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Abstract

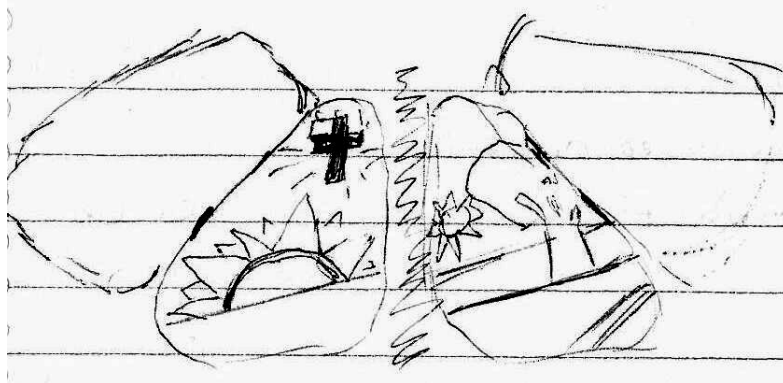
Breathing and Breathlessness: Chronic Obstructive Pulmonary Disease in Uruguay

Megan Julie Wainwright

An increasingly common part of being human is living with chronic health problems for which management over time, and not cure, is the goal of medical treatment. One such chronic condition is chronic obstructive pulmonary disease (COPD), a lung disease caused by breathing-in smoke, dusts and chemicals, including tobacco smoke. This ethnographic study set out to explore how COPD is lived with and cared for in Uruguay, where rates of COPD are amongst the highest in South America and where most cases go undiagnosed. The aims of the research were to explore the following questions: a) what does it feel like to be breathless and how is COPD experienced within family and healthcare relationships? b) how is the lived-experience of COPD shaped by cultural, social, economic and political contexts? And, c) what are some of the challenges and opportunities for preventing and treating COPD? The objective of this ethnography is to contribute a unique case study to the anthropological literature on chronic illness both in terms of the disease under investigation and the cultural context. The thesis responds to a call in the literature for more sophisticated phenomenological approaches. By incorporating a multitude of field methods into ethnographic fieldwork I combine a sensorial medical anthropology approach and a political-economy of health perspective. The ethnography begins with a cultural and sensorial analysis of breathing and breathlessness in Uruguay in order to situate the expressions of this disease across a diverse group of participants. I argue that the experience of COPD is shaped by healthcare systems and inequalities and highlight two healthcare contexts where space is made for people to socially interpret sensations in the body. The thesis culminates in the critical assessment of public health goals and makes recommendations for improving COPD prevention and care in Uruguay.

Breathing and Breathlessness: Chronic Obstructive Pulmonary Disease in Uruguay

Number of Volumes: 1



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List of Abbreviations

ALAT	Asociacion Latinoamericana de Torax
ASSE	Administracion de Servicios de la Salud del Estado
CAP	Centro de Atencion Pulmonar
CHLCC	Comision Honoraria de Lucha Contra el Cancer
CIET	Centro de Investigacion Sobre la Epidemia del Tabaco
CMA	Critical Medical Anthropology
COP	Conference of the Parties
COPD	Chronic Obstructive Pulmonary Disease
FCTC	Framework Convention on Tobacco Control
FEV1	Forced Expiratory Volume in 1 second
FNR	Fondo Nacional de Recursos
FONASA	Fondo Nacional de Salud
FVC	Forced Vital Capacity
GOLD	Global Initiative for Chronic Obstructive Lung Disease
IAMC	Instituciones de Asistencia Medica Colectiva
NICE	National Institute for Health and Clinical Excellence
QoL	Quality of Life
SCS	Smoking Cessation Service
semFYC	Sociedad Española de Medicina de Familia
SEPAR	Sociedad Española de Neumología y Cirugía Torácica
SNIS	Sistema Nacional Integrado de Salud
SUT	Sociedad Uruguaya de Tabacologia
UDELAR	Universidad de la Republica
WHO	World Health Organization

Statement of Copyright

The copyright of this thesis rests with the author. No quotation from it should be published without the author's prior written consent and information derived from it should be acknowledged.

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Dedicated to the memory of my mum
Claire Marie Wainwright
(1946-1988)

Note on Language and Translation

My Spanish skills can be said to have been intermediate before I left for Uruguay. I had taken Spanish in highschool, as a one-year elective as an Undergraduate, and attended a weekly intermediate Spanish course in the School of Modern Languages at Durham University in 2009-2010. Being fluent in French has helped me learn Spanish as they share a common grammatical structure. I could speak with relative ease however was limited by my vocabulary and by only knowing the present and future verb tenses. I had the excellent fortune of meeting Maria, a Uruguayan sociologist living in Durham who tutored me in “Uruguayan Spanish” before I went to the field for the first time in December 2009. From her I learned the common expressions *ta, che, barbaro* and the *vos* verb tense in addition to illness-related expressions and vocabulary and healthcare terminology. It was also through Maria that I got in touch with the *Instituto de Lenguas Extranjeras* in Montevideo from whom I received one-on-one Spanish lessons with a variety of tutors 20 hours a week (4 hours a day) for the first full month of fieldwork. My approach to learning languages has always been to work on comprehension (written and spoken), speaking and writing simultaneously and the Institute took this approach and was able to help me increase my topic-specific vocabulary rapidly before beginning interviews in October. By then I had had a month of formal tutoring in Spanish as well as a month of meeting health professionals and hospital directors with whom I discussed institutional access in Spanish.

My fluency was advanced enough to carry-out my research without a translator or interpreter. Of the approximately 150 interviews I recorded, only two were carried-out partially in English with participants who were perfectly bilingual. When taking fieldnotes, direct recordings of conversation and informal interviews were written in Spanish and reflections or observations of my own were more frequently recorded in English, especially at first when my knowledge of the tense of opinion-expression (the subjunctive) was not yet part of my repertoire of available verbs. Certainly, my fluency increased dramatically over the course of the year so that when I return to interviews I recorded in the first couple months I am able to understand more details than I was at the time of carrying them out.

Transcribed texts from interviews and focus groups which appear in this thesis were transcribed in Spanish and then translated to English by me. To verify my translations I had Maria’s continued support once I returned to England. She back-translated a few excerpts for me and we compared her translations from my English to Spanish with the original Spanish transcript. We discussed word-choice and clarified some expressions, but overall were very satisfied with the results of the back-translation. The fact that the ethnographic nature of the project meant that I was learning the language as I lived and experienced Uruguay means that I feel quite positive that I am able to, in my imperfect translations, capture the meanings my participants attributed to their experiences. Furthermore, Spanish titles of books and articles, and quotes from them appearing in English in the thesis are my own translations. Original Spanish titles are found in the bibliography.

Note on the Use of Pseudonyms

I have given all participants whom I quote and reference in this thesis pseudonyms. I have chosen not to name the healthcare institutions explicitly apart from specifying whether they were public or private. Both these decisions were made on the basis on maintaining some degree of confidentiality.

Introduction

CHRONIC ILLNESS AND THE EPIDEMIOLOGICAL TRANSITION

Living with health conditions deemed incurable in biomedical terms is an increasingly common part of being human. Non-communicable disease is one category-name commonly encountered in the public health vernacular in reference to chronic disease. It refers to those diseases which are non-infectious and which largely occur due to 'lifestyle' factors, such as low-activity levels, and the consumption of tobacco-products, alcohol, and high-fat nutritionally dubious foods in globalised markets. The diseases of particular concern to global organisations, such as the World Health Organization (WHO), are the so called 'big killers', such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, which are said to account for 63% of all deaths worldwide (WHO, 2012b). In September 2011 the UN held a High-Level Meeting on Non-Communicable Diseases in New York City to discuss these pressing public health issues. However, it is not only 'big killers' which concern the lay population. Many chronic conditions are not immediately life-threatening but are, nevertheless, disabling, life-changing, and strip away a person's quality of life. Examples include such things as bowel disorders, mental illness and eye diseases. These receive far less research and policy attention, however, because they do not contribute to mortality data in the same way as the 'big killers'.

The rise in mortality due to chronic disease in relation to infectious diseases is known as the epidemiological transition. While the control of infectious diseases is still very much a public health imperative in developing countries where many die of preventable infections, equally, the so-called non-communicable and chronic diseases cause more deaths in the developing world than developed countries (WHO, 2005, 2012b). Latin American countries, including Central, South America and the Caribbean, have experienced in the second half of the 20th century an unprecedented shift in their demographic and health profiles (Albala & Vio, 1995; Curto de Casas, 1993; Laurenti, 1975). This transition results from a multitude of factors. One is the demographic transition, referring to the way populations are ageing (WHO, 2008).

Globally, life expectancies have risen as a result of reduced deaths in early life due to better control of infectious disease and medical interventions which prolong life. Over the next three to five decades, Latin America's populations will age dramatically (Palloni & McEniry, 2007) and the number of new cases (incidence) and the total number of people (prevalence) with chronic diseases is rapidly increasing (Alleyne, 2002). However, increasing age is not the only factor driving the epidemiological transition. Another is the nutritional transition (Rivera *et al.*, 2004). In Latin America and elsewhere, activity levels are decreasing while energy intake from fat and high-caloric food is increasing leading to, for example, greater risk of diabetes and hypertension (Rivera *et al.*, 2004).

One reason why research on the experience of chronic illness in the global South is so important is the fact that developing countries, including those in Latin America, "...are growing old faster than they are growing rich" (Marks & McQueen, 2002, p.120). The cost of treating chronic conditions surpasses the cost of treating infectious diseases, even those requiring hospital care (Arredondo *et al.*, 2005). Clearly this has important implications for public health and healthcare systems. Healthcare systems need to adapt to these changes, in terms of financing, human resources, and models of care (Epping-Jordan, 2005). Over and above the impact on formal healthcare systems in caring for chronic illnesses, is the impact such diseases have on individuals and families (Nichter, 2008b), primarily, because of the disabilities chronic conditions can cause (Menendez *et al.*, 2005; WHO, 2008). Furthermore, the impact of chronic illness on individuals and families is uneven locally, in terms of socio-economic differences and globally between developed and developing countries (Manderson & Smith-Morris, 2010).

Medical Anthropology and the Epidemiological Transition

Medical anthropologists are well positioned and equipped to study the complexity and implications of the epidemiological transition described above. Understanding how people live with chronic conditions will include paying attention to health beliefs and practices, family relationships, health systems, and the economics of healthcare and public health at national and global levels. Inhorn (2007) argues that medical anthropology's unique contribution will come from working at the intersections of disciplines. Janes' (2003) definition is particularly suited to this thesis:

"Medical anthropology is placed midway between its parent discipline and the interdisciplinary arena of public health. Its contribution lies in its ability to articulate the meaning that individuals and communities attribute to illness and to locate these within broader systems of social relations. This work explains how universal biological processes are subject to local social and cultural influences" (p.466).

However, in approaching categories of disease defined by biomedicine it is important for anthropologists to retain their uniqueness in terms of not accepting biomedical categories uncritically (Browner, 1999). Biomedicine is a product of social and cultural conditions (Lock & Gordon, 1988), and the body is not a singular entity cross-culturally (Lock & Nguyen, 2010). Lock & Nguyen (2010) argue that ethnography has a place in informing health policy because the embeddedness of biomedical technologies within social and moral worlds is researchable by eliciting the accounts of local people. Bloor (2001) is less certain of ethnography's power in public health policy, which still demands statistics and quantitative evidence to drive change, but suggests ethnographic data has the power to change the everyday practices of healthcare professionals. I argue that ethnography has the power to change both policy and practice and it can do this while remaining critically-informed, *i.e.* contribute to discussions in public health while remaining interpretive and theoretically driven within the discipline of anthropology itself. Anthropological perspectives on the epidemiological transition in the global South are greatly needed, especially with regards to older people living in urban areas in developing country contexts (van Eeuwijk, 2003). Therefore, in this thesis, I lend an ethnographic and anthropological approach and perspective to the study of an emergent global public health concern: Chronic Obstructive Pulmonary Disease (COPD), in mostly urban populations in Uruguay.

COPD: An Example of an Under-Studied Disease in the Epidemiological Transition

COPD is very much part of the epidemiological transition and is, therefore, a timely yet, so far, understudied topic of anthropological investigation. The WHO estimates that by 2030 COPD will be the third leading cause of death globally (currently it is fourth) and 90% of COPD deaths occur in low and middle income countries (WHO, 2012a, 2012b). COPD is a disease category that includes two more commonly known lung diseases: emphysema and chronic bronchitis, which cause progressive obstruction of airflow in the lungs (Fabbri *et al.*, 2006). Historically it

has been called many things, including chronic obstructive airway disease (COAD), chronic airflow limitation (CAL), chronic obstructive lung disease (COLD) and chronic airflow obstruction (CAO). COPD was the preferred term in North America and seems, in the past decade, to have become the established term in national and international guidelines. Symptoms of COPD are predominantly chronic and progressive shortness of breath (dyspnoea), coughing, the production of sputum, chest tightness, wheeze, frequent winter chest infections and impaired exercise tolerance (Currie & Chetty, 2011). Breathlessness is the most troublesome for sufferers (Barbara *et al.*, 2011; Izquierdo *et al.*, 2009). Science is just beginning to conceptually and empirically recognise how COPD is a systemic disease characterised by important and frequent co-morbidities, including cardiovascular disease, lung cancer, osteoporosis, muscle wasting, nutritional deficiencies and depression (American College of Chest Physicians and Chest Foundation, 2004; Fabbri *et al.*, 2006; MacNee, 2011; Mannino *et al.*, 2006; Peces-Barba *et al.*, 2008).

Although there is clearly a large amount of academic and scientific interest in COPD, as can be seen in the abundance of recent publications, it is the position of the Global Initiative for Chronic Obstructive Lung Disease (GOLD) that “...although COPD has received increasing attention from the medical community in recent years, it is still relatively unknown or ignored by the public as well as public health and government officials” (GOLD, 2008, p.iii). In 1989, Williams and Bury, reflecting on how such a prevalent and disabling disease has received so little attention, state:

“The fact that COAD tends to strike in middle to later life, that it is incurable, and cannot be said to be at the ‘cutting edge’ of medical science in the way that, say, the search for the basic genetic defect in cystic fibrosis or the cure for cancer is, may go some way in explaining the relative inattention and the fairly low public profile of COAD.” (p.609)

However, there is little doubt COPD is attracting greater attention. One reason it can no longer be ignored by governments is because people with COPD are frequently hospitalized for exacerbations which has made it one of the most costly chronic diseases to provide care for (Sullivan *et al.*, 2000; Toy *et al.*, 2010).

Risk-Factor, Cause and the Susceptible Smoker

It can get rather confusing for a social scientist to make sense of the medical literature on COPD, particularly concerning the use of the terms risk-factor and cause. Some sources clearly say that the main or predominant cause of COPD is the inhalation of tobacco smoke, either as a passive or an active smoker (Booker, 2005; WHO, 2011). Other sources shy away from the term 'cause' and prefer to speak of 'risk-factors', which include but are not limited to smoking (Dartnell & Ramsay, 2005; Midgley, 2008). Midgley (2008) defines COPD as a "multi-factorial disease" (p. 28), which arises as "...a result of damage to the lungs caused by long-term exposure to inhaled particles of smoke, dust, or fibres and sometimes noxious gases" (p.1). These inhaled particles may come from cigarette smoke, occupational dusts and chemicals, and from indoor air pollution from cooking fuels, which accumulate due to poor ventilation (Bruce *et al.*, 1998; Midgley, 2008). Some of the substances which cause damage are carbon monoxide, nitrogen dioxide, sulphur dioxide, formaldehyde, and particulate matter (Devereux, 2011). Some of the occupations which have been associated with higher rates of COPD include coal mining, hard rock mining, tunnel working, concrete manufacture, construction, farming, the manufacture of plastic, textile, rubber, leather and food, as well as transportation and trucking (Devereux, 2011).

The guidelines for COPD management produced by GOLD, state that most of the data we have on risk-factors is from cross-sectional epidemiological studies that have identified associations and not direct cause and effect (GOLD, 2011). In many cases, people with COPD have been exposed to more than one risk-factor, such as being a smoker and working in smoky or dusty environments. An official public policy statement from the American Thoracic Society titled *Novel Risk Factors and the Global Burden of Chronic Obstructive Pulmonary Disease* states that now with better data on COPD globally, it is clear that, although the most important cause of COPD is smoking, smoking alone cannot explain a substantial proportion of COPD cases (Eisner *et al.*, 2010). Their review finds that there is conclusive causal evidence to show that genetic syndromes and occupational exposures are causally related to developing COPD and that outdoor pollution, second-hand smoke, biomass smoke and dietary factors are associated with COPD but more data is needed to establish causal links. Indoor exposure to biofuels from cooking is an important risk-factor for COPD development among non-smoking women, especially in developing countries (Bruce, 1998; Devereux, 2011, GOLD, 2011).

The fact that not all smokers, nor all cotton-workers breathing in cotton fibres, nor all factory workers breathing-in chemicals, nor all women breathing in smoke from cooking fires develop COPD, helps to differentiate between cause and risk-factor. Better data regarding smoking as a risk-factor exist so I will focus on that as an example. It is estimated that between 10 and 20% of smokers will develop clinically significant COPD (Booker, 2005; Devereux, 2011). Evidently, smoking does not always cause COPD or every smoker would develop it, however, for those 10 to 20% of smokers who do develop COPD, the predominant cause of damage to their lungs is smoking. Risk is calculated by an equation called pack-years. This is the number of cigarettes smoked per day divided by 20 (20 is the number of cigarettes per standard pack), multiplied by the number of years smoked. The calculation enables researchers and clinicians to circumvent the issue of comparing differences in the amount of cigarettes smoked and the number of years and draws attention to the fact that the effects of cigarette smoking is cumulative (Midgley, 2008). A smoking history of 15-20 pack-years or more presents a significant risk of developing COPD (Booker, 2005). For example, a person with a 20 pack-year history may have smoked 20 cigarettes a day for 20 years or 10 cigarettes a day for 40 years. Therefore, it is not just how much one smokes but for how long they have smoked. Rates of airflow obstruction in smokers rise with age. 27% of smokers over 35 and 48% of smokers over 60 will have airflow obstruction (Booker, 2005). Currently why some smokers develop COPD, and others do not, remains unknown. This reality has been developed into the notion of the 'susceptible smoker'.

It is believed that smokers who are vulnerable or susceptible to COPD may share certain characteristics like having had respiratory infections in childhood (American College of Chest Physicians and Chest Foundation, 2004), having had tuberculosis (Devereux, 2011), having been exposed to respiratory allergens, having 'hyper-reactive' airways, dietary deficiencies, poor lung development in childhood and a susceptible genetic make-up, which we currently do not understand (Midgley, 2008). These may be the same susceptibility factors that account for why it is that some people who breathe in wood smoke develop COPD and others do not. Currently the only known genetic cause of COPD is alpha-1-antitrypsin deficiency, which is thought to account for 1 to 2% of COPD cases (Booker, 2005). Alpha-1-antitrypsin deficiency should be a suspected cause in people who develop COPD before the age of 40 and have family members with the disease.

COPD as 'Not Asthma'

Asthma is also an obstructive lung disease and one school of thought is that asthma and COPD share epidemiological and clinical origins, a proposition known as the Dutch Hypothesis (Bleecker, 2004). However, both clinically (*i.e.* the clinical presentation), and in terms of the person's experience, asthma and COPD have distinct clinical histories. Asthmatics tend to develop their disease in early life; their symptoms may come and go across the lifespan and certainly from week to week, month to month, and season to season. Also, in contrast to COPD, the onset of asthma is not inextricably linked to smoking or other risk-factors, although its exacerbation can be. Asthmatics tend to have a cough, breathlessness and wheezy breathing in the mornings and the evenings, whereas these nocturnal patterns are not common in COPD (Currie & Chetty, 2011). COPD rarely develops before the age of 35 and has a very high rate amongst smokers. Symptoms will fluctuate much less, meaning that breathlessness is generally progressive, *i.e.* gets worse over time, and there are no big differences in airflow obstruction from day to day.

Medically speaking, the distinguishing feature at a physiological level between asthma and COPD is 'reversibility'. The standard tool necessary for confirming a diagnosis is a spirometer, a device used to measure the amount and speed of air inhaled and exhaled (Bellamy, 2011; Peces-Barba *et al.*, 2008). Both asthma and COPD are diagnosed with a spirometry test, otherwise known as a lung-function test. During the test, the patient is told to take a deep inhalation and wrap their mouth around a tube attached to a computer, which they blow into as hard and fast as they can, exhaling until the technician tells them to inhale. What is measured is the volume of air in millilitres forcefully exhaled in the first second, in relation to the total volume of air exhaled. These measurements are known as Forced Expiratory Volume in one second (FEV1) and Forced Vital Capacity (FVC), respectively. An FEV1 equal or less than 80% and an FEV1/FVC equal or less than 70% of the predicted value based on age, gender and weight, is indicative of airflow obstruction (Bellamy, 2011). The test is repeated until three measurements are obtained which are within 5% of each other.

Then the person is given a dose of a bronchodilator to inhale, is asked to wait 15 minutes, and then returns to do the spirometry test again. It is at this point that 'reversibility' is measured. If the bronchodilator improves the results of FEV1 by 15% or more than 400ml, the obstruction is considered 'reversible' and, therefore, characteristic of asthma. Airflow with COPD, because it is a progressive and 'permanent' obstruction of the lungs, does not improve

significantly with the simple inhalation of bronchodilators, although it can improve slightly, which is why COPD is defined as partially or not entirely reversible (Booker, 2005; Midgley, 2008). Therefore, although intimately related, biomedically they are two very different diseases. To add to the complexity, around 10% of childhood-onset asthmatics and 25% of adult-onset asthmatics will develop airflow obstruction that is irreversible or fixed, thus fitting a COPD diagnosis (Booker, 2005). Improperly treated asthma over the lifespan is thought to reduce reversibility and asthmatics who smoke, are at higher risk (Booker, 2005). Also, many individuals will have both asthma and COPD (Devereux, 2011). In summary, although the symptoms of breathlessness and crises are similar in COPD and asthma; when they occur, what triggers them, starting from what phase of life, and what can be done to improve them, differ significantly. I now turn to Uruguay, my field site.

THE CHOICE OF URUGUAY AS A RESEARCH SITE FOR THE STUDY OF COPD

The fact that Uruguay is characterised by having some of the highest rates of COPD in Latin America, was a motivating factor to undertake the study there. Uruguay is an upper, middle-income country of 3.3 million inhabitants. The country is divided into 19 departments and a 20th has been designated symbolically as representative of the 1 million additional Uruguayans who live outside the country. It is one of the wealthiest economies in South America. Minimum monthly wage rose from 6000 pesos (\$294.00 USD¹) to 7200 pesos (\$353.00 USD) in December 2012 (Presidencia, 2012). Its demographic and epidemiological profile matches those of developed, high-income countries. Life expectancy at birth in Uruguay is 73 for males and 80 for females. The infant mortality rate is 11.9 for every 1000 live births and mortality due to communicable diseases is lower than in other Latin American countries and the lowest of the Southern Cone (Argentina, Chile, Paraguay and Uruguay) (Figure 1.1) at a rate of 58.1 per 100 000 compared to the Southern Cone average of 67.5 per 100 000 population (PAHO, 2008). Cancer mortality rates are the highest of the Southern Cone countries at 240.4 versus the average of 147.9 per 100,000 population. Ischemic heart disease and cerebrovascular disease also far exceeds the rates found in Argentina, Chile and Paraguay (PAHO, 2008).

Menezes *et al.* (2008), a team of researchers from around Central and South America, conducted the large *Proyecto Latinoamericano de Investigacion en Obstruccion Pulmonar* (PLATINO) study to uncover the burden of COPD in Latin America. They administered a

¹ 1 US dollar equals 20.41 pesos based on January 7th 2012 exchange rates

standard questionnaire and a post-bronchodilator spirometry test to 800 randomly selected subjects in Sao Paulo (Brazil), Mexico City (Mexico), Montevideo (Uruguay), Santiago (Chile) and Caracas (Venezuela). They found the highest rates of COPD in Montevideo, particularly among Uruguayan men at 27.2%. I was interested in studying COPD in Latin America because qualitative studies there on COPD are very scarce, chronic diseases such as COPD are becoming increasingly prevalent and many Latin American countries, including Uruguay, are reforming their healthcare services in response to growing inequalities and healthcare needs. Studying COPD in Uruguay enables one to study both the condition and the issues which occur in the global South in a country that still has limited resources in the face of growing healthcare needs. Additionally, to study diagnosed chronic illness, as this study has done, one needs a context where there is a possibility for people who are experiencing symptoms to have access to some form of diagnosis. In Uruguay citizens have access either to public healthcare institutions, private healthcare institutions and what I call private mutual institutions. I aimed to meet participants across all three forms of healthcare. These three pillars of healthcare will be explained in more detail in Chapter 4.

Another motivator for my choice of field location was that relatively little English-language anthropological material is available on Uruguayan culture and society compared to its Latin American neighbours. Within Uruguay, however, there is a vibrant Anthropology Department at the University of the Republic in Montevideo, which publishes the Annual



Figure 1.1 : Map of Uruguay indicating Montevideo and Tacuarembó (Left) and Uruguay within South America (Right). Source:

<http://www.worldatlas.com/webimage/countrys/samerica/uy.htm>

Review of Social and Cultural Anthropology in Uruguay and includes many medical anthropology contributions such as reflections on intersubjectivity in hospital settings (Alvarez-Pedrosian, 2009a) and research on the bio-politics of HIV-AIDS in Uruguay (Reihling, 2007). There is also an active *Programa de Antropología y Salud* (Anthropology and Health Program). They have been involved in projects ranging from, research on risk-factors for the dengue fever vector (Wainwright, 2012), analysing from a critical, socio-cultural and psychological point of view the case of a Uruguayan doctor who was shot and killed by the widow of a patient (Romero Gorski *et al.*, 2009), and, during my fieldwork, were embarking on a study of the take-up of alternative and complementary therapies within biomedical practice.

Anthropological research published in English on Uruguay are less prevalent but recent research has been conducted by Renfrew (2007) on lead poisoning and environmental politics in Montevideo, by Oliver (2006) on family farming and food sovereignty, by Proctor (1956) on changes in social organisation in a rural problem area, by Moates (2009) on the practices of urban pig farmers during the economic crisis in Montevideo, and by Andrews (2010) on Afro-Uruguayan culture and history. These works demonstrate that, in the past decade, Uruguay has received wider anthropological attention and this thesis contributes to that burgeoning area of study. One reason why Uruguay has not received more anthropological attention may be because the country has proclaimed itself to be without indigenous peoples. Indeed compared to Chile, Paraguay, Bolivia and Peru, for instance, it has no large self-identified indigenous groups. I believe anthropologists have been drawn to countries in Latin America with large indigenous populations, which has meant that Uruguay has fallen through the cracks of the ethnographic record. This topic will be reviewed in Chapter 4.

Another reason Uruguay makes for a fascinating and important country in which to study a global health problem like COPD, is that there are data to suggest that Uruguay faces the same problems of under-diagnosis, as have been reported in countries all over the world, including Spain (Peña *et al.*, 2000), Sweden (Lindberg *et al.*, 2006), Japan (Takahashi *et al.*, 2003), Poland (Bednarek *et al.*, 2008) and England (Shahab *et al.*, 2006). In Uruguay, Menezes *et al.* (2008) found that of the people they diagnosed in the PLATINO study as having stages 3 or 4 of airway obstruction (severe and very severe COPD) only 20% had previously received a medical diagnosis, only 24% had undergone spirometric testing and only approximately 21% were taking medication. Talamo (2007), also writing of the PLATINO study, reported that 92.5% of the participants, who they discovered had airflow obstruction, were receiving the diagnosis

for the first time. However, equally importantly, almost half of all their participants across the five capital cities, who self-reported a diagnosis of COPD, were found to not meet the clinical criteria. The publications interpret these results as a reflection of the insufficient availability of spirometry and/or the expertise to carry out the test and interpret its results effectively. They also found an association between undiagnosed COPD and younger age, lower severity of obstruction, no symptoms and no prior asthma diagnosis.

For all these reasons an ethnographic study of COPD in Uruguay is a unique contribution to the medical anthropology and qualitative health research literature. While the PLATINO study demonstrates COPD is a public health issue in Uruguay, we know little from these types of epidemiological studies about the actual lives of people who are diagnosed with COPD. Some of the ways COPD is commonly described in the medical literature is “a chronic slowly progressive disease” (Dartnell & Ramsay, 2005, p.89) “debilitating and life-threatening” (Midgley, 2008, p. 6), “...a major global epidemic” (Currie, 2011, p.viii) and a condition which is disabling (Booker, 2005). However, medicine’s engagement with COPD rarely looks at concepts, such as disability, life-threatening, progressive, slow or chronic from the patient and family perspective, in terms of what they mean in everyday life, outside of controlled clinical and experimental contexts. Indeed, Jean Bourbeau (2009), a prominent COPD specialist who is involved in producing the international GOLD guidelines, argued in his paper that:

“Little is known about how internal personal factors, such as sex, age, disease, severity, coping styles, social background, education, past experience, etc., impact disability. The impact on disability of environmental factors, such as social attitudes, legal and social structures, physical characteristics of the environment, climate, etc., is equally unclear” (p. 197).

Ethnography, as an approach to mixing-methods is well placed to fill this gap in a “...qualitatively driven way” (Mason, 2006, p.9).

AIMS OF FIELDWORK AND OBJECTIVES OF THE THESIS

One of the main objectives of this research was to explore some of these “...internal personal factors” (Bourbeau, 2009, p. 197), as a way of gaining insight into how COPD is lived-with and cared-for in a middle-income but still developing country context. Here I divide my aims and objectives into aims of fieldwork and the objectives of this thesis itself. The aims of fieldwork were to explore the following questions and gather data to help answer them:

- What does it feel like to be breathless and how is COPD experienced within family and healthcare relationships?
- How is the lived-experience of COPD shaped by cultural, social, economic and political factors and contexts?
- What are some of the challenges and opportunities for preventing and treating this disease?

The objectives of the thesis itself are to:

- Make a unique contribution to the growing field of anthropology of chronic illness, by contributing a rich ethnographic account of a little-known disease in a little-known place.
- Demonstrate how fieldwork which explored, via multiple methods, the sentient body as the location of the social and body politic, can help merge a sensorial medical anthropology approach with a political-economy of health perspective.
- Illustrate how context is crucial for understanding COPD, by providing a rich account of Uruguayan history, customs, beliefs and healthcare politics through the ethnographer's narrativisation, in addition to participants' narratives.
- Show how the results of a multi-modal and multi-sited sensorial ethnography can critically inform public health goals in the area of COPD treatment and prevention.

THESIS OUTLINE

This thesis is organized into a number of self-contained yet interrelated chapters, each one written to make an original contribution as well as come together to meet the aims of the research overall. The topics they cover, including, Uruguayan citizen and healthcare history, the phenomenology of breathing, the expressions of COPD, the political-economy of COPD care, sensorial work in group-care and the prevention and treatment of COPD, together fulfil the primary aim of this research which was to answer the question 'how is COPD lived-with and cared-for in Uruguay'? The way the research achieves this aim is unique in its theoretical and methodological approach to both conducting the fieldwork and constructing this ethnography. The priority was capturing as wide a variety of people with COPD as possibly in order to gain a more accurate picture of COPD in all its complexity.

Chapters 2 to 4 present the theoretical, methodological and historical groundwork for the thesis. The literature review and theoretical framework chapter, Chapter 2, situates this research in the growing field of anthropological research on chronic conditions. I review this literature and draw out some of the principal topics investigated, and theoretical frameworks drawn upon, in this field. The guiding theoretical framework of the thesis is sensorial medical anthropology and its original theoretical contribution lies in explicitly incorporating a political-economy of health perspective as part of a sensorial approach. The individual body in this research was approached as the location of the social and body politic, which express themselves in various ways and contexts. Exploring these was achieved via a multimodal approach to ethnographic fieldwork. I discuss methodology in Chapter 3 and trace how I came to meet the people I met and how I carried out research across two cities in Uruguay, Tacuarembó and Montevideo. This research included patients and family members, healthcare professionals, hospital administrators and policy makers. I review my methods which included participant-observation in diverse contexts, formal and informal interviews, pile-sorts, drawing, definition-elicitation, demographic questionnaires, family trees, biometric lung-function data, and focus groups. Characteristics of my 37 participants with COPD are also presented. My sample is unique within the qualitative literature on COPD in that it included people of diverse ages, socio-economic background and disease severities. This was enabled by gaining access to various public and private healthcare institutions and contexts such as outpatient clinics, smoking cessation groups and hospital wards. In Chapter 4, the reader is introduced to the history of Uruguay from the 16th to the 19th centuries through answering the question, “Who are Uruguayans?” This citizen-history is followed by an outline of the major historical developments of the 20th century, as told through the narrative of healthcare and the medicalisation of Uruguayan society.

Chapters 5 to 8 delve into the individual, social and political bodies of COPD, as they express themselves through the individual sentient body. Chapter 5 begins with contextualising breathing and breathlessness in Uruguay, drawing on theory from the literature on the phenomenology of breathing and the anthropology of wind and climate. I argue that discourse in Uruguay about breathing concerns both the body and the environment, particularly, air. The qualities of air, whether humid, dirty or cold, are perceived to interact directly with the body and produce health-effects. These beliefs are not hidden; rather they are ubiquitous in social and healthcare settings. Therefore, a strictly inner-body engagement with the issue of

breathing in Uruguay would be incomplete. In this way, I propose that sensory-ecology be considered an important concept for medical anthropologists taking a sensorial approach in the study of chronic conditions, particularly COPD.

Chapter 6 explores the expressions of COPD. The chapter showcases the diversity of ways in which COPD can be expressed in language and metaphor, the body and emotions, and in images. It draws specifically on data generated from definition-elicitation, pile-sorts and participant-produced drawings of their lungs. The aim of the chapter is to provide the reader with a more in-depth appreciation of the sensorial experience of COPD than is currently available in the qualitative literature. Furthermore, it shows how the sensorial experience is inseparably emotional and physical and is shaped by deep social realities, such as family life, ability and disability, biomedical imagery and ideals of masculinity.

Chapter 7 investigates the way in which the experience of COPD can be deeply shaped by the political-economy of healthcare inequalities in Uruguay at the time of fieldwork. This chapter exemplifies how a sensorial approach which focuses on the micro level of the individual and family members becomes a way of studying the macro-structural factors which express themselves through the body politic of the individual. The story of Marcelo and his family's last five months of illness provide the guiding narrative to the chapter. Their story touches upon a number of pillars in COPD care, such as diagnosis, inpatient care and the role of families, end-of-life care, homecare, genetic testing, and home oxygen therapy. By comparing Marcelo to other participants I explore not only what is lacking in care for COPD but also the resources Uruguay has. It is argued that COPD is something created and can be made into a disease that is chronic or terminal.

Chapter 8 takes up two other pillars of COPD care not present in Marcelo's story: pulmonary rehabilitation and smoking cessation. In comparing them, I emphasise that they are intersubjective forms of care, which include spaces for 'sensorial work' to occur between patients and between patients and healthcare professionals. In quitting smoking and in re-incorporating exercise, a number of sensations arise in the body and sometimes these are conflictual, or become so in the process of comparison. Health professionals in each context attempt to guide patients towards re-scripting sensations so as to support patients in experiencing them, particularly of breathlessness, in positive ways.

Chapter 9 draws the previous chapters together to critically theorise on the challenges Uruguay faces and the opportunities it has in working towards three COPD public health goals:

1) to diagnose COPD and diagnose it earlier, 2) to prevent already diagnosed COPD from getting worse and 3) to prevent COPD altogether by reducing exposure to risk-factors. From this critical analysis, I recommend considering the potential for, 1) smoking cessation professionals to be involved in screening for COPD, 2) reframing smoking cessation as a treatment for COPD, and 3) focusing awareness-raising campaigns around the symbolism of 'pure, clean air', which would include not only tobacco-smoke but also other environmental and occupational factors affecting the quality of air breathed.

Finally, Chapter 10 provides a concise summary each chapter's main contributions and synthesizes how the aims and objectives of this research were met. It also reiterates the ability of anthropological approaches to fill important gaps in qualitative health research in COPD and concludes with suggestions for future research.

Chronic Illness, Critical Sensorial Medical Anthropology and ‘Situating the Breath’: A Framework for an Ethnography of COPD

INTRODUCTION

This research on COPD in Uruguay is firmly grounded in the anthropological literature on chronic illness. Many anthropologists have studied a range of health conditions labelled ‘chronic’ and have taken to critically reflecting on the validity of the label in light of the growing body of ethnographic data about the lives and experiences of those so-labelled (Manderson & Smith-Morris, 2010). In this chapter I begin with giving an overview of medical anthropology’s contribution to the study of chronic illness and draw out some of the principle theoretical frames represented in this literature. Secondly, I turn to reviewing sensorial anthropology as an emergent field of phenomenological anthropology, focusing particularly on its relevance in medical anthropology. I then turn to reviewing critical medical anthropology and the political-economy of health perspective. I spend a considerable amount of space and time reviewing these literatures and theories to make the case for my approach which is to, theoretically and methodologically, incorporate a political-economy of health perspective as part of a sensorial approach. I achieve this by taking a slightly different approach to the three bodies proposed by Scheper-Hughes and Lock (1987). I conceptualise the individual to be at once an individual, social and political body and that a multi-modal and multi-sited ethnographic approach (Chapter 3) enables a merger of sensorial and critical perspectives, methodologies and analysis. The chapter ends with a review of the qualitative literature on the experience of COPD and how this thesis contributes not only to medical anthropology but to the growing body of interdisciplinary research on the perceptions, experiences and needs of individuals, families and healthcare professionals faced with COPD, and the unique contribution ethnography can make in this area.

ANTHROPOLOGY OF CHRONIC ILLNESS

In order to think about how best to go about studying COPD and then later writing about it, I looked widely across disease categories for anthropological, particularly ethnographic, research in the area of chronic illness. The empirical anthropology literature within which this thesis situates itself and upon which it drew inspiration, pertains explicitly to articles, ethnographies and book chapters written by anthropologists who studied various health conditions labelled 'chronic'. By focusing on the anthropological literature I was able to assess its contribution to this field as well as draw inspiration from ethnographic modes of writing and analysis. While related social sciences, such as medical sociology and geography, also publish widely on the topic of chronic illness, these literatures were only included if directly relevant to the topic at hand (Bury, 1982). Although Bury (1991) published a review of the sociology of chronic illness, an explicit review of the anthropology of chronic illness has not yet been carried out; hence my focus on anthropological contributions in this thesis. As COPD is a disease which affects people in adulthood and normally after the age of 35, I focused especially on chronic illness literature which concerned adults. As a first step I began by looking at what illness categories anthropologists have so far investigated.

It is important to note that a non-disease-specific approach to investigating chronic illness has been carried out by a number of anthropologists (Janes, 2003, 2004; Gibson, 2001; Livingston, 2003; Becker, 2004), meaning these studies included participants with a variety of chronic illnesses. This work attests to how the care-needs of people with chronic conditions are different from those suffering from conditions which are curable and relatively short-lived. These include, but are not limited to, requiring tertiary level care of specialists, access to acute, inpatient and outpatient follow-up care, access to long-term medications to be taken on a daily basis and greater coordination between health professionals, services in the community and the family. A more common approach for medical anthropologists, however, has been to base research around a particular disease category. This trend is a product of the applied turn in medical anthropology (Pelto & Pelto, 1997). By focusing on the experiences of illnesses which share a common diagnostic label, it is possible for anthropologists to lend their perspectives to discussions occurring in medicine and public health concerning that particular disease. Clearly both approaches to the topic are necessary and complementary. Some anthropologists have even analyzed their own experiences of chronic illness through auto-ethnographic accounts, such as Greenhalgh's (2001) harrowing experience of misdiagnosis of chronic pain, and

Murphy's (1990) narrative of what he calls 10-years of 'fieldwork' on his own life's transformation at the hands of a tumour along his spinal cord. The disease-specific literature remains the largest and it is clear that some diseases have attracted greater attention than others.

