

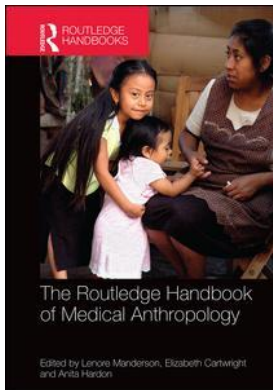
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Luis the Son, 2007. Tiahuanacu, Bolivia.

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Note: Originally published in Jerome Crowder, 2013. *Becoming Luis: A photo essay on growing up in Bolivia*. *Visual Anthropology Review* 29(2):107–122.

About the photograph

After helping his family in the fields all morning, Luis returns to the house and waits while his mother, Basilia, prepares a midmorning meal of quinoa with fresh milk. He sits on the bench, where his uncles usually sit when the family eats together in this room, and talks about life with his mother on the farm. He shrugs, saying, "I see my mom nearly each week. Either she visits me or I see her here, sometimes she comes with grandpa to church, but usually I come back out after school lets out. Now that I'm 11, she says it's time for her to return to El Alto and find a job. Life here is hard, but there it's just expensive."

By 2011 Luis and Basilia were living in their own home in Urbanizaton Bautista Saavedra (El Alto) near his aunts and uncles and across the street from his former school. At 15, Luis decided he wanted to make money rather than attend school, so he became an apprentice to his uncle, a carpenter, who lives next door. Together they make furniture, doors and windows, which are sold in various markets across El Alto, such as the largest one in Villa 16 de Julio.

—Jerome Crowder

Chronicities of Illness

*Lenore Manderson, Elizabeth Cartwright
and Anita Hardon*

Chronic conditions illustrate the complex relationships that contribute to the risks of ill health and disease, and shape their outcomes. As we have already illustrated, social organization, economy and politics, as well as health systems factors, interact with pathogens and biology to determine the epidemiology and chronicity of disease. These factors influence episodes of comparative illness and stable health, the progress of disease, decline, and functional impairment. Many people with chronic conditions also have other unrelated ongoing health conditions, frequently associated with the same personal and socioeconomic preconditions. At the same time, many co-occurring conditions interact biologically and in relation to structural factors. As we noted in Chapter 1, Merrill Singer (2009) developed the concept of syndemics to capture these multiple interactions, where two or more diseases interact at the level of biology, but also, concurrently, the diseases and structural factors interact, with the synergy resulting in an especially high prevalence and/or different mutations and expressions of the diseases (see also Ostrach and Singer 2012; Singer 2014; Singer and Bulled 2014). Such syndemics arise especially in extreme settings, as occur in periods of war, in fragile states, or in societies with marked inequalities. But outside of these circumstances too, people may experience a number of chronic conditions, often co-occurring and interrelated, and they struggle to manage these and head off complications. The result, for many, is a downward economic spiral and growing social exclusion, as accrued poor health inhibits workforce participation; as care, treatments and medications eat up available financial resources; and as poverty and illness combined erode family resilience.

In a single chapter, it is difficult to capture the chronicity and co-occurrence of long-term health problems, given the diversity of chronic diseases, including both those that are infectious and those that are non-communicable. In the following, we concentrate on three major themes where an understanding of social and cultural context helps to make sense of the persistence of particular diseases. We first consider, as a single case study, two chronic, infectious parasitic diseases that are highly prevalent in impoverished environments; the case study related to this illustrates how the politicization and economics of global health policy and medical interventions continue to impede their control. We then turn to chronic non-communicable diseases—the social perceptions of these diseases is that they are unavoidable or inevitable because interventions have failed as a result of their inability to address the structural factors that contribute to the development and influence the progress of diseases. In the third case study, we illustrate the impact on identity when a chronic disease is out of control: in this example, when uncontrolled diabetes results in amputation. In the final case study, we examine how long-term degenerative

conditions impact social life, and explore questions of agency and the role of social support in enabling people to work around the impositions placed on them in ways that help them head off further decline.

The Chronicity of Infectious Disease

Many infections—most upper respiratory tract infections, for instance—are commonplace and of nuisance value only, with little or no long-lasting effects. However, a significant number of infectious diseases are treated today, as in the past, with fear and stigma (Briggs and Nichter 2009; Brown and Kelly 2014), with severe morbidity and the high mortality rates characteristic of spectacular epidemics, their equally spectacular measures of control, and their devastating socioeconomic impact: consider, as examples, cholera, yellow fever, new emerging diseases such as SARS (severe acute respiratory syndrome), H1N1 (swine flu), and MERS (Middle East Respiratory Syndrome), Marburg, Ebola and other hemorrhagic viruses (see Chapter 15). While these infectious develop rapidly, various infectious diseases are chronic, and while fear of infection and its associated stigma pertain, people live with these infections, often at a subclinical level, for decades. Tuberculosis and HIV infection are common all over the world, and the challenges associated with adherence to medication and monitoring are precisely because of the combination of their chronicity and infectivity.

Chronic infectious diseases may be diagnosed long after the time of infection, hence the focus on their prevention, or they may result in generalized lethargy rather than frank illness. Their signs and symptoms may be subtle and confusing, and so these infections are frequently untreated, leading to continued transmission. Large numbers of people worldwide suffer from underdiagnosed parasitic infectious diseases, generally transmitted and most prevalent among people living in extreme poverty. They are increasingly referred to as ‘neglected diseases of poverty,’ with the populations afflicted, as well as the specific diseases, largely ignored by global medical science and industry (TDR 2012; Manderson et al. 2009). In the following case study, we discuss two of these parasitic infections, schistosomiasis and filariasis, for both of which drugs are readily available and safe, and have been available and used for decades. The diseases, in theory, are able to be controlled if not eliminated. But the chronic conditions of local living circumstances, the chronic underfunding and limited resources of health services, and chronic problems related to state governance, all inhibit the effectiveness of control programs.

Some 250 million people are infected with schistosomiasis (bilharzia) worldwide, the majority living in poor rural communities in sub-Saharan Africa. Parasite eggs from the feces or urine of an infected person are transmitted to snails in slow-running water used for everyday purposes—personal hygiene, children’s play, washing clothes and household utensils, watering animals, irrigation and fishing. Swimming, wading or standing in this water, people are constantly at risk of infection and re-infection from parasites shed by the snails. The infection is often unnoticed, marked only by a brief period of fever, rash or itching—everyday changes in bodily wellbeing that are rarely considered worth a visit to a clinic. But the parasites multiply, and cause serious problems over time: anemia, malnutrition, pain and lethargy, impaired growth and development in children, impaired school performance and work, infertility, and in some cases, cancers and liver and kidney failure. Health education campaigns and community participation programs exhort people to avoid contact with infested water and use toilets, but this is unrealistic where people lack alternative water resources, taps and toilet facilities, and where the availability of the requisite infrastructure depends on state investment for its provision and maintenance. Further, infection in humans is often maintained because animals are reservoirs, and because economic development programs create new ecologies of infection rather than reducing risks, by disrupting

water flows, as occurred for instance with the construction of the Aswan High Dam in Egypt (1967) and the Three Gorges Dam in China (2006).

The second disease considered in this case study is filariasis, which like schistosomiasis is a chronic parasitic disease, affecting some 120 million people in parts of Africa but also in South and Southeast Asia and elsewhere. Mosquito-borne parasitic infections and arboviruses, such as malaria, dengue, yellow fever, lymphatic filariasis and onchocerciasis (river blindness), often co-occur with schistosomiasis, highlighting the interplay of social and biological environments. Filariasis is transmitted in urban and densely settled rural areas where mosquitos breed in stagnant storm water drains, pit latrines and swamps. Health education campaigns for filariasis exhort people to avoid being bitten, but this is difficult. Depending on the species, the mosquito may rest indoors and feed at night, or bite both day and night, so limiting the effectiveness of preventive methods like bed nets, and people are at risk of being bitten and infected as they go about routine activities. As with schistosomiasis, people are often asymptomatic at time of infection. The first signs of filarial infection—again rashes and itching—are easily ignored by people who live in unsanitary environments with limited ways of ensuring hygiene. The disease manifests years after infection, when it becomes profoundly debilitating and stigmatizing: lymphedema, elephantiasis, scrotal swelling in men, and breast and vulva swelling in women. These conditions limit people's capacity to participate in social and economic life, and cause extreme social exclusion (Person et al. 2009; Weiss 2008).

Drug treatment for both schistosomiasis and filariasis is effective. But drug treatment deals with infections in individuals, and where infections remain in a community, people are at risk of re-infection. As a result, countries have implemented mass drug administration programs, when entire populations are treated concurrently to interrupt transmission and so break the cycle of infection. Often mass drug administration programs for schistosomiasis and filariasis include additional drugs to treat endemic soil-transmitted helminth infections (worms), with the drugs donated by pharmaceutical companies and able to be administered by school teachers, local pharmacists or community health workers. But the logistics are complex because of the need to ensure the concurrent treatment of all people in target communities, and so the programs are rolled out as if they were military operations. The process is complicated too where populations resist participation because of their lack of involvement in governance, limited understanding and suspicion of the medications, and confusion about the rationale for particular treatment regimes. Further, as Tim Allen and Melissa Parker illustrate in the case study below, weak health systems at national and local levels, difficulties in procuring and distributing drugs to ensure adequate and continuous supplies, and the leakage of freely available drugs from public health posts into the private sector, interfere with the scale up, success and sustainability of these programs. Medical anthropologists working closely with communities may not be surprised by these institutional and community problems, but others involved in the mass administration of drugs have reacted strongly to the criticism associated with the difficulties in delivering such programs, and their putative success, fearful that the resources directed to these 'neglected' diseases will be withdrawn if operational challenges are exposed.

