

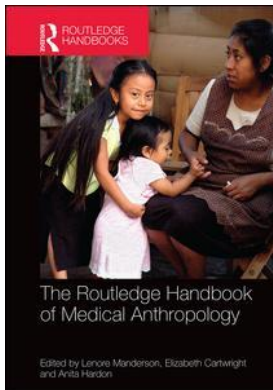
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## **The Routledge Handbook of Medical Anthropology**

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### **Bodily Resistances**

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Smoke Free Homes Initiative, 2013. Kerala, India.  
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### *About the photograph*

*Tobacco-related mortality in India is among the highest in the world. In this photo, a young girl in Kerala State in South India reads a poster which explains the dangers of smoking and the harms of secondhand smoke to women and children. This social movement, spearheaded by anthropologists and public health specialists, has reached her village. In this poster and through various activities, community members are asked to join together and ban smoking inside their homes. As part of this intervention, school children are provided education about tobacco, and are asked to talk to their fathers about not smoking inside the home to protect their family members from the harm of secondhand smoke. Ethnographic research in Kerala, in which I was involved, revealed that daughters were able to “touch the hearts” of their fathers, and were able to convey a stronger message than their mothers. I took this photograph when I working as a Co-Principal Investigator on Quit Tobacco India.*

—Mimi Nichter

## Bodily Resistances

*Elizabeth Cartwright, Anita Hardon  
and Lenore Manderson*

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The body is a canvas, both physical and abstract, that is used to demonstrate who we are, where we belong and how we are taking a stand in the world. In this chapter, we deal with issues surrounding bodily resistances. We begin with the tensions inherent in acts of rebellion and resistance, and the desire for particular kinds of social belonging. Tensions are created via bodily rebellions at both the individual and social level, simultaneously creating difference and distance, as well as acceptance and inclusion. Tattoos, scarification, and circumcision are among the bodily practices that individuals use to signify something about themselves; so too are the ways we wear our hair, cover our bodies (or not), perfume ourselves, and otherwise decorate and manipulate our corporeal selves. In some instances, where an individual refuses to undergo a particular practice (female circumcision, for instance), the social risks are high even though the practice may increase other bodily risks. With each of the particular ways that individuals make these flexible, artistic, sometimes desperate statements about who they are, different constellations of bodily strengths and weaknesses are created that have both social and health implications. Identities are not constructed in isolation. They emerge in social networks that shape their way of being in the world in relation to each other, and to the institutions that they encounter.

Resistance is often directed at groups of people and institutions and the rules and regulations that they have put in place that shape people's lives through coercion or consent. Health care programs in particular have implications for the way people live their embodied lives. We are encouraged to eat less, move more, and refrain from smoking, and to engage in elaborate accounting mechanisms to ensure that our health care costs are reimbursed. In resisting such prescriptions and proscriptions, people make statements about authority, power and agency, and identity. Smokers cut themselves off from their 'non-smoker' friends, for example, while gaining friendship and belonging with the other 'smokers.' People with eating disorders learn new rules and ways of being within different social worlds where denying nourishment, bingeing, and purging are valued, while leaving behind the deeply social acts of sharing mealtimes and the sensual pleasures of savoring food. People may refuse medication and reject other behavioral prescriptions in acts of resistance to the particular subjectivity of the body to a diagnosis, its treatment regimes, and the power of medical practitioners, biomedicine, and often family. They may seek the support of others in their acts of resistance, or be influenced by social movements that encourage them to adopt certain health practices, while resisting others. Others embrace medical and surgical procedures in ways that defy normative views: the decision of a man or a woman to pay for a surrogate in order to parent is a resistance to hetero-normative and biologically based

ideas of human reproduction. What can we learn about the ways that people act in response to medical and public health advice, and how they interact with health care institutions, and how and in what ways they resist?

Anthropology has a particularly strong history of theorizing small-scale rebellions and everyday acts of resistance (Abu-Lughod 1990; Scott 1985), and describing the forms of resistance to biomedical ideas and practices has been an important trajectory of inquiry in medical anthropology over recent decades. It continues to be a fertile ground for research (Marshall 2012; Nahar and Geest 2014; Sivaramakrishnan 2005). In the end, one must ask, what does it matter? Does it do any good to resist? Who is harmed? And conversely, what is changed for the better? What new configurations of care can be imagined once the dominant 'health' paradigms have been challenged?

Anthropological studies of resistance provide us with a starting point to tease out the essential components of everyday forms of resistance that can then be applied to matters concerning health, healing, and bodies. In his now-classic volume, *Learning to Labor: Why Working Class Kids Get Working Class Jobs* (1977), Paul Willis described the ways in which young men in the United Kingdom rebelled against formal schooling, and by doing so destroyed their chances for obtaining a good education and so the possibility of getting a job that was not tied to physical labor. The brilliance of Willis's work was in describing the verbal and non-verbal ways that these young men enacted their small rebellions with educational institutions that, in many ways, neglected their needs. The stated goal of the educators with whom Willis worked was to encourage youth to study hard, succeed in school, and so proceed, via university or other sorts of advanced training, to white-collar jobs—this goal was only partially conveyed to the working class 'lads.' By skipping school, dressing and talking in rebellious ways, and taunting those students who were good at their studies, the 'lads' sealed their own fate of failing high school. The lads' primary goal—to establish strong friendship networks while in high school, so that they would have friends on the shop floor when they went to work in factories—made good sense when looked at from their perspective. Studying took valuable time away from engaging in the kinds of adventures and 'larks' that created social bonding among their peers, which would be essential for their social survival at school and beyond school, once they had to start working as the breadwinners for their families. These young men had insight, if limited, into how the educational system worked. They knew they would never get high-paying jobs without degrees, but they also knew how to establish the social bonds—and so the social capital—that would allow them to get what they needed to survive in the world of industrial workers in 1970s Britain. In addition, perhaps there was also a sharp understanding of the implications of class in Britain at that time: they probably would not have had an equal opportunity to gain employment in the areas of their training, even with a higher education, and so saw the futility of staying at school.

James Scott, in *Weapons of the Weak* (1985), continued exploring and elaborating Willis's ideas of how less powerful groups in society have or don't have insight into how they are being controlled. Scott maintained that systems of power are rarely fully hegemonic. If, drawing on Gramsci's work (1992), hegemony is defined as the material and ideological methods used to force, trick, or subtly pressure groups of people to comply and so ensure their consent or compliance, then resistances can be found and described at many levels. Hegemony is rarely, if ever, complete, as it is enacted through a mixture of control and consent. To truly create a revolutionary moment, people who are oppressed need to gain material and intellectual control over the ideas and the resources being used by those in power, and to take them for their own. These understandings of hegemony and everyday acts of resistance can be fruitfully applied to understanding bodily resistances as they are acted out via resistance to the dominant biomedical and social ideas of particular situations. Following Scott (1985), such resistance may include foot-dragging, feigned ignorance, passivity, slander, and pilfering, and other similar acts,

providing often subtle ways of rebellion and subversion for people who lack formal avenues to oppose others' authority over their lives. As Sivaramakrishnan (2005) points out, the more complete analysis of protest includes not only everyday forms of resistance, but also an analysis of everyday enactments of power.

Biomedicine's hegemonic dominance varies by situation. While it is the primary form of curing in many resource-rich countries, and for those of the upper classes in poorer countries, many of the world's poorest people have limited access to biomedicine and further, depending on their health status and the information they have about various approaches to treatment, they may reject it as a curing option. Biomedical technologies generate their power through a nearly all-encompassing system of visualization, diagnosis, and bodily manipulation. The institution of biomedicine, in its fullest expression, is found in high-tech hospitals where patients can be monitored, controlled, and treated using this logic of healing. As the enactment of biomedicine moves further from resources of all kinds, its grip on the local logic of curing is loosened; its hegemony is diminished.<sup>1</sup> Moreover, there are as many forms of biomedicine as there are places where it is being used. Resistance in each of those situations comes in different forms that are telling of the particularities of biomedical hegemony, local knowledge, traditions, resources, and inclinations.