One of the most studied chronic diseases has been diabetes (Borovoy & Hine, 2008; Ferzacca, 2000, 2001, 2010; Garro, 1995; Meyers, 2007; Poss & Jezewski, 2002; Schoenberg *et al.*, 2009; Smith-Morris, 2006, 2010; Wiedman, 1987, 2010). This is not surprising considering the prevalence of diabetes worldwide and the unequal distribution it has in society, particularly its overrepresentation in indigenous peoples and other minority groups. Whereas populations with higher risks of diabetes such as indigenous North Americans are sometimes blamed for their 'poor lifestyle choices', an anthropological perspective situates these in a colonial and post-colonial context of inequality, control and rapid lifestyle changes which were largely imposed, not elected. Anthropologists have also taken an interest in conditions which are poorly understood and poorly treated within biomedicine. A good example of that is chronic pain or conditions which share pain as their primary symptom such as lumbar injury, fibromyalgia and Irritable Bowel Syndrome (Betrisey, 2009; Greenhalgh, 2001; Kleinman, 1995; Kleinman *et al.*, 1992; Oths, 2003; Throop, 2010; Wainwright *et al.*, 2011).

Anthropologists have also contributed to our understanding of chronic kidney disease (Kierans, 2005; Kierans & Maynooth, 2001; Russ *et al.*, 2005, 2007), lupus (Miles, 2010), hypertension (Dressler & Bindon, 2000; Schoenberg & Drew, 2002) stroke (Mshana *et al.*, 2008) Alzheimer's (Cohen, 1998; Lock *et al.*, 2007), atherosclerosis (Mol, 2002) and epilepsy (Good & DelVecchio Good, 1994). Fertility problems is another chronic condition which is not given the explicit label of disease but which causes tremendous suffering and which is becoming increasingly medicalised (Inhorn & Birenbaum-Carmelo, 2010; Kahn, 2000; Manderson, 2010). There has also been an important trend, particularly in North American medical anthropology, in studying chronic mental health problems such as psychiatric disease (Biehl, 2005; Estroff, 1981; Estroff *et al.*, 1991), post-traumatic stress disorder (McLoughlin & Warin, 2007; Young, 1995), schizophrenia (Good *et al.*, 2010; Jenkins & Barrett, 2004; Scheper-Hughes, 1979), depression (Kleinman & Good, 1985; O'Neill, 1996) and transient mental illness (Hacking, 1998). This literature frequently demonstrates the inseparability of the physical and the psychological, so that studying chronic diseases of the mind/brain does not deny the lived-body. Those disease categories which, even in medicine, straddle Cartesian notions of the mind and the

body, such as pain (Kleinman *et al.*, 1992) and anorexia (Warin, 2010) are explored in all their complexity via an ethnographic approach. Furthermore, mental and physical health problems frequently co-occur (Manderson & Smith-Morris, 2010)

Another area of anthropological study has been the exposure to toxins and their effects on long-term health. Petryna's (2002, 2009) ethnographic works on radiation exposure after Chernobyl and the hierarchies of compensation, illustrate the very chronic consequences to health of human-produced chemicals and pollutants. Exposure of human beings to toxic smoke from cigarettes, has received surprisingly little attention from anthropologists and the research that has been done has received modest attention (Kohrman & Benson, 2011; Nichter, 2008b; Singer, 2004). However, there is a growing body of interdisciplinary research being conducted on smoking cessation programs to which anthropologists are contributing their expertise (Castañeda *et al.*, 2010; Kruger *et al.*, 2012; Ng *et al.*, 2010; Nichter *et al.*, 2009; Thankappan *et al.*, 2009), and the medical community is increasingly recognizing the value of anthropological ways of thinking and doing in this domain (Goldade *et al.*, 2012). On the particular topic of structural violence, the recent article by Lewis and Russell (2013) emphasised how, amongst their teenage participants in a deprived ex-mining village of North-East England, the normality of youth smoking represents a complex web of post-industrial community deprivation and learned coping behaviours, the availability and social-acceptability of cheap, illegal tobacco, and youth social relations. They warn that campaigns for smoking cessation with subtle and unsubtle moral undertones are picked-up by young people and may contribute to greater marginalisation when they lack the self-efficacy to quit. Bell (2010) also critically examines public health and claims that it has gone about representing the risks of second-hand smoke by drawing more on abjective, mimetic and affective qualities of cigarette smoke and its association to the bodies of others, than on the actual evidence of risk.

Toxins in the air are brought into the body through breathing and enter our airways and lungs. To the best of my knowledge, despite how serious a public health concern it is, there are no studies of COPD in the anthropological literature, although researchers have drawn on some anthropological methods (as will be discussed later). There is, however, anthropological literature on other respiratory diseases such as asthma, tuberculosis and cystic fibrosis. Two interesting themes in asthma research are participants' ambiguous relationship with asthma medication (Pohlman & Becker, 2006; van Sickle, 2009; van Sickle & Wright, 2001) and the difficulties of knowing when to access emergency care (Becker *et al.*, 1993). Manderson and

Rose's (2000) study of asthmatic women in Australia, discusses the murkiness of distinguishing asthma from COPD and of asthma diagnosis generally from the patient perspective. Interestingly, van Sickle & Wright's (2001) Navajo respondents were reluctant to take long-term medications because asthma was perceived to be a series of acute episodes and not a chronic disease requiring continuous treatments. Todd's (2003) research on asthmatic children in Teeside, UK, also demonstrates how asthma can disappear for individuals but for public health officials it persists as a once and for all diagnosis recorded in statistics. van Sickle's (2009) research on diagnosing and treating asthma in India highlights how the 'underdiagnosis' of asthma is explainable not only in terms of a lack of knowledge amongst physicians but also because the label 'asthmatic' was rejected by parents and so physicians were calling it by other more socially-acceptable names, such as 'wheezy'.

In Harper's (2005) critical assessment of tuberculosis treatment programs in Nepal it is argued that the stigmatising nature of tuberculosis, which is linked to notions of impurity, was a barrier to achieving direct observation of treatment taking. Nichter's (2002) work on tuberculosis resonates with van Sickle (2009) and Harper (2005), in that the label was stigmatising and referred to instead as 'weak-lungs'. The case study he provides shows how poverty was an inextricable part of intra-household transmission of the disease. While families would be labelled as ignorant and non-compliant, in reality the health care system did not deliver treatment adequately to individuals and their exposed family members. Smith-Nonini's (2009) study draws similar conclusions from a study of tuberculosis transmission in New York, USA and Lima, Peru. The author concludes that the disease is not only caused by poverty but also causes poverty.

Cystic fibrosis, a fatal chronic lung disease which develops in childhood, has been studied in terms of the impact it has on siblings and family (Bluebond-Langner, 1991), the perspectives of children, particularly regarding the time-consuming and physically unpleasant practice of chest physiotherapy (Bellisari, 1987) and the motivations behind electing risky surgical procedures (Maynard, 2006, 2010). Maynard's (2006) analysis of the stories of ten people with cystic fibrosis who were pre- and post-double lung transplant found that the desire for transplant was wrapped-up in a desire for normalcy within an American society heralding the virtues of work, hope, ambition and confidence. Despite the fact that this cohort had far outlived their prognoses, and that those that opt for transplant die sooner than those who do not, many still chose the risky option compared to the option of becoming increasingly disabled

by deteriorating lung function in an ableist society. Participants “...wanted to disappear (sic) their disease by striving for normal lives” (Maynard, 2010, p.196). This kind of cultural analysis of decision-making also highlights the impact of structural factors such as insurance coverage. Insurance companies were more likely to cover the costs of transplant and post-transplant care than they were to cover the costs of health and social care support if one were to become disabled and unable to work or care for oneself (Maynard, 2006).

Common Approaches to the Study of Chronic Conditions

The work of anthropologist and physician-psychiatrist Arthur Kleinman cannot be underestimated in relation to its impact on the field of medical anthropology and the anthropology of chronic illness more specifically. Furthermore, Kleinman’s work has spanned both mental and physical disease categories. Two common theoretical perspectives present in the literature stem from his work: explanatory models (EM), and illness narratives. The EM approach is based on the premise that the lay community and healthcare professionals are likely to have different understandings of the cause, treatment and prognosis of a particular illness and that these can be elicited in interviews and reflected upon in order to identify problems of communication and mutual understanding between the healthcare professional and patients (Kleinman, 1987). The EM framework has been applied to studying lay and medical beliefs about epilepsy in Mexico, Brazil and Bolivia (Carod-Artal & Vazquez-Cabrera, 2007), type 2 diabetes in an indigenous group in Canada (Garro, 1995), diabetes amongst Mexican Americans (Poss & Jezewski, 2002), stroke in Tanzania (Mshana *et al.*, 2008), tuberculosis and susto in Mexico (Rubel & Moore, 2001) and hypertension amongst elderly African Americans (Schoenberg & Drew, 2002). Mshana *et al.*’s (2008) study, for instance, was commissioned in Tanzania because it was discovered that people who had experienced stroke were reluctant to go to hospital and the hypothesis on the part of the government was that it was because they believed witchcraft caused stroke. The EM interviews with 80 participants found that the rural Christians and the urban Muslims had different explanatory models, thus stressing the importance of taking into account religious, historical and socio-cultural differences when designing interventions.

The EM approach includes a theoretical distinction between disease, illness and sickness. For Kleinman, sickness encompasses both illness – the subjective experience of ill-health – and disease – the biomedically defined pathology. Young (1982) considers ‘sickness’

underdeveloped in Kleinman's work and considers this a result of the EM approach being aimed towards clinical anthropology with the goal of improving care delivery. Young (1982) further defines sickness as the "...process through which worrisome behavioural and biological signs, particularly ones originating in disease, are given socially significant outcomes" (p. 271). He argues that seeing 'sickness' as that which encompasses illness and disease, downplays the importance of giving an account of how sickness is shaped and distributed through social relations. While this thesis does not explicitly draw on the term sickness, the social relations surrounding ill-health are ever-present. Generally, I prefer to use 'illness' as a holistic term relating to subjective experience, however, I do use 'disease' when speaking directly about the diagnosis and treatment of COPD or other categories as they are defined in biomedicine (*e.g.* heart disease).

Eliciting and analysing illness narratives, defined by Kleinman (1988) as "... a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term suffering" (p.49), has been another approach to understanding the impact of chronic illness (Bluebond-Langner, 1991; Good & DelVecchio Good, 1994; Kierans, 2001, 2005; Kleinman, 1988; Lock *et al.*, 2007; Meyers, 2007; Miles, 2010; Pohlman & Becker, 2006). According to one of the most influential thinkers in narrative theory, Jerome Bruner (1990), "We have the biological or "innate" capacity for narrative organization as human beings but it is our culture that shapes its expression through various traditions of telling and interpreting that we participate in from our earliest days" (p.80). Similarly for Kleinman (1988), experiences are arranged in meaningful ways through narrative which itself draws its structure from cultural and personal models including core metaphors, rhetorical devices and plot lines. Pohlman and Becker (2006) highlighted the way American society and biomedicine's discourse on stress were permeating the narratives of a multi-ethnic group of participants with asthma. However, participants also rejected and complicated these discourses. For Becker (1997), paying attention to the ways narratives are constructed and told is part of an embodiment perspective. Listening to and recording illness narratives occurs in almost all medical anthropology ethnographies because there is widespread appreciation in anthropology, and social science more generally, that narratives represent the connections between the personal and cultural and help uncover how actions are understood and given meaning (Garro & Mattingly, 2000; Mattingly, 1998; Riessman, 1993, 2008; Saris, 1995). The narrative-ethnography approach draws these connections explicitly by combining the "...epistemological,

methodological, procedural, and analytical sensibilities...” of both (Gubrium & Holstein, 2008b, p. 251)

Alongside a focus on narrative, medical anthropologists have focused on exploring and presenting the macro-structural factors which negatively impact upon peoples’ health, particularly marginalized groups. To do so, anthropologists have favoured a critical approach calling attention to the health inequalities and political-economic factors which shape the experience of disease in particular contexts (Baer, 1982; Becker, 2004; Bourgois *et al.*, 2004; Dressler, 1996; Farmer, 2005; Gibson, 2001; Hyde, 2007; Janes, 2003, 2004; Janes & Corbett, 2009; Kaufman, 2005; Miles, 2010; Singer, 1998; Scheper-Hughes & Wacquant, 2002). This research provides rich qualitative data about how macro-level factors such as healthcare provision and reforms, discrimination, violence and global markets impact individuals’ and communities’ ability to prevent chronic illnesses, to receive care, to maintain care, and to survive and eventually die with dignity; not to mention how individuals might use informal and illegal markets (*e.g.* organ-trafficking) to survive no matter the cost to oneself or other human beings.

Chronicity

The category chronic disease often appears interchangeably with other terms such as non-communicable, diseases of westernisation or modernisation, lifestyle diseases, and incurable disease. As such, it has frequently been posited in binary opposition to infectious, communicable and acute disease categories. The most recent theoretical development in the anthropology of chronic conditions is a critical engagement and rethinking of these dichotomies. Manderson & Smith-Morris’s (2010) edited volume *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, brings together many studies of the anthropologists working in the area of chronic illness and is a landmark contribution firmly establishing this topic as a growing area of medical anthropology. The volume prefers to speak of chronic conditions as opposed to chronic disease (a wider concept not dependent on biomedical diagnosis), and offers the “idea of chronicity”(p.19) as a way of thinking about chronic illness and recognising the problematic nature of biomedical categories and the fluidity of the lived-experience of the so-called chronically-ill. Although the volume does not provide any absolute definition of chronicity, the authors explore via the concept the ways in which

health states are fluid and shaped by socio-cultural as well as biological factors. For one, they challenge the temporal assumptions of the classifications.

“The use of a temporal marker – the chronic or long-term aspect of disease – has largely gone unquestioned until now, at a time when some previously acute and infectious diseases can be survived long term, and when medical technologies allow a symptom-free experience of “permanent” medical diagnoses. The old dichotomies – acute and infectious on one side, non-communicable and chronic on the other – no longer hold, although neither medical anthropologists nor other health social scientists have done much to destabilize this chronic-acute typology or the representations and organization of diseases that are its fallout” (Manderson & Smith-Morris, 2010, p.1-2).

Indeed, anthropologists have examined numerous examples of infectious disease and emphasised their sometimes hidden chronic, morbid and disabling effects. Examples of such anthropological research include leprosy, which causes disabling deformations and disfigurement (Bijlveld, 1982; Mull *et al.*, 1989), hepatitis C which can lead to liver disease, cancer and cirrhosis (Bourgois *et al.*, 2004), tuberculosis (Rubel & Moore, 2001; Harper, 2005; van Sickle, 2009; Nichter, 2002), HIV infection leading to AIDS (Farmer, 1993; Fassin, 2007; Hyde, 2007; Kendall & Hill, 2010; Thornton, 2008), vector-borne diseases such as lymphatic filariasis, which can cause disfigurement, elephantitis and disability (Coreil & Mayard, 2009) and chagas disease, which can lead to degeneration of the heart and gastrointestinal system (Bastien, 2003). Furthermore, as mentioned in the above quote from Manderson & Smith-Morris (2010), in this day and age many chronic diseases can be controlled to a degree that they are virtually symptom-free. Nevertheless, the chronicity of the label, of the medical follow-ups, the occasional flare-up and the uncertainty of whether one will remain ‘in good shape’ are still characteristics of chronic diseases, which distinguish them from many acute health problems that can be cured once and for all. Importantly, as attest Kendall & Hill (2010), who have done research on AIDS in South Africa, inequality within societies means that, for some, a disease like AIDS might be a chronic condition controlled by drugs, whereas for others with problematic access to healthcare, AIDS “...is still an acute illness with relatively rapid onset and fatal outcome”(p.177).

A related critical perspective on the chronic/acute dichotomy is put forth by Nichter (2008b) in his book *Global Health: Why Cultural Perceptions, Social Representations, and*

Biopolitics Matter. He argues that communicable and non-communicable diseases are interlinked in more ways than simply the fact that some infectious diseases become chronic health problems. For Nichter, these links become obvious when looking closely at households. In his words:

“Studies of the impact of chronic disease on the household production of health might further drive home the point that for every adult breadwinner who becomes ill, many others suffer...instead of conducting body counts on the afflicted or assessing DALYs [disability-adjusted life-years, a quantitative measurement] lost, we need better ways of accounting for the impact of the ill on household units. Such data will allow us to see syndemic relationships that involve the chronic illness or disability of a family member predisposing children to acute and later chronic illness, reproducing a vicious cycle of ill health. The chronically ill also have compromised immune systems, which render them more vulnerable to infection and communicable diseases” (p.163).

Merrill Singer’s work on syndemics has been at the forefront of this perspective in medical anthropology (Singer, 2009; Singer & Clair, 2003; Singer *et al.*, 2006). In *Introduction to Syndemics*, Singer (2009) explains that the term was developed “...to label a dynamic relationship involving two or more epidemic diseases or other disorders and the socio-environmental context that promotes their interaction...” (p.29). One syndemic relationship he reviews in the book is the Asthma-Influenza Syndemic. It is well known that asthmatics are more prone than non-asthmatics to acute infections, such as influenza. These can be life-threatening, especially when the influenza leads to pneumonia in vulnerable populations. What the syndemic theory emphasises is that the relationship between these conditions is not a simple case of co-morbidity, but rather a relationship which exists because of a common context, including social, economic, political and environmental contexts. This is true of other respiratory diseases as well, for example the vulnerability of people with COPD to chest infections. The same socio-environmental factors, such as exposure to tobacco, living in precarious overcrowded housing, and malnutrition, put certain people at risk of developing both COPD and chest infections. Nichter (2008b) considers tobacco part of a syndemic of harm and dependency at three sites: for households consuming tobacco, for the land which becomes dependent on environmentally devastating tobacco production, and for the government which comes to depend on tobacco-tax revenue. The idea of ‘chronicity’ proposed by Manderson &

Smith-Morris' (2010) volume relates to the literature on syndemic relations in that the idea of chronicity emphasises how diseases are not just 'chronic' but so is poverty, discrimination and inequality – "...risk itself is chronic" (p.15). However, syndemics is mentioned only in the introduction of the book and not drawn on by any of the contributors. In this thesis, the concept of syndemics emerges in Chapters 5, 6 and 7, because COPD is a timely example of the blurred boundary between a chronic and acute illness, it has effects on families, and is frequently accompanied by other tobacco-related diseases.

Despite agreeing with and providing supportive evidence for the importance of revisiting and critiquing the chronic/acute dichotomy, I continue to apply the term chronic throughout this thesis. It is unavoidably part of the name of the condition I studied. However, I also believe it is a useful term for distinguishing certain kinds of conditions within the large realm of human disease. Rather than change or abandon the term 'chronic', it makes sense to change its definition, and change the way we use the dichotomy (Smith-Morris, 2010), which is what the emergent literature in medical anthropology on the topic of chronic illness is doing. In this thesis I discuss participants narratives and explanatory models, however I focus these particularly around the question of what it feels like to be breathless because of damaged lungs. For this I am guided by sensorial anthropology to which I now turn.

SENSORIAL ANTHROPOLOGY AS AN EMERGENT FIELD OF PHENOMENOLOGY

Sensorial Anthropology is an emergent area of phenomenological anthropology (Desjarlais & Throop, 2011). According to Pink (2011), "...an increasingly influential phenomenological anthropology, with an emphasis on experience, has developed new ways of understanding human perception, as well as a focus on the senses and affect" (p.274). A comprehensive review of phenomenology in anthropology has been carried out recently (Desjarlais & Throop, 2011) and it is beyond the scope of this thesis to attempt to reproduce such a review. However, I will begin with an overview of phenomenology and its uptake in anthropology in order to situate the origins of sensorial anthropology and its uptake in medical anthropology.

Phenomenology has been defined in anthropology as "the scientific study of experience" (Jackson, 1996, p.2) with the work of phenomenologists Husserl and Merleau-Ponty at the forefront of anthropological thinking in this area. Husserl defines pure or transcendental phenomenology as "a science of essences" (Husserl, 1983, p.xx). For Merleau-Ponty (1958) phenomenology as a way of thinking about the world was a movement before

becoming a philosophy. A phenomenological style of thinking is an emphasis on the immediate experience of the world, and the conviction that this experience of the world comes before and is in fact necessary for science to exist (Merleau-Ponty, 1958). Merleau-Ponty builds on the thinking of Husserl by focusing on the role of sensory perception in our experience of the world. For anthropologists, phenomenology guides both theoretical analysis and methodology and appears under a multitude of distinct yet inter-related names including phenomenological ethnography (Katz & Csordas, 2003), phenomenological anthropology (Jackson, 1996) and cultural phenomenology (Csordas, 1994a; Katz & Csordas, 2003).

In contrast to the philosopher “...the anthropologist is satisfied only by making the argument in terms of empirical data” (Csordas, 1994b, p.270) and has done so through focusing on the way people experience and describe their lives, while upholding a principle of *epoché*. This is described by Husserl as a conscious process of ‘bracketing’ one’s own pre-conceived ideas and ways of seeing the world in order to suspend judgement (Husserl, 1999), and describe rather than explain or analyse (Merleau-Ponty, 1958). To bracket one’s preconceived ethnocentrism has long been a principal of the ethnographic method and the pursuit of making the strange familiar and the familiar strange. However, despite this similitude in epistemology, anthropology’s conception of phenomenology is clearly different from phenomenological philosophers. Philosophers contend that by virtue of verbalizing experience, we are reflecting upon it and therefore destroying our true pre-reflexive experience of the world. Merleau-Ponty (1958) considers phenomenology’s unfinished nature part of its role in revealing “...the mystery of the world and of reason” (p.xxii-xxiv). Recognising the unfinished nature of phenomenology has meant that anthropologists and other social scientists have freely re-interpreted it and drawn on the principles of phenomenological theory and methods.

In anthropology, a number of concepts signify a certain phenomenological way of thinking and approaching the study of human beings, including, habitus (Bourdieu, 1977), *epoché* (Husserl, 1999), the pre-objective (Husserl, 1999), perception (Merleau-Ponty, 1958), embodiment (Csordas, 1990) and intersubjectivity (Husserl, 1999). Intersubjectivity for Husserl means that decision-making and persuasion are interpersonal so that there is reciprocity in individual perspectives and interchangeability of standpoints (Crossley, 1996). The work of Alfred Schutz (1944) has played a key role in relating the concepts of phenomenology, particularly the work of Husserl, to the social sciences. In particular, the notion of the everyday life-world, which is the day to day inter-subjective and social world we inhabit and know, has

given substance to the study of everyday realities which interest social scientists (Schutz & Luckmann, 1973). Narrative description in anthropology is a central part of focusing on the life-world (Jackson, 1996).

For medical anthropologists, phenomenological approaches which take life-world and narrative as tools for understanding humans' experience of health and illness have been valued. Phenomenology's place within medical anthropology was solidified with Scheper-Hughes & Lock's (1987) proposition of the mindful body. In this seminal paper, they propose a 'three bodies framework' for medical anthropology: the individual body, the social body and the body politic. Individual body refers specifically to the phenomenological experience of the individual – their lived-experience of illness.

"The "three bodies" represent, then, not only three separate and overlapping units of analysis, but also three different theoretical approaches and epistemologies: phenomenology (individual body, the lived self), structuralism and symbolism (the social body), and poststructuralism (the body politic)." (p.8)

This approach places the body at the forefront of research. In *Phenomenology of Perception*, Merleau-Ponty (1958) contends that human beings experience and make sense of the world through their bodies, particularly their sensory systems. In this way the three bodies and Merleau-Ponty's *Phenomenology of Perception* are bridges to the emergent area of sensorial anthropology.

Sensorial Anthropology and its take-up in Medical Anthropology

Anthropologists, interested in the body in context, have taken a cross-cultural perspective in investigating how human beings sense their world, how sensations are expressed, described and lived and how these are intimately related to cultural beliefs, values and worldviews. In socio-cultural anthropology, the interest in senses and sensations falls under a number of labels including: anthropology of the senses (Classen, 1997; Howes, 2006), sensory anthropology (Pink & Howes, 2010; Ingold, 2011), sensory ethnography (Stoller, 1989; Pink, 2011) and sensory ecology (Shepard, 2004). Each author interprets the meaning of their respective terminologies in particular ways which has led to debate within the field (Pink & Howes, 2010; Ingold, 2011). My aim here is not to analyse the intricacies of this debate or even the ways in which these bodies of work differ but rather to focus on the way the turn towards

senses and sensations has been taken up in medical anthropology. Two main sources in this area include Nichter's (2008a) *Coming to our senses: Appreciating the sensorial in medical anthropology* and Hinton *et al.*'s (2008) article *Toward a medical anthropology of sensations: Definitions and research agenda*, both from the same issue of *Transcultural Psychiatry*.

Nichter (2008a) defines sensorial anthropology as the exploration of "...how sensations are experienced phenomenologically, interpreted culturally, and responded to socially" (p.166), a definition which fits closest to the approach I have taken albeit with a few additional points. Nichter's seminal article reviews six concepts he posits as central to a sensorial medical anthropology, including: embodiment, the mindful body, mimesis, local biology, somatic idioms of distress, and the 'work of culture'. Of the six, this thesis draws particularly on embodiment and the mindful body, which I have already discussed. A good example of the combination of ethnography, sensation, embodiment and narrative in the study of chronic illness is the work of Kierans (2001, 2005) on the experience of chronic kidney failure. For Kierans,

"The use of narrative situates the compromised body, enabling chronic renal illness to unfold and be understood as a continual alteration of experience and sensation, changing in a multitude of directions through time, involving a dynamic between reflections on the past and projections toward the future" (p.240)

As for Hinton *et al.* (2008), they call for combining insights from neurophysiology, phenomenology, anthropology and psychology for a medical anthropology of sensations. The most interesting and relevant part of their argument for this thesis concerns their conceptualisation of breathlessness as a polymodal sensation. Shortness of breath they say is polymodal because the following monomodal sensations are all involved:

"muscle-and-tendon-tension (*e.g.* in the respiratory muscles in the chest or neck), temperature (*e.g.* a hot day), skin-pressure (*e.g.* a feeling of the stomach not rising as one inhales), gastrointestinal-tract-distension (*e.g.* the abdomen being distended, preventing normal inhalation), and O₂ and CO₂ senses" (p.146).

Their thinking on metaphor, external stimuli, as well as Csordas' 'somatic modes of attention', proved particularly useful and relevant in Chapter 5 on the phenomenology of breathing and breathlessness. Their work confirms that breathlessness is first and foremost a sensation, and

one that is complex and worthy of study. A review and discussion of the literature on breath and breathlessness will be kept for Chapter 5.

Sensorial anthropology is about paying attention to the ways in which research participants sense the world, but it is also an approach to fieldwork which prioritises sensing and embodiment. For Ferzacca (2001), culture is very much embodied. He states:

“For cross-cultural conversations through sensoria about sense and sentiment a certain Universalist position seems inevitable- not that there are commonalities among senses and sentiments, but that these ethnographic sensoria are the basis of human life in the first place.”(p.8)

Similarly, Nichter (2008a) explains how he had to adopt a Brahmin diet in order to embody a Brahmin way of life. By adopting a Brahmin diet and learning how to pay attention to the sensations within the body and the way food plays in their balance and regulation. Sometimes, however, one cannot feasibly embody the sensations one is studying. In these cases, intersubjectivity and empathic witnessing of others’ sensation brings one as close as possible. Throop’s (2010) ethnography of pain amongst the Yap is one particular example. In expressing the emotions conjured by watching, he experienced a kind of embodiment-by-proxy which facilitated his relationship with a healer. His analysis of pain articulates how the expression of pain can serve as an indication of the virtuousness of the hard-working person who provides for family and community – consistent with the moral sensibilities of the Yap. Pain, therefore, became meaningful and valuable. Desjarlais (2003), in his ethnography *Sensory Biographies*, is interested in “...how members of a single society live out different sensory biographies” (p. 4) demonstrating that perception and sensory experience vary not only between societies but within them as well. In considering two biographies of elderly Yolmo Buddhists in Nepal conversing about life, death and dying, he guides the reader through an appreciation of how vision and hearing, respectively, take precedence in their ways of experiencing and expressing their lives.

Within Nichter’s (2008a) concept map for a sensorially engaged medical anthropology is also the notion of ‘embodied memories’, which is particularly relevant in the case of COPD. He contends that sensations can trigger embodied memories of past spaces and places and associated feelings such as fear, vulnerability, well-being and protection, just as embodied memories can trigger sensations in the body. Furthermore, practices and material things can

represent these intersections of memory and sensation. For example, embodied memories of colonisation can be relived and given meaning in the present through dance, possession and other embodied practices (Stoller, 1995; Stoller, 1997), just as embodied memories of place and landscapes can be remade and re-consumed through motifs embodied through embroidery and cooking (Dennis & Warin, 2007; Warin & Dennis, 2005). In chronic illness, the concept of embodied memories has been under-examined. Clearly some conditions, certainly the ones that blur the acute-chronic divide, are deeply shaped by embodied memories especially, as this thesis attests to, respiratory diseases which affect the very fundamental and taken-for granted process of breathing. Clarke's (2002) *Memories of Breathing* captures this notion of embodied memories, and their intersubjectivity, in describing in sensual terms how the signs, symptoms, and eventual attack of asthma was experienced between herself and her asthmatic daughter. What the literature relating to colonisation and immigration highlights, which can be brought to bear on the study of embodied memories of illness, is an appreciation for the way sensations experienced in intersubjective bodies are inextricably linked to wider structural realities.

The Political-Economy of Health Perspective as part of a Sensorial Approach

There have been a number of critiques of the phenomenological approach which can be extended to sensorial approaches. These critiques have been carefully discussed in the review by Desjarlais and Throop (2011). One critique is that phenomenological approaches focus too much on the individual and can ignore the larger structural and political factors at play. However, as stated by Desjarlais and Throop, many phenomenological approaches are combined with other approaches including political-economy. French's (1994) study of amputees on the Thai-Cambodian border and how they experienced their damaged bodies is a good example. She explains how she first approached the research with an orientation towards the psychological and cultural but was quickly faced with "...a set of responses that could not be understood without reference to the political, economic and historical context of the amputees..." (p.71).

The Three Bodies framework proposed by Scheper-Hughes and Lock (1987) urges the anthropologist to extend their focus from the individual body to the social and political body and vice versa. Furthermore, embodiment is not only about one's lived experience of the body but also "...one's experience of life mediated through the body as this is influenced by its

physical, psychological, social, political, economic and cultural environments" (Nichter, 2008a, p.164). However, it remains true that in practice merging phenomenology and political-economy can be challenging, especially within the same text. One of the aims of this thesis is to provide an example of how it can be done through multi-modal and multi-sited ethnography. Indeed, methodology has been highlighted as a means of achieving this and my thesis responds to the following call put out by Desjarlais and Throop (2011):

"What is most called for are careful, sophisticated phenomenological approaches in anthropology, realized through ethnographic field research methods, that attend at once to the tangible realities of people's lives and to the often interrelated social, biological, corporeal, sensorial, discursive, cultural, political, economic, psychological, and environmental dimensions of those realities" (p.97).

Knibbe and Versteeg (2008) daringly ask "Why not a critical phenomenology of power?" (p.61). Power in anthropology is captured in a variety of theoretical perspectives, the political-economy of health being one of them. Baer (1982), whose work precipitated the explosion of political-economic approaches in medical anthropology, defined the political-economy of health as "...in essence a critical endeavor which attempts to understand health-related issues within the context of the class and imperialist relations inherent in the capitalist world-system" (p.1). Over time the political-economy of health perspective in anthropology became known as Critical Medical Anthropology (CMA) (Singer, 1989) - a historical process described by Baer *et al.* (2003). A plethora of critical approaches, engaging with the notion of power, emerged including Political Economic Medical Anthropology (PEMA) (Morsy, 1996), Critically Applied Medical Anthropology (Scheper-Hughes, 1990), Critical-Interpretive Medical Anthropology (Lock & Scheper-Hughes, 1996) and the Critical Anthropology of Global Health (Pfeiffer & Nichter, 2008). A range of analytical concepts are drawn upon by anthropologists to think through and articulate the political-economy of health and particularly issues relating to structural violence (Bourgois *et al.*, 2004; Farmer, 2004), the body-politic (Lock & Scheper-Hughes, 1996), biopower and governmentality (Burchell *et al.*, 1991; Foucault, 1973), and biopolitics (Agamben, 1998; Rose, 2007).

Another related approach is that of social determinants of health taken by Burbank (2011), for example, in her ethnography of stress in an aboriginal community in Australia. A social determinants of health perspective would be a suitable way to study the patterns of

COPD incidence or smoking at a more general level (Janes & Corbett, 2009) but in my fieldwork what I was seeing and participating in was what was occurring to people who had been diagnosed. Estroff (1993), who writes of chronicity, considers the question "...who does not get well, and why, and what happens to and about them..." (p.11) as equally important to questions about why people get ill in the first place. To answer this question, I found a political-economy of health perspective suitable because my participants, based on their social and economic class, had access to varying forms of healthcare which shaped the experience of their illness.

I would argue that structural violence, body-politic, social determinants of health and the other frameworks mentioned above share a commitment to approaching the study of health and illness with special and *critical* attention paid to the political-economy of health. These approaches are intimately connected and overlap in their perspectives and the authors who contribute under their name. All draw attention to the ways in which what happens on the ground, in families, households, communities and healthcare systems is shaped by and shapes the more macro structures in which they are situated – governments, nations, the global economy – in addition to cultural and social factors. Or, as Singer and Baer (1995) put it,

"...paying close attention to what has been called the "vertical links" that connect the social group of interest to the larger regional, national, and global human society and to the configuration of social relationships that contribute to the patterning of human behaviour, belief, attitude, and emotion" (p. 33).

In terms of the role of the anthropologist, critically applied medical anthropology, as obvious from its name, foregrounds the imperative anthropologists have to 'do' something with their research *i.e.* not just understand problems but advocate for those they study. However, critically applied medical anthropology also insists on a "...radical calling into question of the materialist premises of biomedicine..." (Scheper-Hughes, 1990, p.191). The critical anthropology of global health is still interested in critically considering biomedical and public health goals but is also very concerned with understanding, critiquing, commenting on and advocating for change in medical practice and the global-level processes, which shape the unequal access to biomedical care for suffering and disease around the world (Janes & Corbett, 2009; Nichter, 2008b; Parker & Harper, 2006; Pfeiffer & Nichter, 2008; Whiteford & Manderson, 2000). I share this perspective. Four contributions this perspective can make

according to Janes and Corbett (2009) are: 1) ethnographic studies of health inequalities in diverse political and economic contexts (directly related to CMA). 2) impact of health technologies on local contexts globally; 3) critically interrogate international health policy and programs and 4) evaluate the health impact of changes to social relations brought about by health development. Similarly Pfeiffer and Nichter (2008), in their article state that one contribution of medical anthropology is to “...provide insights into the impact of poverty and economic insecurity on patterns of social support and mutual assistance...” (p.413). In relation to Janes and Corbett’s (2009) third point on health policy and programs, Whiteford and Manderson’s (2000) edited volume *Global Health Policy, Local Realities: The Fallacy of the Level Playing Field*, remains a seminal collection in this area. The contributing authors provide an anthropological perspective on the globalisation and commoditisation of health and healthcare, arguing that there are no global answers or simple solutions for health inequality. The political-economy of health must be understood in each context, as well as the cultural and ethnic backgrounds which shape and are shaped by national and global processes.

For instance, Becker’s (2004) research on the uninsured chronically ill in the United States critiques the healthcare safety net purportedly in place to serve the uninsured community. Evidence from her respondents reveals that it is profoundly inadequate for people suffering from chronic conditions. An important barrier to care was cost, and the hit-and-miss nature of the healthcare system’s provisions. For example, if money was an issue for consulting and filling prescriptions, people might try to get care through the emergency system and hope to be written long-term prescriptions. Continuity of care and follow-up care, important elements of chronic disease management, were not supported in this system. Similarly, Janes’ (2003) research in Mongolia criticises the World Bank for prioritising funding for primary care because chronic conditions are inadequately provided for within such programs. Chronic conditions, unlike more acute and easily treatable health problems, require specialised care, long-term follow-up, long term and stable access to treatments and therefore care needs to be affordable and well coordinated to avoid confusion on the part of the patients. The volume *Anthropology and Public Health: Bridging Differences in Culture and Society* (Hahn & Inhorn, 2009), now in its second edition, is also a testament to anthropology’s role and contribution to studying and helping to address health inequalities resulting from local and global systems of power.

Making a Political-Economy Perspective part of Sensorial Medical Anthropology in Practice

So far, I have situated my thesis in the growing anthropological literature on chronic illness. I have reviewed common approaches such as explanatory models and narrative, which are drawn upon in this thesis. However, the theoretical framework underpinning the fieldwork, methodology and writing of this thesis is sensorial medical anthropology. I mentioned already how Merleau-Ponty's (1958) theories of perception and Scheper-Hughes and Lock (1987) individual body act as bridges between phenomenology, sensorial anthropology and sensorial medical anthropology. My approach to the study of COPD in Uruguay is situated within a particular interpretation of the three bodies, particularly in relation to embodiment. The notion of embodiment has shaped my conceptualisation of the three bodies as embodied within the individual. Csordas (1990), by drawing on two theories of embodiment, one of the problematic of perception (Merleau-Ponty, 1958) and the other habitus (Bourdieu, 1977, 1984), proposes embodiment as a paradigm for anthropology on the basis that the "...the body is the existential ground of culture" (Csordas, 1990, p.39). I would add that the body is the existential ground of politics and economics as well, which shape and are shaped by culture. Therefore, while the social body and the body politic can be studied in their own right as distinct topics of inquiry and often distinct 'sites', the individual can also be imagined as a balance of these three bodies, a balance which shifts from one to the other at any given time depending on circumstance.

Csordas (1993) highlights how the three bodies can be approached through the semiotic/textual lens of 'body as representation' or they can be approached from a more phenomenological 'being in the world', which focuses on the embodiment of practice, performance and enactment. My approach is consistent with the latter. The enactment of the body politic, for me, is epitomised by the example of a patient anxiously waiting at a hospital director's office in a busy public hospital to ask for much needed medication not normally covered by the healthcare provider, which claims that the global pharmaceuticals simply charge too much for such medication, especially for a small country with low purchasing power. The sensation of increased breathlessness in that situation of stress reflects not only an individual phenomenological body but also a body politic experienced phenomenologically. In this example, although the body politic is indeed the collective body that is controlled by State policy and regulation, it is also the individual body that is shaped by those policies, regulations and lack thereof. The structural violence is not only experienced, it is felt in the individual body and indeed in the social body too.

I interpret the social body to refer to how the ill person is not only an ill body but a person in a web of social relationships; relationships which shape and are shaped by illness. The role of the family and social network in living with illness and the ways in which social conventions, expectations and norms influence the way illness is experienced in the phenomenological body is what to me makes up the social body. For example, when a person with COPD laments the humid weather alongside a person without COPD because both share this social convention, as well as health beliefs regarding the detriment of humidity, what is being enacted is the social body. When a family member is anguished at the sight of their loved-one's breathlessness, it is their social body *feeling* another's suffering as well as one's own. Suffering, should not be assumed to be an inextricable part of illness or disease, it is subjective and personal (Cassell, 1991). However, struggling for breath at that point where each breath feels like the last, was almost always a sensation which caused great suffering among my participants as will be seen. If in those moments one is not alone, then there is the enactment of social bodies. Everyone has a social body, and the family member or friend of a person with COPD also experiences the illness and sensations of breathlessness sensorially because "...the sensorial is not just experienced individually, but 'dividually'" (Nichter, 2008, p.166).

I propose that the social and the political are embodied in the individual and a phenomenological and sensorial approach can help uncover them. Methodologically, this theoretical stance is mirrored in the principle of studying-up, *i.e.* starting research at the community level with individuals and through witnessing their daily lives and struggles within their life-worlds, investigating the social relations, economic factors and policies at the national and even the global level, which directly or indirectly shape those experiences. In studying the body politic I draw upon the principles of a political-economy of health perspective. Scheper-Hughes and Lock (1987) purported that in terms of theoretical approach, the individual body implies phenomenology, the social body structuralism and symbolism, and the body politic, post-structuralism. However, I argue that a sensorial (phenomenological) approach is not solely the way to investigate and understand the individual body but a way of seeing and analysing the social body and the body politic too. In keeping with a call for more creative and sophisticated approaches to phenomenological research in anthropology (Desjarlais & Throop, 2011), the next chapter will describe how I went about taking a critical sensorial approach in order to make an original contribution to the anthropology of chronic illness. However, now

that I have described the theoretical approach underlining this thesis' contribution to the anthropological literature on chronic illness, I turn now to the topic at hand, COPD. Although this ethnography is the first in the anthropological literature on COPD, it is not the first qualitative study to be undertaken on its experience.

