range of international healthcare arenas the on-going promise and hope of what is described as “personalised medicine” is unevenly coalescing in relation to pre-existing medical institutions focused on genetic screening or the practice of “community genetics”.¹ This expanding field of public health genomics operates at the interface with transnational research collaborations and frequently inequitable healthcare resources and provision (Taussig, Gibbon, 2013). The paradox of a range of high end medical technologies – including not only genomics but also pharmaceuticals, ART, stem cell techniques and cosmetic surgery – now being made available to patients, even when other basic public healthcare resources are not, has begun to be explored by anthropologists and others (Bharadwaj, Glasner, 2009; Biehl, Petryna, 2013; Gibbon, 2013a; Edmonds, 2010; Roberts, 2010; Ecks, 2013). These are all domains in which the ever-present possibility of creating “new subjects of bio-medical compliance” (Whitmarsh, 2013) exist alongside novel claims to citizenship and articulations of healthcare rights (Petryna, 2013; Gibbon, 2015).

Understanding how these trajectories are uniquely conjoined, unevenly reproduced or mutually transformed in conjunction with specific medical technologies and healthcare interventions remains a key task for social scientists examining subjectivities and citizenship in an era of biomedicalisation. As Adele Clarke (2010) points out, there is a need here for socio-historic specificity in analysis, which takes account how medical knowledge and technologies can be homogenizing in some instances, yet partial in their operation or effect, whilst also generating local heterogeneous meanings in the way they are used and practiced. Responding to this challenge, this article examines how one particular research and medical domain within the expanding field of genomics, namely cancer genetics, has emerged as a focus for research and healthcare in two contrasting regions in Latin America: Cuba and Brazil. Drawing on long-term ethnographic research undertaken in regionally focused community genetics clinics in Cuba and fledgling cancer genetics services in the south of Brazil, the article examines how the knowledge and technologies associated with this novel area of healthcare are translated and put to work by researchers, health professional, patients and their families. In illuminating the comparative similarities and differences in the way cancer genetics is emerging and evolving in Cuba and Brazil in relation to particular aspects of a diverse and increasingly transnational area of genetics research and medicine, the article illustrates the importance of considering these developments as interacting with specific social and cultural dynamics. This includes the history, as well as the contemporary practice and politics of public health, along with perceptions of embodied vulnerability to cancer that reconfigure the scope and meaning of genomics as “personalised” medicine.

Cancer genetics, “personalised medicine” and transnational research

The medical and scientific field of cancer genetics and in particular the high profile sub-field focused on breast cancer is at the forefront of an increasingly transnational field of genomic medicine and research. The incorporation of predictive genetics testing for the well-known “BRCA” genes associated with an increased risk of breast cancer as a “standard of

care” in many nations in the “global north” is now unevenly filtering into other international medical practices. Emerging social science research is demonstrating how these interventions within Europe and North America, and increasingly beyond, are diversely situated across different landscapes of private or public healthcare, enlisting and producing various patient subjectivities, as well as practitioner communities, that challenge the notion of a uniform reproduction of genomics as personalised medicine (Gibbon et al., 2014).

While cancer genetics constitutes a visible “absent presence” in some national contexts (Macdonald, 2014), in others an expanding emphasis on “prevention” fuels an effort to address the “unmet needs” of those not currently able to offer or access genetics testing services (Joseph, 2014; Gibbon, 2015). Yet, alongside a moral discourse concerning issues of access or even “rights” to new, so-called “preventive” healthcare services in “underserved populations” there are also scientific questions about the meaning of genetic risk beyond high risk groups in Europe and North America. It has been argued that these questions can only be validated through the expansion and provision of genetics research and testing to include diverse populations (see Bustamente, 2011).² In this way the involvement of what Rapp (2013, p.574) describes as “exquisitely stratified research populations” are essential to a transnational genomic healthcare enterprise, where they serve as both “potential global [scientific and medical] resources and [underserved] market beneficiaries”. This is particularly evident in the context of BRCA genetics. This has been a flourishing area of transnational scientific research for some time, focused mainly on an effort to identify common founder mutations and or biomarkers that might significantly contribute to cancer risk in different national and regional contexts (Lee, 2013; Gibbon, forthcoming). High throughput “next generation” testing technologies that enable thousands of mutations to be identified quickly are central to this task, at least where such technologies are immediately available. Nevertheless, the complex epigenetic context of personal or so-called stratified medicine means the immediate healthcare application of post-genomic fields of inquiry such as pharmacogenomics are somewhat elusive – if still powerful – promissory dimensions of this expanding international area of cancer-related genetics research (Jones, 2013).

