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Ancestry, Temporality, and Potentiality:

Engaging Cancer Genetics in Southern Brazil

Sahra Gibbon

Lecturer in the Anthropology Department of University College London (14 Taviton Street, London WC1E 6BT, United Kingdom [s.gibbon@ucl.ac.uk])

Abstract

In this paper I examine the variety of ways potential is articulated, entailed, and produced in how the field of cancer genetics is being constituted as a domain of transnational research and an emerging site of health-care intervention in southern Brazil. Drawing on analysis of fieldwork in Brazilian cancer-genetics clinics, I explore how different expressions of potential come to inform dynamically the pursuit of prevention, care, and research as diversely scaled investments for those working and living with cancer-genetics knowledge and technologies. It illustrates how specific temporalities help to constitute and “abductively” frame the meaning of these different potentials particularly as this relates to a focus on ancestry. Colonial histories of migration, the embodied effects of dietary habits, or the moral failings of near and distant ancestors as well as promissory futures and the contingency of lived lives become at different times templates for identifying, materializing, and transforming how the potential of cancer genetics in Brazil is articulated. Potential is also expressed through an idiom of “choice” in different efforts to situate participation in cancer-genetics research as prevention or to negotiate access to basic public health. I explore how these expressions of cancer genetics as potential powerfully yet unevenly work to sustain knowledge practices as well as propel patients and their families into fledgling domains of clinical practice and scientific research. At the same time there is always an “excess of meaning” in these endeavors that make visible lines of fracture and disjuncture in collective efforts to make future histories of and from the pursuit of cancer genetics in southern Brazil.

Developments in cancer-genetics research and medicine, including the well-known discovery of two inherited susceptibility genes—BRCA1 and BRCA2—in the mid 1990s, have been one of the most high-profile aspects in an evolving field of genomic science and medicine. It is an arena where the promise of genetics as preventive and/or predictive medicine has been ubiquitous. Despite ongoing clinical and scientific uncertainties about the meaning of genetic risk, the knowledges and technologies linked to BRCA genes are increasingly incorporated as a “standard of care” in Europe and North America (Narod 2011) whose promise is now sustained by the possibility of targeted treatments for breast cancer in new fields of postgenomics (Bourret, Keating, and Cambrosio 2013). Against a background of ongoing genetic and increasingly epigenetic complexity, breast cancer genetics is being incorporated across a transnational terrain of research and health care.¹

This paper contributes to a growing field of social science research examining the global arena that breast cancer genetics is fast coming to occupy (Bourret 2005; Gibbon et al. 2010; Kampriani 2009; Lowy and Gaudillière 2008; Mozersky and Joseph 2010; Palfner 2009). It examines how cancer genetics is emerging in southern Brazil as a dynamic domain of clinical practice and both national and transnational research, increasingly marked by both standardization and instability. Drawing on ongoing analysis of ethnographic research with patients and their families in cancer-genetics clinics of public and private hospitals in three major urban cities in the south of the country, I explore how different articulations of cancer genetics as potential are expressed, acted on, or made viable for and by patients, their families, researchers, and clinical practitioners.² I examine the range of discourses and practices that help to sustain Brazilian cancer genetics as potential and the way that potential is expressed in terms of both a possible risk to health and as a resource for health. I show how these different meanings of potential are dynamically refracted through a variety of diversely scaled investments that mobilize individual and collective efforts to pursue and participate in cancer genetics. In exploring how the pursuit of predictive or preventative futures are enfolded with and made viable through reconfigured pasts and contingent presents, this paper contributes to recent anthropological research that has taken “time itself” as a category to be examined in life sciences (Adams, Murphy, and Clarke 2009; Fortun 2011; Jain and Kaufman 2011), particularly as this concerns developments in population and medical genetics (Abu El-Haj 2007; Helmreich 2007; Mozersky and Gibbon 2013; Nelson 2008; Palmie 2007).³

The first part of this paper examines the emergence of cancer-genetics research in Brazil at the interface with global genomic health agendas relating to population difference and genetic ancestry and the challenges entailed by the translation of biologically standardized categories of risk. While the productivity of the “not yet known” parameters of cancer genetics in Brazil is foregrounded, the potential of genetic knowledge for health and research is also articulated in relation to colonial migratory histories that highlight the possible role of European ancestry in the constitution of genetic risk. The discursive meaning of genetic ancestry as potential is also, however, made more mutable in the clinical domain, where it is refracted through notions of Brazil as a place of *mestiçagem*, or race mixture. The second part of the paper expands an analysis of the different ways that potential is being articulated in Brazilian cancer genetics by exploring how patients and their families come to and engage with its possibilities. Here the potential of genetic risk, linked to ancestral pasts as future danger, is filtered and transformed through idioms of relational

¹Recent efforts to use BRCA testing and tumor profiling to develop targeted treatments for breast cancer as part of a “personalized” approach to health care (Bourret, Keating, and Cambrosio 2013; Rios and Puhalla 2011) reflect its sustained position at the forefront of an evolving field of genomic medicine.

²This paper draws from 18 months of ethnographic research working in cancer-genetics clinics as part of a collaborative project working with genetic health professionals, patients, and their families. This work was funded by the Wellcome Trust (grant WT084128MA) as part of a project titled “Admixture, Ancestry and Breast Cancer in Brazil: An Ethnographic Investigation of Population Genetics, Disease Risk and Identity.” The fieldwork included periods of participant observation in cancer-genetics clinics and interviews and questionnaires with patients and their families and health professionals including geneticists, clinical cancer-genetics specialists, and oncologists.