A particular poignancy arises when considering acts of resistance in the context of ill health; the stakes are high, emotions accentuated. Acts of rebellion, resistance, dissimulation, and non-compliance can be seen variously as ill founded, ignorant, enlightened, or brave. To go against the locally accepted norms of maintaining health, being cured of a malady, or managing bodily processes elicits strong feelings from onlookers and puts the individual or groups of individuals engaged in the resistance into a fraught position, both bodily and socially. For instance, women in the US and other heavily biomedicalized places who choose to give birth at home can be subjected to stories of risk to the health of their babies, ridiculed by biomedical practitioners with whom they come in contact, and censured for less than optimal birth outcomes. Legislation also controls what people can access or refuse, limiting the options available to them. Going against the norm, especially when it is a biomedical norm, puts individuals into the uncomfortable social position of asserting their right to control their bodies and to opt out of biomedicine's grip.

Aengst's work (2014) in Ladakh shows how women consciously resist local norms that prohibit out-of-wedlock sexual relationships. When women in this situation become pregnant, their private resistances are exposed bodily through their pregnancies. The women with whom Aengst worked tried to hide their pregnancies for as long as possible. The difficult choices the women faced—in the context of the highly negative stigma that their ex-nuptial pregnancies carried, included of shaming themselves and their families—led them to endure the risks of pregnancy without any medical attention and sometimes, tragically, taking on the responsibility of killing their child. Narratives of how women dealt with their competing needs of sexual pleasure and intimacy, in the absence of the protective elements of social acceptance of these acts and/or of effective birth control, are not unique to Ladakh (see Briggs 2007), but they clearly show how a particular bodily act can put into motion both physical and social reactions that place individuals in extremely difficult situations.

Hilary Graham's (1976; 1987) research on the social ramifications of smoking provides a rather different perspective of resistance. The idea that smoking was a danger to women's health, and to their pregnancies, was just coming into the public conscience at the time of her original research, and women for the most part saw smoking as less a risk to themselves and their fetus than doing heavy housework or having sex in pregnancy (Graham 1976). Women reasoned, too, that they would become irritable if they gave up smoking and this would cause problems with their spouses, families, and friends. Seen from this vantage point, the women's different assessment of health risks makes sense. In a later article, Graham wrote about a "backcloth

of poverty” that shaped the choices women made, which included resistance to health messages to give up smoking (1987: 51). The women who smoked, in contrast to non-smokers, were less likely to have a friend in whom they could confide and had problematic relationships with their mothers; their partners were often unemployed, and they were worried about money. Tired, stressed, and lonely, women used smoking with a cup of tea or coffee to take time out from the work of caring. For these women, Graham argued, women’s smoking made sense in the “hidden world of caring in poverty . . . a cigarette can be the only purchase that women make, and (smoking) the only activity that women do, just for themselves” (1987: 55).

In this chapter, the case studies illustrate situations where individuals rebel in ways that seem, on the surface, to be self-defeating; for instance, we see people rebelling against medical authority by continuing to smoke despite clear evidence of its impact on their health, and young women practicing self-starvation. These acts of resistance reveal what matters most to individuals and those with whom they identify and interact in particular circumstances. In the first case, Megan Wainwright describes a Uruguayan woman named Julia, who has chronic obstructive pulmonary disease (COPD), diabetes, cardiovascular disease, and an array of aches, pains, and sufferings. Her resistance to her doctor’s command to stop smoking is couched in the fact that in her life she has given up many other things because of her medical conditions; she can no longer have sugar, salt, or bread. She draws the line at giving up her cigarettes too. Julia views cigarettes as her one ‘guilty pleasure,’ a pleasure that poses the least threat to her health. This is not a view shared by her physician or, over the years, by her husband.

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## 6.1 Rebellion and Co-Morbidity

### *Megan Wainwright*

In 2010, while conducting ethnographic research on chronic obstructive pulmonary disease (COPD) in Uruguay, I met 61-year-old Julia. Over time, I learned that COPD was just one of several conditions she lived with, including diabetes, gastric reflux, hypertension, cardiovascular angina, mild renal disease, and chronic back and leg pain. Many of these are considered smoking-related illnesses. Julia had smoked on average 15 cigarettes a day for 46 years, six more years than her relationship with Fernando. She also had long-standing relationships with a plethora of health professionals whom she saw so regularly that her adult children referred to the hospital as her ‘other home.’ This is where my story begins.

### **October 2010**

I was in a public outpatient respiratory clinic in Montevideo when a physician invited me to meet a patient who was developing respiratory illness and still smoked:

- Julia:* I quit smoking for seven months but started again. My husband has many health problems and his situation made me start up again. I don’t smoke during the day when at work, but my husband smokes indoors so I smoke with him after meals, but less than before.
- Doctor:* Your complexion is looking really lovely since you’ve cut down on the cigarettes.
- Julia:* Yes, people have been telling me that.
- Doctor:* Have you noticed a change?
- Julia:* Not really . . . I don’t have as much phlegm.
- Doctor (to me):* In 2009 they found that the small airways were affected, but it wasn’t quite obstruction.
- Doctor (to Julia):* This is the time to do something, you are starting to develop a chronic disease (COPD). (She picks up Julia’s chest X-ray and looks at it in the light.) You’re as

*Julia (to me):* beautiful on the inside as you are on the outside! I don't want to scold you, I'm just saying, each time you take a cigarette think about it, do I really want this cigarette? If you come to the house you will meet not one smoker but two! My husband will not quit. With all his health problems he has a lot restrictions put on him, so he says, "they're not going to take this from me as well."

### **November 2010**

Upon entering Julia and Fernando's four-bedroom apartment within a cooperative housing development, I noticed the walls, once white, but now, from decades of smoking, yellowy brown. That afternoon, the conversation around health and smoking was particularly lighthearted.

*Fernando:* We know that smoking is killing us, but we're just racing each other now, to see who will be the first (to die). With so many years together, we do not want to go one without the other. What they are doing now with smoking is prohibitive (smoke-free laws), and that makes you want to do it more . . . We come from a generation that lived through many struggles, the dictatorship for one, and we always fought against it. Well this is the same. Doctors need to know that. Anything that is forced, annoys us. The policies may work better for those that came after us.

*Julia:* There are too many impositions. Well ok, it's harming me, but the thing is . . . smoking is a satisfaction for me, and I smoke a third of what I smoked before, now I smoke one every once in a while . . . I can't eat sugar, salt, pasta, bread, pastries, a sandwich. There comes a time when you ask yourself, why am I living if I can't do anything? I can't run, I can't walk, well a little but I get tired and I have to stop, that limits you as a person . . . Even though it is bad for me, (smoking's) the thing that does me the least harm. Because if I eat sugar I can go into diabetic coma.

### **January 2011**

I learned over the phone that soon after my November visit, Julia had had a heart attack. On this visit, they argued profusely and the mood, unlike our previous encounter, was tense. It was the only time I heard Fernando comment on Julia's smoking in a concerned and disapproving way:

*Julia:* I'm still smoking like before. I've not cut down at all, I smoke even more than I did. I'm stuck here in the house all day (she quit work) and all I do is smoke.

*Fernando:* She smokes, and I mean she smokes! She smokes more than me!

