Anthropologies of Cancer in Transnational Worlds

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Chapter 3

Anticipating Prevention: Constituting Clinical Need, Rights and Resources in Brazilian Cancer Genetics

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3 Anticipating Prevention

Constituting Clinical Need, Rights and Resources in Brazilian Cancer Genetics

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The ubiquitous promise of personalized medicine associated with developments in genetic research, including the field known as breast cancer genetics, has long been grounded in an assumption that this knowledge will facilitate the movement towards individualized and targeted treatment based on knowing a person's genotype. Despite emerging possibilities for using knowledge of the two well-known inherited susceptibly genes, BRCA 1 and 2, in the treatment of sporadic cancers (see Bourrett, Keating & Cambrosio, 2014), this promise has been limited for the most part to the possibility of providing a personalized risk susceptibility estimate based on genetic testing to detect mutations on these genes. The normalization of the *anticipatory habitus* (Joseph, 2014) associated with predictive interventions related to new fields of clinical intervention such as breast cancer genetics is reflected in the growing incorporation of genetic testing for breast cancer as a standard of care across diverse fields of public and private health care, particularly in North America and Europe (see Gibbon et al., 2014). The announcement in 2013 by actress Angelina Jolie that she had undergone a prophylactic mastectomy following a positive result for a mutation on the BRCA genes provides a striking and very public example of this rationality in action, which as this chapter will illustrate, continues to have repercussions in many diverse cultural contexts, indirectly and directly informing the expansion of predictive interventions for cancer.[1]

The terrain on which genetics operates means that the promise of personalized medicine now coexists alongside an emerging field of public health genomics (Bauer, 2013; Brand, Brand, & in den Bäumen, 2008; Taussig & Gibbon, 2013). This is changing the boundaries of how and where genetic knowledge is being made relevant to health care as well as the parameters of what is described as a preventative approach to cancer. Genomic research is now directly tied to large-scale epidemiological studies for communicable as well as noncommunicable diseases. At the same time, newer and faster sequencing techniques and technologies, which enable thousands of mutations to be rapidly identified, are informing and propelling novel terrains of genetic and epigenetic research in relation to cancer and other diseases. Questions of human biological variation and population differences have

also reemerged in recent years as central to, if problematic and evolving dimensions of, public health genomics. Some suggest that the turn to public health is about reenergizing a field of science that has failed to live up to expectations (Whitmarsh, 2013), helping to extend its importance and relevance (Lindee, 2013). However, as Karen Sue Taussig and I note elsewhere, also of significance is the "social action set in motion by researchers seeking to translate genomic knowledge and technologies into public health" (Taussig & Gibbon, 2013, p. 3).

Social science research has begun to examine the way that a range of high-end medical technologies are now being unevenly translated across diverse terrains of global health care delivery, such that these often coexist and are made available to patients against a backdrop of precarious public health care or a lack of basic health resources (Bharadwaj & Glasner, 2009; Biehl & Petryna, 2013). In such cases we see how hopes for and investments in medical technologies are being invigorated, even in arenas where there is a ubiquitous scarcity of other health care resources.

One striking example of the expanded terrain of specifically genomic health care is evident in the incorporation of some aspects of breast cancer genetics into public health in countries such as Cuba, as I have explored in previous research (Gibbon, 2009, 2013a). Nevertheless it is important to note the selective and partial nature of these developments, which often take place alongside a discomfort about and recognition of the difficulties associated with translating the potential of genomic interventions into health care, particularly in terms of the promise of personalized medicine. What has been described as the "absent presence" of predictive genetic interventions associated with an increased risk of breast cancer has also been noted by others in contexts such as India and Italy (Gordon, 2014; Macdonald 2014; see also Kampriani's work on Greece, 2009). In these domains, concerns about the lack of basic clinical care for those with breast cancer and/or the irrelevancy of predictive interventions, in the light of often scarce resources, directly and indirectly informs diverse responses to and engagements with novel fields of health care intervention and technology. Despite these concerns, high-profile technologies such as breast cancer genetics have now become part of transnational fields of research carried out in relation to diverse and highly variable public health care provision (Gibbon et al., 2014). Such developments reflect and also fuel the extremely fluid relationship between research and care that has, as Hallowell and colleagues (2010) note, been a particular feature of cancer genetics.