7.1 Mass Drug Administration for Neglected Tropical Diseases

Tim Allen and Melissa Parker

Since the turn of the century, there has been a dramatic change in global and national responses to a range of chronic infections, increasingly referred to as the Neglected Tropical Diseases (NTDs). The term 'NTDs' was first coined in 2005 by scholars and activists who were lobbying to move them

to the center of discourse on health policy in affected regions, particularly in parts of sub-Saharan Africa. A case was made that the ‘other diseases’ mentioned in the Sixth UN Millennium Development Goal should focus on the NTDs, because an effective strategy was at hand and the results would be dramatic.

The number of afflictions grouped together under the label of ‘NTDs’ has expanded, partly because of successful attempts in attracting funding and assistance from international donors and drug companies. The WHO currently highlights 17 NTDs caused by a variety of pathogens: viruses (dengue and rabies), bacteria (buruli ulcer, leprosy, trachoma and yaws), protozoa (Chagas disease, human african trypanosomiasis and leishmaniasis) and helminths (cysticercosis, dracunculiasis, echinococcosis, foodborne trematodiasis, lymphatic filariasis, onchocerciasis, schistosomiasis and soil-transmitted helminthiasis) (http://www.who.int/neglected_diseases/A66_20_Eng.pdf).

A sub-group of these afflictions has been a particular focus of attention, with some scholars and activists arguing that they can be easily treated, controlled and, in some cases, eliminated with a combination of available tablets. In a key paper, Molyneux, Hotez and Fenwick (2005) suggested that lymphatic filariasis, schistosomiasis, intestinal helminthiasis, onchocerciasis, and trachoma could be targeted by a program of mass drug administration (MDA) with praziquantel, albendazole, ivermectin and zithromax. The medications could be sourced from major companies, notably GlaxoSmithKline, Merck and Pfizer.

A remarkable momentum developed, with drug companies offering free tablets for MDA to people living in endemic areas. The drugs were deemed to be safe and efficacious, and the aim was to treat everyone, especially children, at annual intervals; for this purpose, considerable funds were allocated by the Gates Foundation, DFID, USAID and other donors. Essentially, large-scale, vertical distribution systems were introduced, with medications delivered through ministries of health to community drug distributors. Integrated treatment for multiple infections was simultaneously introduced in several countries, notably Uganda (2006/7) and Tanzania (2007). It was anticipated that these countries would provide models for others to follow.

Spectacular claims soon started to be made about what had been achieved, and fearing that it might be sidelined, the World Health Organization decided to seize the initiative. In 2010, the newly established NTD Division released its first global report on NTDs, presenting an overwhelmingly positive assessment. The following year, the WHO published a ‘Roadmap’ which outlined control, elimination and eradication targets to be reached between 2012 and 2020. This was followed by the London Declaration of 2012. The World Bank, the Gates Foundation, 13 of the world’s leading pharmaceutical companies, and government representatives from the US, UK, United Arab Emirates, Bangladesh, Brazil, Mozambique and Tanzania participated in a joint meeting, held under the auspices of the WHO, at the Royal College of Physicians in London. They committed themselves to achieving the NTD Roadmap Goals, with donors offering hundreds of millions of dollars, and pharmaceutical companies offering indefinite supplies of free medications.

In this context, anthropological research has proved to be contentious. Evidence from places where people have been receiving the treatments has raised doubts about some of the grand claims being made, especially about the possibilities of disease elimination. Fieldwork carried out at over a hundred sites in Uganda and Tanzania shows that the effect of integrated MDA programs are very mixed. In some places, the uptake of drugs for NTDs is high, especially where populations are contained, such as displacement camps in Uganda (where tablets have been provided together with food relief). There are also locations where understandings of MDA are such that there is willingness and even eagerness to be treated. An example is among fishing populations living on islands in the River Nile, to the north of Lake Albert in Uganda. Elsewhere, however, sometimes close by, there may be resistance or outright rejection of the tablets. Rumors circulate about the real purpose of distributing them. Fear of sterilization campaigns is common, as are local conceptions about the signs and symptoms of afflictions that counter biomedical perspectives. Overall, findings suggest that the drug take-up rates are below those necessary to systematically control infection (Parker and Allen 2013). Our anthropological findings on NTDs, drawn from fieldwork in Tanzania and Uganda, may be summarized as follows.

First, predominantly politically and economically marginal populations are the most likely to be infected with NTDs and the least likely to have access to information about the infections or therapeutic care. It is neglected people who have neglected diseases, and this social problem cannot easily be addressed by vertical biomedical interventions. Indeed, top-down delivery mechanisms are as likely to reinforce power relations as to undermine them. In Panyimur sub-county, north-western

Uganda, we found that MDA was failing in large part because the treatment program exacerbated antipathies among the fishing population towards district officials and towards the government. A crucial factor was the lack of respect shown by officials towards those who were supposed to benefit from treatment. There was disinterest in discussing the programs in public meetings or seeking support from local leaders, such as the traditional chief, leaders of religious groups, and local healers. Resisting disease control here was a form of what Scott (1985) has called 'weapons of the weak.'

This lack of respect for target populations reflects a broader concern about the orientation of MDA programming. Despite rhetoric emphasizing the need for community engagement and a list of sensible WHO guidelines, in practice MDA can end up being worryingly top-down and divorced from local realities.

Unpaid and poorly trained community drug distributors are often used. They are supposed to understand the purpose of persuading their neighbors to take medicines for diseases that they often do not know they have, and about which they may have very different local understandings. For those infected with *Schistosoma mansoni*, for example, it is possible to have no signs or symptoms of infection and to feel quite well during the early years of infection. In such circumstances, it is hard for community drug distributors (whose biomedical understanding of the signs, symptoms and etiology of the NTDs is typically quite limited) to persuade their neighbors to consume medicines on a regular basis. A similar issue arises with lymphatic filariasis. The drugs need to be given to people well before they develop symptoms. Also, in places like coastal Tanzania, the symptoms themselves are not normally connected with the parasitic infection, but with a range of other causes.

There are important differences between the kinds of tablets being offered and between the diseases being treated. Some tablets are welcomed. Albendazole is a good example. It tastes like a sweet and it has an observable effect. If it is given to people with particular kinds of intestinal helminthiasis, the worms pass out in the stool. In contrast, praziquantel tablets are large, several have to be swallowed at once, and they smell horrible. In addition, they have side effects if taken by individuals heavily infected with *Schistosoma mansoni*. People may feel sick for days, and in Uganda, stories were circulating about people dying from the drugs. As a consequence, integrating treatment into a homogeneous and vertical delivery system is far from straightforward, and may be counter-productive. If one drug is disliked, none will be taken.

A lack of engagement with targeted populations, including poor explanations for the rationale for mass drug distribution and ineffective health communication about the signs, symptoms and etiology of NTDs, lends credence to conspiracy theories. Without such engagement, rumors about population control can escalate into dangerous situations. There were, for example, violent riots in Tanzania in 2008, initially triggered by attempts to implement MDA for schistosomiasis in schools.

Given the poor communication, ethical issues arise about the treatments, but tend to be brushed aside. Ethical issues apply particularly to the treatment of children, who are effectively compelled to take medications without their parents being properly informed or their teachers being properly briefed. Children have occasionally been observed being compelled to take the tablets after trying to run away, and angry parents berating the teachers is not uncommon. We have also observed the distribution in schools of the wrong tablets, the wrong combination of tablets, and the wrong health education leaflets for the medication. In certain places, such as Ukerewe Island in Lake Victoria, these problems have been overcome and observed take-up in schools is high. However, elsewhere, school distributions are partial. On occasion, unopened containers of tablets were found in school store rooms. It became apparent that teachers lacked the confidence or commitment to distribute them to the children as they had been instructed to do.

Rigorous assessment of MDA often does not occur. Even the most basic information tends to be guesswork, and treatment rates are commonly inflated. This became apparent from combining participant observation, careful collation of data from community drug distributors, and checking of reported drug uptake data as it passes from points of dispersal to national reports. For MDA to have clinical benefits, those being targeted have to actually consume the drugs being offered in the correct doses, and while this happens in some cases, in other cases it does not. Without knowing what is happening at very local levels, it is impossible to address this issue. In practice, it is mostly ignored.

Finally, ethnographic evidence from villages and anthropological assessments of MDA programs at district, national and international level has revealed that some of the literature emphasizing positive results, published even in well-respected medical journals, is linked to securing and sustaining grants. There is a pronounced tendency to de-politicize public health, with the roll-out of MDA clearly resonating with Ferguson's notion (1990) of the 'anti-politics machine.' Assertions emphasizing

poverty alleviation are conflated with dubious data, and many passionate supporters of MDA end up believing their own rhetoric. This has been reflected in some defensive reactions to evidence from anthropological fieldwork showing that results are mixed. That has been especially so with respect to our findings on lymphatic filariasis in Tanzania (Parker and Allen 2014).