THE EXPERIENCE OF COPD

COPD is a good example of the kind of ambiguous, multi-faceted chronic illness Manderson and Smith-Morris (2010) refer to in their critique of the acute/curable – chronic/life-long dichotomy. In terms of the medically measurable impairment to the lungs, COPD is characterised as irreversible, progressive and degenerative, hence incurable. However, as this thesis will demonstrate, COPD is probably rarely *experienced* as a static, unchanging diagnosis of life-long affliction. In this way, this thesis adds the case study of COPD, an increasingly global health epidemic, to this body of research.

When the notion of experience from a subjective perspective is translated to a medical vocabulary its investigation tends to be reduced to the use of validated quality of life Likert-scale questionnaires. However, allied health professionals in particular have criticised these quantitative tools and approaches for not taking the person's interpretations, experiences and priorities into account and for failing to recognise how these can vary person to person and place to place (Guthrie *et al.*, 2001; Leidy & Haase, 1996; Monninkhof *et al.*, 2004; Nicholls, 2003; Williams *et al.*, 2007). For example, Guthrie *et al.*, (2001) discuss how health-related measurement tools can fail to represent experience because they do not situate psychological states in their social, biographical and interpersonal context and they do not recognise that even in cases of life-threatening disease other issues, such as family relationships, may be more important to patients.

Quantitative approaches have also been challenged by those demonstrating that qualitative approaches can lead to very different findings. For example, Monninkhof *et al.* (2004) found that health-related quality of life scores showed no change after participation in an education program, whereas their qualitative interviews found important improvements from the patient's perspective. Similarly, Williams *et al.* (2007) were surprised by their quantitative findings in their study of the quality of life of people living at home with end-stage (very advanced, almost terminal) COPD and undertook a qualitative follow-up interview to help interpret their quantitative results. Their quantitative data suggested that despite patients

experiencing numerous limitations in their daily lives, they did not ask for help which could be interpreted as proof that patients suffered in silence. Interestingly, a theme which emerged from the interviews was that many participants did not consider themselves ill with COPD, except for when they were hospitalised and, therefore, it did not occur to them to ask for help outside of crisis episodes. Understanding their interpretations of the illness, therefore, made their actions understandable. This brief section has highlighted how qualitative approaches offer more thorough ways of studying illness experience. I now turn to reviewing the qualitative literature on COPD.

Multidisciplinary Qualitative Contributions to Understanding the Experience of COPD

Using a combination of Medline, Web of Knowledge, Google Scholar and bibliography-research I retrieved and assessed 47 original research articles about COPD published within the past ten years in addition to a few older but frequently cited papers. I used a combination of the following search-terms 'qualitative', 'chronic obstructive pulmonary disease' and 'experience'. Experience could refer to patients', family members' or healthcare workers' experiences. Appendix A includes a table listing the publications, their topics, journals, participants, countries, theoretical frameworks and methods. Before reviewing what it is this research can tell us about the experience of COPD, it is worth briefly highlighting a few distinctive features of this body of literature.

Firstly, all research projects but two were carried out in high income countries and the remaining two were upper, middle income countries (China and Brazil) according to the World Bank classification (World Bank, 2012). Furthermore, China and Brazil were the only non-Western countries where the research had been carried-out. Otherwise, what we know about the experience of COPD comes predominantly from Canada, the USA, the UK, New Zealand, Australia, Denmark, the Netherlands, Iceland and Ireland, demonstrating the lack of studies of COPD in low and middle-income countries where it is making its most significant impact (WHO, 2011). According to the WHO (2011), over 90% of COPD deaths occur in the developing world. Although a country's 'development' and their economic classification do not correlate perfectly, generally low and middle income countries tend to be considered developing countries (World Bank, 2012).

Of the 42 articles which specified the severity of participants' disease, almost all participants were ill with or said to have 'moderate', 'severe', 'advanced' or 'end-stage'

disease. This confirms that the full spectrum of COPD and its associated experiences are not represented in the current literature. This probably has to do with the fact that many people are diagnosed only in later stages of the disease, and if one is recruiting from outpatient clinics, inpatient wards, or pulmonary rehabilitation, one is more likely to encounter symptomatic patients with more advanced disease. Very few studies included more than one group of participants, *i.e.* very few looked simultaneously at the views of patients, family and health professionals, and the vast majority relied entirely on interviews for exploring their topics. Only two included participant-observation.

Analytically and theoretically, we can see that phenomenology², narrative, grounded theory and thematic analyses have been considered useful frameworks for guiding the methods and analysis of the qualitative research in this area. Lastly, all the articles were published in the fields of nursing, medicine, physiotherapy, public health and counselling. Only one study, published in a public health journal, identified itself as anthropological in its approach and employed participant-observation in pulmonary rehabilitation services and ethnographic interviews to analyse illness experiences of the urban poor in Brazil (de Sousa Pinto *et al.*, 2008) and the effect on family members (de Sousa Pinto & Nations, 2012). Families' and professionals' views have also been studied as can be seen in Appendix A but to a lesser extent. I turn now to drawing out a few emergent themes regarding the experience of COPD. It is important to keep in mind that this purports to moderate and severe COPD.

The Literature as a-Contextual

The most notable feature of the qualitative literature on the experience of COPD is its a-contextual style. It is not common in medical and nursing journals to make something of the 'place' in which the research was carried out. Often the reader is not directly told in which country the research was carried out. Despite wide-ranging accounts from Australia to Iceland, we know little about if and how particular socio-cultural and political-economic aspects of the community, region or country interacted with the experience of the disease. There is some appreciation of the ways in which the family or the institution impacts upon the experience of

² Phenomenology as it is defined and used in the health sciences tends to be quite different from anthropology. Often in the nursing and health science literature, phenomenology is simply used as a synonym or a proxy for experience. Some studies provide slightly more in-depth analyses, however otherwise the difference between narrative, phenomenology or just simply qualitative is almost undetectable in the nursing literature in the way the topic of study is approached and how the research is written.

illness. For instance, Crawford (2010) provides information about the healthcare context in which health professionals are having end-of-life conversations with COPD patients in England. Castro's (2008) research about continuity of care for COPD patients in a hospital in Spain identifies coordination issues between primary care, emergency care and in-patients, which led to COPD patients experiencing long-waits, longer times in-between follow-up, and generally more difficulty accessing care. Poor coordination also led to unnecessary duplication of clinical tests and referrals.

Other studies have identified but not elaborated on references made to the healthcare context within which participants' narratives are situated. For instance, long waiting-lists for living-aids, such as nebulizers, amongst a population in Northern Ireland led to them having to purchase their own (Hasson *et al.*, 2008). In O'Neill's (2002) interviews with women in the USA the issue of cost of medication and the cost of oxygen arose in patients' narratives. High cost led some participants to stop taking their medications or stop being able to exercise at home because oxygen was needed but could not be purchased. The financial burden of medications, oxygen and oxygen equipment was also reported amongst people with COPD in Canada, where, despite having a socialised healthcare system, patients are expected to contribute to the cost of their treatment (Wilson *et al.*, 2008). de Sousa Pinto *et al.* (2008, 2012) are the only group to discuss context at length, providing insight into how being a marginalised person from a poor urban area of Brazil affects one's experience of COPD as patient or carer. For example, sufferers of COPD whose professions involved physical strength, such as mechanics and construction workers, became unable to carry out their work and in turn unable to economically sustain their families, pointing to the way in which COPD amongst the working class can strip them of their ability to earn a living.

In terms of social and cultural context and in addition to de Sousa Pinto *et al.* (2008), the two papers published about experiences of people with COPD in Taiwan discuss their participants' narratives in relation to wider cultural practices and beliefs. References made in the narratives to 'following the doctor's orders' and practising a form of meditational exercise in local parks, were discussed in relation to the norms of doctor-patient relations in Taiwan and beliefs in traditional medicines and exercises (Chen *et al.*, 2008; Jeng *et al.*, 2002). It is as though because the research has predominantly been carried out in high income Western countries, where the journals themselves are based, only research carried out in non-Western

countries has been analysed more in terms of local beliefs and practices. Opportunities to take a similar approach to illness narratives of people with COPD in developed Western nations have so far been missed.

Experience of COPD as Physical and Emotional

The most common symptom experienced by people with COPD is breathlessness. However, cough, fatigue, frequent chest infections, weight loss, difficulty sleeping and pain are also commonly associated with COPD. Pain, in particular has been an under-recognised part of living with COPD (Lohne *et al.*, 2010). Lohne *et al.* (2010) interviewed 16 people with COPD who experienced pain, in order to understand better these experiences. Pain in the arms, neck, back or hips, which sometimes travelled through the body, was described. The pain could be excruciating and was strongly linked with breathlessness although the authors express the need for more research to understand the nature of this relationship.

Research focusing on illness narratives has highlighted the links between physical symptoms and emotional symptoms that are frequently made from the patient-perspective. Emotions oscillate with the physical experience, and so at any given time people with COPD can feel depressed, anxious, sad, meaningless, fearful, angry, irritable and frustrated (Bailey, 2004; Barnett, 2005; Ek *et al.*, 2011a; Gullick & Stainton, 2008; Habraken *et al.*, 2008; Hasson *et al.*, 2008; Jeng *et al.*, 2002; Robinson, 2005; Seamark *et al.*, 2004). McMillan Boyles *et al.*'s (2011) study claims to be one of the first studies to investigate COPD as a disability. Their 15 participants in Canada highlight how they are caught between wanting to conceal their disability but also wanting others to understand and recognise it. Physical markers of disability, such as oxygen machines, are what make disability 'visible' to others and depending on the situation this can be welcomed or can cause feelings of embarrassment about the visibility of the equipment (Williams *et al.*, 2007).

Disability in the case of COPD takes the form of being very limited in one's ability to walk, dress oneself, do any physical work around the house, and, in advanced cases, simply eat a meal (Odenrants *et al.*, 2005). Personal care, such as showering and going to the toilet, becomes difficult without assistance (Barnett, 2005; Gullick & Stainton, 2008; Hasson *et al.*, 2008; Lomborg & Kirkevold, 2008; Robinson, 2005). Becoming homebound by any disabling disease is likely to lead to social isolation and feelings of worthlessness and sadness (Ek & Ternestedt, 2008; Williams *et al.*, 2007). For spouses caring for persons with advanced COPD,

knowing that the loved ones' state could change quickly and dramatically, led to a difficult situation of constant uncertainty (Ek *et al.*, 2011b). Another way of conceptualising the link between emotions and breathlessness is the dyspnoea-anxiety-dyspnoea cycle described by Bailey (2004). Her participants' narratives illustrated how dyspnoea can cause anxiety, which causes more dyspnoea which leads to more anxiety. She found that family members saw their loved ones' "emotional vulnerability" (p.764) as part of the disease. Anxiety is a common theme in the literature, especially in relation to acute episodes of breathlessness.

Acute Exacerbations: Breathlessness and Dying

A distinction is clearly made, from the patient-perspective, between everyday forms of breathlessness and acute breathlessness, referred to as an exacerbation in medical terminology (DeVito, 1990). An acute exacerbation of breathlessness can begin suddenly and for no apparent reason (O'Neill, 2002), or commonly, because of a cold or flu (Jeng *et al.*, 2002). A number of studies have shown that for sufferers, extreme breathlessness equates to dying or feeling like death is imminent (Bailey, 2001; Ek *et al.*, 2011b; Yu *et al.*, 2007). To feel extremely breathless can feel like one is being choked or suffocated (Barnett, 2005). The study by Ek *et al.* (2011b) of the experience of four people in Sweden living with advanced COPD found that living alone was valued by their participants who strove for independent-living, however, they also feared being alone when an acute exacerbation occurred and dying alone.

Environment and Breathing Highlighted but left Unexamined

Unlike the experience of acute exacerbation, or illness experience in general, the significance of environmental factors affecting people with COPD has received surprisingly little attention. Recently however, a fascinating study by Williams *et al.* (2011) carried out in South-East England, reported on how people with COPD in their study interpreted the air around them as either stagnant or in movement and that this affected the interpretation of their symptoms. The importance of fresh air for people with COPD is under-recognised, they argue. Stagnant, indoor air made sufferers feel worse and fresh air, represented as moving, lessened their experience of physical limitation. Their work is particularly relevant to Chapter 5 on the phenomenology of breathing, where I provide evidence indicating the importance of variously understood definitions of 'air', in the illness experience of COPD. Despite Williams *et al.*'s (2011) study being one of the first, if not the first of its kind in the qualitative literature, many

articles make brief references to environmental factors which are important to people with COPD such as smoke, dust steam and weather, although they do not make them the object of study in their own right (Barnett, 2005; Chen *et al.*, 2008; Gullick & Stainton, 2008; Jeng *et al.*, 2002; Nicholls, 2003; O'Neill, 2002; Small & Lamb, 1999) . These are discussed in greater detail in Chapter 5.

Interpretations and Experiences of Smoking and COPD

As the leading risk-factor and cause of COPD, smoking has been investigated by COPD researchers using qualitative methods. There is variation in the area of people's understanding of the link between smoking and COPD. Barnett (2005) unambiguously found that most of her ten participants saw smoking as a cause of their COPD. However, Hansen *et al.*'s (2007) 19 participants in Australia were more sceptical of the link between smoking and COPD and only four explicitly stated that cigarettes were the cause of their breathing problems. Nicholls' (2003) participants were also sceptical about the link between smoking and COPD, especially based on their experience of knowing more intense smokers who were better-off than they were. Similarly, Schofield *et al.* (2007) found that 13 of their 22 participants continued to smoke and their narratives were inconsistent in their perspectives on the link between smoking and their health status. Rather, people with COPD frequently had multi-causal explanatory models of their COPD-causation including occupational fumes or pollution, increasing age and family history (Barnett, 2005; Hansen *et al.*, 2007; Schofield *et al.*, 2007). In one case, smoking was considered something that irritated one's COPD (Schofield *et al.*, 2007). In that same study, elderly participants with COPD reported more benefits of smoking than benefits of quitting, explaining that smoking helps when feeling upset, improves breathing, facilitates expectoration (coughing up phlegm) and that it could be harmful to quit if your body is used to it. Motivation to attempt to quit smoking came from health scares, being diagnosed with COPD, wanting to see grandchildren grow up and feeling that it was morally wrong to keep smoking while the health service paid for care (Robinson, 2005; Schofield *et al.*, 2007).

CONCLUSION

In this chapter I have reviewed the anthropological literature concerning chronic illness. It is to this body of literature which I contribute this ethnographic study of COPD in Uruguay. I reviewed some of the primary approaches to studying chronic illness and provided the

necessary background to justify my own approach: a sensorial medical anthropological approach which incorporates a political economy of health perspective. Within the anthropological literature this ethnography is a novel contribution because of its topic, the location of the research and the theoretical and methodological approach. As a contribution to the growing body of qualitative literature on COPD, this thesis fills a gap in rich, ethnographic accounts of the experience of COPD that are contextualised in cultural, political and historical terms and carried out in non-Western countries where COPD is expected to make its greatest impact. In the next chapter, I describe the process of fieldwork, the multiple sites of inquiry and the various methods incorporated into my ethnographic approach.

Methodology

INTRODUCTION

This ethnography is based on three years of engagement with Uruguay, thirteen months of which were spent in the field, what Watson (1999) refers to as the period,

“...of intensive, close engagement of a limited duration, in which through the employment of various techniques and strategies, of which ‘immersion’ is the most well-known, the anthropologist is able to engage in different styles of learning and understanding, acquiring discursive and practical knowledge, being simultaneously ‘in’ but not ‘of’ the other culture” (Watson, 1999, p. 2).

In this section I want to convey my methodology, however without restricting it to this period. Many decisions are made about fieldwork long before the ethnographer enters the period of heightened intensity (Watson, 1999) and here I try to trace how I began to find ways of carrying out fieldwork in Uruguay. I will discuss how the field sites were chosen and how the project began to take shape during a pilot-fieldtrip in 2009, before moving into discussing the primary fieldwork period during which I focused on people with COPD, their families and their healthcare professionals, on the field of smoking cessation and on healthcare and health policy. As is made obvious, I did not enter the field without direction, my training in social and medical anthropology and my chosen topic shaped the ‘sites’ within the field I would most frequently experience.

The focus will be on how I went about choosing and gaining access to institutions and how I met my participants and finally provide a reflective evaluation of the multimodal approach I took to ethnographic fieldwork. Sanjek (1990a), in his book *Fieldnotes: The Makings of Anthropology* defines three pillars of ethnographic validity: theoretical underpinnings, the ethnographer’s path, and the field note evidence. The rest of this chapter will focus on the second of these - the ethnographer’s path.

PILOT FIELDWORK TRIP: DECEMBER 2009

Retracing the Branches of the Ethnographic Tree

I landed at Carrasco International Airport in Montevideo on December 6th 2009 for a two week fieldwork trip. The purpose of the trip was to get a feel for the country and begin making some contacts in the health sector in order to smooth access to healthcare institutions. I knew by then that Uruguay had a mixed public-private healthcare system and I wanted to meet a wide variety of people with chronic obstructive pulmonary disease in terms of both socio-economic status and healthcare coverage. My initial impression of Montevideo was overwhelmingly positive. In the car, my conversational Spanish limited me from making complex chat with the driver, but instead I looked around eagerly at the houses, the roads, the palm trees, and of course the *Rio de la Plata* (The River Plate) and the *Rambla* (the boardwalk that runs along 20 km of the coast). I was captivated by the sight of it from the airplane let alone my initial meanderings through the city centre which works its way from the peninsula of the Port and *Ciudad Vieja* (Old City) outwards and northwards. The city centre feels distinctly European with the colonial architecture, the pizza shops, cafés, bookstores, theatres, and shady squares along the main road *18 de Julio* (18th of July) (Figure 3.1).



Figure 3.1: Plaza del Entrevero on 18 de Julio street, Montevideo City Centre. Photo by the author.

I remember thinking “it is so green”. So many streets in the city centre were lined with trees creating a comfortable shade for the many pedestrians out doing their Christmas shopping. The consumer-madness of *18 de Julio* immediately gave me the impression that people seemed to be doing well economically and that the capitalist neoliberalism discussed by Renfrew (2007) and Alvarez Pedrosian (2009b) in their respective ethnographies was, like the trees, in full bloom. Over time of course, I developed a much more nuanced perspective on the economic growth the country has been experiencing since the mid-2000s, particular since the financial crisis of 2002.

My fieldwork trip dates were both good and bad timing. As it was leading up to Christmas and the summer holidays for Uruguayans, everyone was busy with work and with parties and this made securing meetings a bit difficult. On the good side, those I would meet were cheerful and keen to show me around in the great weather. Through one particular family, I will describe in the next section, I discovered the streets, markets, and Candombe (drumming processions) of Montevideo. I discovered through them that in Uruguay birthday parties have open-invitations so that if you tag along to someone’s birthday you are unhesitatingly welcomed with some finger-foods –*picadas*- and a glass of whisky. Here everybody knows everybody and if you know somebody, anybody, you are on your way to meeting all kinds of people.

I went with plans to meet five people (or groups) in particular, people whose names I had acquired throughout my first year in the UK. My ethnographic journey began in an important way with four of these five contacts. These had been mediated through a third person and these four turned out to be positive encounters which opened doors for carrying out my research. I will turn to describing these and how the one that was unsuccessful may have been so because of not having been mediated through a third person. I have visualised these initial contacts in Figure 3.2. Each starting point is numbered and I will describe them each in order.

(1) The first line of contact, and ethnographically, probably the most important, was a Montevideo family. I was first put into contact with Fernanda, via an Argentinean student at Durham University who I met at an evening anthropology barbecue. He told me he had many wonderful friends in Montevideo and copied me into an email introducing me to them and

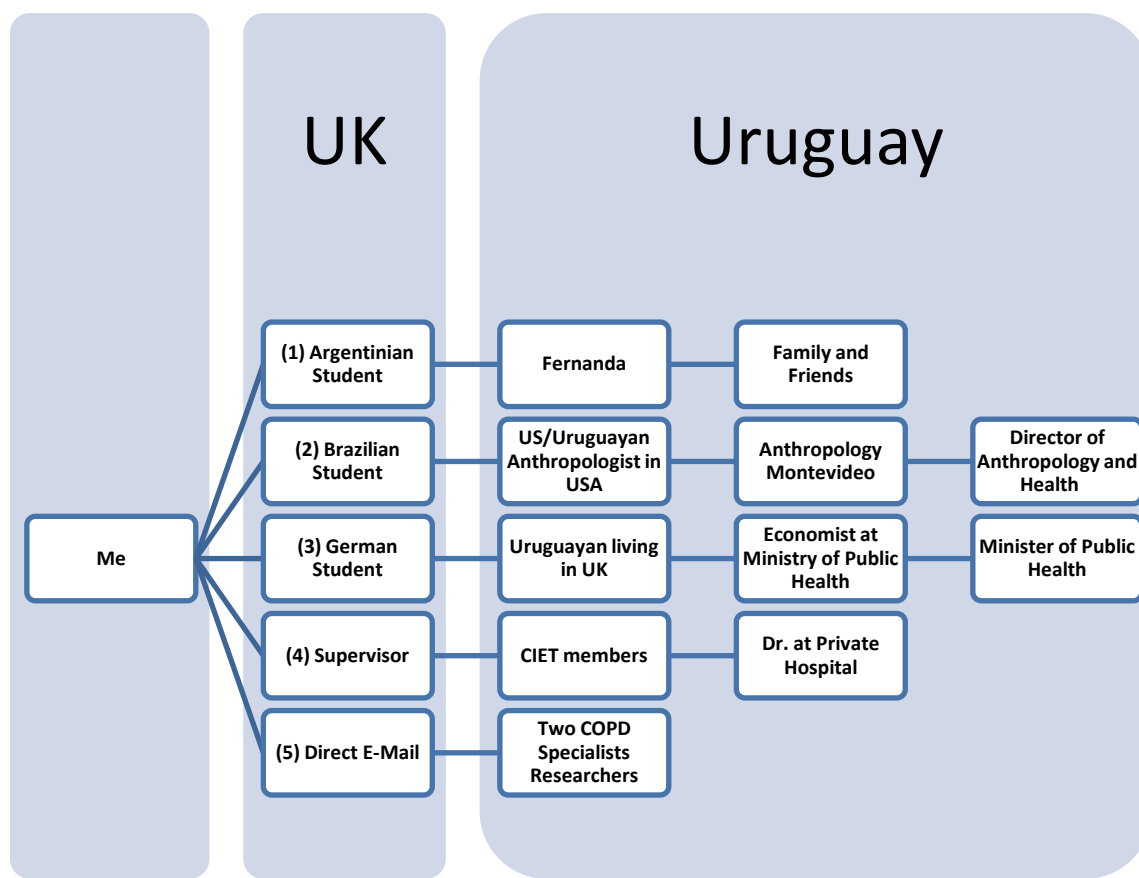


Figure 3.2 Initial contacts in Uruguay made in the UK

asking if anyone would be willing to show me around. Fernanda responded and after back and forth email exchange she not only agreed to show me around but also arranged for her father and husband to pick me up from the airport. From this point forward, Fernanda, her husband and her family became my best friends and surrogate-family in Uruguay.

(2) The second line of contacts made for the pilot-fieldwork trip began with meeting a visiting student from Brazil at Durham University. She recommended I get in touch with Professor Renfrew of West Virginia University, a Uruguayan-American anthropologist, who, as already mentioned has done work on the lead poisoning crisis in Montevideo (Renfrew, 2007, 2009, 2011). He gave me the names and contact details of various anthropologists including Eduardo Alvarez Pedrosian (whose work I make reference to in this thesis), Javier Taks and Sonnia Romero, the director of the Anthropology and Health research group at the *Universidad de la Republica*, whom I all met during the trip. Professor Romero offered me any institutional support I might need during my fieldwork and membership in her research group. Although I

had little to do with the group over the course of fieldwork, at the end of my time in Uruguay I organised a seminar in Tacuarembó on the contribution of anthropological perspectives and research to the study of health and illness in which the research group participated (Wainwright, 2012).

(3) Early in the 2009 academic year in the UK while having lunch in Van Mildert College, I mentioned my plans for Uruguay to a German student and teacher at the University. Surprisingly, he had done his masters at Durham with a Uruguayan woman who was living permanently in the North-East of England with her family. He put us in touch and soon enough Maria became my Uruguayan-Spanish tutor in preparation for my December trip. She also put me in touch with a friend of her husband, an economist in Uruguay who worked for the Minister of Public Health particularly on the health care reform. We communicated back and forth about the reform via email and met in person in December. He offered to get me an interview with Sr. Olesker who was to take up the post of Minister of Public Health in March 2010. The following week I was sat in Olesker's office and as we conversed informally he sipped mate and pledged his support for facilitating access to healthcare institutions and ministry officials if I so needed. He also provided me with Ministry publications and reports on the healthcare reform.

(4) My fourth line of contacts was the tobacco research and interest group *Centro de Investigacion sobre la Epidemia del Tabaco* (CIET) in Montevideo. One of my supervisors, Andrew Russell, met representatives from CIET at the conference 'Tobacco or Health' in Mumbai in 2009 and acquired their contact details for me. They were enthusiastic in their emails and even more so when we met in person. I met one member, a doctor, at a private hospital for a meeting. He was the first to suggest that Tacuarembó could be an interesting contrasting fieldsite to Montevideo. He also arranged for me to meet a respirologist at the private institution. The respirologist was enthusiastic about my research and guaranteed that it would be perfectly feasible for me to carry out part of the study at the hospital and from within his outpatient respiratory service. This at least guaranteed me a site which fell into the most elite private healthcare coverage in the country.

(5) Every contact mentioned so far had been mediated through a third person. The fifth contact, with which I scheduled a meeting during my pilot trip, was the exception. I contacted two Uruguayan doctors and researchers through the contact details provided in some of their co-authored publications on the epidemiology of COPD. They agreed to a meeting but the meeting was tense, negative and dismissive. I got the impression from the researcher in charge that she had very little interest in the approach I was taking to her topic of study, knew little if nothing about qualitative research and had negative things to say about the feasibility of carrying out the project at all. I left feeling bewildered and disappointed that the authority on COPD in the country was unsupportive whereas everyone else was. Her dismissiveness turned into outright 'blocking' when I returned to Uruguay for fieldwork. She happened to be the head of one of the public hospitals and home of the department of respirology and was the director of the respirology unit in one of the largest private mutual hospitals with some of the most developed services for COPD, and denied my multiple attempts to gain access. I can only hypothesize that, even though her attitude may not have been any different, it would have been better to have waited to be in the country and be introduced to her through a third person. This would inevitably have occurred considering the "everybody knows everybody" nature of Uruguay, which is an appropriate way of fostering a climate of trust.

Despite this one false-lead, I considered the trip a success: I had secured support from the Ministry of Public Health to facilitate my entry to research sites and access to policy-makers; I had the support of CIET, a non-governmental organization (NGO) highly involved in research and political lobbying; I had at least one hospital to start with upon my return; I had anthropologists I could interchange with and I met some very kind families. I went back to England and began designing my methodology and continuing with my background research in preparation for September 2010, when I returned to Uruguay for twelve and a half months. Understanding descriptively how these initial contacts were made is important for contextualizing the ethnographic web of relationships that flourished thereafter and to which I now turn.

FIELDWORK: SEPTEMBER 2ND 2010-SEPTEMBER 17TH 2011

Before leaving for fieldwork I spent 10 days in a respiratory unit at the University Hospital of North Tees in the UK in order to gain greater understanding of the clinical bases of COPD care. This was very useful for improving my knowledge of medical vocabulary, recognizing diagnostic

equipment and getting a sense of the biomedical understanding of COPD. This supplemented my previous research experience with COPD at McGill University which had included participant-observation at nurse-training in COPD, recruitment from inpatient wards, and interviews with three women with COPD (Arnaert & Wainwright, 2008).

Multi-sited Ethnography

By the time I returned to Uruguay to begin fieldwork I was committed to the idea of carrying out research in two cities, one being Montevideo and the other from one of the 18 other departments (counties). Uruguay is a highly centralised country. Government offices, major banks and specialised healthcare, are all concentrated in the capital and unfortunately much of the research too. I had no firm plans for the thesis to be a comparison of the two sites explicitly, and neither did that become the case when it came to writing the thesis. The idea rather was to broaden the scope of my understanding of how COPD is 'lived' in the country, and knowing that the capital and the 'interior' differ on so many levels, it seemed methodologically sound to not neglect the 'other' Uruguay where half the population reside. I chose Tacuarembó after visiting it in January because it seemed like a good example of an interior town at a significant distance (400km) from Montevideo and was the centre of *Gaucha* culture exemplified in its annual *Fiesta de la Patria Gaucha* (Chapter 4). Other differences included that Tacuarembó's local government was the *Partido Blanco* and Montevideo's the *Frente Amplio* and that the economy of Tacuarembó was based around the meat, rice, and forestry industries, whereas Montevideo's was around the service sectors and banking. Other more general contrasts will be discussed in Chapter 4.

Living in a variety of households helped me experience, with all my sensory abilities, the difference between the capital and the interior. In Montevideo I lived in *La Ciudad Vieja* with a young couple, in *Cordon* with Fernanda and her husband, and in *El Barrio Ruiz* with two women in their thirties who shared the house which once belonged to one of their grandmothers. All these neighbourhoods were commonly referred to as *feo* or *medio feo* (translated as ugly but meaning dodgy or dangerous). I was advised not to walk alone at night (at least not farther than the block from the bus stop), so I generally did not. If it was after 9 or 10 pm I usually paid for taxis. In fact, transportation ended up being one of my primary expenses, taking multiple buses per day, the occasional taxi, and the five hour bus ride between Tacuarembó and Montevideo at least 10 times. In Tacuarembó, I lived with a

professional couple in a two-storey house whose children had all moved to the south to study or work, with a 65-year-old widower in a typical cement and very well-kept home in the city-centre, and with a thirty-year-old single mother of two pre-teens in *Barrio Lopez*. Whereas in Montevideo the central neighbourhoods have been progressively abandoned by the middle class (in favour of the trendier coastal neighbourhoods like *Pocitos*) leaving more dilapidated buildings and deprived neighbourhoods, a similar process is only beginning in Tacuarembó. Tacuarembó's city centre is still the wealthiest area although the same street may have a modern villa next to a typical cement bungalow (Figure 3.3 and 3.4).

However, it is not uniquely because I carried out fieldwork in two cities, and lived in multiple households that I consider my approach multi-sited. Rather, I take the view of Lock and Nguyen (2010) in their recent book *An Anthropology of Biomedicine*, that multi-sited

"...does not necessarily mean literally visiting a string of field sites but rather documenting how larger forces past and present impinge on local sites. Giving voice to peoples without power whose opinions and experiences are rarely heard or known has been common anthropological practice. Such research continues to be important, but by taking a multi-sited approach, the many factors relating to an object or phenomena selected for investigation can be described, including the perspectives of experts, policy-makers and practitioners" (p.9).

Therefore, I consider the ethnography multi-sited because I carried out fieldwork in multiple sites such as homes, the clinic, multiple hospitals, the community, the Ministry of Public Health, NGOs, government and academic organizations. In the previous chapter I described how, theoretically, I envisioned making a political-economy perspective part of a sensorial approach, particularly by viewing the sentient body as at once the expression of individual, social and political bodies. Methodologically speaking, this approach translates to a multi-sited approach which Marcus (1998, p.90-91) would call "Follow the People" and to a lesser extent "Follow the Thing". I would in a literal sense accompany my participants and their families to the clinics, to their homes, on holiday or other social events, and to government offices as a way of exploring the complex systems (healthcare and otherwise) of which they were a part. I would also follow the health professionals who cared for them, around the hospital, to meetings, to professional events, and community events. Occasionally, I would follow the thing. For example, home oxygen therapy, which is discussed in Chapter 6, emerged as an important example of



Figure 3.3: A two-storey wealthy and modern home in Tacuarembó. Photo by the author.



Figure 3.4: Cement homes with typical structure in Tacuarembó. Slanted roof, window and door opening almost directly onto the street with backyard. Photo by the author.

healthcare inequality. I therefore followed the 'stories of oxygen' by contacting oxygen companies, going to directors of institutions to enquire about oxygen, and by making appointments with staff in the ministry of public health to discuss the issue. I turn now to describing how I gained access to institutions, because part of the complexity of fieldwork was that I was not simply seeing healthcare at the receiving end as an accompanier of patients but seeing healthcare from the provider-perspective as an accompanier of healthcare professionals. This access required more formalized kinds of approvals.

Gaining access to institutions and meeting people with COPD, their families and their healthcare professionals

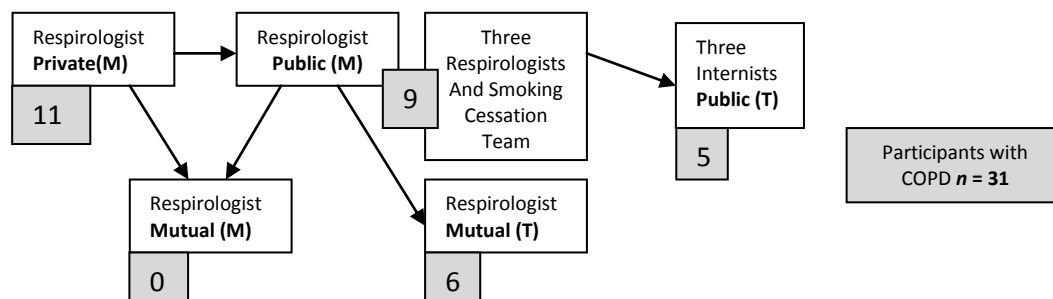
This research set out to study diagnosed COPD and not self-identified COPD or people with symptoms of COPD in the community. Because COPD symptoms overlap with so many other respiratory diseases, and because I wanted to study this burgeoning public health issue specifically, I focused on secondary and tertiary care, that is, hospital outpatients and inpatients service sectors where I would meet people who were diagnosed with COPD. Studying diagnosed COPD is like studying the tip of the iceberg, for many, if not most, people with COPD in Uruguay will not know they have it (Menezes *et al.*, 2008; Talamo *et al.*, 2007), and access to diagnostic technologies outside the capital are dubious. I was unable, for example, to find documentation on the availability of spirometry across healthcare providers. The participants from the public hospital in Tacuarembó did not have access to spirometric testing at the time of my study, and therefore their diagnosis would be considered unconfirmed by international guidelines. It is possible that they did have COPD, it is possible that they did not. Talamo *et al.* (2007) indeed found that there was a considerable problem with false diagnoses of COPD in Uruguay. However, what was important to me in cases where it was impossible to recruit people with spirometric confirmation, was that they had been labelled as someone with COPD based on a clinical history. The disadvantage of studying the tip of the iceberg, *i.e.* diagnosed patients, is that it is a narrow group, and generally by virtue of being diagnosed they are people who access and follow-up with medical care. Those who are diagnosed and never return to their doctors for follow-up, for instance, had less of a chance of participating in this research although one participant was a person with mild COPD who avoided medical care.

The advantage in studying the tip of the iceberg is that I could study the way COPD as a diagnosis was made, remade and identified-with and I could identify the issues involved in COPD diagnosis and care via the exploration of people's retrospective accounts as well as real-time experiences. I was particularly interested in seeing how COPD is enacted across the healthcare spectrum in Uruguay. In order to meet people with COPD from various backgrounds and healthcare coverage, two strategies were used (Figure 3.5). The preferred strategy was to meet people with COPD through healthcare institutions. This had a number of advantages. For one, it was a way of getting to know the healthcare system from the inside and seeing healthcare delivery in action. Secondly, by meeting people through institutions that had approved my study and given me access to their records, I could easily gain access to patient files and to copies of spirometry results (with permission from the participant). This was helpful in that I could evaluate whether the participant had COPD and through which means the diagnosis had been attained. The third advantage was that before going to most participants' homes, we had already met in a formal context in which patients trusted the healthcare professionals they were electing to see and "...often extend this type of trust to others who step in when a consultation or procedure is ongoing" (Sobo, 2009, p.211). However, not only did they trust me because I was introduced to them by their doctor but I trusted them because I was introduced to them by their doctor. Although it was made clear that I was not working for the healthcare institution but that it was facilitating my research, my participants tended to associate me with their institution and this association offered me a kind of legitimacy. As a young female ethnographer working alone, having this connection with participants before going to their homes, located all over the city was comforting.

In order to be granted access by administration I had prepared the following documents into a portfolio: Information Sheet (Appendix B), Consent Form (Appendix C), Research Ethics Committee Approval Letter from the University, confirmation of registered student status from the University, a letter from my supervisors and my CV. I estimated that approximately 30 to 40 participants would be a feasible number for me to achieve the goals of exploring a wide range of experiences while having time to have multiple contact as well as explore the views of family members, health professionals and policy makers. Figure 3.5 illustrates how I met the 37 people with COPD I went on to interview.

I began with the Doctor I had met in December in a private hospital in Montevideo (Figure 3.5a). He put me in touch with the technical director and after a meeting with her I was approved. Recruiting other healthcare institutions occurred through finding health professionals, preferably respirologists, who were happy to have me follow them, and then approach the institution for permission. A snowball strategy (Bernard, 2011) for meeting health professionals in various institutions was facilitated by the ‘multi-employment’ nature of Uruguay’s health system. A report released by the Ministry of Public Health in 2010 reported that 55% of doctors work in two or more healthcare institutions, 22% in three or more and 9% in four or more (Buffa *et al.*, 2010).

3.5a) Recruitment Via Institutions.



3.5b) Recruitment Via Snowballing

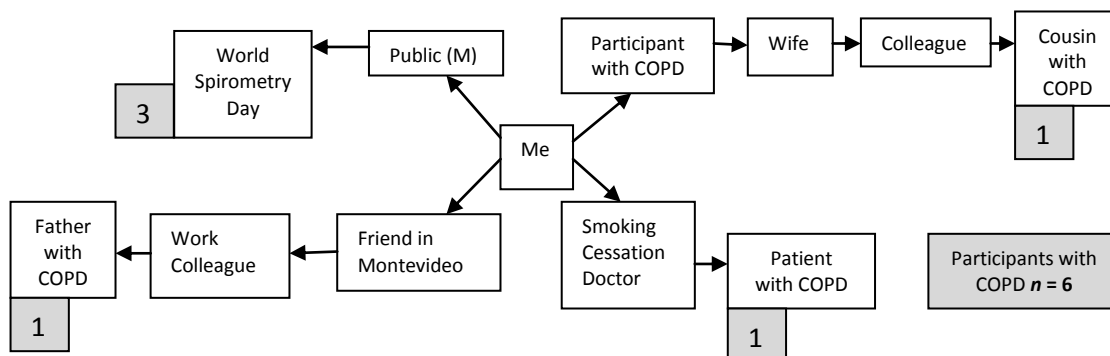


Figure 3.5: Recruitment process for participants with COPD: a) Via participant-observation in Institutions: Public = Public Healthcare Institution; Private: Private Healthcare Institution; Mutual: Private-Mutual Institution; M=Montevideo; T=Tacuarembó; *n*=number of participants b) Via snowballing through institutions, healthcare professionals, other participants or friends.

Having ‘a person in common’ between each participant and myself whether health professional or their patients, helped me strive towards “non-violent” communication via proximity and familiarity with participants as defined by Bourdieu (1999, p. 610). The respirologist in the private hospital introduced me to another respirologist and smoking cessation expert in the private hospital who worked in many other institutions including the public hospital in Montevideo (Figure 3.5a). She introduced me to the respiratory team there and after sending my portfolio and a letter soliciting my approval from the head respirologist the institution gave me access. As long as I wore a white coat (which all health professionals wear in the hospital) and a handmade name badge, I could move around freely. This same respirologist put me in touch with another respirologist in a private mutual hospital. After securing a meeting with the technical director my study was approved there and I began attending respiratory outpatient clinics and smoking cessation services at this institution in November as I had been in the other two institutions.

In January I visited Tacuarembó for the first time and via a very helpful respirologist in Montevideo, I met the only respirologist at the private mutual hospital who was happy for me to shadow her clinic to meet patients. When I moved to Tacuarembó in March we formally submitted my portfolio to the administration for approval. The head of respirology at the public hospital in Montevideo also put me in touch with a doctor in Tacuarembó who arranged a meeting with the sub-director of the public hospital who granted me permission to meet with healthcare professionals and patients on the wards. Figure 3.5a illustrates how many participants I met within these five institutions ($n = 31$). Meeting people through these five institutions represented the primary way I went about recruiting potential study participants.

The second strategy that was employed for meeting people with COPD, was the snowball method (Bernard, 2011). This occurred in two ways, either through people I would meet introducing me to someone they knew with COPD or by participating in World Spirometry Day 2010 at the public hospital in Montevideo. At this event I met three members of staff at the hospital with COPD who received care from various private mutual institutions (Figure 3.5b). The most important difference between participants recruited via approved field site institutions and those recruited via snowballing is that I have institutional participant-observation data (*i.e.* fieldnotes from observing clinic or ward care) with the former and none with the latter. Five of the six participants recruited through snowballing received their healthcare from institutions outside the five I had gained access to and therefore I know little

first-hand about how those institutions operated and could not always access patient-files or test-results unless participants themselves had personal copies.