*Julia:* Yeah, let's say I was smoking 10, but now I'm smoking like 30 a day. When I first got back from that episode, I just didn't have the energy to get up and move. I slept and slept and slept and I mean really slept. Fernando felt like I was getting depressed . . . I felt like I'd been mistreated in the hospital (describes how doctors missed the diabetes and questioned her chest pain). I know I'm a difficult patient.

*Fernando:* She's a difficult patient because she doesn't listen to the doctor. She doesn't follow what they say . . . The patient also has to help themselves.

*Julia:* I take my medications.

*Fernando:* You do whatever you like.

*Julia:* What, because I smoke?

*Fernando:* Ah there you go.

*Julia:* Ah, well! I cannot handle any more (restrictions) . . . There's nothing else to take from me. No Coca-Cola, none, just water. You watch everyone eat and you can't eat anything. All those things, for what? I take 25 pills a day. Now I'm here, inside . . . I would like to keep on living yes, at least a year and a half more, for my granddaughter's 15th . . . The truth is I'm tired . . . I'm not able to do things, because I'm not able to breathe, to move, more and more . . . My nerves (stress, anxiety) are the worst. My nerves kill me, there's so many things that have happened in this period. We've never had economic problems, but you know, my diseases, his diseases.

*Fernando:* Me! I'm in the best shape out of anyone.



- Julia:* Oh shut your mouth.
- Fernando:* Can I speak? Right. You have to focus on the solutions, not the problems. (to me) I cannot accompany her in this depression.
- Julia:* He says he's a healthy person . . . he's had heart problems for a year and he has emphysema which he sees a respiratory physician for, and every two months he has to go for biopsies from his stomach! All that affects me, he thinks it doesn't, but yes it does affect me. The thought that he may have something.
- Fernando:* First of all I am not a sick person, I have a disease, but I am not sick. I have a disease and I live with it. If you ask me how I am, I'll say "better than you." I don't feel sick. It's all in here (in your head).
- Julia:* No, it's not all up here (in your head). He's talking about fighting and facing what you have, that is something different . . . I'm not the type to stop everything for any little thing. But now, I just feel unwell. Maybe my body has just gotten tired, maybe I've given it too much of a beating.

### *August 2011*

In the months I lived in Tacuarembó, Julia experienced no more acute episodes. During this visit they smoked and smoked and smoked, without any discussion of it or comment made to the other. The mood and views expressed echoed my first visit. Spontaneously Fernando started the following conversation:

- Fernando:* Her way of doing things, her way of living life, has helped us overcome the difficult things in life. I don't think the medications have helped as much as that.
- Megan:* The way of thinking?
- Fernando:* That rebelliousness that we have against things, helps you confront it, not complain about it even when you feel awful. And even though the smoking is making the problem worse and worse, she is in much better shape than others with this problem of COPD that might not even be smoking. She rebels against it, not only against COPD, but against a society that's always telling you, "you can live better" . . . What I'm saying is not a scientific view.
- Julia:* That rebellion that you have, it goes as far as stopping you from quitting smoking. Because I want to live, I don't want to extend my life. Because you start to analyze all the things the doctors prescribe to you and tell you and you realize it is all, no, no, no. You're surviving but not living . . .
- Fernando:* She enjoys it, she experiences smoking with intensity . . . We know that we contradict ourselves, we know that cigarettes are harming us yet we keep smoking . . . but we are rebels (smiling).
- Julia:* I'll tell you what, this thing is a reality. If I quit, will my COPD go away? Will my angina? No, I have it. Can I make it worse by smoking? Yes. But would quitting cure it? No, it's not going to leave my body. So why sacrifice? The sugar, yes, I sacrifice because I don't want to go into a diabetic coma, you can become blind, I don't want that. Hypertension too, I don't want to have a stroke.
- Megan:* Do you see COPD as serious?
- Julia:* In the long run yes, it's not letting me breathe, but that's also because of the angina. Recently I found out that 40 percent of my artery is blocked . . . That's because of COPD and because of having smoked all of my life. Yes you can reverse it a bit by doing exercise to help the blood flow better, but I can barely walk.
- Megan:* Because of shortness of breath?
- Julia:* Yes, shortness of breath, and recently I found out the arteries in my legs are all blocked, not because of the heart but because of the diabetes.

Later in a pile-sorting exercise, Julia elaborated on her experience of living with multiple illnesses.

I am a plague machine! I'm all plagued (laughing). I kill myself laughing about it all. There are people who for all these problems would be like, "oh, no, I can't take it." I take it as natural. I

have to take care of myself, and I do. Shortness of breath I have when I walk, when I do things, that's permanent. That comes not just from COPD but from the other as well (the heart). It's very hard to say what side it is from.

### February 2014

Two and a half years later, Julia had 'made it' to see her granddaughter turn 15. She was even more homebound and outspoken about not having 'any quality of life.' Both she and Fernando were smoking their loosely hand-rolled, filterless cigarettes incessantly and Julia reiterated that she had no intention of quitting. She spoke for the first time about not prohibiting her kids from smoking because she was certain that would just have made them want to smoke more. However, she told me:

*Julia:* With my grandkids, I tell them not to start smoking, to look at me and see what cigarettes can do to your health.

*Fernando:* It's not what they can do, it's what they *do* do.

*Julia:* I am not telling them they can't smoke, but I am offering myself as an example. It's one thing to be an example and another to prohibit.

*Fernando:* The biggest effect cigarettes have is reducing pulmonary capacity . . . You're going to be 40 and you're going to feel old.

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The more I met people of Julia and Fernando's age, the more I saw them and their views as illustrative of smokers of their generation—the generation of leftists that fought against a brutal 11-year military dictatorship, a dictatorship which restricted, oppressed, killed, and disappeared, and which gave Uruguay the highest political incarceration rate in the world (Andrews 2010). Julia and Fernando's prediction suggests that, as times change, newer generations will have a lessened reaction of rebellion against restrictions such as tobacco laws.

Julia's and Fernando's narratives merge in and out of each other, as fluidly as the smoke emanating from their shared cigarettes. In Julia's doctor's appointment, she expresses that her husband will not quit because he has many other prohibitions, yet I only ever heard her express her decision not to quit in this way. Similarly, taking illness as something 'natural' was a strong narrative of Fernando's, which Julia espoused to different degrees too on various occasions. The stark contrast was of course the period of acute illness—the heart attack, and the ensuing chronic disability—shortness of breath, fatigue, pain in the legs. In this episode, the risk of death was not so funny anymore. And Julia's physical state, and probably an acute episode of depression, wore away at her ability to keep up her spirit as a *luchadora* (fighter), and her 'laugh in the face of illness' way of being in the world—a way which both Julia and Fernando explain to be a help rather than a hindrance to their health. Even Fernando, under the threat of acute illness, stops joking, at least for some time.

At the time of fieldwork *el tabaquismo*—tobacco use or addiction—was actively defined as a chronic disease with physical, social, and psychological causes (Muñoz et al. 2009; Steinberg et al. 2010). Although I was at first critical of this medicalization, I saw its enactment in people like Julia. Her smoking history is filled with moments of having quit, of having cut down, and of having increased dramatically. Like the respiratory infection of chronic lung disease, the heart attack of heart disease, and the infected toe of diabetes, the smoking 'relapse' is the acute state of a chronic illness—addiction. Her illness of addiction oscillates within a chronic and acute spectrum in relation to all her other chronic conditions. Her leg pain, breathlessness, and fatigue keep her homebound, and she experiences an acute increase in her addiction. Similarly, the acute heart attack sets off an acute state of depression with chronic repercussions. The line is blurred, constantly, when trying to attribute a symptom to a biomedically defined disease. Her inability to walk is the meeting point of breathlessness, pain, and physical deconditioning. Her shortness of breath is likewise the intersection between damaged lungs, a sick heart, and an anxious state.