³I am grateful to a number of participants at the Wenner-Gren Potentialities Workshop who drew my attention to the significance of these temporal dimensions, particularly Tine Gammeltoft, Stefan Timmermans, Karen-Sue Taussig, and Klaus Hoeyer. This paper has also benefited from discussions at the Brocher Foundation in December 2011 as part of a workshop on BRCA gene research and medical practices, particularly the comments of Martina Schundler, Susanne Bauer, and Rayna Rapp.

and temporal embodied vulnerability that reflect the plasticity of the biological and localized readings of heredity. We see also how for patients and their families the pursuit of cancer genetics is linked to different temporalities where preventative futures and the “choice” to participate in research are formulated against the immediate backdrop of precarious health-care provision. While slippages between these differently scaled investments in the emergence of Brazilian cancer genetics at the level of transnational research, clinical practice, or patient engagement reveal the power of the multivalent potentialities being articulated, their meeting points are not always enabling. The third part of the paper explores one case study where the disjunctures and fault lines in the collective efforts of patients and practitioners to articulate the potentials of cancer genetics as meaningful risk, preventative health, or as resource for research are made visible.

“Oncogenética” in Brazil

The development of specialist cancer-genetics clinics and services in Brazil has emerged in the last 10 years propelled mainly by the research interests and transnational collaborations of individuals and research teams working in mostly public or mixed private/public health hospitals in the relatively more economically developed southern part of the country. It is a location that mirrors differences in cancer incidence, with higher rates of breast and prostate cancer in the southern regions, while also reflecting the socioeconomic stratifications that have come to be a characteristic feature of genomic science and medicine (Montoya 2011, 2013). While private predictive genetic testing is available for the small numbers of the population able to pay the \$2,000–3,000 cost of sending the sample to be fully sequenced abroad in the United States or marginally less for specific mutation testing in one of Brazil’s growing private testing services, for the vast majority of the population, neither of these is an option.⁴ As a result, eligibility for genetic testing is very much tied to monies linked to transnational research collaborations between individual scientists and their research teams. However, while testing is often done through research protocols or funds, screening and monitoring of patients and their families recruited into cancer-genetics clinics are often incorporated into normal clinical routines and services publicly funded by the national program of health the Sistema Único de Saúde (SUS). Cancer-genetics services in Brazil therefore operate in a hybrid zone. 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 and knowing how Brazilian cancer genetics can be mobilized in collaboration and conjunction with transnational research agendas.⁵

It is notable that an emphasis on the “unknown” parameters of genetic risk informs and propels the emergence and development of cancer genetics in Brazil. This is often expressed by health practitioners and researchers in terms of a need to *padronizar*, or standardize, testing protocols and criteria—to know what is and is not a mutation that poses a risk for the

⁴Fierce lobbying is afoot, mostly by Brazilian medical genetic communities, to ensure that the government and private health insurers (which cover a significant portion of the growing middle class) pay for genetic testing, but this has not as yet proved to be comprehensively successful.

⁵The close relationship between research and clinical practice has been noted by others commenting on the development of BRCA genetics in other national contexts who have drawn attention to the “ethical” dilemmas this can generate (Hallowell et al. 2010).

Brazilian population. This was clearly conveyed in the remarks of a research scientist who worked closely with clinical cancer-genetics teams in a public hospital in the southern part of the country:

This is the difference here compared with the U.S., to know what is happening here with our mixed population and if we can categorize it. And if any of these categories will have a greater risk than others, or whether this risk is diluted in the mixtures that we have here ... we will need to find new tools to understand, for example, if there is a difference between a person who is 80% European and one that is only 20% or 30% European.

These comments reflect how the pursuit of cancer genetics in Brazil is related in part to clinical and scientific uncertainties about the relevance of risk categories and protocols for risk assessment developed elsewhere. But while the importance to Brazilian cancer genetics of a globalizing agenda for genetic research associated with questions of population difference and genetic ancestry is acknowledged, the comments of the biologist also raise questions about its meaningful translation in the context of Brazilian “race mixture.”

Theorizing Genomics, Ancestry, and “Race”

Social scientists have recently begun to critically examine the growing interest in human biological variation, population differences, and genetic ancestry in medical and population genetic research (Fullwiley 2007, 2011; Koenig et al. 2008; Lee 2005; Whitmarsh and Jones 2010). For some the conflation between health disparities and genetic research concerned with examining and explaining population differences in disease incidence and mortality has been and continues to be problematic, particularly in the United States. Attention has been drawn to how these developments “molecularize” categories of difference in ways that ultimately may undermine efforts to address health inequities (Duster 2005; Kahn 2006). Others argue that renewed interest in genetic ancestry (Abu El-Haj 2007) or its mapping to describe population differences in relation to continental ancestry as a form of “genome geography” (Fujimura and Rajagoplan 2011) can not easily be rendered as racial typologizing. Nevertheless, genetic ancestry is of central concern to emerging fields of pharmacogenomic research, where some researchers expect variations in disease and drug response to relate in significant ways to biogeographical ancestry profiles.