Anthropologists who explore the now broad global terrain of clinical trial research have consistently demonstrated how participation in research is a process that can constitute subjectivity and citizenship in ways that both include and exclude (Biehl, 2007; Nguyen, 2010; Petryna, 2009; Rajan, 2005). Although inequities characterize these social relations, participation in clinical trial research can also become a strategy for obtaining medical care (Biehl, 2007; Fisher, 2009). In this way ancillary care has the potential

to become an expression of the ethical variability (Petryna, 2009) of the global outsourcing of clinical trials. Marissa Mika (2013), exploring the social repercussions of global clinical trial research on the practice of oncology in Uganda, also points to the way that such research can become a resource for wider communities of health care professionals and practice.

This chapter examines how, in the context of Brazilian cancer genetics, research becomes caught up with constituting clinical need, rights and care. It explores the uneven and disjunctured ways that research on cancer genetics in Brazil is framed and reproduced as a resource. I show how patients and practitioners engage with and are constituted by predictive and risk-reducing interventions resulting in diverse forms of patient/professional activism. My goal is to shed light on the sociocultural dynamics and tensions by which prevention, public health and clinical need are being calibrated at the meeting points *and* interstices between global cancer genetic research, the limits of public health as well as its pursuit as a national imperative and the rising incidence of cancer in Brazil. In this way I illustrate how global research trajectories, propelled in part through an emphasis on genomics as a form of preventative public health, inform local clinical practice at the same time that inequities in the Brazilian health care system comprise and propel the pursuit of cancer genetics as both a right to health care and a resource for research.

The data discussed and presented here draw from 18 months of ethnographic research carried out in three urban locales in the southern region of Brazil, including periods of participant observation in cancer genetic clinics, interviews and questionnaires with patients and their families, and also interviews with medical practitioners and scientists in cancer genetic clinics linked to public and mixed private/public hospitals including cancer genetics specialists, oncologists, mastologists and biologists.[2]

ONCOGENÉTICA IN BRAZIL: BETWEEN UNMET NEED, RESEARCH AND PUBLIC HEALTH

The appearance of *oncogenética* or cancer genetics in Brazil is a recent development emerging in the last eight years partly in response to the high national incidence of cancer. Brazil has over 50,000 newly diagnosed cases of breast cancer each year, a rate that is comparable to the US population. According to the *Instituto Nacional de Câncer* (INCA, 2014) linked to the Brazilian Ministry of Health, based on data gathered from population registries, there are also regional differences in the incidence of cancer with the highest rates of breast cancer reported for the southern states of Brazil (see also Lee et al., 2012, p. e96). Whereas some northern states and cities are reported to have an incidence of breast cancer that is 10 times lower than some of these southern regions, the northeast and north have significantly higher rates of incidence and mortality from cervical cancer (Azevedo & Silva, 2010) .

There have been recent efforts to address rising rates of breast cancer in Brazil, including legislation in 2009 by the Brazilian Ministry of Health to recommended mammography screening every 2 years for all women between 50 and 69 (and at 35 years of age for those with a family history). However, limited data suggest not only that the infrastructure for providing mammograms are starkly different between northern and southern regions, but overall national mammography screening rates remaining substantially lower than WHO recommendations to screen over 70% of the population, with doctors in Brazil reporting that 80% of breast cancer cases are identified and brought to their attention by patients (Lee et al., 2012; p. e96). Moreover a recent Brazilian study examining breast cancer outcomes across different regions in Brazil found that women who received public health care had more advanced disease, less access to modern health care and treatments, and lower survival than those treated at private institutions (Simon, et al., 2009).

These disparities in access to and provision of breast cancer services reflect the broader complexities of public health provision in Brazil. The constitutional right to health emerged in post-dictatorship Brazil, informed by the efforts of various social movements to democratize health care. Nevertheless, the changes that this brought about have been contradictory and uneven (Biehl, 2005; Edmonds, 2010; Sanabria, 2010). About 75% of the population has access to health care only through the public health care system or SUS (Sistema Único de Saúde), with the rest of the population making use of health plans and insurances.[3] At the same time, the availability and relative affordability of health insurance for the middle class has meant that many choose not to use public services, seeing them as offering substandard care, a process that Faveret and Oliveira (1990) describe as "excluding universalism." Nevertheless, there is, as Sanabria (2010) in her examination of hormones and public health in Brazil points out, a great deal of movement of doctors, patients and protocols between private and public health care domains.