As mentioned, one drawback was being unable to actually meet anyone with COPD from the private mutual hospital in Montevideo. Despite having shadowed the respirologist in his outpatient unit for a month, I only met one person with spirometry-confirmed COPD who agreed to be visited at home. However, this person's wife fell seriously ill and he decided it was not good timing for him to receive a visitor. Otherwise, there are a few reasons why the private mutual hospital was not a fruitful recruiting site. One reason was seasonality. By the time I began in this institution it was November and summer was just around the corner. In the spring and summer people with COPD tend to have fewer exacerbations and consult their physicians less (Donaldson *et al.*, 2012). Furthermore, even though the private mutual hospital served 200 000 people (making it one of the largest), it had a younger demographic patient-profile than some other institutions and therefore, some illnesses more frequently diagnosed in later life (like COPD) are less represented. The other issue was that spirometry was available but outsourced at this institution and therefore it was not possible to access spirometry test results. In other institutions I could find out when the appointment would be and look-up the results from within the hospital to determine whether COPD was confirmed. In the private mutual hospital because spirometry was performed by a private company contracted by the institution, I could not and missed one or two opportunities to recruit some potentially 'newly diagnosed' people.

Participant Characteristics

Table 3.1 lists all participants and some basic illness and healthcare related information. The sample can be summarized in the following way:

- Five institutions participated as approved field sites (one private hospital, one private mutual hospital and one public hospital in Montevideo and one mutual private hospital and one public hospital in Tacuarembó)
- 11 doctors (seven respirologists and four internists) were shadowed across these five field sites and introduced me to 31 people with COPD. One person with COPD was recruited from the smoking cessation service of the public hospital in Montevideo. Nobody with COPD was recruited from the private mutual hospital in Montevideo (explained above). Six people with COPD were recruited via snowballing.

- In total 37 people with COPD (14 women, 23 men) were recruited to this study
- Participants ranged in age from 36 to 88 years old
- Eight were smokers, and everyone else except for one (who was a lifelong asthmatic) were former-smokers
- 13 were oxygen-dependent
- More than two thirds suffered from one or more other chronic illnesses, most frequently hypertension, diabetes or heart problems.
- At least 20 had been hospitalized for a COPD exacerbation in the previous 12 months and sadly four passed away during my fieldwork.

My aim was to meet people with different severities of the illness, of different ages and with different healthcare (private/public). This diversity, as mentioned in Chapter 2, is rarely captured in the research to date on the experiences of people with COPD. Severity as already mentioned in the introduction and Chapter 1 is not simply a measure of FEV1/FVC, although it is an important indicator. As can be seen in Table 3.1 some participants were on the cusp of a COPD diagnosis with FEV1/FVC of approximately 70%, however participants' FEV1/FVC scores ranged between 28 and 70 and FEV1 ranged from 14% to 92%. Therefore there is a mix of people with mild (FEV1 equal or more than 80%), moderate (FEV1 between 50 and 80%) severe (FEV1 between 30 and 50%) and very severe (FEV1 equal to or less than 30) obstruction as measured by spirometry (GOLD, 2011), with or without other illnesses, or experience of hospitalization. Table 7.1 (Chapter 7) demonstrates the economic differences among participants. Overall, the multi-sited approach to encountering people with COPD was a successful way of recruiting people to the study who had wide-ranging experiences of COPD.

Fieldwork in the Interior vs. the Capital

Participant-observation was the primary method of this ethnographic study, not only in healthcare contexts but also home contexts where I would 'hang-out' before and after more formal interviews which were recorded. It is important to acknowledge a difference between the participation in the daily life of my participants in Montevideo and Tacuarembó. In Montevideo, a city of one and a half million people, although small on some scales, it remains too large to bump into participants on the street. My participants lived all over the city and even outside the city, in other departments, in one case two hours up the eastern coast.

Furthermore, 'they' were not a 'community'. Most people with COPD did not know anyone else with COPD. A former patient association for COPD and oxygen-dependency in Montevideo had ceased to exist a year before I arrived. Therefore, my physical 'community' in Montevideo tended to be located in the healthcare field. One community was that of the smoking cessation professionals which I will turn to in the next section. However, concerning COPD directly, the community I became most embedded and familiar with was the public hospital in Montevideo where I would go multiple times per week for pulmonary rehabilitation, team meetings, and outpatient clinics. I would sit around in the office and chat with the health professionals and frequently typed notes there. Integration into this community happened naturally and had much to do with the fact that they themselves were a community that shared a physical work space and were also engaged in research. Within this institution the pulmonary rehabilitation class was as close to a 'COPD community' as I could get and I followed a group 2-3 times a week for almost three months (Chapter 8). Nevertheless, because of the geographical dispersion of my participants and the unlikelihood of casually bumping into one another, most home-visits were planned and occurred every couple months.

Tacuarembó was a completely different story. As a town in the interior of the country the sense of community and openness of people was more apparent as the pace was slower, neighbours more familiar, and healthcare professionals and patients were more frequently in contact outside the clinic. It was a relatively large interior town of 54 000 people, with three *plazas* (squares) constituting its centre and it was possible to come to know people in the street and working at certain businesses. I travelled around Tacuarembó by bicycle. Once people started calling-out "hello" to me as I pedalled by, and I could stop to speak with someone I knew standing outside their home catching the morning sun or sipping an afternoon mate in front of their house, I started to experience the pleasantness of living in a town, rather than a city. The physical proximity of everything in Tacuarembó meant that I could see my participants much more regularly. I quickly learned that if someone said "come by anytime" and I had not returned within a week I would surely receive a text-message saying "where are you?" (mobile phones are pervasive and were relied on for making contact with participants).

Therefore, I decided early, within a few weeks in Tacuarembó to delve into this delightfully different fieldwork experience by concentrating on meeting fewer people with COPD so as to have the time to be properly social with people who were all too pleased to

Table 3.1: List of participants diagnosed with COPD, their demographics and clinical data: *= smokes hand rolled tobacco Pack Years based on an equivalence estimate of a pack of loose tobacco is 60 cigarettes. P=permanent oxygen used, at least 15 hours a day. F-S= Former Smoker; S= Smoker; P-S= Passive Smoker; BD=Bronchodilator

Participants diagnosed with COPD	Age	Sex	Healthcare	Smoking status	Pack Years	Home oxygen therapy	Suffer from another chronic condition?	Hospitalised For COPD?	Spirometry							
									Year	FVC		FEV1		FVC/ FEV1	Post- BD FEV1	
										Litres	%	Litres	%	%	Litres	%
1) Javier	73	M	Private	S	60	Yes (P)	Yes	Yes	2006	4.81	113	2.73	82	56.76	2.97	+8
2) José	53	M	Private	F-S	120	Yes (P)	Yes	Yes	Most recent spiro not considered reliable, but prior results = COPD							
3) William	70	M	Private	S	52	Yes	Yes	No	2010	3.44	99	1.29	47	38	1.20	-7
4) Ian	72	M	Private	F-S	96	Yes (P)	Yes	Yes	2003	2.89	67	0.82	24	28	0.92	+3
5) Vivian	62	F	Private	F-S	21	No	Yes	Yes	2010	3.08	104	2.19	92	71	2.31	+5
6) Mónica	74	F	Private	S	71	No	Yes	No	2000	2.93	97	1.88	78	64	1.83	-2
7) Soledad	72	F	Private	F-S	125	No	Yes	No	2009	1.31	51	0.92	44	70	0.95	+3
8) Roberto	70	M	Private	F-S	25	Yes (P)	Yes	Yes	2010	3.70	107	1.41	56	38	1.56	+10
9) Tomás	60	M	Private	F-S	80	No	No	No	2000	2.56	51	1.78	45	70	2.14	+9
10) Ignacio	70	M	Private	F-S	47	No	Yes	Yes	2009	4.22	111	2.40	81	57	2.36	-2
11) Marco	55	M	Private	F-S	30	No	Yes	No	2010	3.13	80	1.77	56	57	1.84	+4
12) Macarena	59	F	Public	F-S	17	No	Yes	Yes	2010	2.39	82	1.34	56	56	1.34	0
13) Jessica	65	F	Public	F-S	37	No	Yes	No	2009	2.18	86	1.01	50	57	1.02	+1
14) Daniela	61	F	Public	S	28	No	Yes	No	2009	2.18	85	1.84	78	74	1.62	-12
15) Lucía	61	F	Public	F-S	45	Yes	Yes	Yes	2010	1.92	77	0.77	38	40	0.78	+1
16) Mateo	43	M	Mutual	F-S	20	No	Yes	Yes	2010	1.70	41	0.52	15	30	0.52	+4
17) Sebastián	36	M	Public	F-S	14*	Yes (P)	Yes	Yes	2010	2.07	42	0.70	17	34	0.88	+24
18) Martín	60	M	Public	F-S	38	Yes (P)	Yes	Yes	2010	1.31	29	0.81	22	62	0.95	+17
19) Valeria	53	F	Public	S	140	No	Yes	No	2011	2.15	69	1.41	55	66	1.41	0
20) Sofía	48	F	Mutual	F-S	17	No	No	No	2002	3.02	86	1.80	62	60	2.21	+23
21) Nicolás	55	M	Mutual	F-S	35	No	Yes	No	2010	2.63	74	1.52	53	58	1.95	+28
22 J- Carlos	48	M	Mutual	F-S	42	No	Yes	No	2010	3.45	100	2.43	85	70	2.01	-17
23) Mauricio	70	M	Private	F-S	n/a	Yes (P)	Yes	Yes	Not available							
24) Bruno	71	M	Mutual	F-S	21	No	Yes	No	2011	3.07	122	1.32	67	54	1.41	+7
25) Rodrigo	76	M	Mutual	F-S	32	No	No	No	2010	3.77	85	0.85	25	29	0.87	+2
26) Joaquín	72	M	Mutual	F-S	52	No	Yes	No	Not available							
27) Bruno	81	M	Mutual	F-S	30	Yes	No	Yes	Not available							
28) Claudia	50	F	Mutual	F-S	26	Yes	No	Yes	2010	1.44	48	0.35	14	30	0.52	+21
29) Verónica	88	F	Mutual	P-S	-	Yes (P)	No	Yes	No spirometry performed							
30) Marcelo	54	M	Public	F-S	n/a*	Yes (P)	No	Yes	No spirometry performed							
31) Peter	50s	M	Public	S	20-40	No	Yes	Yes	No spirometry performed							
32) Micaela	47	F	Public	S	32	No	Yes	Yes	No spirometry performed							
33) Federico	70	M	Public	S	68*	No	Yes	Yes	No spirometry performed							
34) Florencia	56	F	Public	F-S	40	Yes (P)	Yes	Yes	No spirometry performed							
35) Nelson	70	M	Public	F-S	44*	No	Yes	Yes	No spirometry performed							
36) Gustavo	54	M	Public	F-S	31	No	No	Yes	2010	2.19	56.5	0.73	23	40.9	n/a	
37) Patricia	45	F	Public	F-S	28	No	No	No	2009	1.88	65	0.55	22	29	0.53	-3

open their homes to me, share a meal, and speak at length about diverse topics. Therefore, while I had over 20 participants with COPD in Montevideo, I had only 11 in Tacuarembó. With much less time needed for travel, I had more time and was encouraged by my supervisors to contextualize my research by investigating other topics of interest to me. These included medicinal plant-use, *vencer* (a spiritual healing ritual), and funerary practices. However, as this thesis concerns mostly how people with COPD lived in Uruguay, I will turn to speaking about the family context and then the multiple methodologies I employed over and above participant-observation in order to engage with participants' sensorial experiences, world-views, hopes and understandings.

The Omnipresence of Family

Family members moved freely in and out of the spaces in which conversations occurred with my COPD participants. 28 out of the 37 participants were accompanied by various family members during our interviews and informal conversations, whether in the home or the hospital space. The nine participants that tended to be interviewed alone either lived alone ($n=2$), were not interviewed at home where family members could participate ($n=4$), or simply invited me to speak with them in private areas of their home ($n=3$). The voices of family members are woven into the many hundreds of hours of recordings I accumulated in my fieldwork. Nine daughters, seven sons and twelve partners of my COPD participants contributed their views to this study in substantial ways. Family members constantly appear within fieldnotes, especially those written about doctors' appointments and on-ward hospitalizations where my COPD participants were usually 'accompanied' (Chapter 7). Some family members were even interviewed privately (five daughters, four sons and seven partners).

A Multi-Modal Approach to Multi-Sited Ethnography

Having outlined how I gained access to institutions and how I met participants, I want to now turn to what methods were employed to help explore the topic of living with COPD with participants, families and healthcare professionals. In the words of Hsu (2008) in her article *The Senses and The Social*, "Research on bodily dispositions and sensory experience cannot rely solely on interviews and questionnaires but calls for innovative forms of fieldwork" (p.438). Embodiment according to Csordas (1993) is not just a theoretical paradigm but a

methodological one too. In this section I outline the multiple methods I employed within a sensorial approach to fieldwork. Table 3.2 is a visual representation of the depth of information gained from participant-observation and interviews with my participants. The approach to fieldwork and interview-design followed an emergent approach with a focus on narrative (Gubrium & Holstein, 2008b). The first recorded interview asked that each participant tell the story of COPD in their lives. These, in addition to the observations I had been making in daily life and in clinical settings fed into the design of other methods for uncovering the richness of participants' experiences. As Parker & Harper (2006) remind proponents of the anthropology of public health, incorporating multiple methods while undertaking participant-observation helps free researchers so that they can approach their research in an open-ended way. In my case, it was through a multi-modal and multi-sited approach, that exploration of the social and political bodies of my participants could be engaged with through the lived sentient body.

The Home Context: (Table 3.2, Column 1):

In the table this column identifies all the participants whose homes I visited. Being in the home was considered a priority for getting a feel for everyday living with COPD, family dynamics and material/social helps and hindrances. All home-context data were recorded in fieldnotes. However, visiting the home was not always possible either because sometimes participants suggested meeting elsewhere or because of transportation difficulties and coordination problems.

The Clinical Encounter: (Table 3.2, Column 2):

This column illustrates all the participants for which I have fieldnotes recording observations of healthcare professional-patient interactions during appointments. A drawback of my methodology was that it prioritised physician-patient relationships and although I paid attention to nurses, physiotherapists and other allied health professionals in in-patient contexts, I did not have much contact with them. This is also due to the fact that healthcare generally is dominated by physicians in the sense that physicians were responsible for many aspects of my participants' care including what would be considered "paramedical emergency care", smoking cessation and pulmonary rehabilitation. This feature of the Uruguayan healthcare system will be discussed in greater detail in the following chapter. Suffice to say that participants I did accompany in clinical contexts were recruited from their appointments with

their respirologists ($n=12$) or internist ($n=1$), smoking cessation appointments ($n=1$) or rehabilitation programs ($n=6$). Again, this was an advantage of meeting people with COPD in healthcare settings as opposed to simply out in the community. Through these 20 participants I was able to observe clinical interactions and compare and contrast care.

Life on the Ward: (Table 3.2, Column 3):

Eight participants were first met while they were hospitalized. Although, thereafter, many of my participants were hospitalized over the course of fieldwork, I was not always able to visit them on the wards. Sometimes it was because I was not in town, was not aware they were in hospital, or I was ill and could not visit. Because they are susceptible to infections, if I had a cough or cold I did not visit them. My fieldnotes on these say a lot about the experience of hospitalization, the role of the family and the differences between different institutions.

Family Tree: (Table 3.2, Column 4):

In the words of Combs (2003) genealogy is “...more than merely the tracing of bloodlines and the drawing of trees. Genealogy becomes the study of social worlds...” (p.252). Genealogies are a common tool of social anthropology to explore family structures and relationships and have also been employed in bio-social anthropology to assess, for example, the influence certain bio-social factors have on fertility and mortality (Reddy & Sudha, 2010). In line with Combs’ (2003) holistic view of the potential of “...genealogy as an ethnographic enterprise...” (p.252), I employed them rather loosely not so much for the aim of producing highly detailed and precise genealogies but rather as a point of discussion and investigation into a person’s family background (origins/ethnicity), of the prevalence of lung disease and smoking within the family, and for mapping out family relations and broad changes in family patterns over generations. Completing this task collaboratively often inspired my participants to tell all kinds of stories. This collaborative and very conversational process was voice-recorded in all but one or two cases.

Table 3.2: Data gathered (blue shading) for each participant with COPD. Fam=Family Tree; Dem=Demographic Questionnaire; Spiro: Spirometry

Participants	Home	Clinic	Ward	Fam.	Dem.	Pile-Sort	Drawing	Definition	Spiro	Recording	Fieldnote Hits
Javier	X		X		X				X	1	9
José	X		X	X	X	X	X	X	X	12	22
William	X		X						X	1	6
Ian	X		X		X				X	2	9
Vivian	X	X		X	X	X	X	X	X	3	4
Mónica									X	1	4
Soledad	X			X	X	X	X		X	3	7
Roberto	X	X							X	1	5
Tomás	X	X	X	X	X	X	X	X	X	3	12
Ignacio	X	X	X		X	X			X	2	8
Marco	X	X		X	X	X	X	X	X	3	9
Macarena	X	X		X	X	X	X	X	X	4	25
Jessica	X			X	X	X			X	2	4
Claudia	X	X		X	X	X	X	X	X	3	5
Lucía	X	X		X	X				X	2	24
Mateo	X	X	X	X	X	X			X	3	18
Luiz Mato	X	X		X	X	X	X	X	X	2	17
Martín	X	X		X	X	X	X	X	X	3	14
Valeria		X							X	0	6
Sofía	X				X	X			X	2	5
Nicolás					X				X	2	4
Lukas	X			X	X				X	2	4
Mauricio	X			X	X					2	5
Bruno	X	X	X	X	X				X	1	42
Rodrigo	X	X			X	X			X	2	6
Joaquín	X	X		X	X	X	X			3	5
Bruno	X	X		X	X	X	X			4	16
MC de M	X	X			X	X	X		X	3	6
Verónica	X	X		X	X					7	12
Marcelo	X		X	X	X				n/a	0	41
Peter			X		X				n/a	0	15
Micaela	X	X		X	???	X			n/a	3	4
Federico	X		X						n/a	1	13
Florencia	X			X	X	X			n/a	6	5
Nelson	X				X				n/a	1	1
Gustavo	X		X		X	X	X	X	X	3	9
Patricia	X	X		X	X	X	X	X	X	3	6
TOTAL: 37	33	20	12	22	32	21	14	10	27	97	407

Demographic Questionnaire: (Table 3.2, Column 5):

After a few months in the field I constructed a four-page demographic questionnaire (Appendix D) to accumulate some basic information about my participants. When it was not completed it was normally because I was unable to see the participant again before I left the field. However, much of the information included in the questionnaire was gathered throughout multiple interviews and encounters anyway. The questionnaire provided a physical space to record basic characteristics such as birth date, family composition, home situation, education, healthcare spending, medication use and alternative healthcare use.

Pile-Sort: (Table 3.2, Column 6):

A pile-sort consists of giving a research participant a number of cards with words on them, objects or photos which you ask them to sort according to certain criteria (Boster, 1994). It is considered a structured data collection technique, developed in psychology and anthropology, for examining the ways in which different people categorize things in a domain (area or topic) thus exploring indigenous categories, folk-taxonomies, and the more covert or implicit culture of individuals and societies (Coxon, 1999; Gittelsohn & Mookherji, 1997). It also can be used to examine relationships among items (Ryan & Bernard, 2000). Pile-sorts have been incorporated into a mixed methods approach and successfully combined with methods such as Photo-Voice (Bharmal *et al.*, 2011), interviews (Calvo, 2005), network maps (Chandra & Batada, 2006), quantitative survey data (Dongre *et al.*, 2009), and focus groups (Singer *et al.*, 2006; Stanton *et al.*, 1993). More recently, pile-sorts have been conceptualised as part of a participatory-approach toolkit for developing community-based interventions (Bharmal *et al.*, 2011; Chandra & Batada, 2006; Dongre *et al.*, 2009; Gollin *et al.*, 2004)

The number of cards used can vary from 30 to over 200 and similarly, the number of participants can be as high as 219 (Hannah, 2005) although, the normal range is 20-30 participants (Harloff & Coxon, 2007). I asked 21 participants to sort 23 cards with words and expressions written on them which I drew from interviews and participant-observation and from the literature on the experience of COPD (Table 3.3). The literature is divided between those who ask participants to sort according to similarity (“place those that are similar together”) (Bharmal *et al.*, 2011; Boster, 1994; Calvo, 2005; Neufeld *et al.*, 2004; Weller, 1984) and those that ask participants to sort according to their own meaningful category or perceptions of relatedness (Brieger, 1994; Chandra & Batada, 2006; Dongre *et al.*, 2009;

Table 3.3: Words and expressions used in the pile-sorting exercise

Sorting/Piling	
Spanish Words	English Translation
Tos	Cough
Problemas de vista	Vision problems
Flema, Expectoración	Phlegm/Expectoration
Falta de Aire	Lack of Air
Ahogado	Suffocated
Cansancio	Tiredness
Falta de oxígeno	Lack of oxygen
Miedo	Fear
Debilidad	Debility/Weakness
Angustia/Tristeza	Anguish/Sadness
Ansiedad	Anxiety
Transpiración	Perspiration
Picazón en la Piel	Itchy skin
Dolor	Pain
Dependencia	Dependence
Falta de libertad	Lack of freedom
Atacado de los bronquios	“bronchial attack” (bronchitis)
Adicción	Addiction
Gripe	Cold/Flu
Enojo	Anger
Pérdida de memoria	Memory loss
Confusión	Confusion
Problemas digestivos	Digestive problems

Drawing My Lungs: (Table 3.2, Column 7):

I was inspired by an anthropologist I met in Uruguay to engage my participants in some drawing to explore how it is they understand what is going on inside their bodies. Research using participant-generated drawings as data is frequently framed within the domain of visual methods or visual anthropology. However, core methodological resources on visual and arts-based methods such as Gillian Rose's (2012) *Visual Methodologies*, Sarah Pink's (2001) *Doing Visual Ethnography*, Marcus Banks' (2007) *Using Visual Data in Qualitative Research* and Knowles & Cole's (2008) *Handbook of the Arts in Qualitative Research*, mention drawing only in passing, despite the fact that drawing has been increasingly used as a way of gaining greater insight into experience (Bagnoli, 2009; Galman, 2009; Kearney & Hyle, 2004). I asked 14 participants to draw what they think their lungs look like with COPD and had them explain their drawings to me.

A similar approach to mine was taken by a team of three anthropologists and 11 anthropology students in Brazil who asked 202 men and women from four shanty towns to draw the reproductive organs onto an empty silhouette given to them by the researcher (Victora & Knauth, 2001). In asking their participants to draw, the "...aim was to motivate respondents to talk about the reproductive system, and to find out the extent to which biomedical views of anatomy and physiology had been assimilated, rejected or re-interpreted by them" (p.23). Also using an empty silhouette drawing, referred to as the Inside the Body Test, Clarke and Newell (1997) compared how children with and without asthma perceived their internal bodies by asking them to draw their internal body parts. The importance of such an exploratory activity for medical anthropology is that beliefs about what is going on inside the body influence the perception and presentation of illness, and how medical treatment is responded to (Helman, 2007). "Images encourage embodied knowledge" (Weber, 2008, p.46) and the sharing of that knowledge between the expert and the researcher. Guillemin (2004) combined entirely participant-produced drawings and interviews in her research on women's experiences of menopause and of heart disease. She argues that

"...drawings are not fixed or stable entities. Drawings are produced in a particular space and time. A woman asked to draw how she perceives her menopause today is unlikely to draw the same thing a year, a month, or even a week later. Drawings are as much about the drawer's history as it is about their present (and, possibly, their future). The drawing as a visual product is a visual record of how the drawer

understands his or her condition at that particular place and time. In this way, drawings, like other representations, can be used as ways of understanding how people see their world.” (p.275)

Definitions of Common Expressions for States of Breathing: (Table 3.2., Column 8):

Following on from the work on drawing lungs I reflected carefully on whether I had a firm grasp of the meaning of the various terms that are used in Uruguay to speak about breathing difficulties and whether there was more to explore in terms of the sensorial experience of COPD and the language used to describe it, particularly metaphors. Sensorial Anthropology asks that one pay particular attention to metaphors for “sensation is a key site of embodying metaphor” (Hinton *et al.*, 2008, p.154). Therefore, I drafted a list of expressions and some metaphors I had come to hear over and over again in interviews and asked ten participants to tell me what each one meant (Chapter 6).

Spirometry: (Table 3.2, Column 9):

This column identifies all the participants for whom I have spirometry results. The results are presented in Table 3.1. Spirometry is the diagnostic tool used to either confirm or discard a COPD diagnosis. It cannot reliably stand alone but must accompany a thorough medical history. Four values are key in spirometry (Booker, 2005):

- 1) Forced Vital Capacity (FVC) measured in litres, refers to the total amount of air a person can exhale when they have been asked to take the largest inhalation possible and exhale as hard and fast as they can.
- 2) Forced Expiratory Volume in One Second (FEV1): This measurement, also in litres, refers to the volume of air a person can exhale at maximum force in the first second.
- 3) FEV1/FVC: This percentage value is the marker for airflow obstruction. It is the ratio of the volume of air exhaled in the first second to the total volume of air exhaled.
- 4) Post-FEV1: This value refers to the percentage change in Forced Expiratory Volume in one second after the person has received a dose of inhaled bronchodilator. This value is important for assessing whether the obstruction is reversible, non-reversible or partially reversible (as reviewed in Chapter 1).

Number of Recorded Interviews per Participant: (Table 3.2, Column 10):

Number of Fieldnotes each Participant Features in: (Table 3.2, Fieldnotes):

Before explaining these two columns it is useful to say something about how interviews and fieldnotes were recorded. Interviews were recorded using a high-quality digital recorder with an external noise-cancelling microphone plugged directly into the device. Interviews were downloaded to a password-protected laptop and labelled according to participant-number and date. Fieldnotes were written in ten 90-page notebooks over the course of the year of fieldwork. I tried to make the notebooks the location of all notes, scribbles and contact details, so as to have everything written down in one location. Family trees, responses to piling/sorting, drawing lungs, detailed notes of smoking cessation groups and any other notes/observations were written directly in these notebooks at the time. Subsequently, these as well as longer detailed recounting of hospital infrastructure or other informal conversations, for example on public transportation, were typed up on the laptop once or twice a day, normally at the end of the day. Keeping direct observations, recall of conversations, direct quotes, telephone conversations and personal reflections all under one roof in a fieldnote gave coherence and context to each day and the activities it was made up of. In the words of Clifford (1990):

"The texts produced in the field are often polyglot. They include large quantities of the local vernacular plus diverse pidgins, short-hands, and languages of translation, along with the language or languages of the ethnographer" (p. 58-59).

I quickly found leaving detailed fieldnotes to be typed-up at the end of the day exhausting, especially in Montevideo. This was because my hosts and I would normally only eat at 10 or 11 at night and therefore I might only sit and begin typing at midnight and might be up for two hours. Therefore, as much as I could I built in time in the day to type fieldnotes, either by returning home or carrying a small netbook computer around with me. Most of the notebook notes were written in Spanish as they tended to be direct recordings of things said, however, netbook fieldnotes tended to be a mix of English and Spanish. They were typed up as a chronology, a story of the day which included all kinds of observations, re-created conversations, thoughts and dialogues. Once fieldnotes were typed in a Microsoft Word document they were entered into the NVivo9 qualitative data software program where they could easily be coded and searched (QSR International, 2009). This was particularly useful

when I was planning a visit with someone I had not seen in many weeks or months and wanted to refresh my memory. I would create a “*Querie*” (search) within NVivo9 using their name and all the fieldnotes in which that person was mentioned would be listed and could be re-read quickly. It can be argued that these kinds of qualitative software tools have revolutionized the way we handle fieldnotes and consequently the way we write them. There is no longer the same imperative to have one journal, one log, one set of typed up interview notes and a system of short-hand codes or colours to organize them, as is described in classic texts, such as *Fieldnotes: The Makings of Anthropology* (Sanjek, 1990b).

When I returned from the field, over the course of four to five months I re-read all my fieldnotes within NVivo9 and coded them according to topic and sub-topics, which formed the basis of my analysis and the prioritizing of major themes which formed the basis of each chapter. I immersed myself in the data, developing more sophisticated categories and codes as time went on and memoing (*i.e.* making analytical notes) as they emerged (Bernard, 2006). This analytical process is common in thematic analysis of different kinds of qualitative data and is very similar to that undertaken by Bluebond-Lange (1991) when analysing data from a study of families living with children with cystic fibrosis. More than anything the process allowed me to organize my fieldnote data and be able to identify topics, evaluate the breadth of data I had for them, and efficiently access them. The specific data drawn upon in each chapter will be identified when and where appropriate.

To return to the topic of fieldnotes and interviews as they pertain to my participants with COPD, I have decided to discuss the two together because they inform one-another. They might both stand as an indicator of the amount of interaction I had with each participant. In a way what I hope to convey is that the number of recordings often does not correspond to the number of times I sat and conversed with my participants. Indeed most interviews were so informal and embedded into a visit, which involved sharing a meal, a tea, general catching-up and personal news, that in reality using the term ‘interview’ is slightly sterile. I would agree rather with Stage and Mattson’s (2003) position that most ethnographic interviewing is contextualized conversation. Furthermore, my approach to interviewing was shaped by the principles of narrative-ethnography (Gubrium & Holstein, 2008b), an emergent method which considers that

“If stories in society reflect inner lives and social worlds, society has a way of sharing, reshaping, or otherwise influencing stories on its own terms. The texts of accounts are

important for narrative analysis, but so are the contexts, which we take to extend from interactional to institutional environments" (Gubrium & Holstein, 2008b, p.15)

Therefore, the various methods incorporated into 'interviews' and participant-observation were considered important not only for the specific information they added, but for their potential to allow space for the narrativization of experience in ethnographic settings.

The aim was to digitally-record as much as possible however this was not always deemed useful, appropriate or feasible. For instance, as can be seen from Table 3.2, there are three people for whom I have no recordings. Two I met while they were hospitalized and were so ill that we did very little talking. Interviews are not a straightforward method when speaking with people with lung-disease. Having to take into consideration the participant's limitations in terms of energy, speaking and breath, is mentioned by other qualitative researchers in this area (Ek *et al.*, 2011). Returning to Table 3.2, I only ever saw Peter in hospital, and he died of terminal lung cancer only a few weeks after we met. On the other hand, I closely engaged with Marcelo and his family over his last four months of life, as is made clear in how many fieldnotes I wrote about him and his family (Chapter 7). His home was one of the most frequently visited. However, recording conversation with him was never deemed appropriate, although I do have recordings from conversations with his wife. It was inappropriate because Marcelo could hardly breathe, let alone speak. The third participant for whom I have no audio-recording is Valeria who I met in a smoking cessation group and saw a number of times in hospital. Her story was recorded in detail and is included in Chapter 9, even though I was not able to record interviews with her because our interactions were limited to discussions in hospital hallways and/or sitting outside while she smoked a cigarette.

I also took a broad interest, as already mentioned, in health beliefs, traditional medicines, spiritual healers and funerary practices, despite focussing most of my social relations around 'living with COPD', 'quitting smoking' (personal and professional perspectives) and healthcare and public health in Uruguay (hospital administrators, healthcare professionals, public health employees). To explore these sub-topics in greater depth, I carried out various formal and informal interviews with key participants separate from the topic of COPD (cemetery workers, *curanderos* (healers), *yuyeros* (persons with knowledge of medicinal plants), which occasionally feed into this thesis. As these interests emerged from my experiences in Uruguay I looked upon my participants with COPD as potential experts on all topics 'Uruguay' and would

ask for their views and experiences on these emerging topics of interest. My participants were not treated only as experts on living with COPD, but as experts on ‘being Uruguayan’. They were also experts on the sensitive issue of smoking and quitting to which I now turn.

Smoking Cessation Services

The second specific population I focused my ethnographic activities on were smoking cessation services and the people within them, particularly health professionals. I had not planned, in my first year, to focus on smoking cessation in such great detail. This interest and commitment was only solidified during the second fieldwork trip when I realized how much investment was being directed into these services by the government and institutions. Originally, I thought of smoking cessation services as another context within which to meet people with COPD. However, I only met one participant from attending a smoking-cessation service. Quickly, however, the services themselves began to interest me. Thankfully, the flexibility of the ethnographic method allowed me to open up this whole new window into potentially very important aspects of COPD care: prevention and treatment. The aim was to approach the topic of smoking cessation in as broad a way as possible. Figure 3.7 illustrates some of the methods I employed and populations I focused on. In terms of writing this thesis, I focus predominantly on the smoking cessation services and, therefore, will limit my methodological description to them.

I began by shadowing the smoking cessation services of the five institutions that approved my study. The private mutual institution in Tacuarembó provided free smoking cessation support for its users and users of the public hospital in Tacuarembó. Also, a church advertising a “quit smoking in 5 days” course was approached and approved my attendance in November. Later, three more services within private mutual hospitals were included through invitation from the service’s lead physician. Contact with these professionals was made either through CIET or the *Sociedad Uruguaya de Tabacología* (SUT) (Uruguayan Society of Tabacology). Figure 3.8 illustrates my connection to each service. Each service operated in its own distinct ways. They varied in terms of how frequently they provided their service (*i.e.* weekly or three times a week), whether they worked with patients in groups or individually and what their use of smoking cessation medication was. These differences will be compared in greater detail in Chapter 8. For the purpose of demonstrating the extent of my participant-



Figure 3.7: Sites and methods of exploring smoking cessation. SUT= Sociedad Uruguaya de Tabacología; FCTC=Framework Convention on Tobacco Control; WHO= World Health Organization; COP4 = 4th Conference of the Parties.

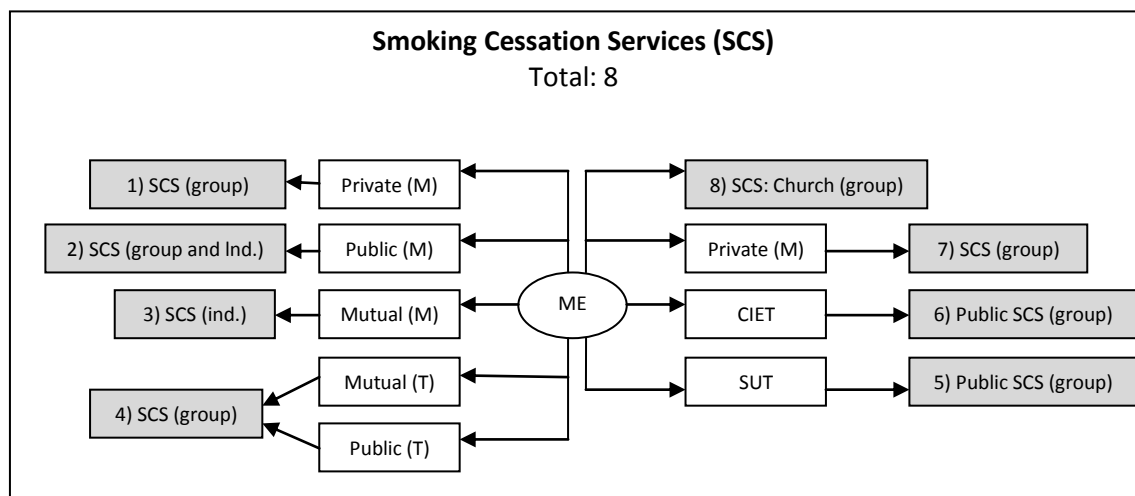


Figure 3.8: Pathways to electing eight smoking cessation services to attend as a participant-observer. M=Montevideo; T: Tacuarembó; Group: Smoking cessation delivered in group format; ind.: Smoking cessation delivered individually

observation of the healthcare professional and patient relationship I have listed how many sessions I attended at each service (Table 3.4). All of the services are more or less continuous except for the church which runs its course only a couple times a year.

Table 3.4: Number of sessions attended per smoking cessation service. Numbers 1-8 correspond to those presented in Figure 3.8.

Smoking Cessation Service	Number of Times Attended
1) Montevideo (private)	10
2) Montevideo (public)	9
3) Montevideo (private mutual)	3
4) Tacuarembó (private mutual/public)	17
5) Tacuarembó (public)	4
6) Montevideo (public)	4
7) Montevideo (private mutual)	5
8) Montevideo Church (public)	5
TOTAL	57

Healthcare and Health Policy

Healthcare and health policy in Uruguay is a topic for a PhD in and of itself. I studied it insomuch as it related to COPD and tobacco control and what I know and present here is of course an incomplete picture. My strategy for getting to know the healthcare system consisted predominantly of accompanying my participants, physically and through their stories, to find out about their journeys through the healthcare system, observing their appointments and sometimes witnessing their struggles. The links I had established in the Ministry of Health meant that I could bring queries and ask for further information from them. This was particularly the case when it came to investigating the topic of oxygen-provision, which will be discussed thoroughly in Chapter 7. Within the Ministry, I received information from various departments including those responsible for the healthcare reform, medication, oxygen-regulation and the chronic disease unit. I had a number of face to face meetings with six

ministry employees and more frequent email contact. Furthermore, I interviewed members of CIET who actively lobby the government for tobacco-control action.

It is important to keep in mind that I only spent a significant amount of time in five institutions and each of these were large and complex enough to be the topics of hospital ethnographies in their own right. Therefore, I cannot claim to understand all the intricacies of the Uruguayan healthcare system especially because each institution varies regarding the way people with COPD move through the system and the services they have access to. Therefore, the experiences of healthcare presented in this thesis cannot be generalized. Nevertheless, a broad spectrum of participants from various socio-economic backgrounds gave me pertinent insight into the organization and challenges of Uruguayan healthcare.

Three additional parallel healthcare contexts were also explored in detail: Mobile emergency services, rural medical rounds and accompaniment services.

Mobile Emergency Services: I received permission to accompany a physician on two 8-hour shifts making home visits with a private mobile emergency service. Both shifts were from 4pm-midnight and involved travelling around in the car with the driver, the nurse and the doctor on-call and entering patients' homes and observing the consultation. Information about my COPD participants' use of these private services was gathered in interviews but this direct participant-observation lent itself to the mobile-method (Buscher & Urry, 2009), wherein you informally gather information and collect views and experience through informal conversations without disrupting the work being undertaken.

Rural Medical Rounds in Tacuarembó: Over the five months I was in Tacuarembó I had the opportunity to follow three different doctors on nine trips around the department of Tacuarembó, lasting a half or a full day. Again, as a kind of mobile-method, I informally interviewed the health professionals while in the truck and once we were at the rural clinics or school houses where they would see patients, I would sit with the awaiting patients and try to strike-up conversation. Usually the community volunteer, who opened the clinic and organized the consultation list for the doctor, was a good source of information about their community. I would also walk around the villages. I did not sit in on consultations with the doctors.

Accompanying Services: Accompanying services are discussed in Chapter 7. They are private services which provide staff, usually with a kind of nurse-aid training, to accompany a person who is hospitalized, for a monthly insurance fee. They sit with the patient, help with meals, washing, and generally occupy a supportive role. Different levels of insurance are available (for various costs), ranging from an insurance for eight hours per day, to 24 hours per day, to homecare after discharge. Sometimes my participants had this insurance and, if in hospital, I would observe the work they do and if possible, informally interview them.

ETHICS

Ethical approval for this research was granted from the Ethics Review Committee of the Department of Anthropology, Durham University. Use of a Study Information Sheet and Consent Form was selective depending on the contexts and the extent of the participation of the 'participant'. I gave out the Study Information Sheet extensively throughout the study and always carried around copies with me. Over time I began to do the Consent Form "orally" as opposed to written because participants found it an odd process or it broke-up conversation and threatened turning a comfortable conversation into something more formal. As opposed to treating consent like a one-off event it was approached as a process which required openness and space for reflection, renegotiation and revisiting throughout the study (Association of Social Anthropologists, 2011).

The biggest ethical issues in ethnography often have to do with being the person in the middle, who knows what might be being said on both sides of a relationship when neither party involved is aware of this. My greatest personal ethical dilemmas in the field were with being asked questions by my participants that I could not answer or admit to knowing the answer, because the information had been gained in an interview where I pledged to maintain the views and information as anonymous. In the final version of this thesis, participants are given pseudonyms to protect their confidentiality. However, there is a limit to which this can be guaranteed seeing that I name the cities I worked in and the institutions who granted me access, although not named explicitly, would be decipherable to any local. To anonymize cities entirely was considered but deemed too detrimental to the contextual depth of this work.