In the increasingly global domain of breast-cancer-genetics research focused on the two BRCA genes, questions of population difference have focused on the Ashkenazi Jewish population, particularly in North America and Europe (Mozersky 2012a) but increasingly also in other locales (Hamel et al. 2011; Mozersky and Gibbon 2013). Interest in population variation has also been situated in terms of identifying and describing “significant racial/ethnic variation in the spectrum of BRCA1/2 mutations” (Kurian 2010:76). For others, this research focus has also been linked to the need to extend BRCA genetic testing services to other ethnic groups, particularly in recognizing the “underserved needs” of African American and Latina populations (Fejerman et al. 2008; Joseph 2013; Oloparde 2004). Lee (2013) notes how the identification of neglected or underserved populations is tied to the technological “scaling up” of genetic research associated with new gene sequencing capabilities, which serves to justify even as it widens the need for diverse population data. In

this way, making clinical sense of the quantity and complexity of genetic information now being generated by new sequencing techniques is closely tied to efforts to make genomic knowledge accessible, meaningful, and equitable for “other ethnic groups” (see, e.g., Bustamante, De La Vega, and Burchard 2011).

Emerging anthropological research in Brazil suggests that global genomic research agendas linked to population difference and health disparities are being calibrated to local contexts in highly specific ways that reflect particular social histories and different politics of “race” or ethnicity.⁶ This includes a history of racial “whitening” in the colonial period linked subsequently to what was described as a “soft eugenics” approach (Stepan 1996), which emphasized the need to improve “population quality” through public health interventions. At the same time, since the early twentieth-century, Brazilian notions of *mestiçagem* (race mixture) have been strongly tied to national identity. It is an association that continues to be simultaneously celebrated but also more recently critiqued by those who see it as perpetuating a “myth” of Brazil as a racial democracy (Santos et al. 2009). These developments are also situated in complex ways in relation to an emerging Brazilian discourse of multiculturalism (Santos and Maio 2006). Of particular relevance is how contemporary Brazilian population genetic and pharmacogenomic researchers, in examining the constitutive genetic dimensions of race mixture in Brazil, have given genetic materiality to *mestiçagem*, thus resituating it as foundational to national identity (Suarez-Kurtz and Pena Sergio 2006). Moreover, this research is presented by its authors as a powerful critique of the molecularized “race” discourses that have emerged in the United States while simultaneously constituting Brazil’s mixed genetic ancestry as a resource for transnational and national genomic research (Gibbon, Ventura-Santos, and Sans 2011; Neto and Ventura-Santos 2011; Santos and Silva 2011).

The Specificity of the Brazilian Population

Moves to expand cancer genetics within Brazil are evolving in relation to these competing and somewhat conflicting transnational and national terrains of genetic research related to population difference. This is particularly evident, as the earlier comments of the Brazilian biologist suggested, in the way that the challenge and uncertainty of translating risk categories generated elsewhere are emphasized. These sentiments are reflected in an excerpt from recent guidelines for managing familial cancer in Brazil produced by the Instituto Nacional de Câncer (INCA):

The Brazilian population has its own characteristics due to its ethnic and cultural diversity, with regional variations, which makes impossible the application of data obtained in other regions of the world about the risks and frequency of mutations related to hereditary cancer syndromes and highlighting the need to know and characterise these mutations and optimize clinical screening in ways that consider the particular aspects of our population. (My translation from the Portuguese; INCA 2009)

⁶See Fullwiley (2011) and Whitmarsh and Jones (2010), who examine similar developments in other transnational domains.

Here the notably high (recorded) incidence and mortality from breast cancer in the socioeconomically developed south of Brazil (NCI 2012) and the regional variations this constitutes have become part of the justification for genetic research and intervention.⁷ At the same time, the presence of “ethnic and cultural diversity” also informs a discussion about the inapplicability of risk frequencies generated elsewhere and the need to characterize the particular genetic components of breast cancer relevant to Brazil, a position that directly reflects the argument of some high-profile fields of Brazilian population genetic research about the irrelevancy of genetic categories of population difference.

The emphasis on examining and addressing the “yet-to-be-known” parameters of cancer genetics in Brazil has in part fueled a research focus on identifying “founder mutations.”⁸ It is thought that such mutations might be of relevance to certain populations or might explain the higher incidence of cancer in specific regions of the country and, perhaps most importantly if identified at sufficient frequency, facilitate genetic testing both in terms of speed and reduced cost (Ewald et al. 2011; Narod 2011).

Founder Mutations and Cancer Genetics in Brazil: The Case of R337h

In the expanding field of “oncogenética” in Brazil, there has been a growing interest in a particular founder mutation named R337h and located on the TP53 gene.⁹ Researchers have begun to associate this mutation with a high incidence of not only breast cancer but a range of other childhood and adult cancers, particularly in the southern part of Brazil. Germ-line mutations on TP53 are infrequent (1 in 5,000 in the United States) but linked to a rare syndrome known as Li-Fraumeni, whose carriers are estimated to have a 90% lifetime chance of developing cancer (Malkin et al. 1990). Since 2005 a series of cancer-genetics studies have suggested that a germ-line mutation R337h is particularly common in southern Brazil. It was associated initially with a high incidence of adrenocortical cancers in children in the southern state of Parana (Ribeiro et al. 2001). Since 2007 researchers have linked the mutation to breast and other types of cancer in the neighboring southern states of Rio Grande do Sul and São Paulo (Achatz Waddington et al. 2007). While generating a good deal of controversy and debate in genetic research communities in Brazil, the state of Parana’s decision in 2006 to screen all newly born children through the “blood spot,” or “teste do pezinho,” for R337h has also revealed the high population prevalence of the mutation, found in 1 in 300 of all children screened, or 0.3% of the population (Achatz Waddington, Hainaut, and Ashton-Prolla 2009). Although this finding has been replicated elsewhere by studies investigating the high incidence of breast cancer in southern Brazil (Achatz Waddington, Hainaut, and Ashton-Prolla 2009), the prevalence of the mutation, its association with different cancers, and the likely epigenetic or environmental factors associated with its expression are all subject to ongoing research and debate. In this sense better epidemiological work seems to both complicate claims about the significance of the

⁷This demographic may in part be due to lack of available infrastructure in the poorer northeast and Amazonian areas where breast cancer cases may not be recorded or where individuals do not live long enough to be diagnosed with cancer.