To have any chance of interrupting the transmission of lymphatic filariasis so that elimination would be feasible, annual rates of drug take-up have been variously estimated at 65–80 per cent over four to six years (Mohammed et al. 2006) and 70–90 per cent over six or more years (Michael et al. 2004). In areas where the prevalence of microfilariae is greater than 10 per cent, such as coastal Tanzania, Michael and colleagues (2004) have suggested that coverage levels of 90 per cent or more may be necessary. Our research showed that there was no prospect of that target being reached. The highest rates of take-up we recorded were around 70 per cent near Muheza town in 2007, where there is a large hospital. Elsewhere in both Muheza and neighboring Pangani districts rates were often less than 50 per cent. For example, at one coastal site in Muheza district, a survey of 146 homes in 2007 found a self-reported drug take-up rate of 22 per cent, a drop from 47 per cent in 2004. A further survey in 2011 of 144 homes found a slightly higher self-reported uptake of 34 per cent for 2010. There is no way that lymphatic filariasis can be sustainably controlled, let alone eliminated, with these low levels of drug uptake. Moreover, actual consumption of drugs was undoubtedly even lower, because some recipients had taken the drugs from the distributors, but either did not swallow them, or only swallowed a partial dose. No serious effort had been made to communicate the reasons for MDA, and the vast majority of people had no idea that mosquitos were the vector of the disease, even after multiple rounds of treatment. The fact that taking the tablets had no discernible effect on those with hydroceles or swollen limbs confirmed to many that the drugs were at best defective, and at worse had a sinister purpose. There was no prospect of the situation altering without a radical change in approach.

We began publishing our research on lymphatic filariasis in 2011. Initially, we did so to illustrate the overblown claims being made about NTD control more generally. In response, two leading advocates of MDA, among those who claim that elimination of lymphatic filariasis is both possible and likely by 2020, wrote a ferocious attack in a medical journal (Molyneux and Malecela 2011). They did not explain why things might be better elsewhere or how targets for elimination might still be achieved. Instead, they argued, treating NTDs was a way of ending poverty, and questioning the effectiveness of the approach was ethically unacceptable; they characterized our work as “disrespectful to endemic countries” and “unethical and grossly negligent”. Further, the authors referred to research at a “sentinel research site” in Pangani District, which they suggested contradicted our results—no such sentinel site existed. Subsequently these and other authors who were leading supporters of vertical MDA wrote a short piece in the *Lancet*, maintaining that anthropological insights into MDA should be dismissed as “cynical” (Molyneux et al. 2012).

Anthropological research on NTDs has, however, had impact, and becomes difficult to set aside when supported by clinical data. In December 2012 we were invited to a meeting at the UK’s Parliament. At that event, the Director of Research and Chief Scientific Adviser at the UK’s Department for International Development highlighted the dangers of exaggerating the results of treatment programs for NTDs. He referred to data on the control of leprosy, suggesting much greater reductions in prevalence (and therefore incidence) than was actually the case. The result was that donors reduced their funding for leprosy control in the mistaken belief that the disease was no longer a serious problem. He also noted that the targets being emphasized to secure support for control programs for other diseases could be similarly counter-productive. In the discussion that followed his talk, we agreed that it was unhelpful to use the term ‘elimination’ with respect to lymphatic filariasis—except in particular geographical areas where there is good evidence that this is technically feasible and realistic. In March 2013, our findings on lymphatic filariasis were foregrounded in a parliamentary debate, and our research and that of others has ensured that MDA programs are now paying greater attention to the specifics of local circumstances.

A commitment to combating NTDs is a hugely positive development, and that is all the more reason to avoid treating fund-raising rhetoric as facts, and to learn lessons from what has happened with such large-scale vertical schemes in the past. That means placing medical anthropology at the heart of programming. Anthropological studies confirm that MDA for NTDs can potentially assist poor and marginal people, while emphasizing the acute need for sober and rigorous assessment of

locally specific effects and reported results. Far from being cynical, anthropological evidence confirms that this approach is sensible. There is an opportunity to help millions of people. It would be disgraceful to waste it.

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Living Uncertainly

Changes in human settlement have influenced the prevalence and distribution of disease, and will continue to do so. In around 30 years, some 50 percent of people in Africa will reside in urban environments; already even greater proportions than this live in urban settings in middle- and low-income countries on other continents. Driven by this shift, by colonization, changes in patterns of work and industrialization, and by globalization, food produced locally has been replaced everywhere by commercially grown, manufactured and distributed products. Increasingly people subsist on a narrow range of foodstuffs, inexpensive but of poor nutritional value, and often aggressively marketed.

In association with urbanization and industrialization, cardiometabolic diseases—the clustering of obesity, diabetes mellitus and cardiovascular disease—are emerging as neglected diseases of poverty that are steadily outstripping infectious diseases in prevalence worldwide. These diseases were commonly referred to as 'lifestyle' diseases as they gained importance in the global North, but this terminology implies that people have a choice in how they live their lives. Regardless of setting, in high-, middle- and low-income countries, the decisions that people make about diet, physical activity and health are subject to environmental influences, social inequality, power, and politics. Unemployment, poverty and social disadvantage largely predict the chronicity of non-communicable diseases (Weaver and Mendenhall 2014), and the development of other co-occurring diseases. These social factors are all implicated in the increased incidence of obesity, diabetes and heart disease, and associated anxiety and depression. Similarly, the personal and social resources available to people—human capital and social capital—influence the likelihood of acquiring both non-communicable and communicable chronic diseases, and interfere with prevention and control, timely diagnosis, effective treatment, and ongoing care.

Treatment advances have altered the trajectory of many chronic conditions, both infectious and non-communicable, and in this context, early diagnosis can be life saving. There is considerable interest in early interventions to ensure that symptoms of disease are addressed when they are relatively minor, in order to prevent complications and early death. This is possible through

effective screening and testing, despite that these technologies may either produce or resolve anxiety about non-communicable disease. People may undergo tests because they are concerned they have signs of disease, for example, or in response to a public health campaign; others undergo tests because of a family history of a condition. Of these, a proportion of people seek out information about risk to decide whether or not to act preventively, to gain information in order to identify potential signs and symptoms, or to make decisions about reproduction (Flaherty et al. 2014; for further discussion, see Chapter 14). Yet anxieties about the potentiality of disease do not necessarily result in behavioral change to prevent its development. People may argue low risk on the basis of local biologies (Lock 1993), or their own experience.

In many places across the globe, screening programs are simply unavailable, their cost-effectiveness in terms of public health gains is questionable, and access for the majority of the population is limited. Delays in diagnosis and treatment may also occur because early signs such as tiredness may be overlooked or dismissed, as we have suggested already, because of the lack of technology to diagnose with accuracy, because of poor access or resistance to attend available health services, or because of fear of the diagnosis. Health service factors, including inadequate and broken equipment, lack of laboratory services for pathology tests and results, and lack of follow-up with patients, all also affect pathways to care. Most cancers in resource-poor settings, for instance, are only identified when the symptoms are distinctive and the disease is advanced.

Everywhere people live with ongoing health and medical problems associated with degenerative changes and their complications, and with the continued fear of the return of a disease, as occurs for people who have had cancer, or a repetition of a life-threatening health event for those who have survived cardiac arrest or a stroke. Cancer's chronicity in particular is framed by fear of recurrence, regardless of age at onset, and people live precariously in a time defined by the years of their survivorship. Even the language around illness and recovery—of remission, not cure—captures the uncertainty of outcome and the limits to our understanding of such diseases. Cancer, too, draws attention to the ways in which biopathology is situated. Family history, genetics, various demographic factors including age and gender, food and diet, environment and exposure to known carcinogens, are all risks for disease (see also Chapter 14). Further, as Julie Livingston (2012) has so clearly illustrated for Botswana, personal- and community-level social and economic factors, area of residence, and country capacity, all also shape outcome, including timely and accurate diagnosis, and access to the technologies and finances for treatment, care and palliation. Paralleled only by HIV, cancer is also a political disease, with people advocating for its prioritization in research effort and funding, the delivery of particular medical services, and the provision of drugs. Breast cancer particularly, like HIV, is highly visible in public space, through screening programs, support organizations and fund-raising activities, and advocacy (Manderson 2011; 2015).

Because chronic conditions are by definition persistent, even if variable in their severity and impact, everyday living is interrupted when poor health intrudes, as normal bodily functions are undermined and as bodies are transformed physically. Individuals must seek to live with the fickleness of their health, restructuring social and economic activities and relationships, and modifying familiar routines and social roles. Illnesses, loss of capacity, repeated hospitalizations and institutionalization, and growing dependence on others place older ill and disabled people particularly in a frequently depressing and liminal space (Turner 2008; van Gennep 1960). This liminality, and embodied frailty, intersect with structural fragilities such as immigrant status (local or transnational), unemployment, geographic isolation and poverty, so further limiting people's social connectedness and the material and emotional advantages this yields.