The transnational research agendas which cancer genetics, and especially breast cancer genetics, unites and reproduces are therefore multiple. They are tied to practices of standardisation and localisation, while being informed by uncertainties concerning the meaning and significance of genetic risk information as well as the current limits of and on-going hopes for personalised medicine.

Taking this transnational area of research and healthcare as a context to be both empirically examined and as a starting point for comparison, this article examines the socio-historical specificity through which cancer genetics is emerging as a focus for research and healthcare in two contrasting regions of Latin America: Cuba and Brazil.

The article first examines how cancer genetics has developed in these two regions, tied to specific national histories and the contemporary organisation of public health services before examining how cancer genetics is pursued and practiced in each of these settings. There is a particular focus on how the lived reality of inequitable access to resources and basic healthcare needs are negotiated and ameliorated by those who work in these fields in Cuba and Brazil. The second half of this article reflects more directly on the kind of embodied

patient subjectivities co-produced in the context of cancer genetics. It examines how the meaning of genetic risk for cancer patients and their families, in both Cuba and Brazil, is diffracted through particular ideas of embodied vulnerability that displace and configure genes in relation to the social environments and the lived experience of interpersonal relations. This raises further questions about how to understand the dynamic consequences of biomedicalisation and the meaning and significance of cancer genetics as “personalised medicine” in these two regions.

The data presented here is based on ethnographic and qualitative research that developed differently in Cuba and Brazil. Research in Cuba was undertaken alongside genetics professionals in three different (some rural) regions of the country, outside of the capital city Havana, as part of a collaborative project examining perceptions of risk for breast cancer. The fieldwork consisted of visiting families in their homes with Cuban medical geneticists as part of the routine collection of family history information and the use of a semi-structured questionnaire exploring perceptions of risk related to breast cancer. The questionnaire was completed by over two hundred Cuban women, all of whom were over 18. The work undertaken in Brazil included participant observation in cancer genetics clinics over a period of 18 months in three different urban centres in the south of Brazil (São Paulo, Rio de Janeiro and Porto Alegre), interviews with patients and family members visiting cancer genetics clinics (over hundred in total), and interviews with practitioners and scientists working alongside cancer genetics specialists (over forty in total). Participating patients were visiting cancer genetics clinics and were either undergoing risk assessment, had received it, or were more frequently awaiting the result of a genetic test. While the majority were women, a number of men were also recruited in the study. All were over 18.

Cancer genetics in Cuba and Brazil

Cuba

While medical genetics began to be incorporated into the Cuban healthcare programme in the 1980s, a rapid expansion of clinical genetics services has since taken place across the entire country, increasing the number of clinical specialists from 15 to around 184 (Lantigua, 2013). The founding of the National Genetics Network in 2003 led to the incorporation of community genetics services in all municipalities, primarily focused on pre-natal and neonatal screening and testing programmes. With the stated aim of developing “a national programme for the diagnosis, management and prevention of genetic diseases” (Teruel, 2009, p.11) there are now currently over 1,600 persons employed nationally in this field as genetic specialists, technicians, counsellors, and nurses as part of a regionally based national network of genetics centres and clinics.

The working structure of Cuban community genetics therefore directly mirrors the system of local clinics established as part of the family medicine initiative in the 1980s, building on a nearly 40 year program of infant and maternal health. This has been central to the goal of the Cuban “socialist” project of realising the principle of “health for all” through a focus on primary healthcare pursued through close integration of hospitals, polyclinics and

community-based services (Spiegel, Yassi, 2004). It has also included the training of thousands of health professionals with many living and working in local community-based clinics. While now subject to the increasingly dynamic political goals (and economic limits) of the Cuban government (see Brotherton, 2012), it is nevertheless a framework that has provided the model for the expansion of community genetics clinics in Cuba.