Some of that movement is reflected in the context of cancer genetics in Brazil, which is nevertheless emerging mainly in the relatively wealthy southern regions of the country. With genetic services not currently covered by the public health care system, cancer genetics operates in something of an interstitial space between research and public health. That is, it is practiced at the meeting point and gaps between the research activities of individual Brazilian researchers or their teams involved in collaborations with other scientists in the United States, France and Portugal, and precarious and limited public health interventions including screening or monitoring interventions such as mammography.[4] In this way, Brazilian cancer genetic services, situated by those who work in the field in Brazil as a *preventative* approach in a context of scarcity and limited resources, is mobilized and enacted in part through globalized clinical and transnational research collaborations.

The first part of this chapter explores some of these dynamics from the perspective of health care practitioners and scientists. It shows how the

activism of these individuals within cancer genetics must be understood and rendered explicit as it serves to constitute clinical need, situate and extend research priorities in relation to transnational research collaborations, and provide care as part of a neglected preventative approach in a context of limited resources. The second part of this chapter examines the experience of patients who participate in, and in some cases pursue the *right* to what is perceived as preventative health.[5]

ACTIVIST PRACTITIONERS: UNKNOWN RISK AND THE POLITICS OF PREVENTION

There has been growing attention to population difference in genetic research tied in part to the emergence of public health genomics. That is, as testing widens across a global terrain it reveals gaps in medical knowledge based on databases of known mutations in previously identified risk populations in national contexts such as the United States, Canada and Europe. This fuels and informs a focus on identifying variation on the *spectrum* of currently unknown mutations that might be implicated across different national contexts as part of the pursuit of public health genomics. For some this has been described as linked to an emerging trajectory associated with the pharmaceutical industry of niche marketing (Lee 2005). Others point to the tensions this has generated in the way that the so-called underserved needs of neglected groups and populations are being reformulated in terms of both a resource and right to research and care. As Rayna Rapp (2013) points out "multiple publics have become part of exquisitely stratified research populations that now serve as potential global resources and market beneficiaries" (p. 574).

As I have explored elsewhere, moves to expand cancer genetics in contexts such as Brazil are emerging alongside and in tension with transnational research agendas linked to population difference (Gibbon, 2013b; Mozersky & Gibbon, 2014). Within Brazil, an emphasis on the *unknown* contribution of genetic risk in understanding the rising rates of cancer in the country reveals the limits of international standardized risk models and fuels the pursuit and activism of practitioners caught up in Brazilian cancer genetics framed in terms of finding more appropriate local estimations of genetic risk for the Brazilian population. In practice, however, efforts to identify the particular genetic aspects of the Brazilian population that may be relevant in terms of genetic ancestry and establish the relevance (or irrelevance) of certain mutations linked to an increased risk of cancer can involve both the incorporation and simultaneous rejection of categories of race and ethnicity (Mozersky & Gibbon, 2014; see also Santos, Silva & Gibbon 2014).

Nevertheless, putting into practice Brazilian cancer genetics and constituting it as clinical need are closely tied not only to efforts by practitioners to attend to as yet unknown national parameters of population difference, but also to a moral economy that conceives of cancer genetics as prevention.

Such moves parallel broader shifts in the way that a focus on population difference, particularly in the field of BRCA genetics, has been constituted as a movement towards prevention.[6]

This was evident in the way one young trainee cancer genetic practitioner in Sao Paulo passionately described the necessity of cancer genetics in Brazil.

> Why do we need this? Because we see the importance when you interview a family that has multiple cases of cancer in the family and understand the desperation of those families when they ask, "what should I look for?" "What should I do?" "Who's going to help me get early screening for my daughter, for my sister?" Because of this, it's vital that Brazil has in its public health system, cancer genetic clinics to try and help these families, and to have in our Brazilian statistics understanding of the genetic diseases that we are transmitting to our families . . . the populations going to grow and develop and transmit these mutations, so we have to know how to deal with this in the long term.