While adjusting to bodily changes, chronic illnesses come to dominate the time of those affected. People must manage care regimens and medications, and monitor physical signs and symptoms that might augur complications and the need for further medical attention, diagnosis

and treatment. People with health problems such as diabetes, COPD (chronic obstructive pulmonary disease) and heart disease may find their lives structured around the routines of self-care including diet, physical activity and medication; for those with diabetes, including insulin injections and blood sugar monitoring; for those with COPD, oxygen. In this way, people's homes are modified to incorporate biomedical equipment and accommodate impairment, with hand rails, ramps, lifts and blood pressure cuffs all converting domestic space into a hospital at home (Pavey et al. 2015; Sakellariou 2015). But there is a significant difference across countries and the affordability of such appurtenances. People in the global North can, in general, access regular supplies of insulin pens or oxygen, for instance, and may be able to join support groups to deal with the challenges of living with poor health. In resource-poor settings, people's lives may be cut short in the absence of access to medicine or its technologies, and they necessarily improvise, using plastic bags in lieu of purpose-made stoma bags; trolleys or wheelbarrows for mobility; or they simply crawl from one place to another.

As we have already indicated, diagnosis enables an individual to make sense of disturbing signs and symptoms and opens the door to treatment, whether it is potentially curative (as is the case for some cancers, or for leprosy, for instance), delays severe symptoms (with HIV and other cancers, for example) or prevents secondary disease, as with the early diagnosis of diabetes. In the process, it establishes an authoritative relationship between the patient and the health care provider—the doctor, usually, often with the backing of pathology results and imaging—and provides a way for the patient and provider to plot a future, or a choice of possible futures (Smith-Morris 2015). People may fear the diagnosis of certain long-term diseases, but may find relief because diagnosis allows them, their families and friends to make sense of particular signs and behaviors, and to begin to plan around the eventuality of changed health status.

In other cases, the development and diagnosis of chronic conditions may simply be regarded as part of an anticipated life-course, even when diagnosis releases the biomedical resources that are available, as Carolyn Smith-Morris illustrates in the case study that follows. Robin, aged 29, already has poorly controlled diabetes with complications, including kidney failure, and she is faced now with the likelihood of lifelong dialysis or, less likely, a kidney transplant and lifelong medication to prevent organ rejection. But Robin's poor health is the consequence not of one disease alone but an interplay of social and biological circumstances; her ill health illustrates what Singer (2009) describes as a syndemic. Robin is a Pima American, and her poor health is very much the product of a long history of colonial oppression, racism and continued structural disadvantages. Her particular health problems are the consequence of interactions in the prenatal environment, genetics, and contemporary social and economic limitations that influence her diet, activity, employment, mobility and care. Her diabetes, that is, is the result of various broad social determinants of (ill) health and the interactions of different physical health conditions.

7.2 Diagnosis and the Punctuated Life-Course

Carolyn Smith-Morris

On the Tuesday morning I last interviewed her, Robin awoke on the couch, having given her bed over to the three young cousins visiting her from Komatke, just a few miles down the road. Her teenage brother was draped over the reclining chair next to her, and there were two more pre-teens on the floor. The TV was still on, playing "The Big Country," and the flickering lights made the silent house glow in a strange half-sleep. Stepping gingerly through the crowd of blanketed forms, I greeted Robin and accepted her coffee and a seat at the table. I had only moments ago left a similar scene, in

the house where I lived during this field season, so the circumstances of this interview did not require any substantive emotional or psychological effort on my part (in contrast to the first years on the reservation, when these intimate encounters were new and unnerving). Robin had already slept through the noise of her two youngest sisters' departure for school. A dark fleece blanket, the kind you can buy roadside or at the fair, this one with an eagle dancer on it, blocked the 10:00 AM light, so we sat in the TV glow talking over her federal assistance checks, her goal to get a high school certificate, and her health. This was our third such conversation as part of my ethnography of stress and diabetes in her community. Robin's grandmother would come home from work around noon and take her to an appointment at the clinic.

The house crowded with extended family, the sense of protection its walls gave from the harsh light and heat outside, even the sleeping arrangements, are all part of a fairly typical, although not universal, embodiment of 'life on the res.' Indian time is just one form of embodied resistance, and its naming a discursive strategy to stabilize a cultural system that is different from the colonial system. Life on the res is slower and driven by internal human rhythms. It involves a passivity about clock-dictated regimens, and an overt rejection of several more cultural characteristics of the Western European, industrial (now technological) complex. Robin's diurnal patterns, her willingness and ability to sleep wherever she lays her head (without sheet or pillow), and her unquestioning attitude toward the irregular company of extended family, are all features of reservation embodiment that strikes me as tethered to a remote, pre-colonial past. They are vestiges of communal Indian life somehow surviving to inhabit this partially modern landscape, a house in the middle of the desert.

The home we are in is one of the Bureau of Indian Affairs (BIA) housing units constructed with money from the Snyder Act of 1921, allocated "to replace and repair housing for the neediest of the needy: American Indians and Alaska Natives" (Bureau of Indian Affairs April 1, 2001). Then, many Pima lived in *olas'ki* (oh-loss 'key) or other hand-made housing. The new housing would include running water, electricity, and toilets with individual bedrooms and doors for privacy, security from theft, and clarity of ownership, and so also individualism. With the houses came a variety of ideologies into which each new generation would grow.

If you have ever driven through a reservation, you might recognize the rows of cinder-block houses, set apart in even increments oriented to a straight line rather than the natural contours of the former landscape. The federal system that oversaw housing for these Indian 'wards' of the US government, along with the disparate other mechanisms for Indian health care, education, and other priorities, had grown complex and tangled over time. Then, in 1975, came a momentous new piece of federal legislation, what is known as the Self-Determination Act. That law addressed health, education and governance, leading many tribes to write contracts for their federal funds, so that they could budget and manage those funds themselves rather than allowing control of federal employees over tribal funds, planning, and management. The new system has promoted tribal capacity for self-governance, many would say better than any other federal legislation since the colonial period. For Robin, this means she speaks with community members in local tribal offices when she needs housing repairs or assistance. A distant cousin helped her mother file an application for their current house (14 years ago), into which Robin moved as a 15-year old. Thirteen people now live in this three-bedroom, one-bathroom, 850-square-foot house; this density is characteristic. The home I left earlier that morning had eleven.

On Tuesday afternoon, Robin had an appointment with a nephrologist to determine her need for dialysis. She had been diagnosed with diabetes when she was eight or nine years old. As an overweight little girl, she raced, played soccer, and explored in the desert with her friends, but like most other American children, she also watched a lot of TV and ate junk food and soda. School programs taught her the facts of nutrition and portion size, but vending machines and vendors of fry-bread (a white flour and lard dough, shaped into 10-inch circles and fried) were more tantalizing. Her story is ubiquitous in America; the country is in the midst of an obesity epidemic because of industrial food's allure. But Robin's genetic code, and that of all Pima and many other Native Americans, makes her vulnerable to more than obesity. For those with the 'thrifty gene,' engineered through the millennia to survive the prehistoric feast and famine cycles of the Sonoran Desert, the constant feast of contemporary industrial Western life leads quickly to diabetes. Robbed in the 1800s of Gila River water so crucial to their agricultural lifestyle, the Pima sunk into decades of extreme poverty and dependence on the federal government, including commodity foods that were high in salt, fat, and packaged goods. Today, geographic isolation, federal food assistance, and widespread unemployment leave many without healthy food options (Smith-Morris 2004).

Robin is 29, more than two decades younger than most US Whites when they are diagnosed, which on average is at 55.4 years of age (2011 data). For the past several years, Robin has worked hard to change her eating habits and to embrace the concept of exercise, to protect the kidneys she can neither see nor feel. A person's kidneys serve to filter wastes from the blood that are produced by normal functions in the body. If

the kidneys cannot perform this function, or cannot perform it adequately, the wastes build up and cause damage. But the kidneys can themselves be damaged, and in the case of diabetes, excess glucose in the blood stream damages the tiny blood vessels in the kidney. Damage from diabetes leaves them unable to function properly and can potentially lead to diabetic kidney disease. This is what Robin is facing, and the treatment options will be grim, especially for a 29-year-old woman: an indefinite and possibly lifelong regimen of thrice-weekly, three-hour dialysis, or to enter the multi-year waiting list to receive a kidney transplant.

Much of my ethnographic work has been about the Pima community of Gila River in Southern Arizona, where half of adults over age 35 have been diagnosed with diabetes. Because this community epidemic is rooted in both historic events and prehistoric genetic conditions, the Pima have had a long time to identify with this disease. And their reactions to the abundant diabetes prevention messages on the reservation, and to the tests they undergo, is intimately tied to this long history. For them, the term 'chronic' takes on new dimensions altogether.

To study diabetes in detailed and historical context requires us to view diagnosis as a punctuating moment within a long life-course. Focusing on that full life-course helps social and behavioral scientists to re-link the pre-, mid-, and post-disease states through which a person will live. We can examine how the diagnostic moment is all about encompassment or exclusion in health care, and how this moment may give the solace of understanding, but may also add a burden of label, stigma, limits, or exclusion.