Most of my participants were not concerned about 'being anonymous', and rather preferred that I use their real names. Institutions and health professionals on the other hand are more concerned and it is true that in relative terms they are easier to identify within the

text simply because there might only be, for example, one respirologist in a hospital, but many respirology patients. I have done my best to keep health professionals anonymous in this thesis. I do not believe the information in this thesis could cause harm to anyone, psychologically, professionally or otherwise. I had the fortune of presenting some preliminary findings at four different settings before I left, attended by health professionals and policy makers predominantly and am aware of where there are points of sensitivity. In this thesis I speak of some of these issues but feel that their importance, especially for people who live with COPD and their families, warrant discussion at the risk of upsetting some institutions who would prefer only to speak of their successes and not the challenges they continue to face in providing the care, which, in an ideal world, they would.

CONCLUSION

This chapter has described the ethnographer's path including how I began making contacts in Uruguay, how I met people with COPD and their families and what methods I used to explore the sensorial experience of COPD. It also highlights the multi-sited approach taken, which included participant-observation and various forms of interviewing in hospitals, in homes, at community-events, with Ministry of Public health officials and in smoking cessation services. This broad ethnographic approach to studying COPD in Uruguay helped achieve the aims of the study in that a) I met a very diverse group of people with COPD with access to private or public care, b) I was able to explore the links (Singer & Baer, 1995) which tied the individual to the larger political-economic factors at play by having built rapport with health professionals, hospital directors, engaged researchers and Ministry of Public Health workers and c) the multi-modal ethnographic approach enabled an in-depth understanding of what it feels like to be breathless, and emphasises how COPD is lived differently for different people. Before delving into an exploration of COPD in all its complexity, the next chapter provides some background on Uruguayan history and healthcare.

La Banda Oriental:

A Citizen-History and the History of Healthcare Provision

INTRODUCTION

“It must be interesting for you, Uruguay. We’re a small country and even we don’t know who we are. Neither do we agree on the exact birth date of our country. Uruguay was the port of Montevideo and the Gauchos lived in the countryside of the interior and the country was formed out of an agreement with the British. Uruguay doesn’t have any indigenous peoples and has very few blacks too, there were a few slaves, nothing more. We were almost all Italians and Spanish. We are a country in development and the Uruguay of today is nothing like the Uruguay of 40 years ago. In that time a Uruguayan woke-up, sat-back and had his mate, went into the fields to check on the animals, came back home to eat, and in the afternoon went back out to the fields. Today, people compete for work. It’s a good economic period for the country. Everything we produce, we sell. But you know youths today have changed. You should not walk through the plaza, it is dangerous, and there are cocaine and other drugs.” (Excerpt from my field notes of a conversation I had with the elderly father of a doctor, in her home, in Tacuarembó)

WHO ARE URUGUAYANS?

The opening story was one I had grown accustomed to hearing by the time I left Uruguay. It highlights many of the reasons why 2010-2011 was an interesting time to be in Uruguay. The country was buzzing with contradictory voices: one was euphoric, excited, and prosperous; the other was one of worry, fear, uncertainty, and apprehension to perceived changes in safety, society and youth. There was a certain amount of shared reflexivity going on as the country, formerly called La Banda Oriental (The Eastern Belt), approached its 200th year birthday. However, as the elderly man quoted above attests to, not everyone agreed that 1811 (the year their national hero José Artigas began a revolt against the Spanish) should be celebrated. Some

would say 1825, when the crusade of the 33 Orientals under Lavalleja began, or 1830, the birth date of Uruguay's first constitution, are the founding years of Uruguay. One certain advantage of choosing 1811 was that Uruguay would be celebrating its 200th year alongside its South American neighbours. Argentina for example celebrated its 200th year as a republic in 2010. Table 4.1 provides a timeline of important events in Uruguay's political history as a reference for this section. I want to follow this timeline only indirectly by focusing on a topic that was clearly in discussion at the time of my fieldwork: who are Uruguayans and what is it to be Uruguayan?

Two common features of many stories I was told about Uruguay were, as mentioned in the above field note, "not having indigenous peoples" and "being almost all Spanish and Italian." This is a version of history that has been revisited, critiqued and partially rewritten, mostly by Uruguayan academics and researchers (Arocena & Aguiar, 2007; Bonilla *et al.*, 2004; Olaza, 2009; Vidart, 2010; Verdesio, 2001). The first half of this chapter is dedicated to giving the reader a sense of who Uruguayans are. I focus here on the citizens who have come to identify themselves as Uruguayan and through them make reference to the major historical and political events of the country's pre-colonial, colonial and post-colonial history (Table 4.1).

Indigenous Peoples' Past, Present and Future

One of Uruguay's most distinguished archaeologists and cultural anthropologists, Daniel Vidart (2010), has carried out much research on the Guaraní and Charrúa indigenous peoples who he estimates would have amounted to between approximately 5000 and 6000 people in the area now known as Uruguay. Gustavo Verdesio (2001), in his fascinating book *Forgotten Conquests: Rereading New World History from the Margins*, analyses canonical and non-canonical texts of the 16th, 17th and 18th centuries to shed light on the pre-colonial history of that piece of land sitting at the northern shore of the River Plate and its inhabitants, who had been forgotten or omitted from colonial studies. Guided by Jacques Derrida's (1981) concept of "trace", Verdesio looks for traces of Amerindian voices in historical texts, to reconstruct a history of its lands and the resistance of its peoples. Through his analyses, he portrays Amerindians as agents who fought with, fled from, traded with and negotiated with the Europeans. The landing of the first Europeans in 1516 on the banks of the river plate on the territory of modern-day Uruguay, did not end well for Juan Díaz Solís, the leader of the exploration, as he was killed by the

indigenous peoples. The resistance shown frightened the Spanish and they quickly moved on (Verdesio, 2001).

Verdesio's account stands in contrast to the position of a Uruguayan historian of prominence whose book *A Brief History of Independent Uruguay* states "...cattle arrived before the settlers, who established themselves *easily* because of the scarce indigenous population" [emphasis added](Nahum, 2011, p.9). Vidart (2010), like Verdesio, would say it was anything but easy for Europeans to colonize the land. Faced with harsh resistance from the natives, the first permanent settlement of the Portuguese, *Colonia del Sacramento*, was founded in 1680, more than 160 years after the first landing. Montevideo was only founded by the Spanish between 1724 and 1730. Colonials were not particularly interested in an area not evaluated as rich in precious metals. However, Verdesio (2001) notes how, in the late 16th and early 17th centuries, the discourse surrounding the northern shore of the *Rio de la Plata* began to change. For the first time, references are made to the territory as abundant and fertile, especially for cattle, which were introduced in 1603 by Spanish colonialists, and a change in attitude amongst the Europeans occurs. Colonization begins, partly through the suppression and assimilation of the indigenous Amerindian population.

Although one will frequently be told in Uruguay that all the indigenous peoples were eventually killed by Europeans, according to Vidart (2010) a fact rarely acknowledged is that most of the Charrúas left the territory and settled in Argentinean territory in the early colonial period. Later, during the 18th and 19th century they returned slowly, a migration that was not explicitly registered in Uruguay. Nevertheless, many thousands were killed by disease and by violence at the hands of colonialists, and massacred, such as at the river of Salsipuedes ("get out if you can" in reference to the battle) in 1831 at the hands of republican armies. Vidart (2010) summarizes the massacre of Salsipuedes as follows. In the wake of independence, customs of hunting livestock and general lawlessness of indigenous peoples and those of mixed-race, *los Gauchos*, was perceived as a barrier to guaranteeing private property and advancement as a republic. President Rivera, along with his military men, called-on the indigenous peoples to meet at the river of Salsipuedes on the pretence that there would be negotiations regarding the return of their territory, but that once there they would be distracted and given alcohol and finally ambushed and slaughtered. Very little was recorded about the event at the time (Vidart, 2010) and when I visited the site in 2011, I was surprised to find nothing to commemorate or to note the horrific events which took place there.

Table 4.1: A selection of important dates in uruguay's political history

16 th Century	17 th Century	18 th Century	19 th Century	20 th Century	21 st Century
1516	1680	1724-1730	1806-1807	1903-1930	2002
Spanish Explorer Juan Diaz lands and is killed	Founding of Colonia del Sacramento (Portuguese)	Founding of Montevideo (Spanish)	English Invasions 1811 Start of the Artiguista Revolution of the Banda Oriental 1816-1824 Portuguese Invasion and Occupation 1825-1826 Crusade of the 22 Orientales waging war on Brazil 1827-1828 English Mediation and Peace Agreement 1830 Constitution and birth of the republic 1830 Election of the first President of the Republic Rivera 1835 Election of 2nd President Oribe 1836 Birth of the <i>Blancos</i> (Oribe) and <i>Colorados</i> (Rivera) and first battle: <i>Carpinteria</i> 1839-1851 La Guerra Grande between <i>Blancos</i> and <i>Colorados</i> . 1865-1870 War of the Triple Alliance against Paraguay Economic Crisis 1876-1886 Period of Military Rule 1890 Economic Crisis	Epoca Batlista Launch of social welfare programs and secularization 1960s Economic Decline 1967 Los Tupamaros urban guerilla movement demand reforms 1971-1983 Military Coup and Dictatorship	Major Economic Crisis (Banking sector) 2005 Frente Amplio government take office – President Vazquez 2010 Frente Amplio re-elected – President Mujica

The genocide was not only physical but also social. History was re-written for school-aged children, to emphasize the white, cosmopolitan and educated nature of Uruguayan citizenry (Hentschke, 2012) and indigenous peoples were silenced. As one middle-aged artisan I got to know explained:

“The education system taught us that our country was almost perfect. There are no natural catastrophes, it is a pleasant country and there are no “Indians” something which was in favour of living in a pleasant country. It was seen as something positive. And afterwards, one faces the reality that there was genocide. The history we were taught negated that part. In a neighbourhood near here there is a group of families descended from Charrúas.”

The work of Uruguayan biological anthropologist Monica Sans has challenged the trope “we are all descendents of Europeans.” Her research in Tacuarembó on indigenous markers in the DNA of children born at a public hospital revealed that 62% of their sample had indigenous mitochondrial DNA haplogroups (Bonilla *et al.*, 2004). Based on the growing body of research carried out by Sans and her colleagues they conclude that “...non-European contribution [specifically indigenous and African] to the Uruguayan population has been significantly greater than the assumptions that moulded the national identity concept, especially in some regions such as the northeast, where Tacuarembó is located” (Bonilla *et al.*, 2004, p.297). It is plausible that this research (which many people I met were aware of) coupled with a global movement for indigenous peoples’ rights and voices has encouraged more Uruguayans to seek out and reveal their indigenous roots. Just among those of my participants with whom I completed a family tree, three knew of having an indigenous grandparent or great-grandparent (Figure 4.5), although they did not identify themselves as indigenous. In fact, ethnic identity *per se* did not emerge as a significant topic of conversation among my participants.

Two questions can be posed regarding indigenous peoples in Uruguay. One is, are there indigenous peoples in Uruguay? In 2008, less than 1% of Uruguayans were reported as having indigenous descent (Henderson, 2009). In the most recent census of 2011, 5% of the population claimed indigenous ancestry, the highest being in Tacuarembó with 8% (*Instituto Nacional de Estadísticas*, 2012). Could these be indigenous peoples who, in a changing wave of international indigenous peoples’ rights movement, feel more able to express their identity? Vidart (2012) argues in his article, *There are no Indians in Contemporary Uruguay*, that having

indigenous ancestry makes one *mestizo* (mixed heritage) not indigenous and, therefore, attempts to revive a contemporary indigenous ethnic group and identity is inconsistent with the archaeological and historical records. In the same issue, Sans *et al.* (2012) responded by debating Vidart's definition of indigenous. This debate over identity-politics in Uruguay is growing in anthropology as well as society at large.

The second question that might be asked is what indigenous customs persist in Uruguay or which customs have partial roots in an indigenous past? In a book called *Uruguay: 200 years, Two Hundred Questions* published in honour of the bicentenary, the author, Figueredo (2011), asks the late Uruguayan anthropologist Renzo Pi Ugarte, "what are, if any, the most important indigenous contributions to our current-day culture?" The response was: "In our current culture, there are no indigenous contributions" (p.173). The only thing that Ugarte said persisted in Uruguayan culture was some Guaraní terms for flora and fauna. This begs the question, what counts as a legitimate or significant contribution to contemporary culture? From my perspective a number of indigenous customs and knowledge persist in contemporary Uruguayan cultural practices and beliefs. One is the use of *yuyos* (medicinal plants). I find it hard to believe that such varied and specific information about native plants would have been acquired only since European settlement. Secondly, in the countryside in Tacuarembó I saw many family mausoleums which continued to be placed on the tops of hills. I was told this was probably an indigenous custom which European settlers adopted. Thirdly, the most visible and country-wide contemporary custom of indigenous origin is consuming *mate* an infusion of dried and crushed *mate* leaves, which is consumed through a metal straw from a receptacle made of glass, wood or a *mate* gourd (Figure 4.1). It is a deeply social custom and was frequently a part of my socializing and interviewing. According to Ricca's (2000) fascinating history of *mate*, different varieties of *mate* were consumed all over indigenous South America and the way Guaraní consumed it is very similar, in terms of implements and custom, to modern day Uruguayans.

The *Criollos* and the *Gaucha*

Criollo (Creole) is a term used in Uruguay and across Latin America to connote people who were born in the new world, often of mixed-ethnic background (European and indigenous), who identified themselves as 'of the new world' and not European (Morgan, 2002). In Uruguay, it is a word used for anything that has its origins in Uruguay whether it be



Figure 4.1: Author searching for the perfect *mate* and *bombilla* (metal sipping straw) in a street market in Montevideo. Photo by the author.

peoples, types of food, language or customs. My participants, in their family trees, would say things like “*mi bis-abuelo era criollo*” (my grandfather was Creole) to connote that that person had been born in Uruguay. *Criollo* is closely linked to *Mestizo* (mixed-heritage) although, I found *criollo* to be less about ethnicity and race, and more about national identity. The *Mestizo* is said to be the antecedent of the *Gaucha*, a peoples who share a style of dress, values and lifestyle (Verdesio, 2001). The *Gauchos* in Uruguay are *criollos*, but not all *criollos* are necessarily *Gauchos*. Furthermore, *Gaucha* identity does not follow political borders as they inhabit the area from *Rio Grande del Sur* in Brazil to the south of Argentina (Bouton, 2009).

At the country’s most important celebration of *Gaucha* culture, *La Fiesta de la Patria Gaucha* in Tacuarembó, I spoke to a man representing a *Gaucha* NGO and asked him “Who are *Gauchos*?” He explained that at one time it referred to an ethnic group, essentially the offspring of indigenous and European unions and, therefore, relates in this way to the term *mestizo*. However, nowadays *Gauchos* are people who share a set of values and customs intrinsically related to making a living in the countryside. Verdesio (2001) agrees with this

definition and says the *gauchos*, as they appeared in historical texts “are defined in terms not of ethnicity but of lifestyle” (p. 89). They did not fit clearly into any particular group, and would only become a symbol of patriotism during the wars of independence in which they fought in revolutionary armies. In fact, *gaucho* was in principle a pejorative term referring to someone with bad habits and instincts, of ‘mixed-blood’ (Bouton, 2009), who because of their semi-nomadic lifestyle across a sparsely populated landscape had little regard for majority-law (Ras, 1996). Nowadays the term connotes many positive character traits such as diligence, active, courteous, trustworthy, and hospitable (Bouton, 2009).

The idealized image of the *Gaucho* is almost always of a man with a weathered face, a white beard, and a cigarette hanging from his lips who wears *bombachas* (tapered trousers), a *sombrero* (brimmed hat) a *faja* (sash), a *rastra* (elaborate belt made of leather and metals) with a *facon* (*Gaucho* knife) tucked into it (Figure 4.2). Of any distinct group in Uruguay, the *gaucho* is most closely linked to smoking. A classic example is the *Patria Gaucha*’s trademark photo of the *Gaucho*, used in materials representing and advertising the annual event (Figure 4.3). This watercolour, by painter Wilmar Lopez, born in Tacuarembó in 1924, was selected by the Organizing Commission as the logo for the *Patria Gaucha* because it “represents the typical expression and image of our *gaucho*” (Arezo Posada, 2011, p.275). Interestingly, in the section on the habits and customs of the *gauchos*, Arezo Posada (2011) mentions almost every distinguishing characteristic, except for smoking. This may be a reflection of changing attitudes to smoking due to strong tobacco control policies to be discussed later in this chapter.

Afro-Uruguayans

Another group of *Orientales* who fought in the revolutionary armies and drove the *Banda Oriental* to its independence were people of African ancestry who had been trafficked to the New World as slaves from sub-Saharan Africa in the 18th century (Arocena & Aguiar, 2007). Many were forced into the army and not allowed to leave even though slavery was abolished in 1846 (Andrews, 2010). As Andrews’ (2010) analysis of Afro-Uruguayan history explains, there was an ambiguous relationship between Afro-Uruguayans and the military. While they were forced to sacrifice their lives for a country that looked down upon them, they have subsequently been able to draw upon this history of service to their country to lobby for equal treatment.



Figure 4.2. *Gauchos* standing in the rodeo ring at *La Fiesta de la Patria Gaucha* 2011. Photo by the author.

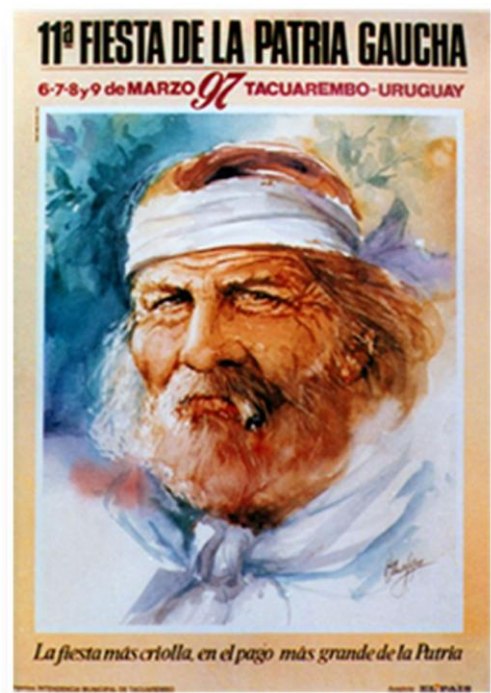


Figure 4.3: Painting of a *gaucho* by Wilmar Lopez, which was selected as the poster-image for *La Fiesta de la Patria Gaucha* 1997, and adopted as an official logo. Photo by the author.

The representation of Africans in Uruguayan history is inconsistent. In the film *La Redota* (Charlone, 2011), released in cinemas in Uruguay near the end of my fieldwork, the story told is of Artigas' elected exile along with thousands of his dedicated countrymen and women as they decided what to do in the face of Spanish domination and Portuguese invasion. Ansina, an Afro-Uruguayan man who accompanies Artigas throughout his life, is portrayed as a skilled fighter and closest friend and confidant of Artigas. In contrast, a clear example of the silencing of marginalized voices (Verdesio, 2001), the historian John Street (1959) almost completely disregards Ansina in his extensive biography of Artigas' life. The reader gets a glimpse of "an aid" and despite the fact that Ansina accompanied Artigas on his 30 year exile to Paraguay his only mention is "...living there with his old black servant and his dog" (p. 371).

Overall, within and outside Uruguay, there has been a lack of recognition of the role Afro-Uruguayans played in the revolution and liberation of their country (Olaza, 2009). However, this is clearly changing. I witnessed one deliberate attempt to make visible the indigenous, *gaucho* and Afro-Uruguayan participation in the wars of independence. This was during the *Fiesta de la Patria Gaucha* which I attended on horseback with a family from the countryside. As Uruguay was celebrating its bicentenary celebrations, the theme of that year's *Patria Gaucha* was "Artigas". The theme is central because one of the main events and attractions are the re-creations of historical scenes by the *Sociedades Criollas* (Societies representing Creole tradition). These societies, whose interests are in *tradicionalismo* (traditionalism) (Arezo Posada, 2011), that is, traditional country ways of life and values, compete for the prize of best re-creation. These are elaborately prepared many weeks before the start of the *fiesta* along the banks of the *Languna de la Lavanderas* (the lagoon of the washer-women).

In 2011 there was a clear focus in a number of the recreations on the multi-cultural nature of Artigas' devoted countrymen and women. Various indigenous and Afro-Uruguayan traditions were represented. In this live-action, open-air museum, the message was that Artigas saw no reason to consider any man better than any other man, and that all were *Orientales* with the dream of being free and defining for themselves who they would be. Artigas's declaration in Article 6 of the *Reglamento* stated: "the most unfortunate shall be the most privileged. Consequently free Negroes, *Sambos* in the same condition, Indians, and poor Creoles, all may be granted *estancia* lots, if with their work and their probity they are inclined towards their own happiness and that of the Province" (Street, 1959, p.227). According to

Street “...this noble sentence proves Artigas’ right to a place in the first rank of the liberators of Spanish America...” (p. 227).

Unfortunately, Artigas’ inclusive vision of *Orientales* did not survive well through the period of civil war and thereafter. Nowadays, Afro-Uruguayans are discriminated against explicitly through racist action and inaction and implicitly through unequal living standards, access to health and education, and employment opportunities as the collections of personal narratives to be found in Arocena & Aguiar (2007) and Olaza’s (2009) books make explicit. Although early in the slave trade period Afro-Uruguayans comprised up to one third of the population of many cities on both sides of the *Rio de la Plata* (Arocena & Aguiar, 2007), since then their proportion in the population has descended to approximately 9% of the population (Andrews, 2010). Some of the reasons for this include: the eventual ban on the slave trade, the increase in European immigrants, and intermarriage with Europeans (Arocena & Aguiar, 2007).

Nevertheless, African traditions not only persisted but were taken up by Uruguayans of all backgrounds. One such tradition is *Candombe* (drumming music performed in processions) which in contemporary Uruguay is seen as traditionally African but participated in increasingly by non-Afro-Uruguayans. Andrews’ (2010) book *Blackness in the White Nation: A History of Afro-Uruguay* discusses how, on the one hand *Candombe* was a way for Afro-Uruguayans to make themselves visible but, on the other hand the increasing commercialization and popularity of *Las Llamadas* (a *Candombe* parade in *Carnaval*) (Figure 4.4) offered a way for the government to construct their version of history and tradition (Andrews, 2010). Another very visible Afro-Uruguayan tradition which has grown in popularity amongst the population is the Umbanda religion. My walk down Ramirez beach on the day of the Umbanda Goddess Llemanja confirmed that, in Montevideo at least, the followers of Umbanda rituals are of every ethnic group. Umbanda, says Hale (1994), is a plural religion that has its origins amongst the descendents of the African slave-trade who lived around Rio de Janeiro who continued to practice a diversity of African religions. Today in Brazil she says, “...millions of Brazilians, of all classes and colors...participate in Umbanda” (p.11). A similar trend is occurring in Uruguay. Although only 1% of the population defines their religion as Umbanda, 4% respond that they sometimes go to Umbanda temples (Arocena & Aguiar, 2007).



Figure 4.4: Candombe drummers at Las Llamadas 2011. Photo by the author.

Mixed-European Descent

Artigas' vision of a federation of United Provinces (which would include modern-day Uruguay and Argentina) never materialised and he was already in exile in Paraguay when Uruguay eventually achieved independence in an agreement between Argentina and Brazil, mediated by the British. Great Britain invaded Uruguay in 1806 but their interests remained in the area of trade with Montevideo. Montevideo's port then and still today, is the largest port in the area and the entrance to the region of South America known as the Southern Cone (Argentina, Southern Brazil, Chile, Paraguay, Uruguay). Three participants I could not complete family trees with had Irish, Scottish and English ancestors. Great Britain has had a long history of investment in the country, particularly in the wool, meat and railroad industries, a history documented in great detail by historian Peter Winn (2010). In turn, these industries attracted huge numbers of migrant labourers from Spain and Italy who joined the original descendents of European, African and indigenous peoples. Waves of Italian immigration continued up to World War Two and today around 100 000 Uruguayans have dual citizenship with Italy and

around 40% of Uruguayans have partial Italian ancestry (Arocena & Aguiar, 2007). Their mark, particularly on the dominant religion, Catholicism, and on food was well established. In Uruguay, the diet consists of meat (clearly from a long tradition), pasta, rice, pizza and dough-based crackers and bread. Native and imported fruits and vegetables are consumed but not with the same sense of necessity as meat and carbohydrates.

What gets acknowledged much less in popular discourse, according to Arocena & Aguiar (2007), is the degree to which Uruguay is far more multicultural than simply Spanish and Italian. Indeed, Uruguay was and is still multicultural in terms of European ethnic origins. Arocena & Aguiar's (2007) research on multiculturalism in Uruguay, which includes narrative interviews with 11 cultural communities carried out by themselves and 27 of their sociology students, gives these minority-cultures a voice and a face and is a must-read for anyone interested in the topic. The data I gathered from my participants with COPD and their partners reflect this narrative of multicultural Uruguay. In Figure 3.5 each circle represents one respondent and the family origins they were aware of on either the maternal or paternal side. It is not surprising that so many of my participants reported having Basque ancestry. According to Arocena & Aguiar (2007), 10% of Uruguayans (300 000 people) have grand-parents, great grand-parents or great-great-grandparents who came from the Basque countries.

Overall, race and ethnicity discourse in Uruguay is attenuated. As Andrews' (2010) historical-ethnographic account of Afro-Uruguayan history suggests, there has been a tendency to downplay the multi-ethnic nature of Uruguay, and to deny that racism was, or is ever, a problem. Questions concerning race and ethnicity were absent from the household surveys conducted by the National Institute of Statistics until 1996 and 1997. The first survey to include the data showed, in glaringly obvious terms, inequalities in all health and social indicators between Afro-Uruguayans and white Uruguayans (*Asociacion Cultural y Social Uruguay Negro*, 2009). Travelling throughout the cities and within hospitals, one will notice very quickly that wealthy areas, politicians and business people and university students are mostly white and as one enters the poorer neighbourhoods at the margins, there are visibly more citizens of darker complexion. On brochures produced by the government, the archetypal face of the Uruguayan is white (Figure 4.6). Socially, what would be considered 'racist' terminology in North America or the UK is normalized amongst the white population in Uruguay. A friend of mine was called *chino* (Chinese) by some because his eyes were more almond shaped than most. The darkest person in a group is frequently called *el negro* (black) or *la negra*. Generally, in home and social

situations it is used as a term of endearment. I was frequently addressed as *mi negra* or *mi negrita* in everyday conversation, such as *hola mi negra, como estas?*, particularly by other close female friends. However, Andrews' (2010) book gives the English-language reader some perspective on the controversy of the word usage despite its prevalence.

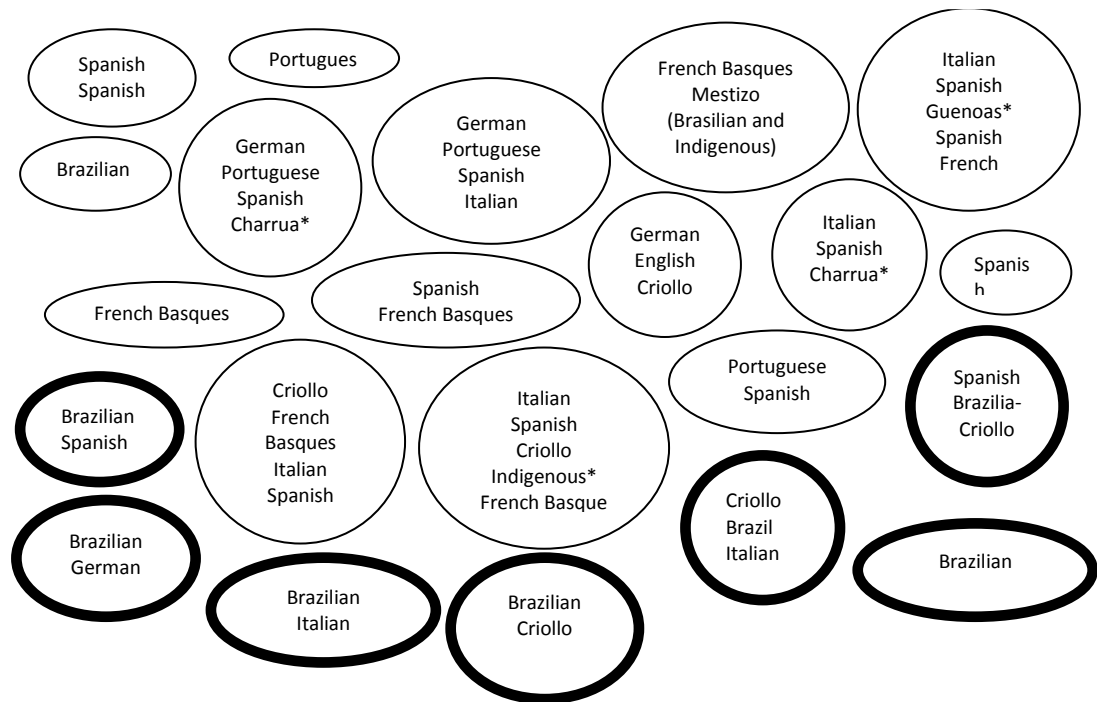


Figure 4.5: Reported ancestry of a sub-group of participants with COPD and their spouses. The dark circles represent participants from the Interior. * = Indigenous Groups.

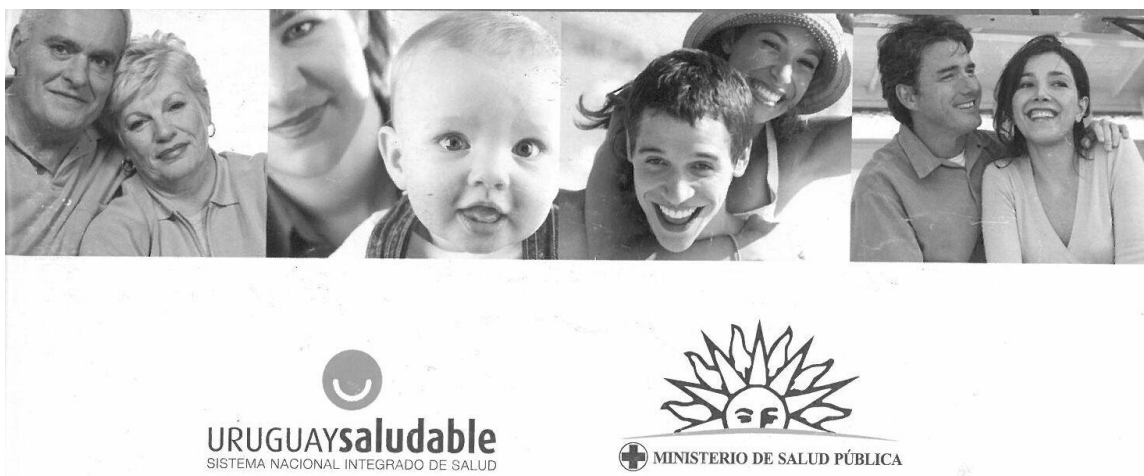


Figure 4.6: Section of the cover-page of the Ministry of Public Health report “La Construcción del Sistema Nacional Integrado de Salud 2005-2009” (Ministerio de Salud Publica 2009).

Uruguayans of Montevideo and Uruguayans of the Interior

A division much more openly debated, not officially a question of race, is that of Montevideo versus the interior. In Uruguay, anyone outside of Montevideo is considered to be *del interior* (of the interior). The country is divided into the capital and the interior (anywhere outside of Montevideo). The division becomes starker the further north one goes. While many Montevideans I met would travel to the south-west towards the tourist town of Colonia de Sacramento and to the south-east for the beaches and hills, far fewer have ever been so far as Tacuarembó and those who had, often made just a short journey to visit family or for work. This division was put most aptly by one of my housemate's parents who said, "The *Rio Negro* is the marker for essentially two different countries." The comment resonates greatly when one looks at a map of Uruguay, representing the percentage of the population under the age of 15 by province (Figure 4.7). Demographically, north and south differ. In the north the percentage of the population under the age of 15 ranges from 22-26%, whereas in the south, almost perfectly below the *Rio Negro*, the population under the age of 15 is between 19.2 and 24%, Montevideo being the only Department with 19.2% of the population under the age of 15.

That Montevideo and the Interior are almost more different than they are similar, demographically, culturally and politically, has deep historical roots. In colonial times, the *Orientales* who lived in the Interior rebelled against a Spanish-controlled Montevideo, which understood little of the needs and ways of life of the interior. The traditional political parties, *Blancos* and *Colorados* emerged to defend the interests of the interior and of Montevideo respectively. Generally, while Montevideo looked eastward to Europe, the interior looked westward to the rest of Latin America. These divisions continue to present day. Montevideo was seen by most of the people from the interior I interacted with as too big, too dangerous, too much like Argentina. Montevideans made implicit and sometimes explicit reference to the interior as being full of *gauchos*, backward, uninteresting and superstitious. However, it was clear to me that the interior-capital distinction was reproduced on a smaller scale all over the interior on the basis of city versus countryside. Contamination was a word used on a number of occasions by people I met in reference to the influence of Montevideo on the interior and of the influence of Buenos Aires and Brazil on Uruguay. A middle-aged *Gaucha* said to me "Montevideo is contaminated by Buenos Aires, and Artigas and Rivera (two interior cities on the northern border) are contaminated by Brazil." The mother in her thirties with whom I lived

in *Barrio Lopez* commented that Montevideo is crazy and really hopes “*Tacuarembó no se contamina*” (does not become contaminated).

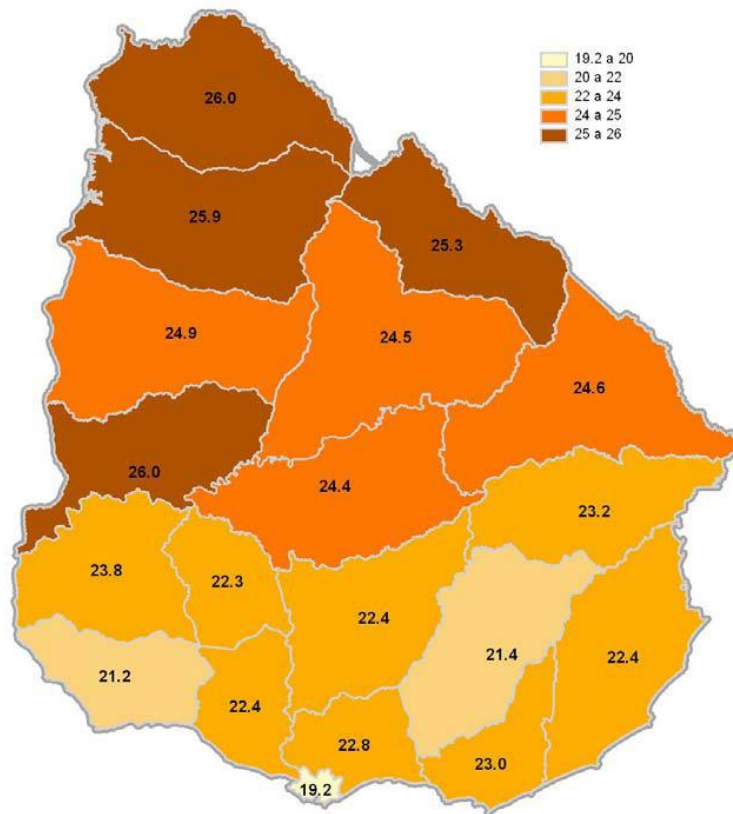


Figure 4.7: Percentage of the Population under the Age of 15 (*Instituto Nacional de Estadística, 2011*)

This was not simply a case of urban versus rural. Uruguay’s population is almost 95% urban according to the 2011 Census (*Instituto Nacional de Estadísticas, 2012*). My fieldsite, Tacuarembó, the city, went from a population of 51,224 in 2004 to 54,757 in 2011. The entire department of Tacuarembó is home to 90,000. The next biggest city, Paso de los Toros, where I travelled to sit-in on smoking cessation groups, has a population of almost 13,000, leaving a modest 27,000 people spread across the biggest department of Uruguay. What was once the sleepy town of Tacuarembó, the town with the most bicycles in the country, has now more motorcycles than people ripping through the streets, all the chain clothing, home wares, and

supermarket stores found in the capital, and luxurious housing next to the typical square, slanted-roof, cement *casa humilde* (humble home).

Certainly, daily life differed significantly between Montevideo and Tacuarembó. In Montevideo I would take the public buses everywhere, which I found worked very well to the amazement of almost all the Uruguayans, with whom I spoke. The hospitals were all concentrated in the same area but my participants were all over the city from the upper class neighbourhoods of Pocitos and Carrasco, to the working class barrios of Piedras Blancas and Barrio Ruiz and finally the slums on the outskirts of el Cerro. A few of my Montevideo participants lived in the interior in the eastern departments of Canelones and Maldonado. These places in the interior were described to me as *mas tranquilo* (more quiet and tranquil) than Montevideo and that people who lived there led calmer and safer lives. To relax and socialise, the people in Montevideo and eastwards headed for the coast. Montevideans met on the *rambla* (the boardwalk which stretches for miles along the coast of Montevideo) to sip *mate* and watch the sunset. Those along the east coast to long beaches to contemplate the waves and the dunes.

In Tacuarembó, there was no public transportation and I moved around the city on a bicycle. Like many other towns in the interior, *la siesta* is practiced and shops are closed between 1 and 3pm. Because the town is small enough to get around quickly, people can return home to eat lunch -the biggest meal of the day- and sometimes have a nap afterwards. The *merienda* (afternoon tea) is also observed, and dinner was eaten a little earlier than in Montevideo. With no coast to flee to, people in Tacuarembó sat outside their homes on permanent benches or chairs on the sidewalks and shared news with neighbours (a practice becoming increasingly rare in Montevideo and probably in Tacuarembó too). If one could get there, the *balneario*, a park with a man-made lake 7 km from the town, was also a popular leisure spot.

The feeling that the country was divided between north and south of the *Rio Negro* was also corroborated by what kinds of television and music people enjoyed. In the evenings in Montevideo, in homes where there was a TV, I found myself watching more Argentinean soap operas (*telenovelas*) and music. In Tacuarembó, being only 100 km from the Brazilian border, people happily watched Brazilian shows in Portuguese, as well as listened to traditional folk music, such as the polka, milonga and tango. A mix of Spanish and Portuguese, *Portunol*, was spoken by a few of my participants and I was impressed by how well most people, especially

children, could comprehend Portuguese. In addition to the interior versus the capital, the other major issue which divides the country at the household level is whether one supports *Penarol* or *Nacional* - the two largest football clubs in the country (ironically both based in Montevideo).

HISTORY OF HEALTHCARE AND PUBLIC HEALTH IN URUGUAY

Now that the reader has a sense of the history of Uruguay and contemporary life, I now continue into the history of healthcare in the country, which is intimately intertwined with the political and economic development of the country during the 20th century. But first, a word on traditional forms of healing and their continued importance.

Traditional Forms of Healing

Any person travelling in Montevideo soon notices the plethora of healthcare services on offer in the city. And while the biomedical system dominates, one quickly notices the prevalence of medicinal plants called *yuyos* (sold in markets, in pharmacies and specialty shops, Figure 4.8), homeopathic medicines and clinics, acupuncture services even within hospitals, and various other options such as flower remedies. What are perhaps a bit less obvious, and require listening attentively to people and meeting those willing to share, are the beliefs in spiritual-healing via incantations, magic words, rituals and prayers. In Uruguay this was frequently referred to as *vencer* – to defeat or vanquish the illness by commanding it to leave the body, normally concluded by saying “in the name of” biblical figures, such as the Virgin Mary, God, or the Holy Spirit. Some people I spoke to who practiced these incantations said that the words are secret and can only be told to three people in one’s life who are supposed to carry on the healing tradition. Although my young professional friends in Montevideo told me *vencer* “was something of the interior”, in a tone connoting all their ‘modern’ scepticism, it clearly was not an exclusive view and I met many people who told me about *vencer* and *vencimiento* across the country. How prevalent its use is would require further research but I lived with a woman who performed these rituals, met many people who had been taken to such healers as children, and I even discovered that some of my participants with COPD had such hidden talents. It was something to be kept quiet however, and two women in particular told me they tell people not to go around saying they perform these healing rituals because “*van a pensar que soy medio bruja*” (they will think I am a kind of witch). A detailed description of these

rituals need not appear in this thesis, however, from repeated interviewing of one such *curandero* (healer - although he did not think his abilities warranted that label) I learned how some of the rituals are performed and the incantations spoken. Spiritual healing was popular for treating rashes and abrasions on the skin, such as shingles (*culibrilla*), digestive problems or stomach pain (*paletilla caida*), evil eye (*mal de ojo*), muscle and joint aches and pains and constipation in children (*el empacho*).