⁸Founder mutations are mutations that appear in the DNA of one or more individuals that can then be passed down to other generations.

⁹See Mozersky and Gibbon (2013) for how these developments play out in relation to research and clinical interventions associated with BRCA founder mutations originally associated with Ashkenazi Jewish populations.

findings linked to the mutation and its expression pathway (as Timmermans and Buchbinder 2013 also shows) while also still holding out the hope that this will be an important contribution to an international field of cancer-genetics research.

There has also been a significant amount of interest and speculation in published papers about the origins of the mutation that would help explain its prevalence and seeming regional specificity. For instance, in a 2009 article in the *Journal of Human Mutation*, a team of Brazilian and international researchers provided a “detailed haplotype analysis” of the R337h mutation, offering evidence for a “founder effect in the population of southern Brazil.” They concluded that “the most likely scenario is that R337h arose in an individual of recent European ancestry” and that the common locus on the gene is associated with a “Caucasian haplotype” (Garritano et al. 2009:128). The article furthermore outlines how carriers of the mutation can be mapped to certain regions in the south of Brazil that are associated with the history of the *Tropeiros* and a trading route that linked cities in the southern part of Brazil in the seventeenth and eighteenth centuries associated with the influx of Portuguese to the country at that time.¹⁰ The authors of the paper hypothesize that the *Tropeiro* route is “the source of most of the original Caucasian population of the cities along this road axis” (Garritano et al. 2009).

This research has also been discussed in leading national media outlets in Brazil. In a 2009 article in the science section of the broadsheet *Folha de São Paulo* alongside the headline “Mutation Creates Explosion of Rare Cancer in Brazil,” there was a full-page outline of the discovery and research to date on the mutation R337h and its link to the high incidence of cancer in the southern part of Brazil. More than a third of the page is taken up by a historical image of the traveling *Tropeiro* and a map showing the trading routes in the eighteenth century where cases of cancer have also been identified.

The explicit use of colonial history and narratives of migration in published scientific papers (and some sections of the media) in relation to this research illustrates how historical pasts are drawn on in making Brazil’s cancer-genetics research nationally and internationally relevant. In emphasizing “European ancestry” and “Caucasian haplotypes,” this research trajectory speaks to a global health agenda about population difference where genomics and race are being made newly relevant. Recourse to colonial narratives might in this sense be seen as a form of “abductive reasoning” that domesticates present and future genetic research through the “telescoping” of the past (Adams, Murphy, and Clarke 2009).

However, these articulations of the potential that constitute Brazilian clinical cancer genetics related to the R337h mutation and questions of genetic ancestry and colonial histories are refashioned somewhat differently at the interface with patients and in interviews with health practitioners and researchers. These were domains where population genetic difference and genetic ancestry were not just made both “present” and “absent” (Wade 2010) but were themselves transformed as they were refracted through popular idioms and notions of Brazil as a place of *mestiçagem*, or race mixture.

¹⁰The article notes how the practice of *Troperismo*, of transporting resources and goods including precious metals such as gold, was considered to be historically essential to the economic and cultural development of the southern region, if not to Brazil as a whole.

It was significant that the association between European ancestry and cancer risk explored in research publications was rarely explicit in discussions with patients and families attending the clinics. When clinicians offered contextual explanations of the R337h founder mutation, they would often describe it as the “Brazilian mutation” (*a mutação brasileiro*) that was “among us” (*em nosso meio*). These descriptions appeared both simultaneously inclusive and productively ambiguous, predicated as they were on the assumption of Brazil as a place of race mixture. That is, they implied both the relevancy of cancer-genetics knowledge for all Brazilians while also not precluding the possibility of this knowledge being more relevant for a delineated region, population, community, and/or individual. Moreover, in discussions with Brazilian health professionals about the significance of research related to genetic ancestry, a sense of ambivalence was evident in how these findings might be interpreted. This was illustrated in the remarks of one cancer geneticist when I asked her what the reference to “Caucasian” that had been used in the research publications related to R337h might mean in Brazil.

The idea of Caucasian in the paper is probably in 1800 or so this single Portuguese guy came to Brazil ... and this person had the mutation and he was the one who started it off. That doesn't mean a European identity! It means that, like all Brazilians, we're some way further away from a pure European origin. Anybody who was born in Brazil and who's got at least one of the parents who are Brazilians, they know they can be anything. I know I have Indian in my blood and all kinds of identities. I don't think it [Caucasian] plays a role in Brazilian identity.

The comments of this geneticist reflect ambiguities and hesitations about the significance of the association of R337h for specific population categories that were widely shared among many health professionals. It is significant that the researcher chose to foreground how these same findings can be read in terms of evidence of race mixture and the mutability of Brazilian ancestry. Here it seems the articulated potential of genetic ancestry lies in the way it can be decoupled from an emphasis in transnational research on “ethnicity or population difference” and reattached to a Brazilian discourse of *mestiçagem*. The potential of the biological, in this case in terms of genetic ancestry, is revealed as and simultaneously becomes more “plastic.”

The next section of this paper examines how patients and their families enter into and become part of cancer genetics in Brazil, revealing how different scales of investment and meaning are enfolded into and entailed by the collective pursuit of cancer genetics. It shows how the potential for risk and risk as potential is refracted through idioms that constitute vulnerable bodies in culturally relevant ways.