Diagnosis is the nucleus of medicalization and the production of medical knowledge about diabetes (and every disease). Although there is consistent debate and revision to many diagnostic criteria, the process of diagnosing is inseparable from medical care (Smith-Morris 2005; Smith-Morris 2015). The American Diabetes Association (ADA) has set the thresholds for diabetes diagnosis at > 126 mg/dl fasting plasma glucose, or >200 mg/dl in either a casual plasma glucose or a fasting plasma glucose at the 2-hour mark in an oral glucose tolerance test, which involves consuming a glucose drink and watching the blood to see how the glucose is absorbed. Using these numbers, a doctor can say with reasonable certainty that the patient will develop diabetes-related complications within a few years. But since the Pima are known to have diabetes at higher rates than average, the ADA recommends they be tested more frequently, and at a younger age than others. If diagnosis can be made early, it is argued, its worst effects can be avoided. But what use is this process of diagnosis and prevention, if the treatment is unbearable or impossible, and if medications are not available and effective?

The importance of the anthropological project is to understand when and why patients embrace these diagnostic meanings, and when they don't. Understanding chronic diseases like diabetes requires a life-course perspective that situates disease within a greater world of competing priorities. There is a great colonizing potential in biomedicine to erase both individual and local cultural legacies, including those personal and creative adaptations that maintained lifelong balance long before biomedicine's arrival. The lifelong identity of illness carried by Pima Indians is imprinted in their bodies and behavior long before they might ever receive a physician's diagnosis of diabetes. Their identity is built on prehistoric foundations but is equally submerged in the contemporary diasporic world and biotechnological marketplace. Pima Indians must harness this identity and those personal and creative adaptations to survive the epidemic.

Beyond Gila River, the cost of an uncritical use of biomedicine's temporality is rising, and the conceptual battle over these concepts impacts real dollars and real lives (Manderson and Smith-Morris 2010). The temporal distinctions between 'chronic' and 'acute' set the direction for global health funding. "Chronicities of modernity" (Wiedman 2010) explain why so many developing communities undergo a transition to high rates of obesity, diabetes, and other metabolic problems as they begin to incorporate into capitalist, high-technology markets where the best paying work is sedentary, and the cheapest foods are saturated in sugar, salt, and fat. Temporal dichotomies of chronic-acute fail miserably to address any of the proximal causes of disease and, instead, shift both focus and burden onto individuals for understanding and treating what are community-based problems. And so rather than making smarter and healthier models for economic development, we repeat in community after community an evolution toward the endemicity of metabolic conditions. This evolution of endemicity happens when disease and related costs rise, and solutions are sought in existing capitalist and biomedicocentric structures, some of which may have helped produce the epidemic in the first place. Failure to come up with new systems and interventions means that old errors are then rolled out in greater force and breadth, entrenching the original

(but flawed) infrastructure, leading to further rise in disease rates. “In these ways, overreliance on a biomedical paradigm actually contributes to longer and greater morbidity around the world by encouraging what could be called a passive discourse of chronicity in developed nations” (Smith-Morris 2010: 23).

In *Chronic Conditions, Fluid States* (Manderson and Smith-Morris 2010), the contributing authors frame the disease experience in new temporalities, pointing to the ongoing and sometimes life-long relevance of a disease condition to one’s experience, and to the punctuations—e.g. diagnosis, inflamed symptoms, changes in treatment technology—that disrupt that chronic period. Life is a series of disruptions, small and large, all of which are related to one another through the memory and identity of each suffering individual. The Pima case study has always struck me as poignant on this aspect of chronicity, because the longevity of disease reaches back through time to parents (through the prenatal environment), through history (in changing federal policy that so defines the political-economic realities in reservation communities), and deep into generations (through genetic code). In this lifelong and culturally and historically embedded view, diabetes is just one punctuation in a life of chronic stress, strong or weak constitutions, greater and lesser wealth, and formative or traumatic life events.

Robin’s kidneys are indeed failing, and she will have to start dialysis. The nephrologist is most worried about the poor circulation in her feet and the real possibility that she will face amputation of one or more toes if her blood glucose does not improve quickly. As a diagnostic event, this news might hit Robin with the overwhelming force of catastrophe. Diabetes is a disease process that can, at different temporal locations and by different speakers, be called a ‘risk,’ ‘pre-disease,’ ‘gestational,’ ‘outright,’ or fatal, but never ‘in remission’ or ‘cured.’ Yet when a diagnosis of diabetes is delivered, little of that complexity or controversy is talked about. For a person with high blood glucose, those controversies probably don’t matter; what matters is health, how one feels, what one’s future holds. For Robin, that future is likely painful, physically limited, and shortened.

But Robin did not see it quite that way. For her, diagnosis was an acute, short-lived disruption in an otherwise roughly flowing stream of life. The ‘disrupted’ portions of her life appear to me through ethnographic research. And so, it is we, the anthropologists, who draw attention to these ‘liminal’ elements of illness. Robin later relates to me that her experience of this diagnostic conversation was “nothing new.” She had heard about these complications and possibilities before, and she did not experience them as ‘new’ when the doctor delivered an official diagnosis of renal failure and a treatment plan that would include dialysis.

The case of Robin’s diabetes suggests that a de-privileging of acute diagnostic moments, and a greater sensitivity to the chronicities of daily adjustment, better reflects the lifeworld of Pimas. Very likely, this is true for all humans. “Continuity is not an illusion,” as Becker exhorts, “the illusion is in our labeling of lifetime illness episodes as distinct from an otherwise disease-free life” (Smith-Morris 2010: 35). Many of my informants experience a continuous life: “I’ve been living wrong for so long that I think that it’s not wrong. It’s only me. Other people may see it, but not me” (Kyle, 29). Anthropological discourse that defragments will privilege continuity of illness and health together in lived experience, especially as these inform the identity of persons with chronic diagnosable conditions.

Acknowledgments

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In the preceding chapter, we considered various ways in which people used their own bodies to resist public health and doctors' admonitions and social expectations for varied reasons. For some people, the need to adhere for life to medication is reason enough to resist. In some cases, as occurs with HIV medication, treatment breaks—'drug holidays'—may be suggested for clinical reasons, including to reduce long-term side effects or to ensure continued efficacy; others interrupt treatment because of cost and the tedium of the regimes. In an article on adherence to diet to control diabetes in Thailand, for example, people routinely 'cheated' between visits to doctors, and reverted to the advised dietary regimen immediately before a visit to the clinic to avoid being detected. For them, it was important that they, not their disease, were in control (Naemiratch and Manderson 2006). But failure to adhere to medical advice can have devastating consequences.

Below, Narelle Warren describes the difficulties experienced by Australian men when they end up with an amputation as a result of uncontrolled diabetes. Their consequent increased dependence on others, and the disability of living with one leg, seriously impact on their 'taken-for-granted' masculine identities. Reinforced in promotional material from the rehabilitation center, they aim to be mentally and physically strong; when they receive their prostheses, they train hard to regain their strength and so maintain their masculinity. This is at a cost: men do not discuss the emotional impact of their illness and amputation.

7.3 Amputated Identity

Narelle Warren

Masculinity is not a fixed state. Rather, it is determined and reconstructed by the physical, social and bodily context(s) in which men live. Cultural ideas about sex and gender, as well as age, ethnicity, social class, and geographic location, all shape how masculinity is understood on an everyday level. These factors in combination shape how men as well as women understand their health, with these in turn influencing their health outcomes. Serious long-term illness and its continuing effects on the body, including limits to activity, increasing dependence on medical surveillance and medication, and impairment, influence how men understand their masculine identity—their 'manhood.'

From 2004 to 2007, I worked with inpatients at four rehabilitation centers in Victoria, Australia, exploring people's adaptation to lower limb amputation (Warren and Manderson 2008; 2013); I still (in 2014) collaborate with an amputee support group. In the cases I present below (all names are pseudonyms), all involving below-knee amputation, I illustrate the ways in which amputation threatened many of the cornerstones of masculinity, as understood by study participants, not only in terms of their level of activity but also in terms of emotional expression.

I have never seen so many men cry. Australian men—most men—value emotional control, and link the performance of masculinity to the containment of their emotions. But of the 44 men with whom I spoke, almost all cried at some point in the interview. The emotional aspects of amputation was challenging for all participants—women and men—but especially for men. Although most underwent amputation for non-traumatic reasons, secondary to vascular disease or diabetes, amputation caused a rupture to men in terms of sense of self; it was emotionally traumatic in its *effect*. Yet, although the men recognized their heightened emotional vulnerability because of the recency of limb loss, they sought to deny or hide their feelings outside of the interview context. Most did not discuss their affective responses with their spouses, but focused instead on the practicalities of their living arrangements post-discharge. Fewer still talked with friends or others about the emotional impact of limb loss.