Julia and Fernando did not fear their own deaths, but they were terrified of each other's. Similarly, Julia did not fear breathlessness and by-proxy smoking, but she was scared of eating too much sugar or salt and ending up in a coma, having a stroke, or having parts of her body amputated (like her brother whose legs were amputated because of diabetes). She weighed up

the costs and benefits of each ‘restriction,’ and COPD commanded the least immediate action. In her mind, there were much more frightening things on the horizon. While she did not fear becoming dependent on an oxygen tank, she did fear depending on others. For one reason or another, COPD did not hold this prospect. Of course, many people did depend entirely on others to dress, wash, and go to the toilet because of COPD. But Julia’s airflow obstruction was not yet severe, and she had never been hospitalized for acute respiratory infection—a common feature of COPD, making it a perfect example of a so-called non-communicable disease which in lived experience blurs the line between infectious and non-infectious (Manderson and Smith-Morris 2010). While these exacerbations of COPD were not part of Julia’s present, they could very well be part of her future.

In global public health discourse on the prevention of chronic disease, smoking as a risk factor is framed as an individual behavior or lifestyle choice. Julia’s story shows that to understand her choice, we need to attend to her generation, her political views, her relationship with her husband, and her co-morbidities, across time. Failure to do so would mask the complexity of her relationship with cigarettes and the very real chronicity of her addiction.

### *Acknowledgments*

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## **Pathophysiology of Resistance**

Various pathologies complicate the notion of bodily resistances. While political resistance often entails such negative things as arrests, beatings, financial loss, and loss of prestige, there are feedback loops of a different order when talking about internal manipulations of the body. Julia’s heart conditions, diabetes, general ill health, and damaged lungs create a personally unique constellation of pathologies accompanied by particular sensations, pains, and emotions. The addictive properties of the cigarettes she smoked created a chemical dependency and physical desire that interacted with her current constellation of pathologies. As Nichter notes, the decision to smoke is also based in the cultural meanings of smoking and the social milieu of the smoker; parents, peers, and friends who either smoke or don’t play into the decision, as do ideas about style, ‘appropriate’ times to smoke and media images of ‘sexy’ smokers having a fun time smoking (Nichter 2003; see also Chapter 5). Julia’s decision to resist medical advice, and to manage her husband’s eventual concern too, was couched in terms of her making a decision and of having agency over her actions. How will this decision affect her as she ages and as her breathing

becomes more difficult, and her heart, kidneys, and other organs suffer more damage from the out-of-control glucose and insulin levels in her body? How will she understand her progressively deteriorating body and what meanings will she create out of her personal health trajectory? How can we understand her 'decision' to continue smoking, in the light of the severe addiction caused by cigarettes? It is not easy to stop smoking. Most people fail. In understanding resistance, we need to do examine the microdynamics of power. In this case, such analysis means acknowledging that nicotine has power.

Another important point to consider while thinking about these case studies is the idea of *time*. In the preceding case study, Julia felt that she had only 'a couple of years' left to live and she made her decision to continue smoking based on that notion. In reflecting on the decisions people make that counter medical advice, it is not clear that they prioritize their health and bodily capacity on a long-term basis, nor that they see the links between present activities and behaviors and their possible health consequences. Neither is it the case that people have capacity to engage in meaningful forms of sociality. There are short-term gains, too, that people consider, for instance being 'someone you can go have a smoke with,' or, as in the case that follows, being 'the thinnest girl in the room.' How are those daily victories situated within bodily resistances that are viewed as harmful and un-healthy by biomedical practitioners?

In the case study that follows, presented by Megan Warin, we consider community resistance, and how collectivities reinforce individual behavior. A foci of anthropology has been on the micro-politics of the interactions between protesters when resistance occurs in groups. Rosario (2014) draws attention to the intimate social details of the interactions of protesters in her research of a long-term political protest staged in Puerto Rico. As an anthropologist, she lived with the protesters and carefully described the micro-politics of decision making, group inclusion and exclusion, and the exigencies of everyday life. It is at the small group level where many of these resistances occur, especially when considering individuals who are institutionalized for their unaccepted behaviors. The interactions between resisters are deeply telling; the ways in which power is asserted both by those resisting and those seeking to control them, the plotting of acts of defiance, and the descriptions of how those are carried out in hospitals, jails, boarding schools, and nursing homes, is rich terrain for medical anthropology.

Megan Warin is concerned with the particular socialities of a group of women who have anorexia, a common eating disorder that often co-occurs with bulimia. Anorexia is a serious psychiatric illness, marked by the refusal to eat, or to eat such miniscule amounts of food so as to prevent the person from maintaining an adequate, healthy body weight. Bulimia nervosa is characterized by recurrent binge eating in combination with some form of unhealthy compensatory behavior (Arcelus 2011). It is estimated that less than half of patients diagnosed from anorexia fully recover; the remainder experience recurring bouts with the illness over many years. Anorexia was once seen to be a young women's disease in the 'North'; now women and men, in many different social contexts, are recognized as suffering from it. The refusal of food is a form of bodily resistance that is, because of organ failure, particularly lethal (Gooldin 2008; Hardon and Moyer 2014; Rich 2006).

In the case study, Warin describes how the relations between young women with anorexia in a hospital unit are part of the social process of learning how to be a 'good' anorexic patient. The competition and complicity among the women who are the central players of this case reflect the processes of group pressure, strategic friendships and learning by watching. The power structure of the institution shapes the forms of resistance taken by the patients, and the rebellious actions of the patients shape the institution's responses via the rules, regulations, and surveillances that are put in place to control patient insubordination.

## 6.2 Relatedness in Anorexia

*Megan Warin*

As I walked across the asphalt car park to Estelle's suburban ground flat, I could hear the sounds of heavy metal music beating out of her open front door. It wasn't often that I heard music in people's homes. I knocked loudly to register my arrival. A figure appeared, opened the door, and invited me in. I was immediately struck by Estelle's distinctive look. Her shoulder-length hair was matted into dreadlocks, and the ends were dyed bright pink, some entwined with silver jewelry. Her fringe was pulled back by clips that sparkled in the light, accentuated by the glitter eyeshadow dotted around her eyes. She was dressed in 'club' gear, wearing two overlapping Lycra black tops (the outer with the animated Japanese character of *Astro Boy* on the front), and a blue hooded unzipped top. She repeated the layering with two skirts, one long, tight-fitting black skirt with purple shoes peeping out, and a shorter red skirt over the first layer. Her shared flat (with her friend 'bulimic Ben') was equally distinctive. It reminded me of a typical teenage/student style place—posters on the walls, a chair acting as a stool, a couch covered with a blanket, ashtrays placed precariously on armchair rests, a TV, and a stereo.

I was visiting Estelle to hear about her experiences of anorexia. She was 14 years old when she was given this diagnosis, and for the next six years it consumed every facet of her life. Sometimes sitting on the lounge room floor, and other times in her bedroom, Estelle told me her story of recovery. Through much laughter and cigarette smoke, she recounted a story that encompassed the highs and lows of anorexia, and highlighted the complex relationships that people with anorexia form with this disorder and each other. This case study weaves her narrative with the stories of other women with whom I conducted fieldwork, describing their desires to become a 'better anorexic,' their intense competition with others, and the difficulty of leaving anorexia behind. For many, anorexia was not an illness but a friend (if not abusive), a marker of distinction, a social support, someone that was always there for them.