Relational Vulnerabilities and the Temporal Horizons of Embodied Risk

While clinical discussions and narratives did not always routinely refer to ancestry or population difference, generational histories were often considered by patients to be agentive in understanding the potential for risk, even as genes were sometimes neither prominent in these discussions nor always considered necessary to the development of cancer.¹¹ In the three patient case studies explored below, perceptions of relationally and temporally constituted embodied risk were variously related to the moral actions, emotional

problems, and dietary habits of past generations. This reflects a terrain in which the potential for risk was configured and expressed through humoral notions of connected body selves, neo-Lamarckian ideas of inheritance, and morally, sometimes religiously, configured ideas of generationally connected personhood.

Marcia was in her early 40s. She worked in a bank and was from a large family in the rural region of the state of São Paulo. I met her in the cancer-genetics clinic of the mixed private/public hospital, although she was herself “um paciente de SUS,” a public health patient. There had been many deaths from cancer in her large family, which had been one of the first in the hospital to be identified as carrying the R337h mutation associated with Li-Fraumeni syndrome. Marcia herself had tested negative for the mutation despite recently being treated for thyroid cancer. Her initial comments suggested that although she had heard from the clinic about the association of the syndrome in Brazil with Portuguese ancestry, these were aspects that simply were not important to her.

My family knows that we are all Brazilians, but when we had the talk here one of the scientists spoke about a Portuguese guy who came here in the 1800 and said that this person had children, and these people were from São Paulo, and it could be that we were descendants of this Portuguese “Li-Fraumeni.” ... But we don’t know anyone in Portugal I think what happened then doesn’t really interest me. What really interests me is my family here now.

Like many other patients I met, what concerned her most was not the past but her own current and future health and that of her family. Nevertheless, later in our discussion she revealed how a perceived sense of relational and embodied vulnerability to cancer was tied to her family history and religious beliefs. This was how she put it:

I think it’s a way of life that people inherit, a way of thinking, lots of religion. In the same way that genetics is a family prison, we can see the same prison in the family with our great aunts and great great aunts who had cancer ... so the Bible explains and sees these sins will multiply every generation. We discovered in our family our great great grandfather was a slave master, so this is something very bad and the bible says this will go on generating consequences.

For Marcia the potential of genetic risk associated with cancer was expressed through religiously infused notions of sins being perpetuated that were associated with difficult generational family histories, in this case slavery. Marcia’s perspective was in fact closely informed by her identification with *Espiritismo*, a growing syncretic and influential religion in Brazil that emphasizes the ongoing influence and presence of past ancestors in one’s present life. As our discussions continued it became clear that Marcia’s understanding of embodied risk was connected to the consequences of emotional dynamics within the family that traversed generational histories. She saw her own cancer as stemming not only from “depression and low self-esteem” following the death of her sister but also from her family members’ “very critical, very perfectionist” attitudes. For Marcia, as she put it, all these “ways of living could be inherited.”

¹¹Discussion of regional differences did form part of both clinical discourse and patients’ narratives in the southern state of Rio Grande do Sul.

A similar rendering of embodied vulnerability was also apparent in how another patient talked of what she perceived as a causative relationship between the risk of cancer, regional cultural identity, family upbringing, and gender. Celeste was from the city of Porto Alegre in the southernmost state of Rio Grande do Sul. She was in her late 40s and worked as a health professional. She had been treated for breast cancer a few years previously and had in fact lost several close relatives to the disease. She had a young niece recently diagnosed and undergoing treatment. As a patient she had been treated at the public hospital in Porto Alegre. She and other members of her family were being screened for mutations on the BRCA genes and were awaiting news of their test results.

The question of risk and vulnerability to cancer emerged in a somewhat surprising manner at the very start of the interview when I asked her how she would describe her “ethnic” identity. She responded without hesitation in ways that moved the question far beyond my open-ended attempt at recording self-perceptions of ethnicity:¹² “I’ll tell you this in one word strict and not very generous This was always really very strong in the family from my mother’s side and my father’s side because they were both of German origin This thing of ‘well-being’ isn’t really a part of German culture you know.”

Reflecting further on this question, she pointed out that “you also have this question of gaucho culture as well,”¹³ what she described as “a very macho part of our cultural ancestry,” adding that “you can imagine this gaucho culture together with this German culture what this does to a person.” In fact for Celeste, her ancestry, described in terms of regional identification that was culturally expressed in terms of particular kinds of emotional dynamics in her family, was causally related to genetic risk. As she put it, “this cultural question interacts, has interacted, and is interacting with our genetic predisposition” (*essa questão cultural interage, interagiu e, está interagindo com a nossa predisposição genética*).

Later in the interview, drawing not only on her own knowledge of the high incidence of breast cancer in the southern part of the country and the cultural history of European migration to the south of Brazil, she suggested that, “perhaps this German culture will mean more generations of those with breast cancer They [geneticists] have to look and see who these women are who have breast cancer in the south, if they are women with German or Italian ancestry or if they are Brazilian without this ancestry.”

In both Marcia and Celeste’s cases, the dangers of genetic risk associated with ancestry, or more specifically a discourse about family history or origin, are refracted through culturally meaningful readings of risky bodies in which emotion and sentiment sediment as risk and danger across generations. It was not unusual for some middle-class patients in São Paulo to describe this concretization of anxiety or fear literally as a process of somatization. As one patient put it, “I am a person who incorporates [physically] problems; unfortunately, I’m

¹²There are particular complications regarding asking about ethnicity in Brazil that can refer to culture, ancestry, race, skin color, and/or lifestyle (see Telles 2004).