Roy: *The Private Life of Emotions*

Roy Smith (80 years old, urban, lived alone) explained how he had become more ‘sensitive’ both in his amputated limb (the ‘stump’) and emotionally after his amputation, which occurred following a number of unsuccessful surgeries for varicose veins:

If you have a leg off, you *do* care to lose it, but [you need] a certain amount of courage . . . (it) upset(s) you for a while, but (you) don’t let your life stop, it must go on . . . I didn’t take it too seriously ’til I start to think, or I start to see what’s going to happen to me when my leg was gone. But um, but it’s a hard thing to take into consideration that your, that your leg was there and now it’s gone. You can’t walk properly, you can’t stand properly, so you feel very sensitive. Yeah. (pause) But I suppose in a way you give in, you know, to however it happened to you. And you take it as part of life. That’s what I think.

Roy found it difficult to express how he felt after the amputation; this was complicated by the fact that he had never learned how to talk about his feelings: “I haven’t done that sort of thing [talked about how he felt]. I don’t do that sort of thing. I just take it as it goes really. But that’s the way I was brought up.” He drew on other life experiences in an attempt to make sense of his affective responses to limb loss: “There’s a funny way you miss something like an old, an old mate (friend) . . . (*Is that how you’re feeling about your leg?*) Oh, I would say so. Oh ah, you went through a war and go through all your sports and your life and you’re laughing. And then it’s gone.” In drawing analogies with long-term friendships, and the loss of a number of these friends in the preceding decade, Roy sought to reframe his feelings of loss from a personal sense of despondency (which highlights personal vulnerabilities and countered his own understanding of masculinity) to become a different type of grief, one framed in a context of male friendship and loss.

Although he cried for most of our interview, Roy was unwilling to broach his feelings with his friends or his long-term partner out of concern that he would place on them an unwanted and unnecessary burden:

There’s no one who, no one sort of ah, who would want to, even would want to [talk about it], those things don’t concern, people like that have worries of their own, troubles and that. They don’t want to be burdened, it is a burden . . . That’s the way I look at it. You just have to take it as it comes and that’s that.

Roy was adamant that men were responsible to keep their emotions in check, and to keep their emotional life contained and private. He expected others to similarly manage their emotions, even though he recognized that there were times that were especially difficult:

I don’t show emotions, not like some people do. And I don’t know how they feel when they’re on their own, so . . . They might do [become more emotional]. I don’t know. Not in front of me. (pause) Which is good, I think. (pause) You don’t want everyone bawling around you, do you? (pause) But ah, the queerest thing is when you see those legs, you know, and they’re not there. That’s when it hits you.

Darren: Anger, Frustration and Bodily Rupture

Unlike Roy, Darren Eaton (63 years old) was much more expressive in his response to his amputation—but only in terms of anger and frustration. He believed that his amputation was due to the failure of a podiatrist to exercise his duty of care to him, which left him feeling powerless:

[The podiatrist] was well acquainted with the fact that I am a diabetic and I couldn't feel my toes and I couldn't see my toes adequately, so I really feel that he has a contributory part in this entire debacle . . . I do feel that he was guilty of, at worse, some sort of contributory negligence, and at the least, he is guilty of not taking his responsibilities to a middle-aged diabetic patient with the seriousness he should have . . . I mean I have lost a considerable portion of my mobility and my, and my leg, as a result of what I see to be his failing to do his job with a reasonable duty of care.

Darren lived alone in a small rural town (population 1,000); he had moved there from the city after retiring from teaching two years previously. He hated the town and was scathing about its long-term residents: "It's a rat hole, it's full of retirees and people who I don't know. I live there because the rent (for his house) is only ninety dollars a week and I'm absolutely independent . . . [and] I can play my bass trombone in the garden or in the house or whatever I want, but for a town to live in it's a really terrible place." He was profoundly isolated socially. He was unpartnered and only had two (female) friends, one living in a community about 60 kilometres away; the other, a new friend, in his town. But contact with both was largely by telephone.

Darren placed particular emphasis on being independent. His amputation therefore threatened his autonomy and potentially rendered him reliant on others in the community, challenged his understandings of who he was, and brought into question his capacity to take part in the activities that he enjoyed: playing music, cycling, and fishing. In thinking through the impact of amputation, he became quite despondent:

Well it's a terrible blow to a person who felt he had another few years of trouble-free cycling, although I did look ahead and realize that my balance is becoming impaired because my vision is quite poor, so I bought a recumbent . . . and I love to watch their movies, and I love dancing, but I'm not going to do a lot of that, and there are a lot of things that I won't be able to do, like, you know, maintain my balance in the middle of a trout stream, try and catch fish, a lot of things. You see, you need good vision and coordination to maintain your balance, so I might, I might be in for a hell of a shock. I'm not quite sure how it will work out. I might need the prosthesis plus a cane, if not two, I don't know. I don't know, but the town that I live in is not maintained . . . and so the footpaths don't get freshly concreted and it can be rather hazardous especially if you have a walking impediment. I may have a difficult time just walking down to the newsagent or walking to the supermarket . . . now I'm sort of dependent on my friend Marian.

Amputation both undermined Darrell's own independence, and he believed it would place pressure on his relationships with others: "I've made one friend in [his town], but she seems to be having a hard time because I've turned from a, a friend, a contributing friend, into a, almost a liability if you like, I mean short of half a leg now . . ." This concern echoed Roy's desire not to be a burden to others, and has its roots in masculine values of control, autonomy and independence.

Darren saw the amputation as more than the loss of his limb; it was a threat to his whole way of life: "I felt terrible about it, because it meant I was losing the fight. It meant that I wasn't going, going to win, going to save my previous life, eventually." At the same time, Darren's amputation threatened his bodily mastery, inhibiting his ability to manage his body: "I'm a slightly more than middle-aged incompetent male person who insists on living by himself, doing his own cooking and gardening and so on, and of course, I never really looked after my health to the nth degree." His pride in his body and sense of bodily wholeness too were threatened by the loss of his leg. Several days after our interview, Darren was given his new prosthetic leg in the amputee gym. Unlike the majority of inpatients, who gingerly held and then tried on their new leg, he threw his across the room, screaming abuse at the prosthetist and other inpatients. Later, he explained that the prosthesis offended every part of his bodily aesthetic; he could not contemplate it as part of his body. Darren felt that his personal ideals of independence, autonomy, bodily integrity, fitness, and strength—all perceived as masculine characteristics or attributes—were no longer present and would not be available to him in the future.

Dale: Masculinity Compromised

Dale (44 years, rural, married) had cut his foot walking on the beach. His foot progressively became infected and ulcerated, and he was informed that the wound would probably not heal due to Type 2 diabetes. Dale underwent nine surgeries in an effort to cut away the necrotic flesh, until his surgeon decided that the only real option was to amputate his leg just below the knee.

Dale had not known he had diabetes at the time of the injury; he was diagnosed as his doctors tried to determine why he wasn't healing. At the time of the wound, Dale was the family breadwinner, with a well-paid managerial position in a large company and the promise of a new, higher-level position; his wife looked after their home and supported their ill (with cancer) adult daughter. He played football each week, and regularly socialized with friends over drinks or barbecues. He had, he thought, no reason to worry about his health. Amputation changed all of this. He was discharged from rehabilitation not to a well-appointed house in his city, but to government-supported housing in a lower-income suburb, close to the rehabilitation hospital. He was bitter:

It's financially tough. We have gone from living on a thousand dollars a week cut down to whatever it is on this pension (about \$300 per week, plus rent subsidies) 'til I start working again. And you don't budget for an accident like this . . . when you are at hospital for a long time, the money runs out, and when you haven't bargained for something like this to happen. We've lived week to week, and we have lived a good life too, but I suppose you don't put that money away thinking one day you will have your leg cut off, plus we were going to a much higher paid job and that's when we were going to start to look at doing something again like buying a house and that sort of stuff.

Dale concentrated on the practical, especially financial, impacts of his amputation. Most men in the study related their masculinity to their role as the main income earner within the family, consistent with broader Australian norms around work and family organization. Dale was continually in and out of hospital for about three months prior to amputation, and so could not earn an income and support his family as he had in the past. He registered for welfare assistance. This was extremely difficult because of the drop in income, and because he could not maintain his prior position in the family. He continually talked about returning to work: "I will be back on my feet again, doing what I am doing." Yet eight weeks after his amputation, he had developed diabetes-related peripheral neuropathy (loss of sensation in his extremities), retinopathy (vision loss), nephropathy (renal failure), and cardiovascular disease (hypertension, which later led to a non-fatal heart attack).

Dale found it difficult to talk about the amputation itself or about how he was feeling afterwards to anyone other than his wife. "You would probably be the first person that I have talked to about it," he explained. "I have dealt with my problems myself anyway. So [there's] no one I have really opened up to." This was related partly to how he was positioned within his wider family: "I have always been a strong sort of bloke, for want of a better word, they [family] have sort of seen me as a manager here and that sort of thing. It has come as a big shock to them."

The affective impacts of amputation were felt in other ways too. Dale described feeling intense pain immediately after his amputation; he had imagined that he would feel little pain and wondered if he was in such pain because of some sort of emotional weakness. He did not want others to think of him as being weak in any way and so, to maintain his self-presentation as mentally strong, he sought to hide his pain:

They did the surgery and I woke up and I was in absolute agony, it was the most painful thing that has ever happened to me. I came out of surgery, I remember it, it was one o' clock, and I was in recovery till seven. At seven o' clock, they took me back to the ward and that was the start of the worst four hours I have ever had in my life. I had my uncle staying there, I was squeezing his hand, it was just absolute pain, I couldn't describe it to you. Evidently what can happen is it [the actual amputation] just throws the nerves out so much that the pain threshold is just unbearable and that is what happened . . . It was the worst of the worst. On a scale, rating in from 1 to 10, this was 20, double, off the scale . . . There were times when I think I blacked out . . . I don't think my wife ever knew.