The main day-to-day focus of community genetics professionals relates to pre-natal and neo-natal screening and interventions. However, the collection of family history information for cardiovascular disease, breast cancer and diabetes has begun to form part of efforts to examine the role of genetic factors in common, adult-onset conditions, with reports of over 43,000 families on national disease registries (Teruel, 2009). The utility of such data is significantly hampered by the limits of healthcare resources for interventions such as predictive genetics testing for common adult-onset conditions. At the time of my research, in 2007-2008, there was no widespread clinical or research genetics testing programme for commonly identified genes such as those associated with an increased risk of breast cancer, BRCA 1 and 2. Nevertheless, interest in conditions such as cancer within the context of community genetics is increasing. This reflects a changing national disease profile in terms of cancer incidence, with lung and breast cancers constituting a significant and growing public health problem (Romero, 2009). There is also a notable, long-standing area of scientific research in Cuba focused on cancer immunology and the development of cancer vaccines within the scientific pole in western Havana (Lage, 2009). While difficult to clearly define, there is also a growing association between community genetics in Cuba and the country's high profile biotechnology industry. This must be seen as part of what Reid-Henry (2010) refers to as the "local experimental milieu" of Cuban biotechnology, facilitated by a close relationship between state funded laboratory research and healthcare services. He suggests that an "alternative discourse of ethics and possibility" is pursued at this intersection, aimed at improving collective public health, strengthening revolutionary values and participating in international markets. The collation of family history data as part of the expanded work of community genetic health practitioners is therefore not only connected to a long history of public health tied to community health interventions, but also constitutes an invaluable resource for a growing "socialist" biotechnology sector. As Reid-Henry's (2010) work demonstrates, it is a sector uniquely focused on developing products that can not only provide cheaper solutions for the national and international healthcare needs of "underserved" populations, but also does not preclude participation in international research (see also Thorsteinsdóttir et al., 2004). While not extensive, there do appear to be a number of international collaborations in the context of Cuban Community Genetics, including collaborative research studies to characterise BRCA mutations in Cuba together with researchers in Canada and the United States (see for instance Rodriguez et al., 2008).

Brazil

The development of specialist cancer genetics clinics and services in Brazil has emerged over the course of the last ten years in the wealthier and relatively more economically developed southern part of the country, where there are extremely high recorded rates of

breast and prostate cancer equivalent to the prevalence in the US population (see Inca, 2014). During the time of my study, private predictive genetic testing for mutations on the two well-known BRCA genes was available for those able to pay the \$2,000-\$3,000 cost in the growing number of private clinics. More recently, in 2012, genetic testing was made available via some private health insurance providers, which are generally used by approximately 25% of the Brazilian population.

However, the hub of emerging cancer genetic research and healthcare services is located within mostly public or mixed private/public health hospitals associated with universities and research institutes in the urban centres of the southern region of the country, including São Paulo, Rio de Janeiro and Porto Alegre. Nevertheless, because cancer genetic services are not currently offered by the Unified Health System (Sistema Único de Saúde, SUS) for the majority of those identified as being at genetic risk for cancer, eligibility for any form of genetic testing is directly linked to national and transnational research collaborations between individual scientists and their research teams, most notably in France, the United States and Canada. As a result, cancer genetic services in Brazil operate in an arena where there is a close and fluid relationship between clinical services and research objectives.³ That is, fledgling clinical services concerned with identifying, addressing, and ameliorating the risks for individual patients and their families are closely tied to research objectives linked to understanding how Brazilian cancer genetics can be mobilised in conjunction with transnational research agendas. At the time of my study, two primary areas of investigation were prominent. This included studies on the two BRCA genes associated with an increased risk of breast cancer, and genetic markers linked to rarer cancer syndromes associated with a range of different cancers, including breast cancer.

While there are clearly differences in how cancer genetics is emerging in Cuba and Brazil, the fact that, in both cases, they are influenced by (and in the Brazilian case mostly dependent on) national and transnational research goals and/or resources is significant. Yet within both contexts cancer genetics is not easily or readily subsumed by a promissory vision of personalised medicine. The next section examines how, instead, it is mobilised within and in relation to a public health system that reflects the activism of researchers and practitioners. This configuration of cancer genetics must also be understood within the context of the very different histories of social medicine in Cuba and Brazil.

Between the promise of personalised medicine, public health and the contemporary legacies of social medicine

The fact that genetic testing for commonly identified inherited-susceptibility genes such as the BRCA genes was not routinely undertaken in Cuba reveals how certain key dimensions of transnational cancer genetic research constitute what has been described as an “absent space” (Macdonald, 2014). Nevertheless, the collection of family history information within the context of regionally focused community genetics activities also highlights continuities with long standing public health goals that facilitate and inform the localization of cancer genetics within Cuba. The routinisation and normalisation of collecting family history information in the local practice of Cuban healthcare to some extent enables the pursuit of

community genetics for common complex adult-onset disorders such as cancer. As I've argued elsewhere, the work of collating family histories and managing the delicate inter-familial relations that are part of genetic interventions are central to tacit community caregiving that serves to reinforce rather than question the role of cancer genetics within the socialist goals of community genetics (Gibbon, 2013b, 2011, 2009).