Here we see how an emphasis on attending to underserved populations who do not have access to basic health services is entwined with the perceived need to understand and gain knowledge about Brazilian statistics related to genetic risk as part of an emerging preventative approach framed in terms of having access to early screening and care for those at risk in the family. Such sentiments were reflected in the comments of another practitioner who described cancer genetics in terms of "protection for the family," stating that such individuals could have "a higher risk of having a tumor." Likewise, she added "I really think that cancer genetics is prevention."

For many of those who worked in the cancer genetics field there was a great deal of frustration associated with trying to ensure those who had been identified as being at risk were offered appropriate *preventative* interventions. In the mixed private/public hospital where I worked in Sao Paulo, I frequently witnessed the convoluted tasks that nurses and geneticists engaged in trying to ensure all those potentially at risk in the family were able to obtain extra screening once a family member had been identified as carrying a mutation. When one person had a *convenio* or private health insurance that covered certain kinds of interventions such as extra screening but others in the family did not, doctors and nurses skillfully maneuvered between the limits of the public health system, research protocols, hospital provision and the rules and regulations of different health insurers to make every effort to ensure that as many family members as possible were able to obtain screening.

The logic of cancer genetics for health for many of these professionals was evident. They emphasized not only the moral economy of prevention in terms of care for the family but the cost–benefits of cancer genetics to identify those at risk compared with the cost of treating those who developed breast cancer. This was how one geneticist in Porto Alegre put it,

> If you have a family who [has] every likelihood of carrying a BRCA1 and BRCA2 gene, it's much simpler to test and know who has the mutation and who doesn't, rather than to screen everyone. If you imagine that 50% have the mutation and 50% don't, for at least half of those you don't have to do anything and that's a saving. The problem is the issue of compromising. I'm seeing a family today that needs the test that I can offer but it's very expensive; *SUS* doesn't offer this. But what happens if I leave it there and not worry about this and pretend there isn't a problem? . . . I just can't for another ten years keep doing research to offer testing . . . with care being something peripheral that [is] just tacked on the side.

In this instance it is not only the logic of cancer genetics as public health and prevention that is articulated, but also a frustration engendered by attempting to manage a clinical service that is ultimately dependent on research funding. Nevertheless, it is important to note that the idea of creating cancer genetic services within public health as part of a preventative approach was not supported by all health professionals I met in Brazil. In one public health hospital where I discussed this possibility with those who worked in the broader field of mastology (a health care specialty focused on breast health), there was considerable doubt about the value of cancer genetics in a *SUS* hospital. One of the mastologists began our interview by pointing to the very same challenge that the Brazilian cancer geneticists had identified, the lack of knowledge relating to the relevance of current knowledge about genetic risk for the Brazilian population. As he said, "there isn't a study of the Brazilian population on wide scale as yet that says what size of the Brazilian population is affected whether its 5, 10 or 15% genetic risk—that data doesn't exist."

But he also by contrast drew stark attention to the costs associated with such interventions:

> It [genetic testing] is just not very common here [referring to the public hospital where he worked] because this involves costs. A hospital like this that looks after essentially a socially insecure population doesn't provide this because of the costs involved in these kind of tests, if they were available and used more freely.

Relating this situation back to the lack of knowledge about cancer risk in Brazil he continued:

> If you don't have the criteria, you start to waste money and here we don't have money to waste . . . perhaps there are other priorities that should be addressed and would help lessen the impact of a particular disease . . . we have to select where we are going to invest our money, resources and materials . . . so I think we still don't have a justification

> for having a big national program that would involve lots of human resources. The test isn't certain even, it just says whether you have a risk or chance of having it or not so perhaps sometimes we are creating problems that we can't resolve and for which we can't really offer a very good solution.