### *Anorexic Wannabes*

Estelle had never met anyone with an eating disorder before she was referred to the eating disorder unit at a major public hospital in an Australian city. She vividly remembers her first visit as an entrée into a world that she had only heard of, a world that required a particular entry card. Whilst she was waiting to be assessed in the patient lounge room, she met another young woman who had just completed a bed program—an intensive bed rest program designed to increase people's weight and give them 'time out' to address underlying issues. Killing time, and unable to resist, this young woman struck up a conversation with Estelle: "You're so beautiful—you look just like a little fairy—I wish I could look like you." Estelle was surprised by her comment, perplexed as to why this woman would want to look like her. "I was freaked out," Estelle exclaimed:

I was heaps thin and this girl, although having finished the bed program, was still quite thin. I looked at her and said, "No, I look disgusting—you look really nice." I hadn't realized at the time that I had really offended her and she took me saying "you look nice" as saying "you look really fat"—all these little things I had to learn after being in hospital about the whole anorexia thing.

Estelle was fast learning about the desires that many people with anorexia have to become more accomplished with their eating disorder. Some wanted to become the best anorexic—walk into a room, sweep it with their eyes, and know immediately that they were the thinnest in that room. Others like Estelle were trying desperately to not belong—to recover and leave, and have limited or no contact with any person with an eating disorder ever again. Many though were caught in a space of trying to do both, to rid themselves of what they described as the 'hell of anorexia'—the shame, the guilt, and the depression—but were not willing to give up what it afforded them. Staff repeatedly joked about the number of times they had heard this inherent contradiction from patients: "They want to get rid of anorexia but they don't want to put on any weight." The people with anorexia put it another way—"I want to get rid of anorexia but I don't know who I'd be." They were fearful about leaving the web of social relatedness—the belonging, the power, the secrecy, and the safety that anorexia provided.

### *Being Anorexic*

After her initial assessment, Estelle was admitted to the psychiatric ward for an eight-week period. Now that she had the legitimating ‘rubber stamp’ of a diagnosis, she began to learn how other in-patients used it as a form of social connection:

I found that there was a whole culture behind anorexia—once I got in there—there was this whole culture thing—they all seem to stick together and they have their laxative abuse and stuff like that but it’s almost like a trade secret—like it was really bizarre for me. Because I’d never really known anyone with eating disorders while I’d had it but I knew about this whole thing because I’d been warned about getting sucked in to the whole anorexia culture and the girls that didn’t want to get better.

Because Estelle wanted to leave anorexia behind, she was called an ‘outside anorexic’ by other in-patients with anorexia. This was a disparaging term that marked her as Other, as somehow distanced from the powerful collective and ties that the others shared. I asked Estelle to explain ‘outside anorexia’: How could you simultaneously be diagnosed and treated for anorexia, but be ‘outside anorexia’? Estelle explained that she had complied with the treatment program: “I was there eating all my meals and stuff and like trying to be really good, and the nurses were coming in my room and searching for food because they wouldn’t believe me—they thought there was something up.” The nurses were suspicious because it is very common for people with eating disorders to exercise secretly behind closed doors, hide food, and vomit into bins. Many are admitted to hospital programs not because they want to get better, but because relatives have pleaded with them to get help, or they are so sick they require medical management. Estelle was different because of her compliance, and because of this, her authenticity as a ‘real’ or ‘true’ anorexic was challenged by other in-patients—“you’re not really an anorexic,” they taunted. “That,” she said, “for some reason offended me because I was like ‘well what the fuck am I then?’—if I’m not a real anorexic and not a real, normal person—what am I?—why should I be a real anorexic anyway?”

Estelle was caught between her own desire to get better, taking expert medical advice on board to recover, and being maligned by other patients for doing so: “I wanted to fit into that culture when I went to the hospital because I wanted to fit in with everyone and they all saw me as this freak that wants to get better and at first I felt really rejected by them . . . I was leaving the thing [anorexia] so they didn’t like me that much.” Even though Estelle’s non-conformity puzzled the group, they tried to seduce her back into the ‘collective ways of anorexia.’ They were surprised to hear that she hadn’t used laxatives or speed to lose weight, so they explained the practice to her, tempering their information with anonymity—“we haven’t really told you about this, okay?” Estelle was ‘being let in’ on a secret.

### *In ‘the Club’*

Anorexia is unlike most other illness categories or disorders because people with this diagnosis think of themselves as different. In psychiatric wards, participants didn’t see themselves as ‘crazy’ like other in-patients with a range of mental disorders, but as distinctive and extraordinary. They didn’t always come together to support each other in recovery, but to support each other in being a better anorexic. On-line networks exemplify this desire to maintain anorexia, and this is what is so puzzling and perplexing for family members, friends, and treatment teams. Why do people with anorexia form these powerful relationships with others with the same diagnosis? What propels them to continue their suffering?

Estelle’s experience demonstrates that anorexia is not simply a psychiatric label. People wanted to embody the symbolic power of a medical diagnosis, but they then transformed anorexia into a powerful network of connection and belonging—it became ‘a religion,’ ‘a competitive sporting team,’ and ‘a fascinating game.’ There were those who were in, or, like Estelle, out of ‘the club.’ Sonya explained the almost suburban and mundane inclusion:

I suppose I sort of see it as like an anorexic club—it’s just like everyone is pretty accepting of you if you are sick, everyone’s friends and stuff like that and there’s a bit of competition going on—it’s sort of like you put in your membership and it’s really hard to get out.

*How do you get into the club—what's your membership?*

It's sort of like a coffee club—you meet, you discuss the illness . . . you have these friends—you're suddenly in this group and people understand you . . . for me it was like my life had just been nothing for such a long time—that was all I knew, it was all I did and I didn't have any outside life and so suddenly I'm meeting all these people who don't have any sort of life either so it was just perfect—what else do we have to talk about—nothing but anorexia.

The metaphoric representations of anorexia as a club signal the workings of desire, seduction, power, and danger that coalesce in this community. Moreover, they point to anorexia as a pivot of as well as a vehicle for relatedness (Warin 2010: 97). This club was not always articulated through language. Participants intuitively knew who belonged to the club or not: they could point to strangers in a crowded shopping mall or on a downtown bus, and distinguish different types of 'skinny,' 'naturally skinny or anorexia.' They 'just knew' who was 'in' by their bodily comportment—the 'dead look' in their eyes, the sallowness of their upper arms, and the heaviness of their gait. Recognition of another 'anorexic' was an invitation to form a relationship. It initiated an exchange of comforting words across the plaza on the university campus, and at other times it allowed for comparisons and exchange of purging techniques.

Creating relatedness through sharing what Estelle called 'trade secrets' was most clearly displayed when people participated in treatment programs, for here the sense of belonging to the 'anorexic' practice was most important and yet most at risk (from the threat of anorexia being exposed and thus disempowered). In-patients drew 'battle lines' against those who wanted to help them. "People [with anorexia] build such a wall around themselves," said Rita, "such a safety net of anorexia, that anyone who comes along and tries to threaten that has got to be viewed as an enemy." The 'enemy' included the doctors and nurses who were seen as taking away the relationship people had with anorexia. Kitchen staff were likened to the old woman in Hansel and Gretel—"they were out to get us skinny kids—scheming to make us fat." Participants would ask the nurses, "what kitchen witch is on today that's spread this butter on so thick?"

Undercover practices of resistance were in place—either solitary resistances or collective, organized attempts. These strategies of 'trickery' and tactical priorities were essential to maintaining a group identity, enabling 'sick patients' to garner power against the constant surveillance of the clinical staff.