Yuyos, on the other hand, were much more common and their use far less stigmatized. Medicinal plants could be used for all kinds of ailments including coughs and colds, bronchitis, indigestion, skin afflictions, nerves and the flu. I was told on a number of occasions that for people in the countryside, these are the first ports of call and only if that which comes from *el monte* (the forest) doesn't work, then they will go to the doctor. It was unsurprising to me that the most common remedies had to do with respiratory problems, stomach and digestive distress and nerves, because all of these were common afflictions. The diet, heavy in meat and bread-products, certainly left one feeling weighed down, sluggish and sometimes with reflux and bloating.



Figure 4.8: Yuyero with his hand-picked and hand-dried medicinal plants for sale in a Sunday street market. Photo by the author.

Medicalisation and the Domination of Biomedicine

Although plant-based, spiritual and more transnational alternative therapies are common in Uruguay, it is their advanced biomedical system and healthcare system that they are known for. Medicalisation of Uruguayan society has been theorized and written about by a famous Uruguayan historian and philosopher, José Pedro Barran, who has written extensively on the history of Uruguay including the topics of sexuality, medicine, religion, and morality. In *Historia de la Sensibilidad en el Uruguay*, Barran (1989-1990) weaves historical documents, textbooks and arguments into an engaging discussion of the way in which the 'civilizing' of Uruguayan society was tied into a growing discourse on health, hygiene and morality in the late 19th and early 20th centuries. Barran describes how textbooks for pupils proclaimed the importance of hygiene for health and framed it as a moral reflection of the person, their respect for themselves and for others. He refers to this process as the "disciplining of the body" (*disciplinamiento del cuerpo*, p.252), which resonates with the writings of Foucault (1973). He says that to clean and keep clean (house and body) was the lay translation of asepsis and represents the medicalisation (*medicalizacion*) of the bourgeois desire to dominate one's drives, including sexual drives.

Uruguay's medicalisation, as a society, has had positive public health outcomes. Historically, it has stood out from its Southern Cone neighbours in terms of its health and social policies and development indicators (Weinstein, 1975). Valuing health and especially the health of those most in need has a long history in the country, arguably dating back to the ideology of their national hero Artigas. Based on letters written by Artigas, Street (1959) contends that Artigas actively helped:

“...an Englishman who came to spread vaccination among the peoples of the Federal League. Smallpox was a scourge, especially terrible among the Indians of the Misiones to whom Artigas gave the greatest consideration in this matter” (p. 242).

The oldest public hospital in the country, *Hospital Maciel*, previously named *Hospital de la Caridad*, was founded as early as 1788 and operates to this day as a state-funded public hospital. It is also the location of the Department of Respiriology of the University of the Republic.

However, it is the period of the early 20th century which revolutionized the country; this time not with arms and warfare, but with social welfare under the President Batlle y

Ordoñez of the historical *Colorado* party. Apart from a commitment to providing free public healthcare, other revolutionary policies for the time included allowing women to divorce without the consent of their husbands in 1905 and the removal of all Catholic religious images from hospitals in 1906. This was done on the basis that public spaces should not impose particular religious groups' symbols on peoples of multiple faiths who frequent them. In education, new programs and professional schools were developed and the interior saw the creation of high schools in each department's capital. In 1909, religious teachings in public schools were stopped. The calendar became officially secular, so that, for example, 'officially' Christmas Day is called Family Day and Easter, Tourism Week. Unofficially, the Catholic terms are still widely used alongside the secular ones, frequently interchangeably.

Over the period to 1930 the presidency was either held by Batlle y Ordoñez or a supporter in the *Colorado* party, which led to a relatively consistent approach to politics over the period, a period referred to as *la Epoca Batllista* (The Batlle Era). Over this period, the eight-hour working day, old age pensions, public education and, especially important in this context, public and secular healthcare were implemented. It was during this period that the idea of a hospital dedicated to medical teaching and research was born. In 1930 the foundation stone of the *Hospital de Clinicas* was laid and it was opened as a public hospital under the direction of the Faculty of Medicine of the *Universidad de la Republica* in 1953 (Figure 4.9). In Uruguay then and now, to study at the University of the Republic is free, there are no caps or prerequisites on admissions to study medicine and consequently, Uruguay has 38.7 doctors per 100,000 people, giving it the highest proportion in Latin America after Cuba (PAHO, 2008).

The golden age of social welfare and a supportive economy of high demand for meat and other products during the 1st and 2nd World Wars, would not last. Weinstein's (1975) book, *Uruguay: Politics of Failure*, is a historical analysis that draws also on field research carried out in 1969 and 1970 and opens with the following:

“‘The Switzerland of South America’ was the title Uruguay enjoyed for much of this century. The reference was not topographical; rather it was meant to describe a small nation-state (almost a city-state) whose citizens enjoyed a standard of living, levels of literacy and health care, and, most importantly, a degree of political democracy and public decency which set the country apart from its sister South American republics. Uruguay was considered an idyllic pastoral land with two traditional and highly competitive political parties, a flourishing academic and cultural life, and two and one-

half million people, almost half of whom lived in the sophisticated urban sprawl of Montevideo. The image, like all stereotypes, was exaggerated, but it did reflect reality, at least until recent years. Today, Uruguay is a *de facto* military dictatorship. The country is economically and politically bankrupt. Congress is closed, unions and most political parties are outlawed, press censorship is strictly enforced, an externally controlled university barely functions, and thousands of political prisoners languish in cells while tens of thousands of their fellow countrymen emigrate.” (p. xiii).



Figure 4.9: The author in front of *Hospital de Clinicas*. Photo by the author.

Economic downfall and corruption across Latin America bred urban guerrilla movements such as the *Tupamaros* in Uruguay, who amongst other actions, captured and held the UK diplomat Geoffrey Jackson prisoner for almost a year in 1971; an experience he describes in his book *People's Prison* (1973). The military soon went from attempts to squash the *Tupamaros* to persecuting any opponents to the regime and leftist-minded citizens in general, particularly intellectuals, artists and writers. As Weinstein (1975) highlights, the military coup of 1973 and the ensuing 12-year dictatorship was a period of suffering; bodily, psychological, and ideological and even more so for a country which had prided itself on being

an advanced democracy. I heard many such stories of suffering by my participants with COPD, and the doctors who studied medicine over that period and was told that almost one third of all adults had spent at least one day in jail. Andrews (2010) similarly reports that “...the armed forces arrested and imprisoned an estimated eighty-seven hundred political prisoners, giving Uruguay the highest rate of political incarceration anywhere in the world” (p.144). Between 1963 and 1975, 200 000 Uruguayans, 8% of the total population, left the country, many of them young professionals (Nahum, 2010). Torture was rampant and 300 people ‘disappeared’.

The military implemented an amnesty law in 1986 to prevent the persecution of those who committed war crimes and human rights abuses and ever since it has been an issue dividing the country. A referendum in 2009 on whether to scrap the amnesty resulted in 53% of the vote in favour of maintaining it. The effects of the dictatorship are documented in national and English-language literature, in the latter category perhaps more so than any other topic concerning Uruguay (Gregory, 2009; Taller de Genero y Memoria, 2003; Weinstein, 1975; Weschler, 1990). The healthcare system, in particular, suffered under dictatorial rule. The *Hospital de Clinicas*, one of the largest public tertiary care providers in Montevideo, became severely underfunded as it received its funds exclusively from the University, which housed the intellectuals whom the dictatorial regime were trying to suppress and torture (Gregory, 2009).

Over this period the public sector became increasingly impoverished due to a lack of investment, while continued economic difficulties widened the gap between the rich and poor, dissolving what had been a very large middle-class. The last major economic crisis in 2002 again dealt a blow to public healthcare. How this played out in one public health hospital, *Hospital Maciel*, is the topic of Uruguayan anthropologist Eduardo Alvarez Pedrosian’s ethnography *Los Estrategas del Maciel* (2009). His ethnography includes testimonies of hospitalized patients, who have always and continue to be identified as ‘the poor’, living out the worst period of the economic crisis when conditions within the hospital and access to essentials, such as basic medications, were lacking. His ethnography is a critique of the neoliberal model of healthcare through an analysis of the subjectivities of those who become subjects of the medical system but ends on the hopeful topic of healthcare reform.

Healthcare Reform

The election of the *Frente Amplio* at the presidential election in 2004 will go down in history as one of the most important events in Uruguay’s political history (Gregory, 2009). For the first

time in the history of the Republic, a government was not of the two traditional parties: the *colorados* and the *blancos*. It was also the first time in the words of Gregory (2009) that the President, Tabaré Vazquez, was “not to be a product of the national political elite – he was born, lived and worked as a doctor in the working-class Montevideo suburb of La Teja” (p.106). Although he was not of the political elite, he was a practicing oncologist; a powerful and elite professional class in Uruguay. This section will focus on the healthcare reform however, it is important to mention that many social policies implemented by the *Frente Amplio* would have an impact on overall human health and well-being, much like the policies of the Batlle y Ordoñez era. For instance, even though the economic situation was only slowly recovering, one of the first things to be done under the *Frente Amplio* was to create the Ministry of Social Development, which put into place an emergency assistance plan that would provide a monthly stipend to families living in extreme poverty. Between 2005 and 2007, 80 000 families accessed these plans (Nahum, 2010) and poverty went from 32% of the population in 2005 to 20% in 2008, meaning that 400 000 people were raised above the poverty line (Nahum, 2010).

One of the most important government programs underway during my fieldwork was the *Sistema Nacional Integrado de Salud* (SNIS) (National Integrated Health System), a large-scale healthcare system reform that began in 2007 and will take at least a decade to fully implement. My understanding of the reform comes from meetings I had during my pre-fieldwork trip with a health economist in the Ministry of Public Health and Daniel Olesker, who became the Minister of Public Health in March 2010, in addition to other ministry workers met throughout fieldwork. The primary documentation I draw on is the report *La Construcción del Sistema Nacional Integrado de Salud 2005-2009*, published by the Ministry of Public Health in Uruguay, which discusses the historical origins, organization and outcomes to date of the new reform (Gonzales & Olesker, 2009) and the 2010 report *Transformar el futuro: Metas cumplidas y desafíos renovados para el Sistema Nacional Integrado de Salud* (Ministerio de Salud Pública, 2010).

The major issue driving the need for reform was that, despite the fact that the private mutual hospitals are heavily regulated by the government, the Ministry of Public Health noticed that the fees for service had become a profit-making enterprise, as opposed to a small disincentive for superfluous use of healthcare services (Ministerio de Salud Pública, 2010). The outcome was that individuals who could afford the monthly cost of private mutual institutional-affiliation were experiencing the cost of *tiqués* (fees for services) as a barrier to

accessing those services. The other problem with the system was that public hospitals, unable to generate sufficient income from largely non-paying users over the years, especially during the dictatorship, became severely impoverished compared to those in the private sector, in terms of infrastructure, equipment and personnel. The situation was, and still is, in some but not all realms of healthcare, an example of what Janes (2003) describes as producing poor medicine for poor people.

The aim of the reform is to make healthcare access and quality more equitable across institutions and levels of care in Uruguay and to support more primary care. One way it does so is by integrating the entire population into a central health-funding scheme called *Fondo Nacional de Salud* (FONASA). Interestingly, the reform does not involve dismantling the strong institutional history of private mutual hospital healthcare provisions. Under the new reform, citizens in formal employment contribute to the FONASA and will choose which healthcare provider they would like to be affiliated to, public or private. The FONASA then pays out a standardized amount, calculated on the basis of various indicators such as age and sex, to the institution who then care for the healthcare needs of that individual. In this way, the private mutual system is maintained, and so is the notion of competition between various institutions to attract members. So far, half of the Uruguayan population has been integrated into the FONASA program. This began with civil servants, then their wives, then all children and is now broadening to other persons in employment. Individuals contribute a percentage of their salary to FONASA and so do their employers. The aim in the next five years is to expand this to all persons, whether legally employed or not. Contributions to FONASA will provide the funds necessary to improve the quality of care in public hospitals. In 2008, Uruguay was spending 23% more on healthcare as opposed to 2004 in real terms, however, that accounted for 7.5% of its Gross Domestic Product GDP on healthcare as opposed to 8.5% in 2004. The amount individuals spend, out-of-pocket, on healthcare as a percentage of national healthcare decreased from 22% in 2005 to 17% in 2008, in line with government objectives (Cabrera *et al.*, 2010).

The Preventive Turn and Tobacco Control

An important aspect of the healthcare reform is also a focus on primary care and preventive medicine. Within the Ministry of Public Health, there is now a Program for the Prevention of Non-Transmittable Disease and I attended the first civil society and governmental Forum on

non-Transmittable Disease in 2011. Within the reform are a number of priority areas, including female reproductive health, diabetes, hypertension and smoking cessation. As was reviewed in the introduction of this thesis, the inhalation of tobacco smoke is the primary risk-factor for COPD. Until relatively recently, Uruguay had one of the highest smoking rates in the world. Half of all men and a third of women in Uruguay have smoked in their lifetime and more than 60% of men over the age of 55 are or have been smokers (*Sindicato Medico del Uruguay*, 2009). Amongst Uruguayans aged 65 years and over, the principle causes of death are cardiovascular diseases, tumours and chronic respiratory diseases, acute respiratory infections and pneumonia (PAHO, 2008), all of which are smoking-related diseases (Sandoya, 2010). The high rate of smoking in Uruguay, 33% in 2006, is intimately linked not only to their estimated rates of COPD but to high rates of many chronic diseases including cancers.

The availability and controversy over tobacco goes back a long time in Uruguay. Artigas, while he was operating as a member of the Spanish army was charged with trying to control smuggling and unlawful behaviour in the interior, which included the smuggling of Brazilian tobacco into the country (Street, 1959). Today, there is still a serious problem with counterfeit and contraband tobacco, which escapes high taxation and lawful sale norms, such as warning messages on packs (Fundacion InterAmericana del Corazon, 2010). Tobacco is mostly smoked either in industrial cigarettes or rolled by hand. I was also frequently told about *naco*, also called *tabaco en cuerda* (roped tobacco), especially in my interior field site, where some of my participants occasionally smoked *naco*. This tobacco is marinated and dried in strips that are woven in a rope-like shape. Pieces are cut from the rope of tobacco leaves into small pieces and traditionally rolled in a corn-husk and sealed shut by tying a string of corn-husk around the cigarette.

On July 24 2004, Uruguay signed the WHO Framework Convention on Tobacco Control under Law 17.793. On the 10th March 2008 tobacco-control policies were incorporated under one law, 18.256. Civil society organizations, in particular CIET, were instrumental in lobbying the government to take this step. Tabaré Vazquez a practicing oncologist, who became President in 2005, began implementing tobacco-control policies, such as a ban on smoking in enclosed public spaces including bars, restaurants and workplaces, steep rises in taxes on tobacco, an 80% coverage of cigarette packs with warning images and slogans and investment in smoking cessation (CIET, 2010). In 2006 the WHO awarded Tabaré Vazquez the World Health Organization's World No Tobacco Day 2006 award for his government's actions and

commitments in tobacco control. Fortunately, for both the healthcare system reform and for tobacco-control, the 2009 elections re-elected a *Frente Amplio* candidate, this time José 'Pepe' Mujica. Mujica represented not only a second-term for *Frente* but also a second-term for a non-conventional President. Mujica had been part of the urban guerrilla movement *los Tupamaros*, was jailed for 12 years under dictatorial rule, escaped prison by tunnelling out with his wife, who is now a senator, and ascended the political ladder to presidency. Although supportive of tobacco-control, Mujica had other priority areas in mind, such as housing for the poor. There was a sense amongst many of my participants in the tobacco-control sector that the new president and Minister of Health were less committed to tobacco-control. Nevertheless, re-election of the *Frente Amplio* meant that they could more easily keep it on the political agenda.

Especially important in this regard was Uruguay winning the bid to host the WHO's 4th Framework Convention on Tobacco Control (FCTC) Conference of the Parties (COP). This meeting occurs every two years during which official delegates from countries who have signed the FCTC treaty, as well as members of tobacco-control NGOs, meet to revise and develop the articles of the treaty and guidelines for tobacco-control measures. In 2010, over 1000 delegates from over 160 countries met in Punta del Este (east of Montevideo) for a week of intensive debate, discussion and consolidation of the international goal of tobacco-control. At this meeting, which I attended with Dr Andrew Russell, a Uruguayan was elected to become the President of COP5 to be held in South Korea, thus keeping tobacco control firmly on the agenda, at least until November 2012. Perhaps the most unforeseen advantage of hosting the COP was the opportunity to publicise the legal war waged against Uruguay by the tobacco-giant Phillip Morris earlier that year.

Phillip Morris International launched an arbitration against Uruguay at the World Bank Tribunal on the basis of a bi-lateral trade agreement between Switzerland (where they have their head office) and Uruguay, which they claim is being breached by Uruguay's stringent policies on the size of warning images on packs (80%), their ban of light cigarette brands and the graphic images they use to raise awareness of smoking-related diseases. Also supporting Uruguay's case in the arbitration, is the impact the policies have had on public health so far. CIET has reported a 19% decline in the number of hospital admissions for heart attacks in the two years since the smoking ban in public spaces, as compared to the two years prior to the ban (Sandoya, 2010). The Global Adult Tobacco Survey (GATS) reported in 2009 that warning

labels on cigarettes had made 44.6% of current smokers think about quitting. Overall, the smoking rate has gone from almost 32% in 2006 to 24% in 2009 since the laws were put in place. Uruguay has the advantage over its neighbours that national tobacco production is not a significant part of the nation's economy like in other countries such as Brazil, Cuba, Argentina and Mexico (Muller & Wehbe, 2008). The far-northern region of Uruguay used to have a significant tobacco production industry (Haverstock & Hoover, 1975), however, at least one large plant in Tacuarembó closed over a decade ago. Recently, after losing a national legal case against the Uruguayan government, the Phillip Morris subsidiary company, Abal Hermanos S.A, closed its processing plant in Montevideo and allegedly moved it to Buenos Aires.

Uruguay has to negotiate two distinct identities in public health in relation to tobacco. One is that of world leader and role-model in tobacco-control, particularly for middle and low-income countries. The other is that of victim of tobacco-industry intimidation and impoverishment through expensive litigation.

CONCLUSION: SOMOS DEL TERCER MUNDO (WE'RE OF THE THIRD WORLD) AND WE'RE A MODEL

At the time of my fieldwork in 2010, as mentioned at the very beginning of this chapter, Uruguay was a place of conflicting narratives. In the tobacco-control world, it was both a model for the developed and developing world for not only its comprehensive application of almost all the FCTC articles, but also for its position as *luchador* (fighter) against the tobacco industry. However, when it joined the First World in terms of tobacco-control, it remained a country with growing inequalities, challenged by limited resources and a precarious economic situation. Although it was doing well economically, the 2002 economic crisis was still very much at the forefront of peoples' consciousness. The 2002 crisis, like those before it, drew Uruguay closer to its Latin American neighbours, from whom, historically, it had tried to distinguish itself. While there is certainly still a widespread idealization of Europe (particularly in Montevideo), which favoured my acceptance in the country, there is also recognition that European dreams and ideals can quickly disappear when housed in Latin American realities. A reality made up of fragile economies and dependence on international organizations. Despite Uruguay's relative wealth in comparison to its neighbours, it was this sense of dependence upon other nations who controlled them (the USA was frequently mentioned), that led people to identify as being "of the Third World."

The narrative “we’re all European” is being replaced with alternative narratives which include recognition of a more multi-cultural and multi-ethnic Uruguay. However, as I found in my study, despite having a sample of people with COPD from various ethnic origins, ethnicity did not figure widely in their narratives. What was a more pervasive category was, as Alvarez Pedrosian (2009) found, simply identifying people as poor if one used public healthcare institutions. However, as higher proportions of people of Afro-Uruguayan and *mestizo* ethnicity are poor and, therefore, are users of the public system, being *pobre* (poor) and being not strictly European is inextricably linked in Uruguay (*Asociacion Cultural y Social Uruguay Negro*, 2009). Therefore, although the rest of this thesis does not foreground ethnicity, it does foreground some differences in public versus private healthcare in terms of COPD care. It is important to remember that because of Uruguay’s history, differences in public and private healthcare imply ethnic differences in socio-economic status and access to healthcare. The healthcare reform aims to overcome some of these inequalities. Therefore, in leaving history and ethnicity in the background, I now turn to foregrounding the sensorial experience of COPD in the following three chapters. I begin with the topic of air, breathing and breathlessness in cultural context.

Sensing the Airs: Sensorial Medical Anthropology of Breathing and Breathlessness

“External perception and the perception of one’s own body vary in conjunction because they are the two facets of one and the same act.”

(Merleau-Ponty, 1958, p.237)

INTRODUCTION

In his essay “Logos and Psyche: A hermeneutics of breathing” (1984), Levin begins with highlighting the double-meaning of the word psyche; *i.e.* psyche the Self/Soul and psyche – breath; “The human Self (psyche) begins with, and begins as, a breathing body (a psyche)” (p.124). This chapter begins with the breathing (and breathless) body as the starting point for an ethnography of living with COPD in Uruguay. In order to understand the situated experiences of the people I got to know over the course of fieldwork, who live with COPD, it is important to know something of how breathing and air are conceptualised more generally in Uruguay. Interest in this topic was not something that I arrived with in Uruguay. Rather, through living in Uruguay for a year and listening to people’s stories, breathing in relation to air and environment became an emergent domain of phenomena to listen for and explore. I present this chapter first because it provides the cultural context for breathing and breathlessness in Uruguay. Understanding something about the way air and breathing are experienced as sensations and narrated, not just among people with COPD but the population more generally, contextualises and adds analytical depth to the expressions of COPD illness experience discussed in the subsequent chapter.

As already discussed, the most characteristic symptom of COPD is breathlessness (feeling out of breath or short of breath). It is surprising that the exploration of the universal experience of breathing has not been taken up more widely by anthropologists. Not only is breathing a universal and largely unconscious human experience, but equally it lends itself to deliberate manipulation and mental attention through all kinds of cultural practices. How breathing *feels* and is experienced is an area of phenomenological, particularly sensorial,

inquiry which will be reviewed here. However, as this chapter will make clear, discourse in Uruguay about breathing not only concerns the body but also the environment, particularly air. The qualities of air, for example, whether humid, dirty or cold, are perceived to interact directly with the body and produce health-effects. These beliefs are not hidden rather they are ubiquitous in social and healthcare settings. Therefore, a strictly inner-body engagement with the issue of breathing in Uruguay would be incomplete. An appreciation of the ways in which people sense their environment, through the breath, is fundamental. The topic of human beings' relationship with and conceptualisations of weather and climate formed the basis of two anthropological collections reviewed here (Hsu & Low, 2007; Strauss & Orlove, 2003b).

Following Nichter's (2008a) assertion that "sensorial anthropology explores how sensations are experienced phenomenologically, interpreted culturally, and responded to socially" (p.166), this chapter will focus on the embodied experience of breathlessness in a broad sense, the ways in which people make sense of (*i.e.* interpret) changes in their breathing, especially in relation to their environment (the air), and the social practices engaged in to respond to breathing problems and their risk factors. Embodiment is central because my observations in Uruguay suggest the sensation of breathing and disrupted breathing is an embodiment of the world outside the body which is imbued with all kinds of social meaning. It is here that I propose another central concept to add to Nichter's (2008a) list for medical anthropologists' appreciation of the sensorial (Chapter 2, p.87), that is an understanding of how the environment, in this case the air we breathe, is given qualifiers, spoken about, interpreted and made meaningful. The concept I have found which most closely reflects this is 'sensory ecology' proposed by Shepard (2004). For Shepard, "...while firmly rooted in physiology, sensation is also shaped by individual experience, cultural preconditioning, and environmental variables" (p.264). In keeping with his position he proposes sensory ecology as a "...theoretical perspective for addressing human-environment interactions mediated by the senses"(p.252).

I will begin by reviewing the literature on the phenomenology of breathing and breathlessness and then flow into the ethnographic evidence from Uruguay I was able to gather via participation and observation in daily life and my numerous conversations and many hours spent in the company of people with lung disease. It is clear that concepts, beliefs and practices are shared amongst people with COPD and Uruguayans more generally. One need

not have COPD in order to understand a thing or two about breathing and air in Uruguay. However, COPD in a way recreates a body which is hyper-aware of breathing and air.

PHENOMENOLOGY OF BREATHING

Breathing or respiration, involves a number of areas of the brain. Primarily, it is at once an automatic activity controlled by centres of the brainstem and a process which can be controlled voluntarily via activity in the frontal cortex. As breathing is largely automatic it normally goes unnoticed unless it is brought under conscious control or is disrupted through illness. It is these two contexts for 'breathing awareness' which are represented in the limited literature on the phenomenology of breathing. One is when awareness of breathing emerges through breathing practices for discipline, health and therapeutic goals (*e.g.* yoga) and the other is becoming aware of taken-for-granted breathing when it becomes problematic due to illness (*e.g.* respiratory illnesses such as COPD and asthma).

Normal Breathing and its Control

The experience of breathing to which phenomenological inquiry has been mostly applied is breathing as a therapy or practice which can help the 'breather' achieve some kind of spiritual or existential wellness or healing (Schipper, 2007). One such example is yoga. Morley (2001) considers an evaluation of the yogic practice of pranayama (breath control) via Merleau-Ponty's existential phenomenology. Morley's reflection on breath control emphasises the way in which breathing traverses the boundary of inside/outside the body:

"Pranayama, or breath control, integral to the practice of yoga, prevails against this alienation: it is the concrete experience of the body as a relation between inside and outside. To breathe is to pull external air into ourselves and rhythmically to release outward something of ourselves. This simple experience, so common to us all, is brought into focus by yoga practice." (p.76)

Similarly, the role of breath and breathing was found to be a theme of particular importance for practitioners of mind-body therapies (Mehling *et al.*, 2011), for its therapeutic potential. Some examples include; using breathing techniques in physical therapy, allegedly as a way of linking emotion with the physical body amongst musculoskeletal and psychosomatic disorder

sufferers (Ekerholt & Bergland, 2008), and using Breath Therapy as a therapeutic intervention for back pain (Mehling, 2001).

Edwards (2008), from the point of view of psychology, contends “that breath psychology fundamentals have already been extolled for thousands of years in many countries in the form of various wisdom and spiritual traditions. These fundamentals may be more immediately, meaningfully and relevantly explicated in terms of such themes as consciousness, embodiment, ecology, spirituality and healing” (p.133). In his descriptive study of reflections about breathing, he comes to the conclusion that such experiences are “associated with the prevention of illness and the promotion of health” and “experiencing the meaning of breathing is to experience more meaning in life itself in all its aspects and phases” (Edwards, 2006, p.11). Lande’s (2007) study looked at how breathing was brought under control, not for therapeutic aims *per se*, but for the embodiment of discipline and virtue. His fascinating article *Breathing like a Soldier: Culture Incarnate* takes a sensorial approach to the study of breathing in the military by drawing on the theory of embodiment and Bourdieu’s concept of *Habitus*. In this case, what was being produced was a military *Habitus* through ‘learning to breathe like a soldier’. His fieldwork involved joining an officer training camp where he investigated the topic as ‘an insider’ via 18 months of fieldwork. He found that certain kinds of breathing are demanded of soldiers and are imbued with social meaning. For instance, huffing is seen as incompatible with leadership and controlling breathing is seen as virtuous.

Breathing can also be brought into consciousness by smoking or by breathing in smoke. Dennis (2011) explains that exhaling smoke makes the breath visible and breathing becomes something peculiar, not just something that one does to stay alive, and neither something that is pathological, rather “in this breath, the body reminds itself of its entailment with the world beyond the sited biological body” (p. 29). In terms of breathing in smoke Bell (2010) contends that the reason there is greater concern for breathing in second-hand smoke than smoke from a campfire, is the fact that second-hand smoke is inextricably linked to the inside of someone else’s body. What this literature on the phenomenology of breathing in relation to smoking highlights, is the role of smelling in our perception and experience of our environment (Richardson, 2011).

Phenomenology of Breathlessness

The literature on the therapeutic potential of breathing stands in stark contrast to the literature exposing the existential crisis posed by breathlessness. In the literature review on COPD, I discussed how the topic of breathlessness and its associated emotions were a frequent part of the illness narratives researchers tried to understand. However, only a few took the experience of breathlessness as the central topic of their investigation (Bailey, 2001; DeVito 1990; Heinzer *et al.*, 2003). Furthermore, although the studies are informed by a phenomenological theoretical frame they have not approached it ethnographically. Rather phenomenology was proxy for interviews about experience. Although their findings, summarised in Chapter 1, offer some insights, two ethnographic examples of breathlessness concerning other lung diseases provide more explicit phenomenological analyses. These examples are of what it is like to not be able to breathe, not because of deliberate physical exertion, which remains within one's control, but because of illness, which makes striving for breath-control a matter of life and death in some cases.

One such contribution is offered by Carel (2008) in her book *Illness: The cry of the flesh*. In it she presents an auto-ethnography of her experience of losing lung function due to a degenerative and incurable lung disease called lymphangioleiomyomatosis (LAM). She was first diagnosed at the age of 35 and as a Senior Lecturer in Philosophy at the University of Bristol, she explored her own experiences from a phenomenological perspective. She asks "...so how is the experience of an ill body different from that of a healthy one?" (p.20) and responds, "It is Merleau-Ponty's emphasis on perception and on the centrality of the body to human existence that I find particularly compelling in relation to illness" (p.20). A second contribution on the phenomenology of breathing in illness comes from van Manen's edited book *Writing in the dark: Phenomenological studies in interpretive inquiry*. Clarke (2002) contributes a chapter on her and her asthmatic daughter's Memories of Breathing. The article includes her daughter's and her own narratives about living with asthma, particularly asthma attacks. She contends, as I do, that unless we engage in exercises such as yoga or have a respiratory illness the tendency is to not reflect on our breathing.

"... but when we hold our breath or when we cannot breathe for a moment we immediately become aware of a different mood. We sense a growing desperation. A tension mounts in the chest: we must do something to still this hunger, air hunger. Soon panic grips."(p.137-138).

This description of the crisis of breathlessness is a description which I think most of my participants would identify with, and hence the importance of this harrowing experience to people with COPD.

Breathing and Breathlessness in Biological Terms

In turning to the medical textbooks on respiration, the lungs and respiratory pathology one can observe the complexity of breathing and breathlessness, even from a medical perspective. When one considers that the "...lungs have the largest surface area in the body in direct contact with the environment" (Dartnell & Ramsay, 2005, p.83), the significance of breathing as the mechanism by which we embody the environment that surrounds us, becomes apparent. Unfortunately, this also implies that lungs are "...open to the environment" and, therefore, susceptible to the harmful effects of foreign materials carried to their surface with every breath (Dartnell & Ramsay, 2005, p.83). When lungs are damaged, difficulties with breathing arise. Although breathlessness and dyspnoea are interchangeable, dyspnoea is a medical term and one which connotes that the sensation of change in breathing is not only noticed but experienced as unpleasant (Murphy, 1986). Richards and Schwartzstein (2012) prefer the term 'breathing discomfort' to represent dyspnoea and breathlessness. The sensation of breathlessness has been likened to pain because it is difficult to quantify and is inherently a subjective experience (Murphy, 1986). However, ultimately, dyspnoea is understood to have a more complex physiology than pain in that it arises from a multitude of receptors across the respiratory system (Richards & Schwartzstein, 2012).

BREATHING AND THE ANTHROPOLOGY OF AIR AND CLIMATE

When one begins thinking about what we mean by climate, weather, air, atmosphere and environment, the realization quickly sinks in that these are complex concepts to unravel, despite the fact that we use most terms unreflectively in everyday life. The atmosphere, one of three spheres of our planet (hydrosphere and biosphere are the others) is "...a thin blanket of air" which surrounds the planet (Lutgens & Tarbuck, 1998). Air, in turn, is composed of solid and liquid particles which change and vary depending on time and place. 99% of clean and dry air is made up of oxygen (21%) and nitrogen (78%). Some of the variable components of air include water vapour, dust particles and ozone, which interact with the motions of the earth

and the energy of the sun to produce all kinds of weather. These form different trends around the world, which we refer to as climate (Lutgens & Tarbuck, 1998). Climate is the long-term characteristics of the environment we live in and weather is the day to day variability. When we speak of climate change for instance, we are speaking of a change in patterns that were considered stable as compared to day to day changes in weather.

So what is the relationship of air to climate and weather? In this chapter, I conceptualize *air* as the carrier of weather and climate and *breathing* as the vehicle which transports weather and climate to our lungs. Air is the medium and breathing the mechanism through which we embody climate. Humans, embody the climate of our environment through air, just as fish embody the climate of their environment through water. We perceive the climate to be humid because we feel the air to be humid or see that the air is humid through condensation. It feels cold because the air is cold. The air feels cold on our skin and as it enters our airways. When we say it is windy it is because we can feel and see the air moving quickly, hitting us, moving us and things around us. Air can be warm, cold, dry, humid, thick, it can be still or can move quickly, it can smell good or bad, it can be transparent or visible (smog) and can be contaminated to greater or lesser degrees. No matter what the air is like, we cannot help but breathe it. It is therefore no surprise that our perceptions of our environment and our bodies are mediated through breathing the air around us.

There are two main bodies of anthropological work on the topic of weather and climate. One is the edited book, *Weather, Climate, Culture* (2003b) by Strauss and Orlove. The other is the 2007 special issue in the Journal of the Royal Anthropological Institute entitled *Wind, Life, Health: Anthropological and Historical Perspectives* (also published as a book), edited by Hsu and Low. Although neither conceptualise their subject as the topic of 'air', I would argue that it is indeed air which they are grappling with. However, it is a particular kind of air they are interested in – air which we can *feel* because it moves quickly and horizontally because of differences in air pressure (Lutgens & Tarbuck, 1998) – *i.e.* air that is wind (Hsu & Low, 2007) or air with particular properties – climate/weather (Strauss & Orlove, 2003b). Their findings and theories are highly relevant to the present discussion, particularly when and how they make reference to breathing, which will be the focus here.

Hsu and Low (2007) explore "...in vivid sensual terms, how wind, the environmental phenomenon, becomes socialized through practice and belief." (p.52). They relate wind (air) to respiration (breathing) in the following way:

“The value of discussing wind lies in what it brings not only, on a theoretical level, to elucidating human relationships with one of the planet’s basic aspects of life but also to exploration of how the materiality of wind shapes social practice at a number of fundamental levels. The particular sensorial relationship we have with wind has persistently led to embedding our experience of the meteorological phenomenon, and of respiration, in a web of associations concerning life and death and the cosmos at large.” (p.siii)

The special issue opens with a theoretical contribution by Tim Ingold. He argues that there is no such thing as objects in the open world. To be in the open world is to mingle in the wind and weather. In this world there is no separation between earth and sky and humans inhabit both. His reflection on breathing is particularly salient for the present chapter. He says “Fundamental to life is the process of respiration, by which organisms continually disrupt any boundary between earth and sky, binding substance and medium together in forging their own growth and movement” (Ingold, 2007, S19). The way in which Ingold evokes the notion of sky is similar to how I am thinking about air. What is the more macro concept of the two? Is the sky made up of air which can be humid air, cold air, slow air or fast air? In a way, I would consider the notion of sky a more problematic concept than air. We agree that air is everywhere, whereas sky is sky in relation to other material factors, such as having a roof over your head or not, or whether you consider the stuff in-between the branches of trees to be sky. Just as air is the medium through which we connect our bodies to our environment, so too sky is the medium through which we connect our bodies and the outside world. Other authors in the issue illustrate how this boundary between earth and sky embodied through wind (air) in many cultural contexts connects the living with the spirits and ancestors (Low, 2007; Pandya, 2007; Parkin, 2007; Roseman, 2007). It is human beings’ bestowing upon wind a certain agency and cultural interpretations of this agency which has justified the focus on wind and not air. Wind is air as sensation, although it is not the only form of air which can be sensed and attributed a kind of power or agency over the body.

In introducing their edited volume Low and Hsu (2007) also speak of how the external phenomenon of wind is linked to the internal experience of breathing. Breath and wind are connected in that we inhale and expulse the winds (air). In the words of Ingold (2007) “...inspiration is wind becoming breath, expiration is breath becoming wind” (p.S31). In Hsu’s

contribution, she grounds the experience of *Qi* in early and medieval Chinese history in phenomenological terms. She says:

“...feeling the airs and winds is a pervasive experience, breathing a *sine qua non* of life. We feel it inside out, tactually as it strokes our skin, warms us up, cools us down, rhythmically relaxes and lulls; panting, we hear it; pounding, wheezing, it squeezes us. Violent, it hits, whips, whistles; hard, dry, soft, gentle, subtle, barely perceptible, elusive, it disintegrates, shudders, vanishes” (p.130).

Ogawa’s (1998) earlier article similarly contends that “...*qi* is a kind of wind, a wind of breathing” (p.322). These works resonate with Morley’s (2001) work, mentioned earlier, which emphasises how breathing with yoga practice is the medium through which the inside world of the body and outside world of the environment are connected. According to Ogawa, the sensory connection between body and wind is made explicit in our linguistic sayings such as “the atmosphere is tense” and “there’s trouble a brewing” (p.322).

Some research has also documented the way in which breathing certain kinds of winds (air) can contribute to health problems. Jankovic (2007) provides an intriguing historical account of the medicalisation of wind in the Victorian period. Theories of miasma, popular at the time, led to an interpretation of winds as “...foul insofar as they pushed infectious material across national, even continental, borders” (p.152). Today, in Leukerbad, Switzerland, the *Foehn* wind is said to bring headaches, depression, thoughts of suicide, and generate a feeling of ill health (Strauss, 2007). In the article, Strauss illustrates how the meaning of the *Foehn* has penetrated both the minds and bodies of mountain inhabitants to such an extent that it is discussed in the health pages of the federal weather service and is commonly blamed for a whole host of individual and societal problems. Strauss mentions several other winds around the world which are imbued with meaning and have distinctive effects on humans and animals including the *Chinook* in Alberta and Montana, the *Santa Ana* wind of Southern California, the *Zonda* in Argentina, and the *Koembang* in Java, the *Sirocco* in North Africa and the *Samiel* in Turkey.

Wind, in addition to being a climatic condition, may also be conceptualized as temperature change and drafts as in the case of the ‘hit by the wind’ syndrome studied by Hinton *et al.* (2003) in their phenomenological multi-method study amongst Vietnamese refugees in the USA. ‘Hit by the wind’ occurred when wind entered the body through open

pores causing varying degrees of: nausea, shortness of breath, chills, dizziness and, in severe cases, fainting and even death. Hinton *et al.* (2003) found that the criteria of the syndrome described by their participants frequently matched criteria for panic attack and was linked to past traumas. The case of 'hit by the wind', particularly its severe form involving temperature-shift, is an interesting example of the relationship between wind and weather in the production of shared embodiment of past events and interpretations of the everyday environment.

Although an engaging body of knowledge, *Up in the air: The anthropology of weather and climate* does not engage greatly with the similitude between the anthropology of the body and the anthropology of nature which the book's introduction highlights. Strauss and Orlove (2003a) briefly review the development of anthropology of the body. Then, they turn to briefly reviewing the growing attention to the natural world. According to Strauss and Orlove (2003a) "...in concrete settings around the world, people experience, discuss, and interpret meteorological phenomena in ways that are dependent not only on the physical characteristics of the events, but also on the cultural frameworks that divide time into current, recent, and distant periods" (p.6). I would argue that people experience, discuss and interpret the weather in ways that are dependent also on the physical body of the individual and perhaps the collective. The strength of the book is the development of a clear notion of the anthropology of climate and weather. Its drawback is that despite the editors' affirmation that "...we have often noted a comparison between the study of the human body and the study of the natural world" (Strauss & Orlove, 2003a, p.5), the volume focuses predominantly on perceptions of climate change and associated practices and it falls short of drawing a more direct relationship between embodiment and the interpretation of weather and climate. The experiences of changes in weather/climate, I would argue, are embodied, not only in the sense that changes in the environment may affect the body and health but also that transformation of the body, for instance through disease, can change the way we perceive the environment. In both cases, interpretation of such experience is made not individually but "dividually" (Nichter, 2008a, p.166) and is shaped by shared cultural beliefs and practices.