In this case, the moral framing of cancer genetics as prevention is contested and brought into question in relation to the unknown component of genetic risk in Brazil and the cost of such interventions in resource-poor contexts. For some medical professionals (in this case those working in a related specialty that in fact prides it itself on adopting a *holistic* approach to breast health and the treatment of breast cancer), cancer genetics sits outside the realm of public health care and prevention due to both cost, unknown relevance and the uncertainty that it intervenes upon and also generates. This points to the limits of practitioner activism highlighting greater variation and diversity in the affective framing of cancer genetics as prevention across diverse domains of breast cancer care within spheres of public health care provision in Brazil.

ACTIVIST PRACTITIONERS AND *ROAD TRIPS*: THE PURSUIT OF RESEARCH AND PREVENTION

Events that provided some informative ethnographic insight on how the *activism* of cancer genetic practitioners facilitated the productive conjunction between participating in global research agendas and pursuing cancer genetics as public health were what were described as *road trips* made by some of the researchers I met. These were often undertaken by teams of the local and international cancer genetic researchers and health professionals to the interior and rural parts of the southern states of the country, as they engaged in efforts to seek out and identify individuals and families affected by hereditary cancer syndromes.

I accompanied one group of health professionals to the interior of the state of Sao Paulo to meet with an extended family who had experienced many cases of cancer, and recount some of that event in the following excerpt from fieldnotes:

We arrived early one morning in a rural region at the family home of one young female patient in her mid-20s who had been treated some years earlier for cancer at the hospital in Sao Paulo. Sonja was a student in Sao Paulo but had a large family in the interior of the state, which she had returned to on an overnight bus to meet us early in the morning at her aunt's house. It was in this moment, noticing the slight anxiety of Sonja as she watched and greeted family members as they arrived, that it became clear how she had been a central figure in the gathering of her relatives to meet the cancer genetics team as aunts, uncles and young relatives arrived at the entrance to the

house. Giving an impromptu talk to the families the practitioner described the visit in terms "a chance to participate in research" and "a way of preventing cancer in the future" and also a "an opportunity to see who is at risk so that they can be offered treatment in Sao Paulo." She added that it was not, of course, obligatory to participate in the research, which was totally voluntary. Later I was told by one member of the team that it was unlikely that many of the family had convenios or private health insurance and living in a rural part of the state were, as a result, without easy access to health care services such as routine basic health care screening. While not explicitly stating that being involved in the research was a means to secure routine preventative screening from the hospital in Sao Paulo it seemed from these remarks that, from the point of view of the health professionals involved, this was perceived as an indirect benefit of participating in research.

Sitting in the make-shift space for collecting blood samples for research, which had been set up in one of rooms alongside the nurse, it was obvious that many of the preoccupations of those who agreed to donate blood for research were related to more immediate health care problems rather than the future risk of cancer per se. One elderly relative had a lot of pain in her neck and she asked if she should see someone in the hospital in Sao Paulo. The response of the nurse in this instance was not to be concerned for the moment about these health problems as the first thing to do was to find out if they were carriers of the mutation that Sonja had, pointing out that if they also carried the same mutation then they would be able to have access to more investigations. It seemed then from what the nurse was saying that a preventative approach was therefore predicated on the necessity through research of identifying those at highest risk.

The steady flow of relatives willing to donate blood and participate in the research generated a good deal of energy and enthusiasm among the researchers. In the car on our return there was much excitement that they had been able to collect so many samples in one visit and discussion about whether this would enable to them to map further clusters of cancer in the region as they had already done with a number of other families. But there was also some discussion of the social context of the family and, given the lack of access to health care through private health insurance, the extent to which other family members might through research protocols be encompassed by the care provided under the aegis of the cancer genetic research protocols at the hospital. There was in fact heightened awareness that this was essentially precarious, predicated on continuous funding from international collaborations and the ongoing willingness of the hospital to include at risk family members, not just those with cancer, in the hospital's protocols for screening interventions.

The events such as the road trips say much about activism on the part of these professionals. I would argue that these are not entirely explainable in terms of a perspective that views them as examples of the exploitation of vulnerable communities simply for the purpose of research collaborations

and publications. There are both moral and affective dimensions associated with practitioners' efforts to pursue cancer genetics as public health via collaborative transnational research. The seeking out families in this way was not then *only* about furthering research ends, or simply identifying those at most risk, but was also about facilitating access to basic health services in efforts to meet what these practitioners perceived as the neglected broader goals of a preventative approach to health care. Nevertheless, as the road trips make clear, the role of patients in facilitating and mobilizing cancer genetic research as prevention is also central. In the final part of the chapter I turn more directly to examine the experience and perception of patients engaged with cancer genetic research in Brazil.