In one of my field sites (an in-patient eating disorder program in a general psychiatric ward), those with anorexia were given private rooms in the direct line of surveillance of the nurses' station. Estelle recalled how those on lengthy bed programs "became very, very devious" as a "self-preservation mechanism." There were many 'tricks' which in-patients laughed and joked about, and people took great pride in telling stories in hushed and excited tones about the most ingenious of places where they could 'stash' unwanted food and drinks (such as in the ceiling panels or scraped into duvet covers). Audrey was terrified of having to drink a liter of apple juice a day, and would try to disguise it as urine in the bedpan, to be unwittingly taken away by the nurses and washed down the sluice.

In this setting, there were strict rules about interaction with other in-patients with anorexia whilst on a bed program. Interaction was curtailed, but handwritten letters were secretly passed from one door to another, the writers swapping stories of how to exercise without being noticed. And those who were allowed the freedom of the ward sometimes established groups of cheating, banding together like a relay team. Rita described how she was included in a network of food avoidance without any warning—the fact that she had an eating disorder automatically meant she was an accomplice in a 'network of deception':

We're a secretive lot . . . this young girl tried to set up a little network of accomplices—like a support system to help her cheat. She even shoved a bag of nuts into my hand that was her supper. We were just walking past each other in the corridor and she shoved a bag of nuts in my hand and kept walking and . . . so I was actually aiding and abetting her by doing that . . . she was so desperate to lose those nuts. She didn't want to put them in her body.

The secrecy that operated within the clinical setting propelled people with anorexia together and encouraged intimacy between them. Secrecy was a distinctive feature of anorexia and its performance enabled participants to hide anorexic practices and so insist that they 'were fine.' Some suggested that there was a "secret language of eating disorders," a language that was articulated through a range

of bodily practices that were only known and shared amongst those with anorexia. Although some participants chose not to engage with the collective secrecy, all knew of its existence and power from their own day-to-day strategies of concealment.

### *Anorexia as Distinction*

Secrecy operated to mark differences between those who had anorexia and those who did not, and so created status and prestige for those who practiced it. Those who maintained anorexia described feeling a sense of superiority over everybody else they encountered. Anorexia was a productive and empowering state of social distinction (Bourdieu 1984). It was not experienced as a debilitating illness, but a “gut-wrenching emptiness” that was viscerally “unique,” “heroic,” “a power trip,” “a thrill,” and “a high” in which people felt “indestructible” and “superhuman.”

While secrecy marked distinct boundaries between those who did and did not have anorexia, there were other clear markers within anorexia. There were internal divisions, where some competed to be the best anorexic within the group. Like Estelle, many spoke about the insidious levels of competition, particularly when people came together in treatment settings. Sonya loved the sense of achievement that anorexia gave her, but was devastated coming into an eating disorder service “because there are so many other people who weigh less and they’re better than I am at it.” Once in hospital, her goal was “to be the sickest—to be the best at it. But the best is dead—that’s when you win—that’s the best you can be being anorexic is when you die.” Because of this competitiveness, Sonya thought the eating disorder service was a pretty “dangerous place—[it fuels] a real competitive spirit.”

People referred to ‘pure’ or ‘true’ anorexia: weight loss by total control through almost total abstinence of food and drink. ‘Pure anorexia’ was not only an important part of distinguishing them from other people, but also from other eating disorders, which were seen as lower down the scale. Estelle described people with bulimia as “having a harder time” because of the shame and embarrassment associated with “the whole throwing up and bingeing process—whereas with anorexia I was proud of the fact that I didn’t eat like everybody else.”

Estelle’s entry into this world demonstrates the relational matrix of anorexia. As Janet Carsten (2000) showed in her ethnography of Malay kinship, relatedness is more than blood ties of kin, and comprises multiple elements. In anorexia, relatedness concerns the everyday exchange and concealment of practices, secrecy, and competitiveness with other in-patients, friendships formed through sharing a common diagnosis, and the creation of disunity by marking those who want to leave anorexia as ‘outside anorexia.’ These complex ties of relatedness speak to boundaries and belonging, and are central to the powerful production of everyday networks, allegiances, and identities in which anorexic worlds circulate.

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This case study highlights Estelle’s self-awareness of her desire to be part of the ‘anorexic club.’ Being part of the anorexic club means participating in secret acts of resistance to the therapeutic norms promoted in the eating disorder clinics to encourage healthy eating and recovery. The members of this group trust each other in the sense that they will not betray each other.<sup>2</sup> Being anorexic gives Estelle a sense of belonging and identity, and yet she is ill at ease with her membership in this form of resistance. She weighs the benefits of her sense of belonging, from others who engage in the same forms of food restriction and purging to attain an ever-more-slender body, with a revulsion at the *techniques du corps* (Mauss 2006 [1934]) necessary for its attainment.



Resisting the size and shape of her present body becomes a way to engage with a social group with whom she can co-construct her identity. The performance of anorexia revolves around visually assessing how thin one's body is, and how it compares with others in one's immediate environment—whether that is physical or virtual.

Marcel Mauss (2006) published his famous extended essay “Les Techniques du corps” in 1934. In it, he described bodily movements, and how even the most ‘natural’ of movements like walking and sleeping varied significantly between cultures. Mauss noted that humans learn bodily movements by imitation and instruction, and that they give meaning to their everyday gestures, postures, and movements. The non-verbal clues that Warin describes as the young women hide their food, engage in forbidden forms of exercise, and showcase their bodies to either reveal or disguise their emaciated conditions, can be understood as ‘techniques de corps.’ In resistances like anorexia and smoking, individuals turn onto themselves, using their own bodies as sites of refusal, rejection, and opposition. Sometimes the counterpoint—the object of opposition—is in plain view; other times, the oppositional subject—the institution, subject, or ideology—is inherent or muted. But in these cases, the individual who exercises resistance by refusing food, refusing medicine, or refusing support, turns on his or her own body. The body is the one accessible site of resistance to which they have access.

## Resisting Institutions

An alternative form of resistance is that of lodging a complaint within a bureaucratic system, although very different circumstances—relationships of power and access to resources—come into play in such cases. Bureaucracies and institutions of all types have protocols for receiving negative feedback, and the health care system is no exception. As medical systems change, so too does the ability of those using the system to protest against such things as the prices of service, the quality of care, or the prevalence of medical errors. Here, resistance is not internalized or passive; rather people are able to access pathways of opposition in order to force their case. In the following case study set in Puerto Rico, Jessica Mulligan describes the labyrinthine complexities of trying to obtain what one needs through interacting with large bureaucratic institutions both public and private.

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### 6.3 Governing by Complaint

*Jessica Mulligan*

I left Acme's gleaming glass office building and drove east. San Juan sprawled; its highways and shopping centers held the outlying suburbs in a concrete embrace. Twenty-five minutes later, the highway abruptly ended, dumping cars onto a two-lane road peppered with traffic lights, box stores, and new housing developments surrounded by mud. Crumbling brick chimneys stood in the empty fields between developments, a reminder of the sugar plantations that once dominated the landscape.

Acme is a pseudonym for the private health insurance company where I worked as a compliance manager and anthropological researcher; Acme contracted with the U.S. federal government to offer Medicare benefits to eligible beneficiaries in Puerto Rico. As a territory of the United States, Puerto Rico participates in the federal Medicare and Medicaid programs, both of which were substantially privatized in the late 1990s and early 2000s on the island.

My destination that summer afternoon in the mid-2000s was Río Grande, a small town on the northeast coast of Puerto Rico located close to *el Yunque*, the rainforest and tourist attraction. There, I met two brothers—Don Enrique and Don Ignacio—who told me about their experiences with

the newly privatized health care system. In their neighborhood, the two-room concrete houses were tightly packed on small lots; some had been modified with a second floor, a new shade of paint, or religious ornaments. Other houses were not aging so well and showed cracks in the cement walls or appeared to be abandoned. The brothers lived behind a cemetery; the government relocated them to the site when their former home was expropriated for the construction of the highway.