For the Cuban genetics health professionals that I met, attentiveness to the family in the context of community genetics practices re-enforced the socialist ideals of "revolutionary medicine" as collectively orientated, often in explicit contrast to what were seen as capitalist individualism and the prominent discourse of personal medicine associated with genomic healthcare. However, in the vocational narratives of these health professionals it was not only the humanitarian concerns of Cuban healthcare that were focused upon, but also a notion of community genetics as a modern cutting edge domain of medicine. Many of the predominantly female genetics health professionals noted how this field was in fact leading the way in addressing the challenges of informed consent and confidentiality that were particularly stark, they suggested, in Cuba given the on-going paternalism in the organisation and practice of state managed healthcare. As I've suggested elsewhere, this points to the heterogeneous ways in which the pursuit of cancer genetics in Cuba is being incorporated into the values and practices of state socialism (Gibbon, 2013b).

The focus on genetic risk information related to family history within the practice of community genetics could, however, also reveal shortcomings in basic healthcare in Cuba, such as the lack of mammogram machines in some regions of the country. At the same time, for these practitioners, the discomfort generated by this situation did not seem to lead to questioning the broader goals of pursuing cancer genetics as community healthcare. Rather, it sometimes served to reinforce the value and worth of socialist goals and a commitment to ensuring that issues of equity and access were positioned at the forefront of community genetics. In this context a promissory discourse of personal medicine was conspicuously absent, subsumed by a concern and desire to make cancer genetics part of the broader goals of socialist medicine. As one genetic practitioner involved in the collection of family history data related to cancer risk pointedly said, "we are not just trying to help one woman with breast cancer here, because science in Cuba is for everyone."

The promise of personal medicine associated with cancer genomics was more easily incorporated in Brazil. Nonetheless, it is important to note how awareness and acknowledgement of inequities in access to healthcare in Brazil also inform how those who work in cancer genetics traversed the gap between the promise of genomics and the daily practice of cancer genetics.

The constitutional right to health has been in place in Brazil for over 30 years, yet public healthcare provision is uneven and complex (Biehl, 2005; Edmonds, 2010; Sanabria, 2010). Approximately 75% of the population only accesses healthcare through the public healthcare system (SUS), while the rest of the population makes use of variably affordable health insurance or health plans. However, while there are differences in the quality of provision both within and across public and private healthcare, the public system is often perceived by both middle-class patients with health plans, and those who use it, as inadequate; a situation described in terms of "excluding universalism" (Faveret Filho, Oliveira, 1990). This affects how and why

those working at the forefront of Brazilian cancer genetic services seek to constitute cancer genetics as public health and also (as explored in later sections) why patients seek out care in the context of cancer genetic research.

For many healthcare practitioners the logic of cancer genetics seemed obvious in terms of a cost-benefit ratio of identifying those at risk compared to the costs of treating those with breast cancer. Moreover, despite the fact that Brazilian cancer genetics is practiced at the junction between the research activities of individual researchers or their teams involved in international collaborations and precarious or limited public health services, it is mobilised, by those who work in this domain, as part of a neglected “preventive” approach to health.

A discourse of prevention has gained increasing prominence in recent years in Brazil in relation to breast cancer with new national guidelines for mammography screening implemented among a range of other interventions (Lee et al., 2012). In a similar way, while many of those I met who worked in cancer genetics were sceptical about the imminent realisation of “personalised” medicine in Brazil, cancer genetics was very directly related to the goal of preventive public health. As a result, there was widespread acknowledgement and a degree of exasperation among these health professionals that cancer genetics was only currently possible through globalised clinical and transnational research collaborations. This meant having to work in a context where screening interventions for those identified to be at genetic risk had to be negotiated with either health insurers (if the patient had a health plan) or individual hospitals. Venting her frustrations, one doctor pointed out how “I can’t keep doing research to offer testing for another ten years... with care being something peripheral that is just tacked on the side.”⁴

The commitment to cancer genetics as part of public health in Brazil led some practitioners to pursue what were described as “road trips” to rural parts of the country beyond the urban centres in which they worked (see Gibbon, 2015). It was a practice that strongly reflected the contradictory contexts into which Brazilian cancer genetics is embedded and is practiced. Here the efforts to fulfil and expand the parameters of transnational research collaborations are conjoined with those to identify individuals and families affected by hereditary cancer syndromes as part of a preventive approach to public health. On one such road trip in which I participated, cancer genetics was explicitly presented as a chance to both “participate in research” and “prevent cancer in the future.” The message was conveyed with an awareness that these families had somewhat limited choices – given that none had private health insurance and lived in a rural part of the state of São Paulo – and thus did not have easy access to healthcare services. While no practitioner explicitly stated to the families that being involved in research was a means to secure basic healthcare, it was implicit that this was an indirect benefit of participation. It is tempting to see such activities simply in terms of recruitment for research, but this does not do justice to the wider affective and moral framing of Brazilian cancer genetics by medical professionals as part of a preventive approach to public health which – like their Cuban counterparts – they actively pursue.