A LONGING FOR CARE AND THE RIGHT TO HEALTH

Only a handful of the vast majority of patients I met while carrying out research in three urban centers was able to muster the $2–3,000 necessary to pay for a genetic test. Most had arrived in the cancer genetic clinics following referral by a family member who had been treated at the hospital for cancer and were for the most part *SUS* patients.[7] As a result, their own and their family members' eligibility for testing was, for the most part, tied to a specific study protocol. Many were waiting for test results but as part of a program of research were also in receipt of other basic screening and health monitoring services. For many of these individuals simply being within the parameters of the hospital's care through participation in research was perceived as prevention. As one middle-aged female cancer patient who had had breast cancer but was now part of a study protocol relating to research on the two BRCA genes put it, "this works as prevention . . . if there was more of this type of research perhaps persons wouldn't arrive with cancer as it was in my case." Referring to her children she added:

> My daughters will now have much more care, they will be examined much earlier, perhaps have preventative screening much earlier and perhaps not come having developed cancer—this is a procedure (*uma regra*) that would be useful for everyone.

For others, being involved in this type of program went beyond prevention to being actively part of the search for a cure. As the following comments from a female patient in Sao Paulo suggest, this perception resulted in an eagerness and willingness to be part of such study protocols, where being a *guinea pig*, far from being something negative, was actively sought out and valued. As she said:

> I think that the future cure for cancer is in genetic research. Look take my cancer cells and make a vaccine! I think this will happen. I think

> that genetics isn't just about prevention but a question of cure as well. Whenever they have this kind of research at the hospital I always say yes, I would really like to be a guinea pig in the cure for cancer.

Although these sentiments were shared by a number of patients, the majority of those I met felt a sense of relief that by participating in the research provided by the hospital they had access to regular screening and specialist health care. As we saw in the case of the road trip described previously, patients recruited into research perceived this as a means of accessing basic health care. This was also the case for Maria, a cleaner in her 40s who worked in Porto Alegre, as she talked about what it meant to her (and the difficulties she had also experienced) in her efforts to be under the aegis of the specialist hospitals' cancer genetic services:

> 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 one 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 genetic research]. Once you arrive here everything's a blessing (*tudo e a abencoada*)—the problem is in getting here. [Now] 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.[8]

The ways patients describe their experiences of participation in research reveal then a particular scale of investments that constitute an expanded space of possibilities for cancer genetics in Brazil. For these individuals this includes hopes for prevention or cure and participation in research becomes a strategic means of accessing often precarious or hard-to-get basic care and resources.

In an examination of the newly emerging field of public health genomics in Barbados, Ian Whitmarsh (2013) suggests that as genetic diagnosis, monitoring and surveillance are increasingly conceived as forms of preventative public health and a social good, there is an ethical imperative for individuals to fashion and discipline themselves into what he describes as new subjects of "biomedical compliance." Although some elements of these forms of subjectivity may be apparent in the narratives recounted in this paper there is, as Biehl and Petryna (2013, pp. 14–15) point out, a need to guard against a "uniform and unilateral diagnosis" to examine the "granular ways" in which supposedly neoliberal principles, tied in this instance to proactive patienthood required by genetic screening interventions, become "part and parcel of public health landscapes and social relations in resource poor contexts." As Petryna (2013) has noted elsewhere, there are often novel possibilities for the crafting of rights and responsibilities in such contexts that must be attended to and accounted for.

One very powerful illustration of this is evident in an emerging phenomenon in Brazil that is transforming the parameters and pathways by which patients are accessing health care services, linked to a process described as the judicialization of health and the phenomenon of patient litigants. In conclusion, I show how this is becoming evident within and developing as a direct consequence of the interstitial space in which Brazilian cancer genetics operates. Such phenomenon serve to further illuminate the diverse vectors through which an anticipatory habitus embedded in the preventative promise of cancer genetics is becoming part of new and novel claims and rights to health in Brazil.