We gathered on their porch and talked over the hum of Mexican ballads interrupted by reggaeton from passing cars. The brothers called out to neighbors, joked about lost loves, and showed me pictures of their children on the mainland and on the island.

Don Ignacio was far more jovial than his brother, Don Enrique, who sat in a wheelchair, shirtless in a pair of shorts with a bandage on his left foot. The white gauze covered his toes and ankle. He explained that he was to have his foot amputated on Monday.

A small cut had developed into gangrene. In the house, they showed me several blood glucose monitors that Acme had sent. They were frustrated with their private health insurance company and could not understand why it kept sending the wrong machine. They wanted the old one with the large-print display, but that machine had stopped working. The brothers both had Type 2 diabetes and neither was able to monitor his glucose levels regularly.

The brothers did not know it, but Acme had contracted with a new durable medical equipment provider as a cost-saving strategy and the transition to the new provider was fraught with complications: orders were botched or never delivered and customer complaints were flowing into the Acme offices. Each time the brothers called Acme to complain, a member of the Customer Service Department opened a grievance in the electronic complaints system and a new glucose monitor was sent to their home.

Don Enrique said he was thinking about the impending operation. His pensiveness contrasted markedly with Don Ignacio, who fried up seafood-stuffed empanadas and insisted that I sample his homemade hot sauce. He showed me big cans of processed bulk food purchased at the new Sam's Club, explaining that the small amount of money he received from Social Security goes much farther at Sam's.

Don Enrique said he had known something was not right with his foot, but he let it go. He put off seeing the doctor for too long. He winced occasionally and mentioned the pain. He blamed himself.

The brothers' case was no anomaly. At this time, the most common complaint at Acme was a delay in delivery of medical equipment. Acme had determined that local durable medical equipment (DME) companies were overbilling and inefficient, so they contracted with a Miami-based DME company to handle all of their orders. Unfortunately, the Miami company was unfamiliar with the topography of the island and lacked the local knowledge to navigate unnamed streets and unnumbered houses (especially in rural areas). They expected that physicians in Puerto Rico would be very similar to those in South Florida; after all, they spoke Spanish in both places. They did not realize, however, that significant differences existed in prescribing customs between the island and Florida. When the new DME company received an order that contained 'insufficient' information (for example, if it lacked a diagnosis code or justification for non-standard equipment), the order languished while overwhelmed customer service representatives tried to obtain the missing information. Physicians' offices were not used to having their orders questioned and did not have the staff to deal with the added administrative burdens imposed by managed care. Ultimately, Acme's attempt at economization and increased efficiency produced a barrage of complaints at the organization, which too often, left beneficiaries receiving suboptimal health care.

These unintentional consequences stem in part from the contradictions inherent in transforming the medical care of the poor, the disabled, and the elderly into a profit-generating enterprise. Clearly, there was a lack of fit between market goals (saving money through a more standardized approach to product delivery) and health objectives (getting the brothers a glucometer that they could read and use in order to manage their diabetes). This example also illustrates how market-based reforms to public services increasingly call on citizens to behave as consumers; the only redress available to the brothers was to complain to Acme through their corporate complaints process.

### ***The Right to Complain***

The question of how privatization reconfigures the manner in which health plan members register discontent and pursue resolution is ultimately a question about how privatization transforms citizenship. In a market-based health care system, the most effective way to register one's complaint is to join the

health plan offered by the competition. Consumers are supposed to express dissatisfaction through purchasing decisions like opting to join a higher-performing health plan or to visit a better-rated doctor. But members of private Medicare plans like Acme can and do complain with more than their feet. In order to protect beneficiaries' rights, the federal government has mandated that private Medicare plans create extensive complaints-processing procedures that are subject to regular audit and verification.

Part of my work at Acme was to ensure that the plan complied with the federal regulations for complaints processing. Being found in compliance hinged on establishing a process for the receipt and resolution of complaints—it did not necessarily involve making a fair or just determination in any particular case. In my time at Acme, individual reviewers were not rewarded for denying coverage, nor were staff instructed to ignore complaints. Instead, complaints were processed vigorously. Even so, the complaints system exhibited a paradoxical quality. The consumer complaints system *appears* to foster a democratic means for beneficiary voices to be heard and due process to be protected. But in practice, the complaints system actually hollowed out (Gledhill 2005), or severely limited, beneficiaries' rights and avenues to redress because it narrowly channeled (1) *how* beneficiaries were permitted to complain, (2) to *whom* they may complain, and finally (3) *what* kinds of issues were deemed legitimate and actionable. Frequently, the reasons that motivated a beneficiary's complaint—issues such as a desire to be treated with respect or to have their unique health-related needs be recognized (like needing more than the standard blood glucose monitor)—were not addressed or recognized within the corporate complaints process. The complaints system also served as a safety valve for containing member and provider dissent, which in turn allowed the health plan to continue rationing care through utilization review.

### ***Novel Forms of Liability and Complaints***

Customer service representatives answered calls piped directly into their headsets and typed customers' information into their computers. Many of the calls were prompted by the receipt of written communication from the health plan. The plan was required by law to issue denial notices to members if a physician submitted a claim and the health maintenance organization (HMO) decided not to pay. The denial notice included a description of the member's rights and instructions on how to file an appeal. The denial notices were often confusing for beneficiaries and ended up generating complaints even when no payment was being sought from the member by either the health plan or the service provider. The process also inadvertently created an adversarial relationship between providers and patients. The following complaint illustrates some of the ironies of these processes that were put in place to safeguard consumers' rights.

Doña Hermina called Customer Service and complained about a notice she received in the mail. She was liable for \$55 for a procedure that Acme had determined was cosmetic and not medically necessary (and therefore not covered by Medicare). Doña Hermina claimed this was a mistake—the podiatrist, Dr. García, never told her she would have to pay out-of-pocket. The customer service representative phoned Dr. García's office and asked for his version of events. The provider, annoyed, said he had already been called about the case. The customer service representative could not reach a quick resolution, so she transferred the case upstairs to the Appeals and Grievance Department.

In contrast to the customer service representatives who were packed into a large room with small cubicles arranged side by side with no dividers in between, the appeals and grievance coordinators worked behind much larger desks where they could spread out the case files in privacy. The appeals and grievance coordinator classified the complaint as an appeal and resolved it by sending a letter to the member. The letter stated that the doctor would not charge the member for the service but that Medicare does not cover cosmetic procedures and next time, she would have to pay.

The podiatrist, Dr. García, after receiving multiple calls from the health plan regarding this case, became quite angry and vowed to file a grievance against the member. He sent a letter to Doña Hermina with a copy to the HMO claiming that he would sue Doña Hermina for libel and defamation of character. The manager of the Provider Relations Department eventually intervened. I sat in with her when she called Dr. García; we spoke to the doctor for 25 minutes. His primary complaint was that his reputation had been insulted. When the patient came to his office and tried to pay the \$55, he refused to see her and much less take her money. He said his daughter can spend that amount on makeup in a weekend. He includes a reminder of the amount owed on patients' appointment cards, but if they cannot pay, he writes it off at the end of the year on his taxes.