¹³“Gaucho” is a term used to define the people of Rio Grande do Sul in general but also references the lifestyle of the past rural populations of the area whose cultural and culinary traditions are still identifiable and widely known throughout the region and Brazil as a whole.

very attached to family” (*Eu sou uma pessoa que somatiza muito os problemas, infelizmente estou muito ligado com familia*). Or as another patient from São Paulo said in talking of her cancer in relation to the difficult relationships she had had with her husband and family, “I was hurt by all this ... so I had a history and this really messes with you as a person. In the end I think it really left something inside of me.” (*Eu estava magoada, entao eu acho que teve uma história e isso mexe coma pessoa. Eu acho que no fundo deixa uma coisa dentro.*)

A sense that “strong emotions,” “hurt,” “sadness,” and “depression” sometimes brought on by the loss of loved ones or emotional difficulties between relatives across generations could leave one exposed to diseases such as cancer was common among many patients I met. These readings of the vulnerable body as subject to the emotional vicissitudes of both distant past and present social relations within the family have a particular resonance in the Brazilian context as suggested by anthropological work exploring the significance of folk illnesses such as *nervismo* and the growth of *psi* culture (Duarte 1986, 2000; Rebhun 1994). At the same time the ways that emotional difficulties leave residues of embodied risk across generations also evoke very particular notions of what might be described as neo-Lamarckian inheritance, as another patient’s experiences illustrate.

Fabio was a truck driver in his early 30s living and working in Porto Alegre. He had recently received news that he had tested negative for a mutation that had been identified in several members of his family, where a diagnosis of Li-Fraumeni had been made. At the start of the interview, talking about his experiences at the cancer-genetics clinic he told me,

I already came in thinking I wouldn’t have anything, you know. Because I’ll say this, me and my middle sister, who I think also doesn’t have it, we’re *more* of a brown color, the color of our mother, so I knew we’d have nothing to do with it. But my older sister Andrea she’s *more* like my father, lighter, whiter Those descended from my mother are descendents of *Bugres* and those from my father are Italian I’m *more* on the *Bugre* side. Because my father was *more* of a big white guy, much whiter, my sister, well you saw her—a white girl, and me and my mother and my middle sister have this dark skin which doesn’t age so easily.¹⁴
(Emphasis added)

My initial reaction to these comments was that Fabio was clearly talking about ancestry, articulated through common usage of skin color categories, including more colloquial terms such as *Bugre*. Following his initial comments, I asked him directly if he felt that “ancestry” was one of the factors for the cancer in the family. He responded immediately and emphatically, saying that “no I don’t think it’s because of Italian ancestry” even as the conversation returned once more to his perceptions of who in the family he was more physically linked to. He concluded, though, by saying, “I think it’s all about food ... because what happens, well, the Indians, they grew what they eat and didn’t eat pesticides or

¹⁴*Bugre* is, generally speaking, used as a pejorative term or in a semijoking way to refer to the category of indigenous or Indian populations in Brazil. It is also often used in the context of day-to-day comment on skin color: “*sou meio Bugre*” (I’m kind of Indian). As an expression it is also popularly associated with a certain character of recalcitrance and resistance.

chemicals, so that's what happens, and so all my mother's side are *Bugre*, they're all nearly Indian."

For Fabio, being "more on the *Bugre* side" of the Italian/*Bugre* mix in his family offers protection and explains to him why he does not have the mutation. Yet his comments suggest that while bodily markers such as skin color are signs that foretell or in this case retrospectively confirm the test result, these do not always directly or straightforwardly connect to ancestry. They may also encompass other ideas of heredity associated with acquired cultural behavior or habits linked, in Fabio's case, to the diet of his perceived ancestral past.

Genetic risk has long been shown to be complexly related to ideas about lifestyle, diet, and environment in the narratives of different patient communities caught up with predictive genetic intervention. The three experiences presented here illustrate how genetic risk is made meaningful through interrelated ideas about bodily vulnerability, *mestiçagem* as both difference and similarity, and what might be perceived as Lamarckian notions of intergenerational inheritance. These ideas transform and inform the meaning of genetic ancestry articulated as potential. They reveal a mutability and plasticity in how risk is inferred from bodies, the meaning of the biological and the significance of generational pasts, in ways that extend and raise new questions about the molecularization of population difference or genetic ancestry. In newly emerging fields of genomic science and medicine—where the interactions between lifestyle, environment, and epigenetics are becoming increasingly important in understanding the causal disease pathways of cancer—it will be vital to monitor and understand how old and new understandings of the biological transform definitions of disease risk and the potentials they help articulate (Lock 2012). This will be particularly important as efforts expand to ameliorate these biosocial risks through both technologized and other lifestyle-focused health interventions across national and transnational global health-care arenas.¹⁵

Living with the Potential of Cancer-Genetics Research as "Choice" for Cure and Care

While for some patients, participating in newly formed domains of Brazilian cancer genetics was connected to the lives and legacies of past generations that articulated the potential for cancer risk in particular ways, for the vast majority of patients, other temporal possibilities were important. These included the hope of realizing certain kinds of preventative or curable futures and negotiating contingent, often precarious presents in terms of access to public health care. Such desires reveal a different domain for the articulation of potential in the collective work of producing cancer genetics in Brazil, where questions of "choice" and the moral responsibility of individuals, families, and the state come to the fore.