While cancer genetics constitutes something of an “absent space” in Cuban community genetics as compared with Brazil, we can see in both cases how developments in this field of medicine are linked in direct and indirect ways to national and international research collaborations alongside efforts to intervene in public health. These intersections are very

much sustained by the actions and investments of health practitioners. These orientations to genomics as public health must also be understood in relation to the historical legacy and contemporary articulation of “socialist” medicine in both of these settings. These are most clearly evident in Cuba, with its long history of state socialist medicine, as outlined earlier. Yet this dynamic is also relevant in the Brazilian context. The influence of the Brazilian Hygiene Movement in the early twentieth century, which advocated widespread public health interventions as a means of addressing Brazil’s social problems (Lima, 2007) and the prominence and role of collective health from the late 1970s to the present (Cueto, Palmer, 2014), provide an important context for discussing why preventive public health is one of the vectors through which cancer genetics is being pursued in Brazil. The findings presented here suggest that the socio-historic specificity and dynamic contemporary articulation of social medicine in Cuba and Brazil shape the biomedicalised trajectories through which emerging fields of healthcare such as cancer genetics flow and in which they are unevenly constituted.

The next section examines the experience of patients participating in fledgling cancer genetics services in Cuba and Brazil in order to consider the contrasting pathways through which they and their families enter this novel domain of healthcare. This provides a further means of reflecting on the complexities and dynamics of biomedicalisation. It examines how – in both contexts – genetic risk is perceived and acted upon as part of a wider understanding of embodied vulnerability to cancer. That is where the actions of genes on the development of disease are only made meaningful in relation to wider environments and lived social relations. This has consequences not only for how we might understand the molecularisation of bodies, but also the promise of personalised medicine and the wider translation of emerging epigenetic understanding of genetic risk.

Patient-citizens and (de)molecularised bodies

The social context and pathways through which patients arrive in the domain of clinical cancer genetics in Brazil and Cuba is somewhat different, with the institutional configuration of these services affecting how patients perceive and engage with cancer genetic interventions.

In Cuba, family history investigations are perceived as a routine part of “family medicine,” where medical attention to and knowing about the health of family members is normal. In this sense, cancer genetics as part of the practice of community genetics is linked to long-standing efforts by the Cuban state to monitor and intervene in the population’s health at a local and national level. As one female participant said, commenting on why she believed hereditary factors were important in relation to breast cancer, “because in consultations they [the doctors] are always asking if you have relatives who are sick.” Nevertheless, while this routine attention to family history facilitates cancer genetics in Cuba, it does not necessarily entail a molecularised understanding of heredity and cancer risk, as I explore below.

For the cohort of Brazilian patients that I met, cancer genetics was anything but normalised. Rather, it was more often than not seen as something valuable, a field of healthcare that was “leading the way in finding a cure for cancer” as one patient put it and sometimes also a means to access healthcare services inadequately provided through the public health system. Most of

the patients I encountered during my fieldwork arrived in cancer genetics clinics following the treatment of a family member for cancer, having been referred by another health professional working in the same hospital. A large number were waiting for genetics test results linked to research protocols and many, as SUS patients, also received a significant amount of other basic screening and health monitoring services. As a result, simply being within the parameters of the hospital's care through participation in a study was often perceived as prevention. As one patient put it "everything is a blessing when you arrive at this hospital" referring to the relief she felt at being part of a cancer genetics research programme. For her this meant that she was able to access basic screening services, such as mammograms, that she would otherwise have to wait months for in a hospital that – to her mind – was substandard compared with the research hospital where she was part of cancer genetics studies.

The way that rights, responsibilities and patient-citizens are constituted through being part of research protocols – particularly those linked to clinical trials – has been explored in other contexts within and outside Brazil (Petryna, 2009, 2013). In a context where clinical care and research are so closely entwined and where there are obvious healthcare disparities, exploitation and the reproduction of "bio-available" populations remains an ever-present possibility (Sunder-Rajan, 2005). Nonetheless given the way that participation in cancer genetics is routinised in public health in Cuba or can be an indirect means of accessing basic healthcare services in Brazil, resisting "uniform and unilateral diagnosis" (Biehl, Petryna, 2013) seems necessary in order to account for the diverse ways that patients enter and participate in emerging fields of medicine such as cancer genetics.

Despite the differences outlined above there appeared to be something of a convergence in the way Cuban and Brazilian research participants and patients understood, constituted and engaged with information on genetic risk for cancer.