Ironically, had the HMO not been mandated by the government to protect consumers' rights by sending out a denial notice, the conflict would never have erupted. Protecting the member's rights caused the complaint as new billing practices and notions of liability supplanted the customary practices that many doctors in Puerto Rico employed in their offices. To resolve the issue, the provider relations manager complimented the physician, assuaged his ego, and explained that the HMO was only investigating because the organization was compelled to do so by federal law. After venting his frustrations, Dr. García agreed to call off his lawyer. Doña Hermina phoned that day, agitated and crying. She couldn't sleep for her nerves since receiving the doctor's letter. The appeals and grievance coordinator told her that the doctor would drop the issue and would she please pick another podiatrist from the provider list. She agreed and vowed to never visit Dr. García again. The appeals and grievance coordinator made a note of the outcome and closed the case in the electronic tracking system.

The complaints process in this example was both dysfunctional and overzealous. The corporation attempted to protect the rights of its members in compliance with federal regulations, but the complaint investigation itself aggravated the situation as multiple Acme employees called the doctor and the member, thereby transforming what was a minor billing misunderstanding into a much larger problem. The physician's reaction—though rare—draws attention to how the initial denial notice and the subsequent investigation ignored local norms for handling billing discrepancies and re-scripted the interaction between the provider and the patient into the idiom of complaints, which created a newly adversarial and litigious relationship. Was Doña Hermina meaningfully protected in this interaction? Unfortunately, she ended up more aggrieved at the conclusion of the process than she was at the beginning.

### ***Unregistered Complaints***

Some of the complaints I encountered while conducting life history interviews never figured in the official registers of managed-care organizations. Consider how Don Luis from Caguas discussed his dissatisfaction. Don Luis did not want the interview to be recorded, so his story is excerpted from my notes. We spoke in his immaculately clean living room, but outside in his front yard overgrown blades of grass reached as high as the windowsill. He explained it was the only way to keep his neighbors' dogs out of the yard.

Don Luis was previously on government insurance through a private plan but had nothing good to say about it. The main thing that the private plan did, in his view, was humiliate poor people. He told a story about a blond psychiatrist from San Juan. She kept an office in Caguas that she visited once a week. Don Luis made his appointment and was told to be there at least by 8:00 AM. He arrived at 7:30 and waited for the doctor who showed up at 2:00 PM. When finally Don Luis was called to be seen, the doctor did not look him in the face. She did not examine him. She simply pulled out her prescription pad and started writing. So Don Luis asked her if she was planning to examine him. She said, oh, so you must be a doctor if you know so much about medicine. He said, I'm not a doctor, that's why I have to come to you. But I do deserve a proper examination. Throughout his story, he spoke to the doctor with the polite, formal address, *usted*. By the way, he asked, do you know how long these people have been waiting for you? The situation escalated and Don Luis ripped up the prescriptions and made a scene in the packed waiting room. He said that the doctor also yelled at those people and told them if they're not happy, they can leave. Don Luis defended the people gathered there: just because we are poor, he said, we do not deserve to be treated like this.

Don Luis explained how this experience and his other troubles obtaining mental health care caused him to drop his privatized government insurance plan. When he received notice of his annual coverage renewal appointment at the medical aid office, he never went. He said it was just as well. One psychiatrist expected patients to line up starting at three in the morning to see him. Then, they might have to wait half the day to actually be seen. He didn't like any of his psychiatrists—they gave him too many medications.

Here we can see another avenue in market-based health systems for patients who are not content with their health care. They have the choice to leave public programs and may elect to pay for private health services instead or forego treatment altogether. In her research on Medicaid managed care in New Mexico, anthropologist Leslie López calls this “de facto disenfranchisement” (2005); beneficiaries fall off the rolls of public programs due to the barriers created by annual recertification procedures or other bureaucratic hurdles. In some ways we can see what Don Luis did as a protest. However,

he never filed a formal complaint, even though he insisted that his rights had been violated. Therefore, his grievances about being disrespected, needing more than medication management, or his inability to obtain timely access to care were never heard by the private plan or the government. The actions he took were severely circumscribed and individual in scope. Instead of seeking redress as a citizen, he acted like a customer and took his 'business' elsewhere. Although there is obviously a conflict between the physician and Don Luis, they have one important thing in common. If people are unhappy with their medical care, they are 'free' to choose another provider. Don Luis now just receives his mental health care from his primary care physician (PCP). He likes his PCP—the man knows how to listen. He currently takes Zanax for his mental health problems. Sometimes he still falls into depressions, but he makes it through okay. The doctor told him to leave the house when he feels something coming on, go for a walk or a drive, just change his environment. Don Luis said this usually works for him. He has a pickup truck and sometimes he'll start driving and end up an hour away in Ponce.

While Don Luis seems at peace with his decision since it allowed him to maintain his dignity and self-respect, this is a man who was once hospitalized against his will and diagnosed with schizophrenia. When he dropped his insurance plan, he no longer received coverage for his prescription drugs. And so his unregistered complaint has also resulted in unmet health needs.

### **Acknowledgment**

This case study is excerpted from Jessica M. Mulligan, *Unmanageable Care: An Ethnography of Health Care Privatization in Puerto Rico* (New York: New York University Press, 2014).

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As Mulligan shows, corporate forms of health care delivery can severely limit how individuals might lodge their complaints, and the corporations define what counts as a legitimate complaint. Akhil Gupta (2012) describes this process in rural India, where the bureaucratic enactment of health care is inefficient, wasteful, and at times absurd. Like Mulligan, Gupta emphasizes the importance of affective relations between those in power within biomedical institutions and those receiving care: "If institutional reform is to be successful, attention has to be paid to generating new narratives that alter the affective relations between the state and its poorest citizens" (2012: 35). Those affective relations can be very important to maintain from a practitioner's point of view as well. In more litigious settings, patients are more willing to pursue malpractice lawsuits when they feel animosity towards a practitioner; in countries where medical errors are handled via systems of educational remediation not monetary castigation, or where they are overlooked because of their recurrence, practitioner-patient relations play out differently (Cartwright and Thomas 2001).

We are in an era that is characterized by an ever-increasing, but always incomplete and changing, reach of biopower, a term Foucault (1980) used to refer to both the disciplining of individual bodies and the regulation of populations. Biopower is constructed via technologies that monitor patients, visualize biological process, and gather bio-data. These data provide clinicians with information about individual patients, and add to databases that reify and refine our understandings of human physiology. Such things as PET scans, MRIs, ultrasound sequencing, and nuclear medicine efficiently penetrate the human body, mapping our interior terrains. Even mobile phones and tablets have the ability to geographically locate us and transmit

readings of our vital signs and ultrasound images, and these technologies are rapidly becoming even more powerful and more sentient. As we will see in Chapter 15, biomedicine moves across geographical and cultural spaces in a myriad of ways, making the study of how it is accepted and how it is resisted reflective of particular times and places.

In this chapter, we have described various kinds of resistance to biomedicine. The case studies indicate possible new directions in medical anthropological inquiry that can profitably pay attention not only to what people are saying, but what they are doing and how they are doing it. Anthropologists are well placed to make sense of the everyday acts of resistance, and the tactics that people use to creatively resist hegemonic institutions (de Certeau 1984). New methodologies, together with increasing ease of obtaining photos and video footage, are changing the way we can ask these kinds of non-verbal research questions (Cartwright 2013).

We should ask ourselves how medical anthropology, as a discipline, takes a stand for or against the particular enactments of biomedicine that we study. We need to question the ethical considerations that come from our particular positions via the powerful institution of biomedicine, whether we align ourselves with the subaltern classes or become handmaidens of biomedicine, whether there is a middle ground, and how our research either reinforces or questions biomedicine and its authority in any given situation.

## Notes

1. As we see in Chapter 15, the ideas and technologies of biomedicine travel and at each stop they are understood incompletely and interpreted differently.
2. For an introduction and references to secrecy as embodied practice, see Hardon and Posel (2012) and Davis and Manderson (2014).

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