The conflation between participating in research and prevention of disease was widespread among patients I met. It was a conflation that could easily render decisions to participate in

¹⁵Emerging epigenetic frameworks for understanding the role and function of R337h in the Brazilian cancer-genetics context as linked to metabolic function and "oxidative stress" may provide an entry point for exploring how popular understandings of embodied vulnerability are reconfigured at the interface with novel genomic approaches and evolving understandings of cancer etiology.

cancer-genetics research as moral obligation to act for oneself and others, as the comments of one of the female patients I met illustrated:

You have to speak to everyone and say that you have to take care, everyone has to have prevention. I've always said this. My sister said, "do you want to go [to the genetics clinic]"—I said, "I do!" I've already convinced my daughter. So the first one came, then me and my sister, my niece, then my daughter, and we've already got the results of the four of us, and we started passing it onto others. Not everyone in the family wants to do the test Of course it's individual, but I think it's selfish [*egoísmo*] not to do this. Because of your own fear you are losing the opportunity to have care, and then it could only be a short time and you could find your child here [with cancer].

The notion of taking responsibility through caring for others has been identified as a strong motivating factor in the narratives of breast-cancer-genetics patients in other cultural settings (Hallowell 1999; Kampriani 2009; Mozersky 2012*b*). In Brazil the cultural significance of the family and the ties or obligations this entails are strongly forged through and inform investment in genetic interventions reflecting and demanding certain kinds of ethical relations to others and future generations. The strength of this alignment is reflected in how the "choice" not to participate in research can be seen in terms of being "selfish" (*egoísmo*). As another patient put it, talking of her decision to go ahead with the offer of having a genetic test, "I have family, I have children, I can't not do this."

For many the promise of genetics was also directly tied to imagined and hoped-for scientific progress in the prevention of cancer. This was clearly expressed in the retrospective imagining of the future history of genetic science, health, and the family that this patient described in talking about her participation in the cancer-genetics clinic: "I think it's prevention and one day we could have a vaccine. I really think that for this mutation, those little numbers, there will be a vaccine I think my grandson will say, 'my grandmother had this mutation and in those days they didn't know what it was but these days we know what causes cancer'" (Sonja, age 50, sales assistant, São Paulo).

Yet for many, being "disciplined" by future scientific promise of medical progress that genetics appeared to offer was also closely linked to their own and often their families' more immediate efforts to secure basic health needs. That is, participation in genetic research was often not just about imagined futures but also about negotiating the everyday trials and challenges of public health in Brazil and the possibility this held of accessing care in a more immediate sense.

This was evident in the way Marina described the difficulties she had experienced in accessing health care and her relief, as a result, of being part of a program of care through participation in cancer-genetics research:

When you manage to get a consultation with the doctor, you're relieved, but to arrive here you have to go through tremendous bureaucracy, queue for hours. In other hospitals you have to wait nearly 1 year to do a mammogram or 8 months for meeting with the doctor—the problem is getting in here [referring to the hospital

associated with the cancer-genetics research]. Once you arrive here everything's a blessing [*tudo e a abençoada*—the problem is getting in here. (Marina, age 43, cleaner, Porto Alegre)

Marina tested positive for the R337h mutation associated with Li-Fraumeni a few years ago and was now part of the program of screening and care linked to the cancer-genetics clinic at the mixed private/public hospital. Powerfully revealing what this meant to her, she said, "I feel protected, I have screening, and if I have a problem I know that I can have chemotherapy or surgery I don't have the words to describe how grateful I am to you for all that you are doing here."¹⁶

These sentiments were shared by many patients who simply felt relieved that by participating in the genetic research protocol provided by the hospital they had access to regular screening and specialist health care. Others saw their participation not only as a short- or medium-term investment in their own or their relatives present/future health but as a beneficial collaboration where advantage was gained in being, as one patient put it, "a guinea pig in the cure for cancer." As another patient said, the logic of "helping others and helping ourselves" was obvious, especially when, as she pointed out, "it doesn't cost anything to collaborate."

The ways patients engage in efforts to secure access to care and resources through participation in cancer-genetics research starkly reveal the different scale of investments that constitute an expanded space of possibility for cancer genetics in Brazil. This has clear parallels in the kind of crafting of rights and responsibilities that Adriana Petryna (2013) describes, where participation in clinical trial research is closely linked to patients' efforts to pursue the "right of recovery" in contexts of scarce resources. Cancer genetics, in its clinical emplotment of future (as well as past) health risks for oneself and others, may make reaching that point of "recovery" somewhat elusive. Nevertheless, the immediate benefits in terms of access to health services suffice for many patients, even as such participation fuels moral injunctions to act on the potential choices for care and prevention that involvement in research would seem to afford and continuously demand. In the final part of this paper, I explore some of these tensions further, focusing on one patient's experiences. In this case, uncertainty generates not potential but instability and unproductivity, illuminating what might be described as the hidden presence of the "uncanny" within the landscape of cancer genetics.¹⁷

Uncertainty and the Stasis of the "Unknown Variant"

When I met Christina she was 45, worked in the legal profession, and had been a patient in the hospital in São Paulo for over 10 years following her diagnosis of breast cancer. She had been one of the first to be recruited into a program of cancer-genetics research in the hospital. Despite this long involvement, she had only just received her BRCA genetic test result, which had been described to her in the clinic as an "unknown variant" (*a mutação*

¹⁶The inclusion in her expression of gratitude of myself and, by extension, the qualitative research in which she was also participating raises important questions regarding the role of the anthropologist in collaborative research and the need for reflexive consideration of how anthropological vantage points may themselves facilitate or be co-opted by broader research agendas.