In the following section, I will pull together the ethnographic evidence I gathered in Uruguay on the topics of air and breathing in order to construct an insightful picture of such health beliefs and practices which shape and are shaped by experiences of breathing and interpretations of air. Most of the ethnographic examples woven into this chapter were

extracted from fieldnotes kept of informal conversations with a broad range of people in Uruguay in addition to the descriptions of participants with COPD.

THE AIRS OF URUGUAY

My first six months in Montevideo introduced me to discourse on air. It began when I mentioned my desire to travel north to Tacuarembó in January. The urban folk of Montevideo could not believe anybody in their right mind would go to the interior let alone Tacuarembó in the height of summer. “There is no air there” I was told. People from Montevideo need the coast because, in the words of a Uruguayan friend, “they need the air from the coast, without it they feel uncomfortable.” Those who can afford a holiday go to the eastern beaches to enjoy the sea breeze and sunshine. This air, air from the ocean which sweeps across the dunes, was often said to be purer air. Even though Montevideo was seen as more contaminated, I was told on a number of occasions that the air in the Montevideo is never stagnant, it circulates and this is why they have little urban pollution build-up. Montevideo certainly is a very comfortable city to inhabit in the summer because most downtown streets are lined with trees which provide shade. However, what is a blessing in the summer is a curse in the spring to residents. I was repeatedly told by those I met that people from Montevideo suffer from terrible allergies in the spring because of the *Platano* tree’s pollen which fills the air. I was told it could get so bad that you would have to cover your face to not get pollen in your nose and mouth. Wind was the culprit; it disperses the pollen. The spring I spent in Montevideo was apparently unusual. There was not a great deal of pollen floating around in the air and when I commented that it did not seem so bad, I was told that because of getting more rain than usual the pollen was washed away. Just as wind was thought to bring disease in Victorian England, wind in spring brings allergies and respiratory irritation in Montevideo.

Not only was the interior seen to be a place with less air than Montevideo according to its residents, there was also a perceived lack of air in Buenos Aires. When again I mentioned I would go to Buenos Aires, for a few days in the summer, the reaction was “you will die of heat, there is no air, they did not build the city on the coast”. The feeling that Montevideo’s air was better, fresher and more plentiful than Buenos Aires and the interior reflects a subtle form of patriotism. This was only one of innumerable contrasts constructed by capital-dwellers in order to define themselves positively in contrast both to the interior and to Argentina. However, people living in the interior also believed that the capital suffered from contaminated air. Even

within the department of Tacuarembó people, living outside the capital city of Tacuarembó, spoke about their air as “pure and clean” in the countryside as compared to the air of *el pueblo* (town). While in Tacuarembó, I spent a couple days at a rural school run by the daughter of one of my participants with COPD. She told the children to come up with a list of positive attributes of their region that they would tell a visitor like me about. This question referred very specifically to their local area. The children suggested things like the Indian burial hill and the museum of tango legend Carlos Gardel, and the teacher supplemented this with *aire puro* (pure air). Although it is not unusual for country air to be described as cleaner and better, it is interesting that these statements are so frequently made in Uruguay.

Britain and Uruguay have similarities with regards to their climate and the way they speak of it. Golinski (2003), in his article *Time, talk and the weather in eighteenth-century Britain*, mentions at least two characteristics which are paralleled in Uruguay, as I experienced it. Golinski says that British diarists at that time “...frequently claimed that the moderation of the British weather was an example of God's providential benevolence to their country” (p.21). In Uruguay, I was told of how children were taught in school that their climate was favourable and stable. Uruguay is not positioned like some of its neighbours in an area of volcanic or tectonic activity, nor is it predisposed to weather events like tornados or hurricanes. Favourable weather is interwoven into the narrative of Uruguay's relative financial and social ‘success’ as compared to its neighbours; something reflected in the account of the artisan quoted in Chapter 4 (see p. 82). Also, like Britain, because extreme weather events are relatively uncommon comparatively, slight changes in weather receive widespread attention and are spoken about animatedly. Finally, Golinski makes the point that in 18th century England talking about the weather fulfilled the definition of polite conversation and was neither too political nor too sectarian. “Weather-talk...” he says “...is an example of what linguists call 'phatic' communication, in which the primary meaning lies not in what is referred to but in the social bonds strengthened by the exchange” (p.29). In Uruguay talking about the heat, the cold and the humidity is an entry into friendly interchange and strengthens social bonds.

HEALTH BELIEFS AND EXPLANATORY MODELS

Sensing the Airs and Breathing

As a result of immersion in my fieldnotes, four themes emerged which suggest widely shared health beliefs about breathing and airs regardless of whether a person had COPD or not: cold and humidity, temperature change and the body, wind and breathing and contaminated air.

El Tiempo Feo: Cold and Humidity

Although directly translated as ugly weather, *el tiempo feo*, refers to horrible, dreadful or bad weather. Early on in fieldwork, I began noticing how often *tiempo feo* and humidity go hand in hand in the discourse of most Uruguayans I met. Humid days might be with or without rain, and might be any day of any season. Uruguay has a temperate climate and I found Uruguayans speaking of the horribleness of humidity throughout the year. In the summer, striking up conversation was as easy as exclaiming *que calor* (wow, it's hot!) and in the winter, *que frio* (wow, it's freezing!). Hearing *hay mucha humedad* (there is a lot of humidity) or *que humedo* (wow, it's humid!) traverses all seasons. When humidity is accompanied by extremes of hot or cold, the day is particularly *feo*, and requires even more safeguarding, as will be illustrated. Overall, it seemed that Uruguayans characterise their country as exceptionally humid and I was frequently told how humidity underlies or affects one's health.

Humidity was seen to be particularly problematic for breathing. A friend over Sunday lunch once told me:

“Uruguay is a humid country that is why there is so much bronchitis and asthma.

Doctors say that if some kids were living in different climates probably they wouldn't have those problems.”

Another friend told me many children in Uruguay have asthma because of the humid conditions in which they live. Interestingly, when she referred to “humid conditions” she was not only referring to the humid country but the humid micro-climates of particular areas of the country, neighbourhoods, homes and workplaces. That humidity could be assessed at the national level as well as local geographical level and the micro climates of work and home is important. A health professional made a contrast between the air of the hospital and the air of the home when he said to me:

“Here, the COPDs (*los EPOCs*) are great, it is when they return to their homes...the humidity, the cold...You’ll see some patients will ask to stay here because they have a bed, food, they are comfortable and they don’t want to leave. We call that hospitalism (*hospitalismo*)”.

Although he was making a clear comment about the poverty experienced by their patients and the precariousness of their homes, he was also making a comment about how the qualities of air (cold and humid) that people breathe affect them. This was backed up time and again by statements like “Humid days are the worst thing you can have for the bronchial tubes” from my research participants with COPD. A social worker in a respiratory team meeting discussed the home-life of one of the research participants and said “...he lives in a really humid zone of the city”. The respirologist I shadowed in Tacuarembó would often say to her respiratory patients, “...it’s the humidity these days that’s affecting you isn’t it? Stay inside.” She would diagnose the day to her patients: “...today it is a humid day, don’t go out.” In Montevideo it was implicit that if it was very humid or rainy, pulmonary rehabilitation would be cancelled. Therefore, the interpretation of humidity seemed to cross the socio-economic classes. I got to know a father and daughter well who both had COPD and when the daughter, during my stay, experienced her first hospitalisation and transfer to intensive care for an acute exacerbation her father exclaimed to me:

“...for days she was running all over the place, leaving work at 7 or 8 at night, with this humidity! She is stubborn. I’ve lived for years with this, I know what I’m talking about!”

But how does one know it is humid, and can people with lung problems feel it more? I have no doubt that they do if that is what they have identified as being a threat to their lungs. However, from health professionals, to university students, to homemakers and farm workers, I was being told humidity is bad for your breathing. When I began to question how it is they “know” it is humid, I reflected in the field about my experience of the weather. I had to admit to myself that I sometimes just could not feel the humidity people were telling me about on a particular day. I felt like I had been to countries far more humid than Uruguay. Countries like Cuba, Thailand and Sri Lanka where your skin is constantly moist with perspiration the moment you step outside and make any physical effort. Then one day a friend said the following, in response to me stating that I could not seem to feel the humidity, “I know it’s humid because

my painting just won't dry." I began noticing other such anecdotes such as "It's so humid today the floors just won't dry" or "the clothing on the line is taking a long-time to dry." I began to understand that humidity is not just 'felt' in Uruguay, it is something people can see and experience in the home through a variety of senses. Humidity is a multi-sensorial experience. It is not only perceived with the eyes, the sensation of dampness or cold on the skin, but also through breathing. Furthermore, this perception and assessment of humidity frequently begins in the home which has much to do with the way the average home is constructed in Uruguay.

The typical home in Uruguay is made of cement with a slanted tin roof. In Montevideo, most people live in apartments. It is only in the last five years or so that the purchase and use of air-conditioning or central air heating/cooling has become more common among the wealthy. Otherwise, homes are frequently not sealed shut and are certainly not centrally heated. This made the boundary between outdoor weather and the indoor micro-climate of the home rather permeable (certainly more than the average Canadian is used to, particularly in the winter). The most common form of heating in Tacuarembó I saw was the fireplace, in Montevideo it was propane heaters. The 2011 census found that 37% of households in the country use wood to heat their homes (*Instituto Nacional de Estadísticas*, 2011). Poorer people, with more precarious housing, live with much more humidity and cold in their homes than the upper and middle classes. I experienced these differences personally in living in a variety of homes. And Uruguay gets cold. The temperature reached an uncharacteristic low of -7 degrees Celsius one night and numerous nights were below zero during the winter I spent in Tacuarembó. The contrast of warm days and cold nights as well as steam released into the home through cooking and bathing all certainly increase indoor humidity. However, if it was not too cold, homes would be opened up during the day. Condensation on windows and mould were other common signs of humidity indoors.

Temperature Change and the Body

A very common health belief among Uruguayans is that rapid temperature change negatively affects the body and can cause ill-health. Most of my fieldnote data on this health belief come from my months in Tacuarembó. However, I am cautious to say that this reflects a difference between the interior and the capital. It probably has more to do with seasonality. As I spent most of the winter in Tacuarembó, this is the time when the threat of ill-health caused by temperature change is greatest and most frequently spoken about. I was told not to sit too close to the fireplace and get "too hot" and then move away from it suddenly, and especially

not to sleep with my head near the fireplace (my friend's children and I would alternate sleeping on a mattress on the floor in front of the fireplace when I lived with them in Tacuarembó). I also witnessed children being scolded for putting their bare feet on the cold floor. When I asked a class of rural schoolchildren during a rural medical round what their grandmothers and mothers tell them so that they do not get sick, I was told "not to sit next to the fire and then walk to a colder part of the house suddenly."

Concern over hot and cold suggests an underlining humoral theory which has been documented by anthropologists as a common paradigm for illness within Spanish-American populations (Foster, 2009; Miles, 2010) and populations around the world (Cronin-de-Chavez, 2011; Helman, 2007). Often, humoral theories shape the categorizations of certain foods as 'hot' and 'cold', however, I did not find this aspect of humoral theory in operation among the people I interacted with in Uruguay. My observations about temperature change in the air, however, suggest, as do Foster's (2009) findings in Mexico, that the humoral theory is at play but that it has more to do with guiding peoples' behaviours in terms of what to do and what not to do to avoid illness and less to do with guiding therapeutic decisions. Miles (2010) mentions in her chapter on women living with Lupus in Ecuador, that a commonly shared belief in the Andes is that contact with cold water is dangerous and debilitating because it can cause a shock to the system which is potentially illness-inducing. Indeed, one of her participants and her mother speculated about whether washing her clothes in cold water every morning before work may have contributed to the onset of her lupus.

In terms of respiratory illness, Rubel and Moore's (2001) study of 400 people in Mexico with tuberculosis found that humoral knowledge was widely shared amongst participants who applied the theory to their tuberculosis. Furthermore careful reading of the narratives in the qualitative research on COPD shows that taking care by avoiding cold and temperature extremes was reported by participants in Taiwan (Chen et al., 2008; Jeng et al., 2002), Australia (Gullick & Stainton, 2008) and the USA (O'Neill, 2002). Steam, particularly from the shower, is mentioned by participants in two studies as a risk-factor needing to be controlled or avoided (Barnett, 2005; Nicholls, 2003). In Small & Lamb's (1999) comparison of asthmatics and people with COPD found that those with COPD were particularly bothered by cold and windy conditions. What is unknown from these studies is whether these beliefs were widely shared as they were in Uruguay. What they suggest is that people with COPD interact with the

environment with bodies that are hyper-perceptive of changes in the air embodied through breathing.

In my discussions with a *curandero* (healer) of sorts in Tacuarembó, I was told about the many incantations and rituals he performed and the conditions he treated, particularly '*golpe de aire*' (being hit with air); a frequent and important health complaint. I asked him to explain how being 'hit with air' makes someone sick and he answered with the following:

"Pneumonia is caused by being hit by cold air. If you are in a hot place and are hot and you breathe in cold air you get congestion, and if it isn't well treated it ends up being pneumonia. Also, being hit by cold air affects the muscles. For example, a person who is working in the heat and there is a drastic change in temperature, it affects the muscles. With heat, the muscles increase in volume, with cold they contract. That movement, all of a sudden, affects you. Therefore, we call it 'air' as in 'caused by air', the scientific word is torticollis."

The passage is insightful both for illustrating lay beliefs about temperature change and their effects and for showing how biomedical and lay explanatory models are intermeshed. As a *curandero*, he had no issue with drawing on biomedical terms, such as congestion and pneumonia. In fact, while he felt confident helping with *golpe de aire* when it affected the muscles, he felt that there was not much he could do for someone with respiratory congestion and a medical doctor should be consulted. Unlike the Vietnamese in Hinton *et al.*'s (2003) study, the Uruguayans I met did not consider death a possible result of *golpe de aire*, but they did expect it to lead to congestion, coughs, colds, flu and muscle and joint pain. Reflecting on this, in terms of my own Quebecker constitution, I believe the same symptoms are attributed to prolonged exposure to cold, whereas drastic temperature change is not as threatening and importantly, is unavoidable considering as Quebeckers we spend our winter days, moving from 20°C indoors to -20°C outdoors. Therefore, although our cultural beliefs shape our interpretations and experience of the environment, the environment itself also shapes those beliefs. Furthermore, factors such as nutrition may play a role in making certain individuals and populations more vulnerable to the prolonged cold, temperature change or other environmental factors.

Wind and Breathing

Although humidity was expressed as problematic to health and breathing across all kinds of people with or without a lung disease, the problem of wind was more particular to people with COPD. Wind can be many things. Air currents are winds within the home and these are seen as undesirable and a cause of discomfort but mostly because of temperature change as discussed above. Cold drafts were generally disliked and avoided. A draft which might cause a sneeze seemed to attract attention. If my housemate in Montevideo heard me sneeze (something I normally pay no attention to) she would come see me and say, “Oh, it must be the draft, I’ll close the window”. It may have been the draft but I was not bothered by the sneeze although it appeared that maybe I should have been. Clearly I was missing the somatic mode of attention to my sneezes and their significance (Csordas, 1993).

For my participants with COPD, wind was experienced in different ways. While cold drafts were generally distrusted, air currents caused more ambiguous reactions. For example, a gentle breeze produced by a fan or opening a window, could be therapeutic, or wind from outdoors could make you feel suffocated. Sensitive responses to wind tended to come from participants who had severe COPD or who had suffered a crisis episode – exacerbation. I remember being surprised the first time I heard, “I hate the wind, wind is bad for me, I feel like I am suffocating”. Windy days were good enough reason to stay indoors. It seemed ironic that a health problem characterised by difficult breathing often expressed as *me falta el aire* (I am missing air, I am breathless) could be made worse by essentially more air being projected onto the face. However, for some, having wind blow into their faces was “too much air” and because of all the air blowing into their faces they felt they could not breathe. This suggests that as obstructive lung disease causes difficulty getting air out of the lungs, sensorially, struggling to push air out is heightened when having to push against air seemingly pushing its way into the mouth.

On the other hand, a few narratives from my study reflected the comfort and therapeutic benefit of a breeze produced by a fan. One woman who was suspected of having COPD told me the story of a crisis she had had one night. She said:

“All of a sudden last night without warning I became very breathless and I could hardly breathe. I barely slept all night. My husband was home and he blew a fan at me to give me some air. Eventually I fell asleep and was feeling better in the morning.”

Another man would bring fans to the hospital. His doctor told me “what this patient needs is air being blown up his nose; he needs to feel that air is going in.” For someone who feels that they lack air and oxygen, generating wind that they feel on their bodies, seems to generate a sense that there is air to be breathed. This resonates with Williams *et al.*’s (2011) study in the south of England, where interviewees with COPD expressed the therapeutic benefit of fresh air and the detriment of stagnant air. The authors suggest that it is not only about how these conditions made people feel but also how interpretations of these environments shaped participants’ perceptions and interpretations of their symptoms. The pursuit of this line of inquiry seems especially important for healthcare professionals trying to improve the everyday quality of life of people with COPD.

Aire Contaminado: Discourse of Change and Pollution

Talk of air, breathing, health and climate in Uruguay is also wrapped-up in narratives of environmental change, both local and global. During smoking cessation group-work, smokers trying to quit frequently voiced their perception that “these days there is so much horrible stuff in the air that isn’t good for you, it’s not just smoking”. One man trying to quit smoking responded to the doctor’s explanation of the dangers of carbon monoxide inhaled through smoking by saying “Yes, but we go out on the street and breathe in all kinds of things”. Similarly, one day when having a coffee with the wife of a participant in my study, I asked whether she used to smoke. Her response was, “Yes, I smoked a bit in University but back then the environment wasn’t filled with as many toxins as it is today”. On another occasion when we met, she told me a slightly different version of the story. She said she does not like that her son smokes and he tells her “Well, you smoked” and she responds “Yes but there wasn’t so much contamination then.”

These kinds of comments suggest that some might perceive smoking these days to be more dangerous than ever because of the extra chemicals one breathes every day. It may also be an indication that ex-smokers have narratives which support the “it wasn’t that bad for you, back then” stance. Furthermore, this concern with increasing contamination was not a uniquely urban phenomenon. When I accompanied a rural doctor on her rounds of the Tacuarembó countryside, a man in a small rural village of 300 people told me that there are not as many people reaching old age as there used to be. I asked why and he said, “because of contamination [used to refer to pollution]; there is much more [contamination] than before.”

The village has only had electricity for 15 years and so, it, like many villages in the interior, has experienced dramatic transformation and modernization in the very recent past. The village and the city are increasingly connected by shared concerns of their inhabitants about pollution. The work of anthropologist and political ecologist Daniel Renfrew (2007, 2009, 2011) on the lead-poisoning crisis in Montevideo and on wider neo-liberal reforms and industrial waste issues throughout the country (and region) are testament that Uruguayans are rightly concerned about *contaminacion* (contamination) and the effects, known and unknown, it has on their bodies.

Dirty air also took on a new dimension and visibility in June 2010 when the Puyehue volcano erupted in Southern Chile on June 4th. The successive eruptions and masses of volcanic ash expelled, created an ash cloud which reached southern Argentina and Uruguay and caused airport chaos. A flight I had booked back from a short break to Chile was cancelled on July 8th (over a month after the first eruption) because of the ash cloud over Uruguay, not Santiago. A light dust covered cars in Montevideo. On a rural healthcare round in the department of Tacuarembó on June 13th, I witnessed the sky so full of ash that you could barely see trees in the distance and the sun was almost blocked out in the white hue, making it look more like the moon than the sun. The volcano was the talk of the town. There were media releases and warnings that parents should keep their children indoors, especially asthmatic children. While a natural disaster of that size attracts widespread concern about respiratory health, concern over cigarette smoke in homes, the importance of protective masks and equipment in the rice, wool and forestry industries, for example, are far less emotive. However, the tobacco-control policies have made huge ground in raising awareness of tobacco smoke as a pollutant of self and, through second-hand smoke, others.

Multi-causal Explanatory Models of COPD: Occupational Airs

So far many of the examples I have provided throughout the text attest to how people with COPD sense the effects of wind, temperature, humidity and air quality on their disease, particularly on the exacerbation of symptoms and the risk of getting cold or flu. These beliefs are largely shared across the population; however, they are sensed with greater acuity and intensity by people with COPD. However, some participants also alluded to the very grave effects different kinds of 'air' can have on the lungs, which not only exacerbate already established COPD but also cause COPD. Other causes mentioned were smoking, genetics,

heredity, and lung infections early in life which left them weak. When the airs they breathed were mentioned as having, at least in part, caused COPD, they were usually in reference to occupation. I met Juanita near the end of my study through her private pulmonary rehabilitation physician. She spoke of smoking only when I asked her about it, otherwise her causal narrative mostly concerned the air she breathed at work. Like many people with severe COPD, while seated (*i.e.* while not physically exerting herself), her disease was virtually invisible. However, any physical exertion revealed her serious limitations. She explained how she ended up with COPD in the following way:

“I used to work in a job that involved walking around dark warehouses in the Port going from hot to cold and from cold to hot while breathing in the exhaust of the machines moving cargo around. It was an unhealthy environment”.

A similar story came from Sebastián, a man who found himself at essentially the very opposite end of the economic spectrum to Juanita. He was a 36 year old father of three young children and lived with his wife in a cement-block, one-room home with an outdoor kitchen and toilet in an informal settlement on the outskirts of Montevideo. He was oxygen-dependent and had been unable to work for some time. His last job was a *recyclador*, a person who travels on a horse-drawn carriage through the city streets picking sellable materials out of the dumpsters, such as plastics, cardboard, glass and food scraps for urban pig farming (see Moates, 2009; 2010). When I asked Sebastián whether he thought smoking caused his COPD, he responded:

“I don’t think so. I think all the years of working as a *recyclador* and having to support the hot, the cold, and the wet conditions did this to me. Also malnutrition lowered my defences [immune system]. When you’re a *recyclador* you have to get out and work every day to survive, whether it is cold or raining. I would go out for at least eight hours a day but not at set times.”

Marcelo, whose story will be the guiding narrative of Chapter 7, worked for close to 12 years for a tobacco plantation company in Tacuarembó which closed over a decade ago. When we spoke of his COPD he said:

“You know, I worked in the tobacco-plant here with a lot of humidity. I worked in the humidification section for the leaves to keep them soft after having been dried.”

His wife added:

“He also worked fumigating in the tobacco fields.”

These narratives show how, at least among some people in Uruguay, the risk-factors thought to cause COPD amongst the lay population are not only those presented in the medical literature such as exposure to occupational dusts and chemicals but also humidity and temperature change which represent shared beliefs about the negative effect these have on the body. Most participants, not quoted here, considered smoking was a factor in causing or at least making their disease worse, however, some clearly felt that breathing bad air was also to blame, and, therefore, an important explanatory model to recognise. In the following section, I want to turn to how the embodiment of breathing and beliefs about airs are related to practices to protect the body from threats perceived in the environment.

THE SOCIAL CONTEXT AND PRACTICES OF BREATHING

Complaints of disruptions to breathing and bronchial problems in Uruguay are very common. The country is known to have high rates of asthma (Baluga, 1993), although one may question how these diagnoses are made with such limited availability of spirometry. It seemed that asthma was such a ‘household’ name that people described any breathing problem as *un tipo de asma* (a kind of asthma). I saw no indication of asthma having a stigmatizing connotation as has been documented in van Sickle’s (2009) study population in India, for instance. In fact, Mario Benedetti (1965), one of Uruguay’s most acclaimed writers, wrote an astute short story entitled *El Fin de la Disnea* (The End of Dyspnoea), lamenting the treatment of his asthma and the loss of his identity and rituals as *un asmático* (an asthmatic). He describes asthma as “a vocation” and so many of his playful descriptions of the many factors leading to the symptoms of dyspnoea, as well as how to cope with them, resonate with what Bourdieu (1977) might call an asthma *Habitus*. The social practices enacted to avoid the risk factors for diseased breathing or to improve diseased breathing are shared across sufferers and also across the non-COPD population I encountered. The flu and colds are interesting because, for the healthy population, they are an annoyance and unpleasant, whereas for those weakened by disease, such as COPD, the susceptibility and consequences of everyday illnesses like cold and flu are far more serious. The influenza-asthma syndemic described by Singer (2009) in Chapter 1 could equally have been called the influenza-COPD syndemic.

That catching a chill, as we would say in English, could lead to a cold is not particularly remarkable. However, I believe what is important is the emphasis these perceptions are given and the shared social practices surrounding them, whether it be the way people speak about the weather, describe how their breathing problem began, or take precautions to avoid problems. Csordas' (1993) "somatic modes of attention", which he defines as the "...culturally elaborated ways of attending to and with one's body in surroundings that include the embodied presence of others" (p.138), applies in this case as does *Habitus*. In fact, one helps sustain the other. Shared practices surrounding breathing difficulties, including the practice of discussing the way breath and environment interact, makes for greater impetus on detecting the sensations experienced as a threat. Equally, a shared 'paying attention to the sensations' in the body leads to greater opportunity for social consensus on how best to avoid or deal with them. In both cases, it is important to remember that what is being sensed is not only difficulty breathing but characteristics of the environment. Uruguayans I met attended to the characteristics of the climate *with* their bodies and they attended *to* their bodies in order to assess climate, which in turn shaped their behaviours. This includes attention to others' bodies too, so that sneezes, congestion, coughs and difficulty breathing are interpreted socially.

Staying-Out of Bad Weather and Avoiding Temperature Change

While in Tacuarembó I learned a lot from the sixty-five year old woman I lived with about protecting one's body from the ill-effects of changes in temperature. We only heated the house by fireplace in the living room first thing in the morning and at night on cold days. She used her electric space heater to add some warmth to her bedroom at night while she watched TV or, most consistently, to heat the bathroom before showering. This practice with the shower was not just about making stepping out of the shower less uncomfortable in winter; it was about protecting oneself from drastic changes in temperature, which might cause a *golpe de aire frio* (being hit with cold air). Cold drafts were also avoided, and people dressed warmly inside and outside their homes in winter. Avoiding temperature changes also involved not allowing oneself to get too hot by, for instance, not sitting too close to the fire and by wearing a hat in the sun. Also, she, like so many Uruguayans I observed, covered her mouth with a scarf when she moved from the house to the outdoors. This lessened the shock of the change in air and temperature to the body.

On humid days, particularly days of rain or risk of rain, the simplest way to protect oneself from the humidity was to stay home. Not showing up to a meeting, a class, smoking cessation group or a pulmonary rehabilitation class was justified if it was raining or looked as though it would rain. Clearly, in a country where owning a car is very expensive it is understandable that rain will limit mobility in greater ways than if everyone had cars to move around in and indoor parking. However, perceptions of humidity alone were enough to cause many of the people with COPD in my study to stay home. This was not always about avoiding disease; it was about recognising the limitations humidity causes someone with COPD. Humidity, I was told, makes it harder to breathe, sometimes impossible to breathe, and breathing becomes more problematic with movement in humid conditions. To cope with humid days, people in my study with COPD would avoid leaving the house or even the bedroom. Humidity was spoken about in terms of percentages reported in the weather reports on television or radio. "Some days there is 100% humidity" said one of my participants. On those days her breathing was severely affected and she would avoid exertion and might lie down in bed, propped up on multiple pillows as lying flat was reported to me as causing more shortness of breath by a number of participants.

Interestingly, for people with COPD in my study the meaningful biomedical intervention for an episode of congestion or exacerbation was the nebulizer. The nebulizer is an intervention which involves placing a broncho-dilating medicine into a machine which produces a mist containing the medicine to be inhaled through a hand-held mouth piece. Some people with COPD had nebulizers in their home; others received nebulizers from emergency departments or on the wards. In those clinical settings it is administered with oxygen. The curious thing about nebulizers is that while humid air is perceived as bad for breathing, the nebulizer's therapeutic potency comes through a humid mist. Clearly there was something different about humidity 'out there' in the air and humid, medicated air aspirated via a nebulizer. Humid air is not just air that is moist, it may also be air filled with various other particles. Tacuarembó city-centre had a particularly thick mist at night in the winter, thickened not only by condensation but also by wood-fire smoke. Surprisingly, wood-fire smoke was never mentioned to me as an aggravator of respiratory symptoms. Perhaps it is too ubiquitous to be considered problematic, or perhaps the way it hangs in the humid air means it is lumped with humidity in everyday speech.

CONCLUSION: BREATHLESS SENSATION AS ENVIRONMENTAL EMBODIMENT

This chapter has taken a sensorial approach to understanding how breathing and breathlessness are experienced at a phenomenological level, and understood and responded to socially and culturally. I have argued that to understand breathlessness in the context of COPD it is important to understand not only the individual experiences of it but wider beliefs and customs surrounding breathing. Data suggest that a purely 'in the body' focus for understanding what it feels like to be breathless is incomplete. Rather, breathing and air (climate/weather) are intimately entangled, in that sensing the breath is sensing the air. We exhale part of our body into the world and we inhale the environment into our bodies. In the words of Merleau-Ponty (1958) "Our own *body is in the world* as the heart is in the organism: it keeps the visible spectacle constantly alive, it *breathes life into it* and sustains it inwardly, and with it forms a system" (p.235, emphasis added). This chapter has added the inclination of sensory ecology (Shepard, 2004) to the conceptualization of a sensorial approach to medical anthropology proposed by Nichter (2008). It builds upon the research of sensorial medical anthropology (Hinton *et al.*, 2008; Nichter, 2008) as well as the anthropology of climate and weather (Hinton *et al.*, 2003; Hsu & Low, 2007; Strauss & Orlove, 2003b), and emphasises their interconnectedness in the case of chronic lung disease among my participants in Uruguay.

In the following chapter, the narratives of participants with COPD take centre-stage. While this chapter has provided the underlying socio-cultural context for breathing and its disruption in Uruguay, the following chapter enters the embodied world of the person with COPD. Through a multi-modal approach to ethnography centred on exploring sensations of breathlessness the multiple expressions of COPD are uncovered.

The Expressions of COPD

INTRODUCTION

The term expression can be thought of in many ways. One way of thinking about the meaning of the word is in terms of facial expressions which communicate affective and physical states such as pain, sadness, surprise, and boredom. In medical language, we frequently hear of ‘gene expression’, *i.e.* the observable features of a gene which is alternatively called phenotype. Expression can also be defined as “something that manifests, represents, reflects, embodies, or symbolises something else” (Merriam-Webster, 2012). In this chapter I explore this broader understanding of expression in terms of the lived-experiences of people with COPD. I am interested in how the disease expresses itself in different peoples’ lives and how they can express their sensations to those around them.

In a way, the chapter explores the multiplicity of subjective phenotypes. Like atherosclerosis in Mol’s (2002) ethnography, COPD is multiple. However, unlike Mol (2002), who looks at how atherosclerosis is enacted and made to be something in different settings, in this chapter I am exploring the multitude of expressions, experiences, and perspectives on COPD, with a firm focus on how it *feels* to have it. Expressing the sensorial experience of breathlessness to a non-sufferer, whether that be friends, family or ethnographer, is no easy task hence the importance of metaphors for a sensation difficult to describe in words (Nicholls, 2003). After initial illness-narrative interviews with participants I decided to explore the potential for other kinds of qualitative research methods, incorporated into an ethnographic approach, to generate deeper understanding of what it is like to live with problematic breathing. Chapter 3 described my multi-modal approach to studying the experience of COPD. In this chapter I draw particularly on data gathered via three methods: definition-elicitation, drawing and pile-sorts.

Definitions are at once audio and visual because they are imbued with descriptive metaphors which trigger a visual understanding. I would argue that drawing and pile-sorts are both visual-textual methods. The drawing exercise elicited narratives that appear here in textual format. The pile-sort, even though it used words and metaphors and not photos or objects, remains a highly visual exercise. Participants manipulate cards with words on them

that they arrange into a visual representation of the categories of experience and how one relates to another (Figured 3.6). The interpretation and understanding of their visual representation of words spread across a table, is impossible without the narrativisation of their meaning. The data is therefore dialogic and inter-subjective. I was asking participants to explore their experience through different tasks and activities and their responses were generated in relation to helping me understand what it was like to have COPD. The theoretical contribution of this chapter is therefore tied to the methods I explored.

Pink (2011), in a paper exploring the ways in which multimodality scholars and ethnographers can combine their methods and approaches, states that "It is interesting, however, that while multimodality scholars are making overtures to ethnography, there is no correspondingly great interest among anthropologists in the multimodality approach" (Pink, 2011, p.273). This thesis, particularly this chapter, aims to help fill this gap and helps to answer some of the questions and uncertainties raised, particularly in the visual methods literature. Examples include Banks' (2007) question to the field "...can visual methodologies yield any new insights beyond those that could be uncovered by other methodological practices? And if so, how robust are these methodologies?" (p.116). Furthermore, Bagnoli (2009) tentatively says that "the inclusion of non-linguistic dimensions in research, which rely on other expressive possibilities, *may* allow us to access and represent different levels of experience" (emphasis added) (p.547).

This chapter focuses on the thick description of my participants' experiences, often using their own words. However, based on the breadth of ethnographic insight which underlies these discreet pieces of data, I bring my own contextualised interpretation to them. I will show that in the case of exploring the experience of COPD, multimodal ethnography did allow me to access different levels of experience and gain new insight, supporting Guillemin's (2004) perspective that "The use of an integrated approach that involves the use of both visual and word-based research methods offers a way of exploring both the multiplicity and complexity that is the basis of much social research interested in human experience" (p. 273).

The notion of robustness, which Banks (2007) questions, comes, I would argue, from the ethnographic approach in which multimodality or a multi-method approach finds itself in this case. Returning to the idea of 'expression', my aim is to show the multitude of ways COPD can be expressed. This goes beyond the reductionist concept of phenotype proposed within biomedical language. The chapter focuses on three forms of expression of COPD linked to three

methods written in brackets: 1) Embodied Expressions of COPD: The Language of Difficult Breathing (Definition-Elicitation) 2) Expressing COPD Pathology: Co-Constructed Imaginings and Images (Drawing Lungs) and 3) The Sensorial-Emotional Expressions of COPD (Pile-Sorts). I make use of the rich narrative accounts shared by my participants as a way of, in the words of Stoller (1989), giving "...readers or viewers a sense of what it is like to live in other worlds" (p.156), in this case the world of Uruguayans having experienced or experiencing the disruption of that most basic and taken for granted bodily function, breathing.

EMBODIED EXPRESSIONS OF COPD: THE LANGUAGE OF DIFFICULT BREATHING

When I learned the words and expressions to speak about breathing and breathing difficulties in Uruguayan Spanish, I came to understand what they meant not simply by listening to peoples' explanations. I also saw what people looked like when they named and described the symptoms they were experiencing 'in the moment', as well as saw how they imitated symptoms they had experienced in the past. Language in relation to experience is important in a general sense because as Sapir (1949) said, language "...does not as a matter of actual behavior stand apart from or run parallel to direct experience but completely interpenetrates with it" (p.8). Furthermore, language draws on metaphors and metaphors are what connects various experiences and helps evoke these connections (Jackson, 1996). Therefore, as a starting point for this chapter on the expressions of COPD, and as a way of giving the reader insight into the sensation of breathing difficulty, I begin with a synthesis of my respondents' definitions of eight expressions I commonly heard in Uruguay. Based on these I suggest a preliminary taxonomy of terms and how they may indicate different expressions of COPD.

Me falta el aire (I'm lacking air)

By far the most common expression used to denote having difficulty breathing was *falta de aire*. Literally this translates as 'I'm lacking air'; however, it seems closest to the expression 'breathless' in English. Participants said it refers to "not being able to breathe", "it being difficult to breathe", "not breathing well", "having little pulmonary capacity" and "feeling like there isn't enough air to be breathed." With regards to the latter, one participant added needing to open a window in the house even in the winter in order to let air in. It was used interchangeably with *falta de oxígeno* – lack of oxygen – amongst my participants. From a medical perspective the two can be very different, someone can be breathless - *faltar el aire*-

but be saturating sufficient oxygen into the blood stream. However, my oxygen and non-oxygen-dependent participants in their narratives and in the pile-sort, which I carried out before the definition-exercise (discussed later), consistently explained that *falta de aire* and *falta de oxígeno* are the same thing. Only one participant, Bruno, 82, said “I am not literally lacking air because there is air, but I am lacking oxygen.” Perhaps their interchangeability stems from the similarity of their construction “*falta de...*” or because oxygen-dependency is often regarded as the end of the line for COPD and, therefore, the primary symptom must in some way lead to problems with oxygen. In any case, I would argue that using these two terms interchangeably made participants think of their bodies as lacking oxygen in a way that might not be reflected in non-Spanish speakers with COPD. However, to confirm this, cross-cultural research is required. Out of the list of expressions, it makes sense to begin with *falta de aire* because in explaining it the participants tended to draw on many of the terms to follow, just as the definitions of those terms draw on *falta de aire*. *Fatiga*, *me cierre el pecho*, *ahogo* and *agito* were variably mentioned by participants in describing *falta de aire*. Lastly, it could be related to COPD or asthma. One participant said *me falta el aire* ends by using an inhaler.

Me ataque/Estoy atacado (I had an attack/ I’m having an attack)

I would frequently hear *estoy atacado* in reference to increased breathing difficulties experienced by my participants. When asked, a few of my participants linked this terminology to asthma and mimicked noisy breathing and wheezing. It was specified that you can use *estoy atacado* (I’m having an attack) to refer to heart problems, back pain and even hunger, in that what it refers to is an increase in the severity of an underlying condition. In English medical terms it seems equivalent to the term exacerbation. A couple of participants said it means you are having or about to have *un ataque de los bronquios*.

Atacado de los bronquios (bronchial attack)

The definitions for this state demonstrated the greatest consensus of all terms. Most said this term is used when you have a severe cough coupled with phlegm and mucus production, making it difficult to breathe. The sensation is one of the bronchial tubes or chest closing or shutting on itself. The cough was described by some as uncontrollable and one person said “it can drive you to the point of vomiting.” Two participants said it was the same as *me cierre el pecho*.

Me cierre el pecho (my chest is closing)

One participant who works in the countryside but lives in the city told me this is a term more common in the interior. Many respondents evoked the term *faltar el aire* in defining this expression which they had not for *atacado de los bronquios*. I noted that a few of the participants automatically put their hand on their chest and pressed into it. Being pressed or squeezed in this way closes the bronchial tubes and makes it difficult to breathe and brings on a feeling of *ahogo* (see below).

Atacado del pecho (chest attack)

Participants said people will use this term to refer to a crisis, particularly an asthma attack, wherein the person coughs, has a wheeze or noisy breathing, and experiences the sensation of a closed or squeezed chest. One participant explicitly said that it implies closed bronchial tubes and chest thus connecting it to the previous expressions. However, two participants also brought up the experience of a cold or flu in relation to this term, as well as pain. One participant said the same sensation can occur because of chest pain caused by heart problems.

Ahogado (drowning, suffocating or choking)

The verb *ahogar* was frequently used to describe what it feels like to have an exacerbation or even what it feels like to have COPD on a daily basis. One participant said “the sensation is equal to that of drowning.” This tended to describe a more severe form of breathlessness, one that might make the person feel like they could die. One participant said “its desperation.” It was explained to me in many ways including: “it’s like the throat closing”, “no air entering at all, leading to a lack of oxygen”, “not being able to fill the lungs, despite how much you try”, “opening the mouth but nothing entering” and, “losing control of one’s body.” One participant made the gesture of strangling himself. Another participant explained that this could happen when doing something strenuous or walking very quickly and being unable to catch your breath and recuperate. Only one participant linked this to coughing uncontrollably, however, another explicitly said it was nothing like *atacado de los bronquios* and indeed *ahogado* seemed to be unrelated to coughing for all but the one participant.

Me agito (getting agitated)

This expression is used among people with COPD in my study in reference to becoming short of breath as a result of physical exertion and tiredness. The exertion might even refer to the exertion caused by trying to breathe. Things that could bring on tiredness were walking, talking and even arguing. One participant put it in scientific terms and said “It’s related to feeling breathless because any small physical effort increases the respiratory and coronary rhythm leading to feeling *agitado*.” Two participants mimicked panting, one saying, “like a dog with his tongue hanging out.”

Me canso (I tire)

This is best translated as ‘tiring myself out’ and is related to *me agito* and can be used interchangeably. However, for this term what emerged from the definitions was the action of having to stop what one is doing because the body cannot carry on, not only due to breathlessness but also to feeling that one does not have enough physical strength. Activities that were mentioned included going up stairs, walking, chasing the bus, making the bed and sweeping the floors. When one *se cansa*, he/she has to stop, pause, rest or sit for a little while.