In Cuba, the notion of genes – or more specifically a genetic mutation – was not widely understood, nor considered necessarily relevant or sufficient to be the cause of cancer. By contrast, family history and hereditary factors were identified by a number of Cuban women who responded to open ended questions about risk factors for breast cancer. This must in part be read alongside an emphasis on family health linked to long-standing community management of health through local clinics and family medicine. However, more striking in the Cuban context was the relative dearth of attention to factors such as "stress" that were within the locus of the individual's control. Environmental factors, ozone depletion, and wars were all frequently identified as explanations for what were believed to be the causes of breast cancer. These responses reflected a general sense that health risks associated with cancer were not necessarily linked to individual behaviour or actions, but rather the wider context of daily life in Cuba.⁵ I explore this further by reflecting on some frequent responses to questions about risk factors for breast cancer, specifically a physical or emotional blow, and also discussion of diet and nutrition.⁶

In Cuba, rather than the idea that an excess of certain foods representing a risk factor for cancer, a deficit in the diet was most often associated with the disease, particularly a lack of vitamins, protein and milk. As one Cuban woman I met said, "It could be some food that you don't eat that causes your cancer, some fruit or vegetable that we don't have the habit of eating, perhaps because there aren't any."

Soya beans were, however, identified as a food that might cause cancer if consumed in excess. While this idea is paradoxically in contrast to popular scientific understanding that consumption of soya in certain Asian diets may protect against cancer, in Cuba this must also be understood in relation to a long history of the use of soya beans by the state as a replacement for a shortage of dairy products. As one participant put it: “Since the ‘Special Period’ they have incorporated soya beans [into the diet] and there is a large number of people with cancer.”⁷

Another commonly held belief regarding risk for cancer among the Cuban women I met related to the notion of “a blow” or *un golpe*. More than half of the respondents who participated in the research project thought that a blow was a factor in the development of cancer. This term can refer to a physical or an emotional blow caused by, for example, a bereavement in the family. It was, however, most often the former meaning that seemed evident, particularly when ideas of female gender were incorporated into this understanding. Not only was the breast considered a “delicate area for women” but also there was also a belief that excessive physical force could be implicated in the development of a cancer. The gendered ways in which the notion of “a blow” was presented seemed therefore to reflect in part new anxieties about the changing role of women in Cuban society, including the dramatic shift to their inclusion in the work force during special period shortages (see Rosendahl, 1997).

These examples draw attention to how factors beyond the control of the individual were most often articulated as risks for or the causes of cancer in Cuba. They reveal a specific articulation of physical vulnerability that must in part be understood in the context of changing socio-political dynamics related to the governance and provision of food in Cuba and women’s changing social and cultural roles. Recent social science studies in Cuba, in urban centres such as Havana, have highlighted the extent to which the governance of health in a context of shortage is increasingly dependent on the entrepreneurial skills of individuals and families in seeking out and exchanging medical resources and products (Brotherton, 2012). Equally, changes in the organisation of healthcare provision have led to far fewer family physicians in Cuba, with the gradual appearance of health promotion drives that are beginning to emphasise the role of individual self management. Yet it is not so clear how these dynamics are playing out in rural and urban locales outside of Havana. As Elise Andaya’s (2009) work demonstrates, any new emphasis on being “self-disciplined” in Cuba must be read in the context of a long and sustained history of state socialism. This includes examining how the historical emphasis on the health of the collective leaves traces in the contemporary lived embodiment of individual risk. This means, in Reid-Henry’s (2010, p.101) terms, being attentive to how, a “socialist epistemology of the body” resonates in novel areas of healthcare such as cancer genetics, where personalised medicine is neither necessarily immediately valued or possible.

For many of those individuals that I met while visiting cancer genetics clinics in Brazil, genetic mutations were more widely acknowledged as a risk factor for the disease. At the same time, they were nevertheless rarely believed to be the sole or sufficient cause of cancer. As in Cuba, genes were almost always necessarily seen as interacting with other factors associated with social, environmental and, in particular, interpersonal relations.

The effect of strong emotions on the body was one of the risk factors most frequently discussed by those I met attending cancer genetic clinics in Brazil. For some, emotions were something that could enter and act upon or materially produce the body. As one patient I met succinctly put it; “these emotional questions affect our thoughts, they produce chemical reactions, and molecular and neurological changes inside our bodies. They transform into something concrete. Our thoughts are not just our thoughts, they happen inside our body as well.”

In my research with Brazilian patients, bodies were in fact seemingly mattered as a consequence of the conjoined effects of emotions and diet, the cyclical trauma of familial cancer, or problematic relations in the family. They were seen as having an agentic action in the body, being both a risk for and a cause of cancer that interacted with genetic or hereditary factors. I give some account here of these ideas of bodily vulnerability by reflecting in more detail on the experience and narratives of a few of the patients that I met.