Central to Dale's identity is a self-, and social, image as physically strong, emotionally resilient, and capable. These ideas resonate with hegemonic understandings of masculinity in Australian society (Connell and Messerschmidt 2005)—amputation challenged each of these conceptualizations in multiple ways.

As Roy, Darren, and Dale demonstrated, with amputation, men experienced challenges to their identity in several ways. First, amputation threatened the affective dimensions of hegemonic masculinity: they experienced the amputation as traumatic and traumatizing, regardless of etiology. As they had perceived themselves as being mentally and physically strong, they expected that they should adapt to their changed bodily state with little distress and when they found they did not, sought to maintain their masculinity by repressing or avoiding any discussion of their emotional reactions to the amputation. Where they did express their feelings, they either drew on more 'macho' emotional responses, such as anger and frustration, or tried hard to avoid public displays of emotion, such as weeping. Second, amputation challenged their understandings of bodily wholeness and integrity; in this way, masculine values of competence and bodily ability were brought into question. These all unfolded before men were able to test their ability to 'do' gender once they had received a prosthesis; what emerged in follow-up interviews (not reported here) was that prosthetics allowed men to mediate their masculinity through maintaining a facade of wholeness and activeness. Finally, amputation was evidence of their declining health, and the lived vulnerabilities associated with this, which, by their very nature, contradicted local hegemonic ideals of manhood.

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Chronic Disease Prevention

In high-income settings, and in poor countries for those who can afford it, many chronic conditions can be treated. In the global North, the direct costs of treating chronic conditions, including medicines, are often limited for patients as a result of state subvention, but elsewhere the costs are born by individuals. Even so, everywhere chronic conditions impact on government budgets and health services, because of the need for lifelong monitoring and care, and the procurement and regulation of drugs; increasingly, these costs account for the greatest health expenditure in all countries. As we have noted, in resource-poor settings, health systems tend to be weak and governments have limited financial and human resources to manage complex conditions. In addition to the lack of trained health professionals, local health centers often struggle to maintain supplies of appropriate and affordable medications for current patients, and to maintain working equipment for appropriate monitoring; even scales to trace the weight of patients may be broken or simply stored away, unused, in cupboards.

Cardiometabolic disease (that is, diabetes, heart disease and obesity) and chronic respiratory disease are considered able to be controlled by 'healthy living'—a better diet, increased physical activity, and the cessation of smoking. 'Lifestyle' factors are routinely identified for health promotion and the prevention of chronic conditions, with an emphasis on individual culpability, reflecting a neoliberal philosophy that emphasizes personal action and obviates structural factors (Rose 2006). Yet as we have also suggested, in many societies health is compromised by structural

inequality, poverty and disadvantage. Health promotional messages and medical advice to patients regarding changes to food intake and activity are often difficult for economic reasons, available time and patterns of sociality—the factors captured in the case study from Carolyn Smith-Morris, above. Gender norms and relations influence health outcomes across different societies too, both within personal relationships and because of the role of gender in determining the kinds of work people do (and whether they work), women's and men's relative access to and control of money, and other behaviors that are implicated in people acquiring and managing non-communicable diseases. There are differences in the freedom of men and women to participate in physical exercise, for instance, and in whether or not, and to what extent, they drink alcohol or smoke tobacco. Gendered norms influence the ability of people to seek treatment and care, take up health advice, manage sexual and reproductive health problems related to such diseases, and provide or receive support from others in bodily care. And as reflected in the previous case study, gender norms and relations influence people's capacity to adapt to the disease and so define a 'new normal' (see also Manderson 2011).

The ability of people to adapt to chronic, debilitating and degenerative conditions can be facilitated by their engagement with others who share their complaints, with whom they forge a sense of identity that allows them to work with and gain support in managing their problematic health. Here the idea of biosociality, dating from Rabinow's work (1996) on genetic commonalities, is especially useful in describing the outcome of a shared social identity that derives from biology, not only in relation to genetics and familial risk, but also to explain social groupings around diagnosed disease and disability (Renne 2013; Rose and Novas 2004; cf. Chapter 4 in which we discuss the limitations to biosociality). This concept has tended to be applied to large communities and their bio-identification, as occurs for breast cancer especially, but also diabetes, Alzheimer's disease and other conditions, through advocacy, fund raising and public awareness events and dedicated days, and online presence. Biosociality also provides a way to promote and understand the effectiveness of interventions in smaller groupings. In the case study below, Marjolein Gysels and Irene Higginson describe how women with COPD found support not through a large-scale consumer or patient group, but through the efforts of one committed physiotherapist. The women who experienced breathlessness—the visible and embodied expression of COPD—had little support and care. Against the background of their disability and suffering caused by breathlessness, the three women describe how they discovered the benefits of pulmonary rehabilitation, as a way to self-manage their chronic condition and so maintain acceptable quality of life. The case is about the social dimensions of care and management, and the role of social support and friendship, not the biotechnical ways in which people's health problems might be ameliorated.

7.4 Facing Up to Breathlessness

Marjolein Gysels and Irene J. Higginson

In an aging world, people live longer with multiple chronic illnesses and these are increasingly important causes of death. Progressive and incurable illness brings high rates of symptoms, especially towards the end of life. Breathlessness is one such condition, causing considerable suffering. It is associated with fear and anxiety, causes disability, loss of independence and social contact, and forms a threat to people's daily quality of life (Gysels et al. 2007). It is responsible for high levels of hospital admission, hospital death, and it is related to increased loss of will to live.

Breathlessness is defined by the American Thoracic Society as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity.” This definition

appreciates the complexity of this symptom coming from interactions among multiple physiological, psychological, social and environmental factors, impacting on both the quality and the intensity of the person's perception of breathlessness, and possibly causing secondary physiological and behavioral responses.

Yet people can experience very different levels of breathlessness. Patients with minimal respiratory changes may suffer considerably, while others with severe disease may experience very little breathlessness. These varied experiences may relate to personal characteristics such as muscle strength and weight, psychological disposition and coping strategies, but also life experiences and cultural background.

Three Friends

We present three cases of women to illustrate the complexity of the life worlds of people who experience breathlessness due to Chronic Obstructive Pulmonary Disease (COPD) in the advanced stages of illness. The accounts are in the first person; the 'I' in this context is Marjolein. The names of the women are pseudonyms. The three women lived near each other in South London. They were old school friends but they had lost contact when they left school. They found each other again in their sixties, all three suffering from breathlessness with advanced COPD. They faced similar challenges but they were exceptional because they were able to have an acceptable quality of life despite the distressing symptom of breathlessness and associated progressive disabilities.

Liz

Liz came from a consultation with the respiratory physician at the hospital when I was recruiting people to participate in a study on the experience of breathlessness at the Cicely Saunders Institute. I still remember, when we had talked that first time and arranged a date for an interview, how she walked away towards the sliding doors out of the hospital. It struck me how energetic she looked with a bottle of oxygen in her one hand, slightly swinging it with the pace of her steps. Not quite the person I expected to suffer from breathlessness in the advanced stages of COPD. Two weeks later, Liz received me at her home for an interview. She was very cheerful, chatty and open, a pleasure to interview.

Before her breathing started worrying her she explained that smoking had been a routine part of her life—she described herself as “marching off to work with a cigarette in my mouth.” She had a job in accounting, finding the work rather boring and retreating to cigarettes and coffees to get through the day. The first signs of breathing difficulties that she experienced were when she couldn't get up the stairs when the lift broke down in the office. Occasionally she had to get air from the window but she did not suspect that this was a progressive problem. She, like her father, had always had some asthma, and she thought she was becoming more like him.

Then one day she collapsed before going into work. Her colleagues at work were worried when she did not turn up and they called her daughter who found her in the doorway. She was diagnosed with emphysema. She realized that it was serious when she told her diagnosis to a woman at work who promptly started crying as her mother was dying of this same condition. Liz stopped smoking which she found terribly hard to do, “the addict of addicts” she called herself, still craving for a cigarette after a year. She started attending pulmonary rehabilitation classes but because these were difficult to get to from the part of London where she was living, she stopped going.

She deteriorated fast, at the same time experiencing problems in her relationship with her partner. He arranged a wheelchair for her so that she was mobile around the house but she became increasingly depressed. The doctor brought her back into contact with the physiotherapist with whom she had been training before. She was surprised by her poor condition and convinced her to work with her.

Liz explained that she was lucky and that the physiotherapist had rescued her. She had hoped for a lung reduction operation, but developed reservations against it as it is a high-risk operation and then learned that the operation was not possible in her case. Her struggles with routine activities echo the stories that others also told me: the good days and the bad days, the unpredictability of what a new day will bring, the sudden chest infections which paralyse all other activities.