As noted in recent studies by Joao Biehl and Adriana Petryna (2011, 2013), thousands of Brazilian patients across different social and economic classes are effectively suing the government for the right to health care resources such as medications, but also now other treatments, examinations and tests, predicated on a constitutional commitment in Brazil to provide health care for all. Patients litigants, who appear to comprise a broad section of social classes, are not simply "waiting for the high cost of medicine technologies to trickle down" but are instead "using public assistance and the levers of a responsive jury to gain full access now" (Biehl & Petryna, 2011, p. 363). Whereas the first such successful cases of judicialization have occurred in the context of participation in clinical trial research for medication related to mainly rare genetic conditions, increasingly patients are pursuing and successfully obtaining the right to health care resources outside these parameters by accessing mostly free legal services. As I illustrate next, this now includes the right to have a predictive genetic test for breast cancer.

In October 2013, I returned to Brazil as part of a research visit to the southern part of the country. Within minutes of meeting friends and colleagues working in one of the cancer genetic clinics there were numerous comments about Angelina Jolie's announcement made six months previously. From what they said it was clear that this had generated a lot of polemical discussion in the Brazilian media, as well as significantly raising the profile of cancer genetics in the country. "Thank goodness for Angelina Jolie," said one genetic practitioner casually as she talked to me of how the numbers at the cancer genetic clinic in a mixed public/private hospital in Sao Paulo had grown exponentially since the highly public statement by the actress and the ensuing media focus. While also pointing out she had as a result been approached by numerous television, radio and media outlets to comment on the announcement, she told me how referrals to the clinic and interest from publics had increased threefold in the ensuing six months. In another public hospital in Rio, it was notable while sitting in on a couple of consultations with practitioners whom I had gone to meet that Jolie's name was mentioned again, this time in the process of explaining the risk of having a BRCA mutation to a patient. The nurse genetic counselor used reference to Jolie's announcement as a way it seemed of almost normalizing the procedures that she was offering the patient; in this case, the possibility

of having a genetic test linked to a particular research protocol. But it was at another public hospital in Porto Alegre where another dimension of these developments came to light.

The genetic practitioner there told me how in the last few months at least one or two of the 30 or so new patients without private health insurance seen each week had come armed with letters from lawyers saying that they were going to "*entra na justicia*" (go to the courts) to demand the government pay for them to have a genetic test, saying that they have a "right" (*um direto*) to the test that Angelina Jolie had. Although not totally supportive of judicialization as the best means by which patients should have access to health care (or equally that the action of celebrities should have this effect rather than reasoned science and research), the doctor I met acknowledged that the phenomenon of patient litigants in the context of cancer genetics was changing the health care landscape in which they were working. Moreover, she thought this was likely to put increasing pressure on the state to incorporate cancer genetics as part of the public provision of health care, a goal that was much sought after by many of those who worked in this emerging field of cancer care in Brazil.

The full consequences of the expansion of judicialization processes to include procedures such as predictive genetic testing is still unfolding in Brazil with cases being examined at federal and state level in what is normally a fairly drawn out process that can take many years. Nevertheless, the very fact that this phenomenon is happening now in Brazil further illustrates the complexities of the interstitial spaces in which Brazilian cancer genetics is coming into being and the way that an anticipatory habitus is becoming bound to a discourse of rights, not in this case to access treatment, but to pursue genetic testing as part of what is seen as preventative approach.

CONCLUSION

In this chapter I have explored the tensions and dynamics surrounding the way one domain of high-technology medicine associated with a transforming terrain of public health genomics is being mobilized and constituted as a social good, linked in part to a discourse of cancer prevention. In Brazil this is emerging in the not-easily-disaggregated meeting points between transnational research and precarious public health care provision in efforts to address and ameliorate the effects of rapidly rising cancer incidence and mortality. As Whitmarsh (2013) points out, while the pursuit of genetic research in resource-poor settings might be seen simply as an effort to simply "join in on cutting edge biomedicine," it also informs and transforms what counts as public health.