Ana Paula was in her early 40s. She lived in the southern town of Porto Alegre and worked in a shoe factory in one of the urban suburbs of the city. As well as having had breast cancer herself, a very large number of her family members had had cancer, including her father, a number of sisters and most recently her teenage daughter was being treated for a rare bone cancer. The family were under the care of the cancer genetics team at the hospital and were awaiting the results of blood tests to confirm if a genetic mutation associated with a rare cancer syndrome had been identified in the family. During our first meeting Ana Paula recounted in detail these traumatic cancer-related experiences she had experienced while growing up. Since she and her family had been treated for the disease in the local public health hospital, she had always heard that it “could be genetic” or, as she put it, “it could that different bolts of lightning fell in the same place at the same time.” In fact she told me that she always thought that it was “emotional”, elaborating she said

I am always hearing interviews on the television with doctors about where breast cancer comes from? It comes from continuous hurt, from anger. During the time that I was undergoing treatment I heard this, that it comes from genetic inheritance so it could be emotional factors... and in my family too I’m beginning to think that it’s this... to be certain that it’s the two together because our head co-ordinates our body. I think that feelings are part of our daily existence and you don’t know but one day you say something bad and you hurt someone or you are hurt. I think that it’s this because my husband left me when I was unwell and then I started to hold my sadness, my hurt and then the breast cancer developed. I did all my treatment alone and finally my cancer was sleeping. But I was deceived by someone else I was living with and the cancer returned in another place.

Similar ideas about the role of emotions were also evident in the way that others I met visiting cancer genetics clinics talked about how emotional problem marked the body. This was evident in the way that Marta – who was in her late 50’s – talked about the importance of her catholic faith in dealing with the breast cancer she had had for 8 years and the role of emotions and their effect on the body and self.

There is a psychologist currently on TV on the ‘better life’ channel, which is a catholic network. Anyway, she wrote a book called *Good and Bad Anger* and she talks about this

question of anger inside you and it left me thinking... if you don't realise that you are angry about something, but it's there, it's going to burst out somewhere because it's a feeling that stays there, waiting. So I think it has a connection with cancer. It might not just be a feeling of anger, but a feeling of hate or something negative so I think these unresolved feelings... 'because your feelings and your emotions they speak, they speak in your smile, in what you are thinking, they are speaking inside'...

Asking Marta more directly how emotions might cause cancer she went on to talk about the how they could affect the digestion of food and pass through the body via blood.

Let's say you are anxious for some reason and you are going to eat, you are really not going to eat well it's not going to be good for you, you'll be eating irritated, with anger or with hate, a grudge or resentment or whatever... you might be eating in a rush, angry with whoever said something bad to you, but you start eating. Nobody knows what's happening inside you, but that feeling is talking to you, so I think at some moment that feeling passes to our blood, and moves inside of us.

In all of these examples bodies were mattered through intersubjective emotions interacting with a seemingly porous notion of the body, in ways that contextualise, displace or redefine the meaning of genetic risk. These ideas of bodily vulnerability related to cancer in Brazil (and similarly in Cuba) fit well-recognised understandings of the body – including the sick body – as subject to and produced through lived environments, outside influences, the suppression of anger and the emotional vicissitudes of selves in relation to others (Duarte, 1986; Rebhun, 1994). More recent research examining new health technologies such as IVF, cosmetic surgery and hormone treatments in Brazil and other regions of Latin America have further illuminated how notions of biological plasticity and bodily porosity inform the response to and the uptake of novel health technologies (Edmonds, 2010; Sanabria, 2010; Roberts, 2010). In her examination of contraception and menstrual suppression in Bahia, a state in the northeast of Brazil, Sanabria illustrates how humoural-inflected notions of blood are an expression of the body not as fixed or defined by rigid boundaries, but as contingent on and subject to the influence of external factors; an expression of “plasticity,” which she argues is also tied to the history of the hygienist movement in Brazil at the turn of the twentieth century (Sanabria, 2010; forthcoming).