For daily functioning Liz relied on a well-organized system of technologies. What she told about being able to function revolved around pacing herself, moving forward slowly, resting and persisting in one's activity. For example, going upstairs was possible as she had a large oxygen bottle for downstairs and one upstairs. But there was the problem of climbing the stairs, which she did in several times, sitting on the steps to get her breath back. She initially took a small bottle with her but had to save these for going out as they only lasted four hours and she was only able to gain three a week through social services. "Flipping things," she said, she depended on them but wished she did not.

Liz talked about the lack of information on where to turn to for advice, in case of doubts about medication, or when emergencies present. Applying for a mobility allowance, or when she needed the smallest of things from social services, was frustrating. She had been turned down for the allowance but reapplied, then waited endlessly, frustrated by inspections and argumentations.

Meanwhile breathlessness interfered with Liz's social life. As she could no longer join her friends in smoky pubs, they eventually stopped asking her to go out with them.

Frances

Frances's story is one of hard work and persistence. She told about the triumph with the first signs of progress, and the emotions, when after months she could manage without her wheelchair.

Frances had worked her whole life in education, first as a volunteer, then in an employed capacity in a school. She spoke about her love for children, her own family of four, and how as an Irish woman, she saw herself first and foremost a mother, and carer for her husband. She was diagnosed 17 years before we met with COPD, and although she became somewhat slower in her daily activities, she could still lead a normal life. Four years ago the illness took a turn for the worse. One day she described how she was on her way to church, greeting the priest on the other side of the street, and while crossing to meet him, suddenly she was hit by breathlessness. She stopped in the middle of the traffic and she could hardly reach the pavement. The next day, the same happened; the day after it happened again. From then on, every time she stood up, every movement she made, was a major struggle.

Frances spoke of her regret of her habit of smoking: "I have nothing else to blame." She explained that she tried to stop smoking when she started to notice that breathing had become more difficult, but she lacked support; her friends teased her and pressured her to take a cigarette. She developed strategies by carrying cigarettes in her handbag herself, which she could then take out but never light. She managed to stop smoking for a few years, but then her husband had a stroke; when she saw him lying on the monitors in intensive care, she sought comfort in smoking a cigarette. Asking her what made her give up in the end she replied: "they gave me up." She stopped when her breathing had already put restrictions on her daily activities.

In interview, Frances reflected on what the doctor had told her when she was diagnosed—"It will take 10 years off your life," and of the meaninglessness of his words, thinking: ". . . well 10 years, I'd be too old to enjoy my life by then. But if I'd been told, that you're not going to be able to walk around your own home, and not play with your grandchildren . . . that would have made me give up smoking immediately."

After years of progressive breathlessness and disability Frances was referred to hospital where the doctor did not think she was strong enough for lung reduction surgery. He advised her to try pulmonary rehabilitation. Sitting in her wheelchair she was puzzled: "I can't walk, how am I going to exercise?"

Frances was the most disabled of the three women. She described how she has to get up at 5.30 AM if she has to leave the house at 10. This is because she has to stop and start constantly. She gets up, takes her medication, goes down to have breakfast, goes back up to her room to go on the nebuliser so that she gets her breath back to be able to have a shower. Then she has to recover, doing everything in slow motion as she calls it. Through time, she learned strategies to keep functioning despite the breathlessness. She found out how she reacts to steroids, when to take antibiotics, she has her inhaler and oxygen at hand, and last year when her family asked what she wanted for her birthday, she asked them to all club together so that she could afford a nebuliser. She spoke too of her wish to have a stair lift: sometimes she is on her way to the toilet upstairs but when she is too breathless to move, she can not make it in time. But social services have so far turned down her request, despite the support letter from the hospital.

Susan

Susan lived with her grown-up son. When I rang her doorbell, it took awhile before she opened the door. Slowly she showed me into her living room and sat down, explaining that the prospect of being interviewed made her nervous, triggering breathlessness. She characterized herself as a nervous, jumpy person, someone whose thoughts were always faster than the actual events. She explained that this is exactly what breathlessness is caused by, plays with and thrives in.

When we met, Susan had learned to take control over her breathlessness and she showed me the posture and the pursed lip breathing the physiotherapist had shown her. Before she learned this technique, she was taken along a vicious circle, the anxiousness and breathlessness exacerbating each other until she couldn't breathe at all and finally, in a last panic, reaching for the phone to call an ambulance.

Susan had become aware that breathing was becoming more difficult but she ignored this for years, concerned instead with a seriously ill husband for whom she cared until his death, from chronic kidney disease, the previous year. After she began to experience continuous chest infections resulting in frequent hospitalization, she was diagnosed with emphysema. "COPD they call it nowadays, don't they?" She added, "it is self-inflicted with the cigarettes."

Susan explained that her breathlessness was 50 per cent due to her lungs and 50 per cent to her mind, and explained that the rehabilitation classes were "God sent." There she had learned the breathing and relaxation techniques that had become crucial to suppress the threat of breathlessness. It was there too that she met with Frances and Liz, and developed a close friendship; before, she was too frightened to leave the house.

Together the three women started up the Breathe Easy group, a patient self-help group to inform and educate others about the benefits of pulmonary rehabilitation and to keep up to date with the latest scientific developments. Twice a week they go to Tai Chi classes, which they discovered has a therapeutic effect on them. In addition, there they are with healthy people, taking part in normal activities, and in doing this they have learned not to be bothered about being different. They do the exercises sitting on a chair at the back of the class at their own pace. They enjoy the calmness the teacher creates with his voice, the movements and the concentration it requires.

Situating the Women's Stories

Liz's, Frances's and Susan's stories reflect what others who suffered from breathlessness caused by COPD had also told us and which we could best capture by the metaphor of invisibility (Gysels and Higginson 2008). Breathlessness is invisible. It typically manifests itself gradually and surreptitiously, often noticeable only by the person herself and therefore easily wished away. The strange ways in which it presents itself to those it affects, blending in with other symptoms and emotions, discourages people from seeking help. Breathlessness is elusive since clinical assessment is not attuned to picking up subjective sensations that resist the conventional measurable criteria. People do not tend to present their problems to doctors as they may be perceived as futile and improbable, and therefore not legitimate. Guilt also plays a role here, as people who experience breathlessness want to avoid disapproval regarding their past of smoking, both from practitioners and from the wider society. Patients also find out that besides the diagnosis of their condition, labeled with a variety of terms such as emphysema, COPD, or chronic bronchitis, there is little information available about how to cope with breathing problems, when and where to go for help, and what to expect for the future.

The women whose stories we presented here are among the few people in our study who had succeeded to transcend the barriers to cope with this symptom as they learned to self-manage (Gysels and Higginson 2009). They were lucky to have discovered the benefits of pulmonary rehabilitation, which they had adopted as a way of life. Contrary to their initial expectations they found that they could train their way out of disability. This required the additional knowledge that the wellbeing they had achieved was not an end point but rather a precarious balance that needed to be maintained carefully with routine practice, and insightful daily management of their condition. This knowledge was based on previous experience; when this balance was tipped, there was the threat of being dragged along a downward spiral of deconditioning, bringing them back to their wheelchairs.

These insights based on people's experience of breathlessness in COPD, as well as in other conditions, helped to inform the development of the Breathlessness Support Service. The evaluation of

this new integrated service for patients with advanced disease and refractory breathlessness in South London provided evidence for improved patient mastery and early introduction of palliative care (Higginson et al. 2014).

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The prevention and control of disease is marked by the need for continued new vaccines, as the initial success in the control of infectious diseases is undermined by drug resistance and virus and parasite adaptation and evolution, failures in drug development for treatment or cure, and the side effects of novel drugs that prevent their wide marketing. Even so, as we have discussed, many infectious as well as non-communicable diseases are now managed as chronic conditions, and life expectancy from all chronic conditions is increasingly extended. This management is largely achieved through drugs, and growing proportions of populations worldwide take medication for increasingly lengthy periods of time. ‘Drugs for life’ (Dumit 2012) now include multiple drugs for multiple conditions for people living very long lives. While this approach is problematic, it is a reality for people who, with diabetes and heart disease, depression and arthritis, for example, are willing and able to pay for beta-blockers for hypertension, statins, anti-coagulants, insulin medication, anti-depressants, anti-inflammatories for effective pain relief, present for regular medical monitoring and follow medical advice, and take advantage of ancillary health care like hydrotherapy pools, massage and counseling. These are not realistic options if a person is poor. For many people with chronic conditions, therefore, as illustrated for people with HIV, simply having sufficient food, of any kind, is difficult enough (Gwatirisa and Manderson 2009; Kalafanos 2010).

The drugs required for people with chronic conditions come at a high cost to national budgets, with growing expenditure on hospitalization and medication for chronic conditions over a growing period of time. Over 17 percent of the US Gross Domestic Product is spent on health, compared with around 10–11 percent in much of Europe, and half that or less in many poorer countries. Over time, unless underlying problems of inequality, poverty and social exclusion are addressed, these proportions may well increase further with the risk that governments will respond by increasing consumer and patient responsibility to carry the costs of their own health. We return to these themes of social structure, inequality and exclusion, as they affect people’s health, in later chapters.

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