In Brazilian cancer genetics, patients participate in research in hopes of accessing basic health care services and what is perceived as the right to pursue prevention. At the same time, the activism of health professionals is

central to collaborations in transnational research on the unknown genetic risks of breast cancer for the Brazilian population and to addressing underserved health care needs as part of a neglected preventative approach to health care. Yet this moral and affective framing of cancer genetics as prevention is not shared by all of those who work in related fields of health care, pointing to the limits of such activism and to differing perceptions about how public health and prevention should be pursued. Nonetheless, the anticipatory habitus constituted by fields of knowledge such as breast cancer genetics in Brazil seems to have found new expression in the wake of the activities of one global celebrity, which in conjunction with an expanding arena of judicialization in Brazil may potentially inform public health in as yet unknown ways.

Transnational research, and particularly clinical trials research, is embedded in complex structures of inequality and power that can work to exploit. At the same time, the particular institutional configuration of research and clinical intervention outlined in this chapter related to cancer genetic research in Brazil is also the context through which patients seek and often obtain basic health care in pursuit of prevention. It is similarly a nexus through which national research initiatives are nurtured and developed, previously nonexisting clinical specialties and professional identities are forged, and the means through which collective demands for wider public health care provision can be made to foreground an ethic of prevention.

As others have noted, the boundary between research and clinical care is often thin in the context of genetic research where research participation is often regarded as having diagnostic consequences or therapeutic benefits (Hallowell et al., 2010). This is particularly so in the context of cancer genetics where many hybrid activities take place given its inherently translational dimensions (Hallowell, 2009). Highlighting how the moral framing of research and clinical care are often closely and complexly entwined, Wadman and Hoeyer (2014) point out that it is important to not see this necessarily as a dilemma or obstacle but as a way to understand how both can thrive on coexistence and the way that knowledge, work ethics and emotions emerge in tandem (p. 7; see also Timmermans, 2010). While the enmeshed boundaries between research and care in transnational research generate different questions and challenges, given inequities and disparities in resources, it is important to see how and in what ways for different groups and individuals in specific local contexts research is constituted as a resource and resourcefully acted upon.

As the changing techniques, including the rapidly diminishing price of genomic screening for diseases such as cancer, are unevenly incorporated across and within developed and also increasingly emerging and developing country contexts, it will be important to monitor in comparative cultural arenas the ways that clinical need, prevention and rights to health become part of diverse efforts to shape and reshape the making of public health genomics.

NOTES

1. This development has generated much discussion across a range of public and social media and there is increasing evidence that the so-called "Angelina Jolie effect" has led to a marked increase in enquiries and referrals to cancer genetic clinics in the UK and elsewhere (Joseph, 2014; Retassie, 2013).
2. 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." Research included participant observation in cancer genetic clinics over a period of 18 months in three different urban centers of Brazil, interviews with patients and family members attending cancer genetic clinics (over 100 in total), and interviews with practitioners and scientists working within or alongside cancer genetic specialists (over 40 in total). Participating patients were attending cancer genetic clinics and were either undergoing, had received, or were awaiting the result of a genetic test on BRCA1 or BRCA 2 or R337h (a mutation thought to have a high frequency in the southern part of Brazil). Whereas the majority were women there were a number of men also recruited in the study, all were over 18.
3. See "Brazil's March towards Universal Coverage" in Bulletin of WHO, Volume 88, pp. 641–716.
4. In 2012 private insurance companies in Brazil agreed to pay for genetic testing for those with insurance schemes or *convenios*. During the time of most of my research however this was not the case, although a number of patients were advised to approach their health insurance provider by cancer geneticists in the hope of being able to secure a test.
5. The activism of health care practitioners is also an aspect that I've explored in the context of research on cancer genetics in Cuba (Gibbon 2013a).
6. This is evident in the growing calls in Canada and Israel for programs of population-wide screening of all Ashkenazi Jewish women and increasing interest in targeted screening interventions for certain populations, such as African American women with breast cancer diagnosed at a young age, with family history or with triple negative tumors (see for instance Churpek et al., 2013 and also Joseph, 2014).
7. Approximately 15% of the over 100 families and individuals who were interviewed had *convenios* or private health insurance and under 5% privately paid for genetic testing.
8. This patient quote also appears in Gibbon (2013b).

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