¹⁷The place of the uncanny in thinking about potential was usefully raised by Emily Martin at the Teresópolis workshop.

desconhecida). This result, also known internationally as a variant of unknown significance (VUS), signifies that a change in the “normal” DNA sequence had been detected but is not recorded as being “deleterious,” according to a (US-based) international database. While the boundaries between a VUS and a mutation are constantly shifting as new BRCA testing expands to include diverse patient populations, such test results are particularly common among “ethnic minorities” (Nanda et al. 2005). Christina’s frustration was obvious on hearing the clinician’s explanation that while the result was not particularly useful now, it might in the future prove to be explanatory for her cancer and/or the cancer in the family when, as the clinician put it, “more was known about the situation in Brazil.” Talking to me later about what this result meant for her and her family, she said,

I wanted to know about the possibilities for my daughter, my nieces, to see if they have a risk, so that they could do what was necessary [*providencia o que o necessário*] I participated in the kind of research that they don’t have here in Brazil, or that’s what they told me anyway; it’s a speciality of the US where they have more resources But with what has happened now ... I’ve got this part here that says that this finding doesn’t exist ... that says there is no connection or at least there isn’t in Brazil. So I was left really frustrated by this; it’s an answer that leaves me the way I was, still am, without an answer. But on the other hand, she’s telling me that there is a possibility that my cancer could be hereditary. When I started participating in this research, I felt more secure, but now I’m back to square one.

While the uncertainties of what constitutes genetic risk at the level of the Brazilian population drives the pursuit of transnational and national research, in the clinical domain such uncertainties could, as Christina’s comments suggest, generate stasis and frustration. That is, the materialization of this uncertainty (as a VUS) often made it difficult to constitute cancer genetics for patients (and practitioners) in terms of the potential for prevention in the future or as a “choice” to care for others. Instead, uncertainty generates an “excess of meaning.” As Svendsen (2011) points out in her examination of how potential is articulated and constituted in relation to human embryonic stem cell research in Denmark, such moments of “excess” in meaning make visible lines of fracture in the collective yet differently constituted investments and engagements of patients, families, and health professionals. In Christina’s case we see how uncertainty can “cut” the flow of potential linked to the collective pursuit of cancer genetics as preventative health.¹⁸

The patient narratives explored in the second and third part of this paper illustrate how a variety of different potentials are articulated in becoming part of the temporal and preventative logics of cancer genetics. These speak of imagined and hope-filled futures, the precariousness of present-day public health, but also the relational and embodied legacies of family history that at the intersection with a discourse about genetic risk (re)constitute or affirm particular kinds of interrelated embodied vulnerabilities, susceptibilities, and dangers. Collectively these examples point to the different scales of investment through which cancer genetics is being powerfully yet also often unevenly mobilized.

¹⁸I am drawing here on the contributions that Bob Simpson made in Teresópolis about the way flows of potential can be “cut.”

Conclusion

This paper, drawing from ongoing analysis of fieldwork in southern Brazil examining the emergence of cancer genetics, contributes to a growing body of anthropological research examining how novel and increasingly transnational developments in the life and medical sciences are being calibrated to local contexts in highly specific ways. It responds to a need for anthropological engagement that takes account of the inequitable terrain in which global and globalizing health technologies are translated and the various “regimes of living” (Collier and Lakoff 2005) they entail and reproduce (Biehl 2007; Fassin 2009; Petryna 2013).

As a “test case,” BRCA genetics and cancer genetics more generally would appear to embody and represent the kind of anticipatory and promissory futures that have come to powerfully characterize other parallel developments in the life and medical sciences (Adams, Murphy, and Clarke 2009; Fortun 2011; Jain and Kaufman 2011). However, cancer genetics does not hold a given or innate potential but depends on local translations of the technologies and knowledges in light of different, competing, and sometimes conflicting articulations.

Potential is expressed and given meaning across different scales of investment and involvement in this emerging domain of scientific knowledge and medical practice in Brazil. It is expressed and acted on in relation to hope-filled futures of progress, contingent and precarious presents, (re)imagined national histories of migration, colonization, and embodied vulnerability as generationally constituted. Parsing how risk, research, care, and knowledge are constituted and the ways that practitioners, researchers, patients, and their families come to and participate in Brazilian cancer genetics, we see how the meaning of potential is made multiple and dynamic.

While a global health research agenda relating to genetic risk and questions of population difference and ancestry would ascribe immense power to the potential of cancer genetics, this is diversely translated and acted on by Brazilian patients, researchers, and clinicians. That is, the meaning of genetic ancestry and cancer genetics more broadly is subject to “transformations” that both make the potentials at stake literally and metaphorically more plastic. We see this in the way that Brazilian cancer-genetics research focused on European ancestry becomes something that reflects transnational research agendas and simultaneously confirms Brazilian *mestiçagem*, productively and inclusively repositioning the focus on genetic ancestry in the clinic. Such transformations are also evident in the way that genetic risk is displaced by patients and made contingent on embodied and interrelated vulnerabilities that evoke different models of inheritance. At the same time, the potential of cancer genetics in Brazil is put to work in relation to questions of “moral” individual and collective choices or rights to participate in research or in accessing care. This reveals the extent to which for patients, participation in cancer genetics is not only about promissory futures but often negotiating and ameliorating the immediate contingencies of public health-care provision.

The translation of emergent fields of knowledge and technology such as cancer genetics in Brazil is highly dynamic and contingent. This paper suggests that it is a process that enfold different meanings of potential that are scalar in how they are produced, the actions they entail, and the ways they powerfully yet unevenly interpolate diverse persons in the hope-filled making of future histories of and for Brazilian cancer genetics.

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