Collectively, this work suggests then that the notion of bodily contingency has a significance in the Latin American region that also informs how genetic risk is translated and acted upon. In this sense, the expressions of embodied vulnerability articulated by patients and research participants in Cuba and Brazil cannot be understood outside the intersection of a range of specific socio-historic dynamics and cultural practices. This includes institutional cultures of state or socialist public health, contemporary histories of socialist medicine, the governance of food, anxieties about the changing role of women, contemporary religious practices and a prominent media informed discourse of self improvement. While these dynamics are clearly somewhat different in Cuba and Brazil, there are some notable similarities in the way in which notions of genetic risk are displaced and reframed. While studies in Europe and North America have also shown that genetic technologies and knowledge may not lead directly to the molecularisation of bodies (Gibbon, Kampriani, Zur Nieden, 2010;

Lock, 2008), the findings presented here raise questions about the assumed pathways and consequences of biomedicalisation linked to the expansion of novel fields of healthcare such as genomics. While notions of bodily porosity or plasticity do seem to be more prominent in certain regions of South America (Sanabria, forthcoming), the relevance of a seemingly “Lamarckian” understanding of disease risk (genetic or otherwise) may also potentially be much more widespread, yet still perhaps somewhat under-examined not only in this region but also beyond. In Brazil and Cuba, genetic risk information does nevertheless appear to be layered into a set of meanings relating to bodies that were perhaps never molecularised in the first place.⁸ In an era in which the master narrative of “the gene” is being replaced by the contingency and complexity of epigenetics and gene-environment interactions, it will be vital to monitor to what extent “popular” notions of risk for common diseases such as cancer intersect with and are themselves reframed by new understandings of genes, risk, bodies and environments in Latin America and elsewhere.

Final considerations

Analysing the contrasting contexts of Cuba and Brazil, this paper has examined the diverse trajectories in which one field of genomic medicine – cancer genetics – is being translated in Latin America. It has plotted the parallels and differences in the way that cancer genetics has emerged in each of these regions, linked to public health and histories of community genetics as well as in relation to national and transnational research priorities and funding. It has outlined the diverse ways that health practitioners in these two contexts negotiate the gap between the promise of genetic medicine as personal medicine and public health in a context of scarce medical resources and entrenched health inequities. In each case the activism of practitioners in pursuing somewhat diverse ends has been at the centre of how and why cancer genetics is emerging in Cuba and Brazil. The pathways through which patients and research participants come to clinical cancer genetics are in part informed by the healthcare institutions that operate in each domain, while the ways in which embodied risk for cancer manifests points to convergences in how the relevance of genes are contextualised and in some cases actively displaced.

The need to examine a “multiple politics of life” (Raman, Tutton, 2010) is now being directly taken up in comparative research of novel health technologies outside Europe, Canada, and the United States. The way in which diverse forms of public health governance are central to the mobilisation of medical research and health technologies is becoming apparent, particularly in those contexts where there are “very different historical and political rationalities” and “more collectivist mentalities” (Greenhaugh, 2009, p.207). Latin America offers a specific lens through which to examine these developments, given that the pursuit of social medicine has a long history and on-going contemporary relevance in the region as a whole (Cueto, Palmer, 2014; Lima, 2007). At the same time, the legacies of different histories of social medicine inform cancer genetics in Brazil and Cuba at the meeting point with transnational research priorities and funding agendas, that also shape the pursuit and practice of this emerging area of medical practice and research. The second half of this paper has examined how patients’ engagement with genetic risk information is shaped by culturally

significant meanings of embodied vulnerability to cancer that, in different ways, emphasise the role of exogenous factors and the seeming porosity of bodies. Yet, in a similar way, these articulations do not exist outside of novel injunctions relating to health responsibilities, often gendered in specific ways, that also form part of the transnational area of cancer genetics and which are so central to the promise of personalised medicine associated with this novel field of healthcare.

In summary there is an on-going need to understand how novel fields of healthcare such as cancer genetics are uniquely informed by socio-historic specificity in dynamic response to broader global social processes. The translation of emergent areas of research and medical intervention, such as cancer genetics in Cuba and Brazil, makes visible the complex and frequently divergent pathways of biomedicalisation and the vital need to attend to how these are partially reproduced and heterogeneously localised.

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NOTES

¹ Community genetics is often described in terms of an effort to bring clinical genetics to underdeveloped and developing countries and address the well being of the individual within society, see Raz (2010).

² See also Sturdy (2015) for further discussion of how this is driven by the need to validate genetic data within Europe and North America.

³ This is reflective of a wider cancer genetics context in which it is often difficult to distinguish research from clinical care (see Hallowell et al., 2009).

⁴ This perspective on cancer genetics was, however not the vision shared by some of those who worked in related fields such as mastology. See Gibbon (2015) for further discussion.

⁵ However, there was evidence of this among those who lived closer to the urban centre of Havana (see Gibbon, Kampriani, Zur Nieden, 2010).

⁶ These are aspects that I have explored in more detail elsewhere in articles in Gibbon, Kampriani, Zur Nieden (2010) and Gibbon (2009).

⁷ The special period refers to the period of economic crisis in Cuba following the dissolution of the Soviet Union in the late 1980s.

⁸ I am grateful to Ilana Löwy for her insights in relation to this point.

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