Me fatigo (to get tired and to get breathless or out of breath)

One of my participants told me that *fatigo* was missing from my initial list of terms and that “when I feel like I am going to *fatigarme*, I take two puffs of my inhaler.” I was able to ask three other participants what they felt this term referred to. There seemed to be agreement that it was a more specific and scientific term than *me canso* which, one Montevidean city-dweller said, “it is what they say in the countryside” *i.e.* the interior. One explained that it was an increase in dyspnoea, not necessarily linked to physical exertion. While *canso* can refer to all kinds of things (*e.g.* I’m tired of that person), *me fatigo* is specific to a physical experience. One participant said tiredness can bring on *fatiga*.

The terms have been organised in a particular sequence here because of the relatedness of certain terms and the way they appeared sometimes to logically merge one into the other. They were not elicited from participants in any consistent order. There is no doubt that these terms are often used interchangeably. Figure 6.1 is one taxonomic representation of the relationships between these terms which I have constructed based on comparison of participants’ definitions. On the left are four expressions that are particularly interchangeable.

Participants either saw these as typical of asthma or of an acute illness like a cold or flu. The three on the right side are largely interchangeable but have some important differences. These were not particularly linked to acute disease states. Rather they related more to physical activity in daily life. In the middle are two intimately related expressions *me falta el aire* and *me ahogo*. Both of these expressions can be evoked when describing the experience of breathing problems represented on both the left and right-hand column. Although they are seen as similar, *ahogo* is a more severe stage of *me falta de aire*.

Dyspnoea is a complex physiological mechanism thought to be evolutionarily adaptive and controlled by various parts of the brain. Some clinicians have taken a special interest in the language used to describe dyspnoea because understanding the subtleties of the language used to describe sensations has the potential to differentiate between pathologies which cause dyspnoea (Caroci & Lareau, 2004; Scano *et al.*, 2005). However, another interpretation is that the frequency with which one column predominates a person's illness narrative may hypothetically reflect whether the person has more inflammation in the bronchial tubes, which produce mucus, or greater damage to the alveoli, which control gas exchange. It also reinforces an observation I made time and again, which was that people in Uruguay commonly call the symptoms on the left 'asthma' even in the case of someone with COPD. I heard a number of times *le vino como un asma*, which can be translated as "he started to get some kind of asthma", in reference to coughing and chest tightness.

It is far more accurate to speak of the sensations of dyspnoea as opposed to 'the sensation' because of the multiplicity of terms used and the different sensory and affective state they refer to. In turn, the perception of dyspnoea is shaped by language and cultural factors (Scano *et al.*, 2005). Chapter 4 illustrated how experience of breath sensations is related to the shared cultural perceptions of the environment, *i.e.* air, which Uruguayans I met perceived as threatening to health and breathing. However, another reason why language use about breathing is important is because it can help the clinician differentiate among severities and causes of dyspnoea (Harrison, 2012; Scano *et al.*, 2005; Williams *et al.*, 2008). Of course, word-preference will vary, and equivalents in different languages may not always exist. For example, von Leupoldt *et al.* (2007) found that the descriptions of dyspnoea given by their German participants converged with the findings of similar studies done in English in the USA, Canada and the United Kingdom, however Vazquez-Garcia *et al.* (2006), in their study of

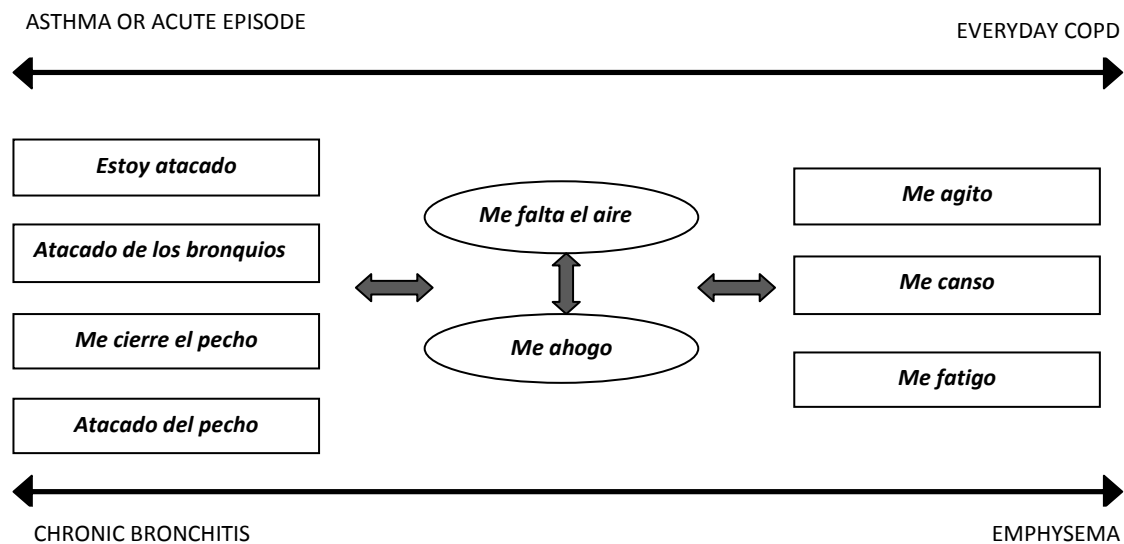


Figure 6.1: Taxonomy of common expressions for expressions for breathing difficulty arranged along two axes: Asthma/acute episode – everyday COPD and chronic bronchitis – emphysema.

Mexican-Spanish descriptors for breathlessness, came across more examples of divergence in language use and problems of translation. They generated a list of 21 terms for breathlessness, described by a mixed study population of respiratory and non-respiratory disease participants, which they then divided into seven cluster groups. Interestingly, *ahogo*, which they define as drowning, was presented in addition to *asfixio* (suffocation) and *sofoco* (smothered). When they looked at which groups were more likely to use which clusters of terms, they found that participants with COPD referred to agitation, exhalation and smothering more than people with other respiratory conditions. Interestingly, the term ‘agitation’ occupied its own cluster as it had a high level of disagreement and there is no equivalent English term, just as ‘air hunger’ has no equivalent in Spanish. According to Scano *et al.*’s (2005) review, the most common terminology in English for dyspnoea clusters around chest tightness, work/effort, unrewarded inspiration, rapid breathing and air hunger. Vazquez-Garcia *et al.*’s (2006) Mexican participants with COPD used *me agito* like my participants in Uruguay, however, the authors’ English translation “I feel edgy, agitated breathing” is different from mine. Rather than try to choose the English equivalent for *agito*, which, as Vazquez-Garcia *et al.* (2006) contend, does not exist, I have chosen to summarise the qualitative description of the term, which suggests that it is a kind of increased rate of breathing. Perhaps one could refer to this as agitated breathing that

comes on usually with some form of physical exertion, although the level of exertion is relative to each person and their physical capabilities.

Language used to describe dyspnoea is not squarely a language relating to the physical body, it is highly emotional too. Williams *et al.* (2008) asked their Australian participants, with and without COPD, to tell them what words they use to talk about their breathing when it is uncomfortable. They found that generally it was only their participants with COPD who would add descriptors such as frightening, worried, helpless, depressed and/or awful to their list of descriptors. It appears as though the use of affective descriptors may reflect the degree of impairment caused by COPD as well as the perceived threat of dyspnoea (Williams *et al.*, 2008). Similarly, Caroci and Lareau's (2004) quantitative study of descriptors of dyspnoea proposed by people with COPD and people with heart failure found that the word 'scary' was given alongside 'hard to breathe', 'shortness of breath', and 'cannot get enough air' among their participants with COPD. The emotional impact of breathing difficulties permeated my interviews as well as observations of families at the bed-side. To investigate the links between the emotional experience of COPD, not only associated with breathlessness but other symptoms associated with COPD, I carried out a pile-sort exercise with a sub-section of participants. This yielded more in-depth understanding of how the emotional and the physical experience of COPD cannot be studied separately as they are endemic to the expression of this disease itself.

THE SENSORIAL-EMOTIONAL EXPRESSIONS OF COPD

Intersubjectivity, sensation and emotion are all related in the ethnographic study of health and illness (Burbank, 2011; Desjarlais, 1992; Jackson, 1994; Throop, 2010; Wainwright *et al.*, 2011). It is clear that living with COPD and the sensation of breathlessness has a very significant impact on emotional and psychological health as determined in quantitative studies employing standardised measurement tools (de Voogd *et al.*, 2011; Medinas Amoros *et al.*, 2011). The qualitative literature, as reviewed in Chapter 2, has explored the emotional impact of COPD via in-depth interviews. In my study, as a way of foregrounding the intertwining of the emotional and physical expressions of COPD, in a more explicit way, I decided to use pile-sorts as an exploratory methodology, after having carried-out narrative interviews. In this section I draw upon these data to emphasise the diversity of expressions of COPD. After all, one of the virtues of the participant recruitment strategy in this ethnographic research was its breadth and

reflection of the diversity of the COPD population, something not present in the qualitative literature presently. I draw on a number of participants' pile sorts and on other participants' experiences when appropriate. Their narratives are italicised while the boxes contain the terms that they grouped together and to which they were speaking.

COPD as a Problem Then not Now

In a number of interviews, COPD was not a major concern. When I asked William, a 70 year old painter with COPD (FEV1/FVC=38%), who continued to smoke, how he deals with his respiratory problem he answered "with tranquility, it doesn't affect me." His wife was quick to add "his problem is his legs." Like at least three other participants (Ignacio, Daniela and Soledad) with obstructive artery disease (another smoking-related disease), William experienced pain when walking short distances, so that his ability to walk is hindered by pain long before his damaged lungs cause him to be breathless. Furthermore, he is elderly and has a sedentary lifestyle, meaning he leaves the house infrequently and does little strenuous activity. He is concerned about his "respiratory problem" when he gets pneumonia as he did the winter before I began fieldwork, when he was hospitalized. The pneumonia was a problem but the COPD was not. He even continued to smoke although far less than he used to.

Another group of participants also did not experience their COPD as a problem at the time of my fieldwork. However, their reasons were different. They had noticed a drastic change in the severity of their symptoms since diagnosis and treatment. Four simply did not identify with the idea of having a chronic respiratory disease anymore (Bruno, Joaquín, Ignacio and Rodrigo), even though a spirometry would show little, if any, change in their underlying airflow obstruction. They had gotten better and were not bothered by their breathlessness upon exertion. This 'before and after' was represented in the pile-sort exercise. Take for example, Joaquín, a 72 year old man who used to work constructing and repairing water towers in the countryside. He smoked 20 cigarettes a day for 52 years but quit 14 years ago. We did the pile sort but he found it difficult to engage with. His wife was trying to help him but eventually he just said "I feel like I don't have anything wrong with me. With the years, everything gets used up, because of age too." Therefore, I asked him to think back to when he was experiencing respiratory problems and to do the pile-sort. He answered "I was really bad, I couldn't breathe" and he lumped thirteen of the cards together which included anger and anxiety. His wife Gladys explained how things were before diagnosis and treatment:

“He never wanted to go to the doctor and when we did, the doctor would come in and say “you have asthma.” We said, “No, he was never asthmatic as a child.” But they would send him to get treatment for the crisis and that’s it. Then we’d call again [the mobile emergency service that is included in their private hospital coverage], I was calling every 4-5 days. I’d say “I’m desperate, I don’t know what to do, and he’s not getting better with the nebulisations.” I couldn’t leave the house relaxed, I would go in the morning and he’d be here going... [mimics panting]. All the nurses knew my house. The doctor finally said “I’ll give you a referral to see a doctor that treats the bronchial tubes.” After that referral I don’t think we’ve had to call them again.”

When I asked Joaquín what he thought has made the difference, he said that getting diagnosed meant that he was being sent for the flu vaccines and without getting the flu he did not need nebulisations all the time. Similarly, the asthmatics in van Sickle and Wright’s (2001) study experienced their disease as an acute disease and not a chronic one, which shaped how and if they took their prescribed medicines. Williams *et al.*’s (2007) participants with COPD also did not consider themselves ill unless they were in hospital. One of the primary reasons for hospitalisation is exacerbation caused by catching colds or flu and the most recent international guidelines for COPD state that a flu vaccine can reduce death and serious illness by 50% in COPD patients (GOLD, 2011).

In summary, despite being diagnosed with COPD on the basis of an irreversible pathology in the lungs, some of my participants did not identify with the term. Two major reasons why were either because another health problem was more troubling, or because symptoms (particularly acute episodes) had subsided after diagnosis, treatment with inhalers and better prevention of acute respiratory infections. Also, if participants were elderly and the acute aspects of their disease were controlled, they were not as bothered by being short of breath as younger people because they were less active and had expectations that this was part of ageing. Narratives of ‘recuperation’ are infrequently included in the qualitative literature. I believe this is partly due to the fact that studies (Appendix A) often select for non-co-morbid participants who recently experienced exacerbation and who have been diagnosed with moderate to advanced and end-stage disease. Co-morbidity is more the norm than the exception in COPD, especially moderate to severe COPD (Almagro *et al.*, 2010; GOLD, 2011). The pile-sort reinforced these ‘then and now’ experiences by virtue of making it almost

impossible for the participant to engage with the exercise without being told to think of “then” or of “now”. ‘Recovery’ is a contentious topic in chronic illness from a biomedical perspective, but perceptions can change. Good *et al.* (2010) describe a similar trend in schizophrenia. They demonstrate, as I do, a heterogeneity in the experience of what is defined biomedically as “lifelong and degenerative” schizophrenia, and highlight narratives of recovery and minimum impairment (p 56). However, they also say that nowadays recovery and schizophrenia can appear in the same sentence, which is perhaps what will occur over time with COPD.

The Acute Exacerbation

For some participants, like William mentioned above, the experience of disease is that of recurrent acute illness episodes. While their breathing on a day to day basis had not, at the time of these interviews, affected them so as to be noticeable, they were susceptible to getting lung infections, colds and flu, which make their breathing very difficult and from which it took a long time to recuperate. Macarena was 59 when we met and was diagnosed with “moderately severe COPD” confirmed by spirometry. Although she could still go for walks on the beach, be active as a grandmother and could ride a stationary bicycle with more resistance and at a faster pace than any other person in her pulmonary rehabilitation group, she was getting frequent exacerbations and required six visits from emergency services (either at home or at their clinic in her village) in 2010. The emergency doctors would give her nebulisations or start her on antibiotics or, if needed, take her to a hospital. It was usually up to her to tell them she had COPD because if she did not they might not take the same approach to her care (*i.e.* they may not pre-emptively start her on a course of antibiotics). During the year of my study, Macarena experienced her first hospitalisation for COPD. I explored her experiences through pile-sorting and the following is a good example of the kinds of emotions and feelings that are associated with acute exacerbations.

Anguish/Sadness
Anxiety
Anger
Tiredness
Cough
Bronchial Attack
Phlegm/Expectoration
Lack of Oxygen
Lack of Air
Suffocated
Flu

Anguish and sadness, yes, I get like that sometimes without being able to justify it. There are moments. I get very anxious; I get angry if people ask me questions when I'm breathless and having to repeat... I feel very tired when I'm in a crisis, with a lot of cough, and having a bronchial attack, phlegm and expectoration, lack of air, lack of oxygen. All of this happens to me when I'm in a crisis. If you ask me I get angry

and I get annoyed having to explain because I'm breathless. When I have a lot of coughing and I feel like I'm bothering my husband, and I start expectorating, I don't like that people see me like that. For me it's unpleasant so I imagine it's unpleasant for others too. Flu is a state I've hardly had. Suffocation, yes, when I'm in crisis, I get up from the bed, go to the couch and I feel suffocated. Breathlessness, yes, I feel horrible.

For Macarena, an acute exacerbation is also linked to a worsening cough and expectoration. The sound and sight of coughing was an omnipresent feature of fieldwork and conversation. The sound of phlegm, sometimes virulent, rattling and churning inside some of my participants' chests was a chilling reminder of their damaged lungs. The effort made to finally bring up sputum, which can be yellow and green in colour, and which must be spat into a cup, dish or tissue, is also visually unpleasant. I had previously done research with people with COPD and, therefore, these sights, sounds and even smells were not new, but they were nevertheless disconcerting and sometimes, no matter how accustomed one is, viscerally unsettling. However, people with COPD learn to inspect the colour of their sputum because different colours imply different courses of action such as starting antibiotics, steroids, or consulting a healthcare professional as soon as possible. Macarena felt self-conscious of the sounds and sights of her disease like other participants did. Gullick and Stainton (2008) similarly reported that,

"The embodied experience of coughing and spitting for our participants drew attention to their now dysfunctional body. It was an uncalled-for, socially unacceptable expression of the body, and was unable to be contained" (p.608-609).

The Chronic Acuteness of Breathlessness

There are those people with COPD whose lung deterioration is so great that they experience acute episodes of breathlessness throughout the day while trying to carry-out daily tasks. Florencia, 56, attends a public hospital, which at the time of this study had no spirometry or respirologist. Thus, her COPD was diagnosed only partially (based on medical history) and therefore inconclusively. Her cement home lies, like that of Macarena and so many people in Uruguay, on a plot of land on which is built her daughter's and her brother's house. Although almost the same age as Macarena, Florencia is oxygen-dependent and was spending time in and out of hospital for exacerbation and oxygen therapy until a concentrator became available

for her home. She had been hospitalised for COPD exacerbation at least five times and had been to accident and emergency at least 10 times in the 12 months prior to our first interview. When we first met, we spoke through her oxygen mask and just conversing a little made her breathless. Over the months she recuperated some strength and was often able to remove her oxygen to chat for a few minutes and sometimes longer. Below she expresses her emotionally-embodied experience of the kind of COPD which makes itself felt multiple times throughout the day.

Lack of Air
Suffocated
Fear
Fatigue
Anguish/Sadness
Lack of Oxygen
Debility/Weakness
Anger
Memory Loss
Phlegm/Expectoration
Dependency
Bronchitis
Confusion

Florencia: *These are all the things that happen to me. Falta de aire (breathlessness), I have that. Suffocated, well sometimes I feel that when all I've done is come back from the bathroom and I'm without air [sin aire]. Fear I have because I panic and that makes me scared. Fatigue too because that occurs when I come back from the bathroom, I feel unwell, I feel tired. Sometimes I feel anguished or I feel sad because I can't get out alone like I could before, I feel bad*

that they have to walk with me, it makes me anguished and sad and you know...Lack of oxygen I have because of my problem. Debility I feel because I feel weak because I walk very little because I don't get out much. Sometimes I can't even eat because of the breathlessness that I feel. Anger, sometimes I am angry because I get nervous, I get in a bad mood, I feel unwell and I get angry. But, you know, it happens, sometimes nobody does anything to me yet I'm angry anyways. Memory loss, like I was telling you, sometimes I call my daughter over to ask her something, and I practically don't remember anything. Expectoration I have for the moment, and with a medication the doctor gave me...I can't remember what the medication is called which they gave me but it's an expectorant.

Megan: *Does it help?*

Florencia: *Yes it helps, now I'm not taking it because it was for 10 days and I've completed that. Dependency on someone, yes I'm dependent, because I can't be alone.*

Megan: *you could be dependent on persons, or things...*

Florencia: *Yeah, but the thing that interests me most is depending on someone to be with me. Of things, yes sometimes but that's not as important as having to have someone with me. At the moment, what interests me is that. And bronchial attack too.*

The other day I had it, thankfully I didn't come down with a flu, because the doctor told me I can't get the flu, well not that I can't, but that I have to take care to not catch the flu.

Dependency is an interesting difference between Macarena and Florencia in their explorations of the emotive sensations of COPD. Macarena finds the exacerbation of her symptoms and the risk of exacerbation frightening and upsetting but if she is not exacerbating, she is not dependent on her family members. To the contrary, her daughter depends on her for childcare. Florencia's dependency is not uniquely about being attached by a small tube to an oxygen machine which needs to be continuously plugged in. Although she does say she feels anguished and sad that she cannot get out on her own anymore, what worries her more is being dependent on the people around her. It is the panic and fear of acute breathlessness that makes her unable to stay home alone, nor sleep alone. Her eldest daughter, who lives on the same plot of land, confided in me how the burden of this moment to moment care falls on her, "My sisters come and visit for a couple hours but when they leave I am the one she calls to because she doesn't want to be alone and my son is the one who sleeps next to her every night." The family even pulled together the money to pay a neighbour to *cuidarla* (take care of her) during the day when all three daughters are at work and the grandkids at school.

COPD and Growing Old

So far we have seen how the physical-emotional experience of COPD at the time of interviewing could be an imagined past, an acute episode, or the daily awareness of illness linked with sadness, anger and anguish at not being able to do things and dependency on others. The experience could also be one of ageing and a sense that one is approaching the end of life. In contrast to some older participants like Bruno (age 71), Joaquín (age 72), Rodrigo (age 76) and Ignacio (age 70), who considered themselves in good health and not chronically ill, other elderly participants were severely affected by their COPD as well as other serious co-morbidities, such as diabetes, hypertension, artery disease and heart disease. For these people with COPD, life was slowing down, becoming more difficult, lung function and energy levels noticeably declining and recuperation from acute episodes ever more difficult. In the words of Mauricio (age 70), who died months after I left Uruguay,

“Each time something happens with your disease you’re knocked down and you never go back to the point you were before. Everything is a knock-down, a cold, a flu, everything.”

The physical-emotional experience of advanced and symptomatic COPD late in life is reflected in Soledad’s narrative in relation to one of the groups she made in the pile-sort exercise. Soledad was 72 when she participated in this study and my visits normally consisted of sharing a meal with her and her daughter or grandsons who normally stopped by for lunch. She had worked as a secretary and had been to university for a period of time. She smoked 50 cigarettes a day for 50 years and reluctantly quit around 2004 because of the pressure from her grandsons. In addition to COPD, which was diagnosed around the same time she quit, she had blocked arteries, diabetes, hypertension, gastritis, and arrhythmia and had had a heart attack. These co-morbidities exist in a syndemic relationship all tied to her long and intense environmental exposure to tobacco smoke. Soledad had the second highest pack-year history of any participant. She had smoked the equivalent of one pack a day for 125 years. However, facing a life with multiple co-morbidities was not the only hardship Soledad had faced in life. During the dictatorship she was a political prisoner and spent a year incarcerated. As a 72 year old, she had an invigorating rebellious streak, which was manifested in her anger at having had to quit smoking, her impassioned opposition to what she saw as an authoritarian way of implementing tobacco-free policy and in her anger with a woman who tried to insist on helping her cross the street. However, there was a sadness that was taking hold of her over the course of my study and she said one reason for her depressive mood was certain disillusionment with politics in addition to dealing with a life that seemed to be shrinking.

Anxiety
Addiction
Anguish/Sadness
Dependence
Lack of Freedom
Memory Loss
Confusion

Soledad: *it has a lot do with, with politics, with the economic situation, with...I don’t know, sometimes with loneliness...it was hard for me and it stressed me out a lot to stop working. That was very difficult, now it’s been almost 2 years.*

Megan: *Yes, I remember you telling me that you quit your job because you were falling asleep at work.*

Soledad: *Yes, I would fall asleep, I would get very tired, but if I could have continued working and just having a little nap...but you can’t do that. It’s not looked kindly upon! What a shame! [laughing]. No seriously, there are things you just can’t do, for just a*

minimum of dignity, you can't do them. But I don't like it, being here all the time feeling useless and more and more everything shrinks. I really like going to the market [feria]...

Megan: *Oh yeah?*

Soledad: *I find it wonderful, just as shopping malls don't attract me at all, going to see those mountains of fresh vegetables, and the people working, and neighbours selling things, the things they sell on the pavement, all that seems marvelous to me, the same as indoor markets, sidewalk sales, I like them very much. Now I never go to the markets. I can't because, it's nice to go buy one thing here and another there, but now I have to ask someone to carry - if I have it in me to get to the market- to carry all my things. There is a saint of a boy who, if I buy things in various stalls, will go around each one and pick up my purchases and bring them to me. Yes, he's lovely the poor boy, but, I don't like that. I also can't go to, for example, to the Candombe drumming processions. Things like that I can't make it through the whole thing, I used to like Carnaval a lot but no.*

Megan: *And if someone goes with you?*

Soledad: *And what they carry me? No.*

Megan: *Walking with someone?*

Soledad: *I tire myself out anyway. I get tired when I have to walk and stand a lot. The only thing I always do is go to the silent march in remembrance of those who disappeared during the dictatorship [Marcha del Silencio], I do the march and arrive at the Plaza de la Libertad dead but...that I always go to.*

...

Well, let's see...I get pain when I have the flu. And I have a lot of pain in my legs too.

Megan: *Those two go together?*

Soledad: *Yes, but the most important pain that I have is in the legs. That stops me from walking, for bad circulation, everything is blocked. When you have the flu, everything hurts. And anger...fear I don't feel. Anger, yes sometimes I get furious, furious with myself, I mean my limitations.*

Megan: *Does that anger come and go just like that?*

Soledad: *I don't know. When that woman helped me cross the street, I got angry! (laughing). And they [family members] tell me "Hey gran, don't do that", "Hey mom, don't do that", its crap, I'll do what I want. "You can't live alone, you have to..."*

Megan: *They've been telling you these things?*

Soledad: *Yes, and I want to convince them that one always dies alone, even if you're in the middle of a hospital room, you die alone. If something is going to happen to me, it will happen to me. At least I have my independence, I don't want it to end with me fighting with everyone, because I can be nasty you know...*

Megan: *But you seem so sweet!*

Soledad: *[Laughing] One gets very nasty you know, especially when you are sick, like this, it's like you take it up with the world. Would you like another coffee?*

Soledad's account is rich in terms of her articulations of the limitations COPD and her other co-morbidities cause her, especially with regards to having to stop working. To others of her age, leaving work would have been a question of retirement. For Soledad, she loved working and was fiercely independent. Work outside the home and having the strength to do things was a feature of many participants narratives. The pile-sort elicited fascinating accounts of how the emotional is also part of the sensation of the limitations COPD imposes on the body, especially among middle-aged male participants, whose narrative I now discuss.

Masculinity and Breathlessness

Gender has been a neglected topic in the study of COPD patients' experiences. Normally, when gender and COPD appear in the literature the focus is on women. This is partly because of the alarming realisation that women are less likely than men to be correctly diagnosed because historically COPD was considered a man's disease (Han *et al.*, 2007). However, these past gender differences in prevalence are thought to simply reflect the difference in smoking between men and women, which no longer exists; hence women who began smoking 30 and 40 years ago are now catching up or even surpassing men in terms of COPD (Han *et al.*, 2007). It is also more likely for women who do not smoke to be diagnosed with COPD, particularly because of gender roles and the exposure of women to indoor smoke from biomass fuels and second-hand smoke (Bruce *et al.*, 1998; GOLD, 2011; Kalucka, 2006).

In this section I want to highlight, however, men's experience of COPD as a threat to masculinity in the Uruguayan context. It has been documented elsewhere, although only very briefly, that the activities reported by men and women with COPD that become problematic are gender-specific (Gullick & Stainton, 2008; Leidy & Haase, 1996; Williams *et al.*, 2007). In particular, men reported losing a sense of manhood from not being able to fix things inside and

outside the house, and women found not being able to carry out housework distressing. My female participants generally were more likely to speak of gender-role activities such as sweeping, making beds and cleaning which they frustratingly could not do without becoming breathless. However, what I want to focus on here is what middle-aged men with COPD had to say. Something very interesting occurred when I carried out the pile-sorts. Somehow, putting the cards on the table in a literal sense allowed some of my middle-aged male participants to face and express their frustration, anger and sadness with COPD in a way they had not in previous interviews.

Sadness – Fear – Debility - Anger

I will begin with José, a 53 year old and father of three adult daughters and grandfather of two grandsons, who retired from his work as a bank manager in 2002 because of poor health. José had one of the most complex disease-profiles of all my participants, living with, in addition to COPD, pulmonary fibrosis, diabetes, severe chronic back pain, hypertension and cardiopathy. Although emphysema was first discovered in 1999, he smoked 60 cigarettes a day for 40 years until 2009. He had been on oxygen therapy 24 hours a day since 2009 and had been hospitalised at least 10 times. He spent almost half of my entire year of fieldwork in hospital. We became very good friends over the course of this study and I was welcomed into the family in a big way over my time in Uruguay. He was enthusiastic about my study and was a very reflexive person who loved to talk about everything including COPD, politics and Uruguayan history. In the pile-sort, he offered a very clear description of an emotional process which resonated with other male participants of around his age.

Anguish/Sadness
Fear
Debility/Weakness
Anger

José: “Fear, anguish and sadness are associated. In general, when you are anguished or sad you feel scared, because you don’t know, generally there is something that causes the anguish or sadness and you fear that you won’t be able to resolve it. There, that’s those two. Which, in turn generate, or let’s say, makes you feel like you are weak in facing those things. And to be weak when faced with these elements makes you angry.”

A man's power over animals

The inability to work or carry-out tasks which were always one's responsibility was experienced by some of my middle-aged male participants as a life-disrupting event. Marco, for instance, was 55 years old and had worked on farms his whole life. I witnessed Marco's process of being diagnosed with COPD and receiving treatment. His mother died of COPD a little over a year before we met. He himself smoked 30 cigarettes a day for 20 years, but quit in 2000. He had never been hospitalised for exacerbation but has had some serious attacks. One such attack was described to me by his daughter. She told me of how one day he was in the kitchen, opened the oven, and the heat and steam hitting his face caused him to be immediately short of breath. She imitated his panting and said he crashed to the floor. Marco attributes his day to day problems of breathlessness to his weight-gain after he quit smoking. In clinic, his doctor told him that losing weight will improve his exercise tolerance and his breathlessness but he just cannot muster up the enthusiasm to start exercising more. In the pile-sort only a few weeks before I left Uruguay, he rejected some of the words on the cards such as anguish/sadness, fear, lack of freedom and confusion as not "fitting within the way I do things." He said perhaps he feels these things once in a while for a specific reason, but not in relation to his COPD. Anger, however, featured prominently. He said:

Lack of Oxygen
Cough
Memory Loss
Anger
Fatigue
Anxiety
Lack of Air
Suffocated
Perspiration

Marco: *Anger, permanently when I "lose air" (pierdo el aire: am short of breath)*

Megan: *And what kind of anger?*

Marco: *Anger with myself, because this happens to you because you don't exercise, because you don't take care of yourself, for this, or for that, you understand? That kind of anger, and I feel bad and I'm in a bad mood with myself for that reason. Only when these things happen [the physical symptoms]. I don't like it...for example, with my personality, I've always been the type to love doing physically strenuous things, I'd be the one in front getting the young bull by the head or throwing myself onto the back of a young horse, whatever it was. And to not be able to do the same anymore, because of age and secondly because of the limitation, well, more than anything the limitation not age, that angers me.*

Marco's account illustrates how the acuteness of COPD, in terms of the disablement it causes him upon exertion, is acute in an emotional sense as well.

Anguish at not being able, anger at being expected to be

Mateo, whom I met in pulmonary rehabilitation class within the first month of fieldwork was 43, married, a father of three and was on the transplant list. He worked in industries where he breathed in chemicals and in construction but eventually his breathlessness made him unable to do the physical work he was qualified for. He also smoked 20 cigarettes a day for 20 years and quit the year he was diagnosed with COPD, 2006. On November 28th 2010 he was flown to Buenos Aires and he received a lung transplant. I carried out the pile-sort interview with him in a coffee shop on 16th August 2011 and he situated his responses in a 'before' and 'after' transplant framework. Some things were different, such as the sensation of breathlessness which had greatly improved. But some things were the same, such as dependency, particularly in relation to his low household income and dependence on a disability pension. In the following you can see how the anger and sadness are linked to his inability to *do* work he would normally do if it were not for COPD. However, he was regaining his strength and during our chat pulled his sleeves up to show me the muscles which were reappearing in his thin arms. He was feeling stronger and he was even able to do a bit of construction work for his uncle's company. He said he had felt debility in the past when he used to "look at myself in a mirror and what I saw was like a walking ghost." Below he tells me about how anger and sadness were part of COPD prior to his transplant.

Lack of air
Bronchitis
Phlegm/Expectoration
Cough
Suffocated
Lack of Oxygen
Pain
Debility/Weakness
Lack of Freedom
Dependence
Addiction
Anguish/Sadness
Anger
Fatigue

Megan: Anger?

Mateo: Yes, I would get angry.

Megan: With what?

Mateo: With myself. Often with other people because they don't understand you because this is a very complicated disease. Because people, they would see me as "well", you see, they saw me as slim, everything you can think of, but they did not understand why I did not work. Because if they asked for a hand with something, I couldn't help them and they look

at you as if saying "What's up with this guy?" That would make me mad, you understand?

Megan: Yeah. Anguish and Sadness?

Mateo: Yes, horribly. I don't know, I don't know how to explain it but it's a big thing. Because if you do everything, in my house I built both houses [his mother's and his own

on the same plot] from zero to everything and to do that you need to chop wood, everything, you see. The fact of getting things done was always me, everything. And then all of a sudden nothing, so you might start to think, and with your mind you can make up all kinds of things. I had to do some electric wiring in the house. To do what I can do in a short while took a whole week, you see, I couldn't even nail a nail. So, that kind of thing makes you feel impotency.

Mateo's narrative demonstrates the intersubjective nature of his sense of threatened masculinity. In his case, as in many, his disease was 'invisible' unless he started to do strenuous things which he could not because of becoming too breathless. His neighbours and extended family members did not recognise his limitation and possibly thought he was not reciprocating favours. He also highlights, how not being able 'to do' things leaves the time and space to reflect on these limitations. The feeling of impotency is the ultimate indication of lost manhood in what is a Latin American country with strong gender roles and machismo. Mateo embodies this loss of masculinity, sadness and anger in a very real way through his emaciated body. A body that he recognises as impaired, although others might not.

I used to be a man of the streets

Sebastián was the youngest person in my study with COPD (chapter 4 p, 128). His home was a simple one-room square cement structure with a tin roof and an outdoor kitchen and toilet. It had electricity only because it was stolen from the main lines. As already mentioned in the previous chapter, Sebastián used to collect household rubbish on a horse-drawn carriage. He also worked for some time in a factory. He noticed he was having trouble breathing at the age of 26 that motivated him to quit smoking after 14 years of smoking 20 cigarettes a day. He became unable to carry on with physical work by 2008/09 and was hospitalised once for exacerbation for 20 days in 2010, during which time COPD was diagnosed. He began permanent oxygen therapy in July 2010 and started attending pulmonary rehabilitation which is where we met. Sebastián and I always got along and he was a joker, quite proud and I would say macho, fiercely unafraid of death, and always pushed through the tough times in one way or another. The pile-sort brought out a side to his experience that he had never come close to sharing with me before.

<p>Anguish/Sadness Debility/Weakness Anger</p>
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Sebastián: *"I feel sad and anguished in the sense that because of my disease...before normally I would do*

everything, so I feel angry, I feel impotency, to not be able to carry out what I used to. And now with the things, with the things I'm doing at home [renovations] or in any work, something like that. So, within that enters anguish and debility/weakness which I have, for me...[voice starts to quiver with emotion and tears building] and sometimes I feel bad, I feel an anguish even in the mouth of my stomach which closes, and I stay tense and anguished and it makes me furious, it makes me mad and it can even make me cry. Because clearly that occurs because of the sense that...I've accepted my disease but I have to continue trying to accept it more. So much so that I have to, like I said, in your head you say, "How do I do it? How do I do it? What do I have to do to try and come out of it a little better, to feel better?". And you know, before I spent all my time in the street and now I feel locked-in, because now I'm practically stuck between four walls. I was a person of the street, my work [recyclador], from work to home. I'd be in the street, then home but out meeting people, being with friends. But I was always outside in the streets. But now I feel more, that I have to be locked in more than outside [voice cracking] and I get bored. I get bored and I get angry because I have to do things inside the house. So, I feel anguished [voice quivering as he ends the sentence and he coughs].

Megan: *And do you feel like that every day or just at certain moments?*

Sebastián: *No, there are moments that it comes on and there are moments when nobody can stand you, when nobody can stand me, not even I can stand myself.*

Sebastián' narrative vividly portrays the shrinking world of men with COPD who are accustomed to being outside – *doing*. He goes from being a man in men's space outside the home to a man locked in the female home space. More than anything, it is his oxygen-dependence which keeps him indoors. Like Mateo, not being able to do, not only meant feeling sad and anguished but also being unable to adequately support their families financially. COPD affects people unequally in this regard too. If one makes a living from their own strength and ability to carry out manual labour, COPD can strip them of their means to support themselves and their family; something de Sousa Pinto's (2008) study of the experience of COPD among poor Brazilians also highlights. In my study, participants like Marco who owned a ranch, or José who received a retirement pension from the bank, could carry on earning because their employment did not depend on their physical strength. Interestingly, however, none of the men described here mention finances. Their sense of threatened and damaged masculinity is

shared, no matter their earnings, because their expectations of themselves, as men, cannot be met with such badly damaged lungs and weak bodies.

EXPRESSING COPD PATHOLOGY: CO-CONSTRUCTED IMAGININGS AND IMAGES

So far I have argued that paying attention to the kinds of words and metaphors used to describe breathlessness can help us understand the embodied experience of COPD. With the narratives generated through pile-sorting I have also illustrated how COPD is as much a physical disruption as it is an emotional disruption and that emotions are not simply consequences of COPD but are the sensorial experience of COPD itself. As already seen in the previous section, the narratives of COPD and emotional upheaval of the middle-aged men who carried out the pile sort reflected the expectations of men in Uruguayan society. For proponents of narrative-ethnography Gubrium and Holstein's (2008a, 2008b) stories do not just reflect inner lives but society's ability to shape, reshape and influence stories so that while texts themselves are important "...so are the contexts, which we take to extend from interactional to institutional environments" (Gubrium & Holstein, 2008a, p.15). In this section, I look at how participants expressed their understandings of COPD through drawing their lungs. I focus on the 'texts' by providing verbatim narrative, however, I also provide an analysis of the context, particularly the medical institutional context, which help shape them. I have named these: The microscope perspective, the x-ray perspective, folk representations of reduced pulmonary capacity, and co-morbid lungs: COPD as hope.

The Microscope Perspective

Macarena represented her understanding of what was going in inside her body by comparing it to a normal lung. She said that her lungs are obstructed. On the right she has represented a normal lung by drawing a bronchial tube (the circle) and alveoli (the cauliflower-shape) (Figure 6.2). On the left is how she imagines her lung. She said you can see that her bronchial tube is obstructed so that "there is not much capacity for air to enter and leave." Then she explained that the things "that look like little bags or a vine of grapes, which are called alveoli, transport blood and are where the oxygen gets in." These are also obstructed. She said "it lets the air in but not out so that you can't oxygenate properly."

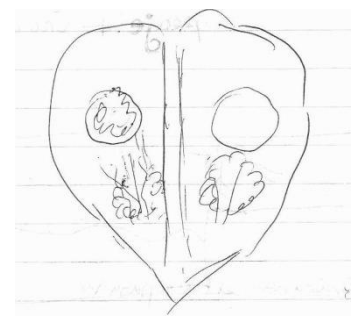


Figure 6.2:
Macarena's lungs

Martín has a distinct understanding of his lungs which is related to his dual experience of being asthmatic before the age of 25 and as someone with COPD at the age of 60. His picture represents the lungs (above) and the bronchial tubes (below) (Figure 6.3). He said that the way he understands it is that the bronchial tubes are not in the lungs, they are outside. “My lungs are damaged because they have COPD and cigarette smoking has dried them out.” However, his breathlessness comes from his bronchial tubes being small because of asthma and therefore he takes the inhalers to open his bronchial tubes, not treat his COPD. He explains that the oxygen, which he uses permanently, is what he uses for the COPD.

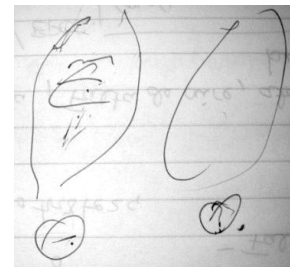


Figure 6.3: Martín's lungs

One striking feature common across both Macarena's and Martín's drawings is the way in which bronchial tubes and alveoli are represented as distinct drawings within or even outside the lungs. Also, in both their drawings the bronchial tubes appear as a cross-section. When reflecting on how this representation has taken hold in their minds I remembered the pictures of the lungs I have used in presentations and which are often used in pulmonary rehabilitation to explain the dual diagnoses of bronchitis and emphysema. Below are Martín's and Macarena's drawings flanked by images I have borrowed from Dr. Jean Bourbeau's "Living Well with COPD", materials produced from the Montreal Chest Hospital (Figure 6.4).

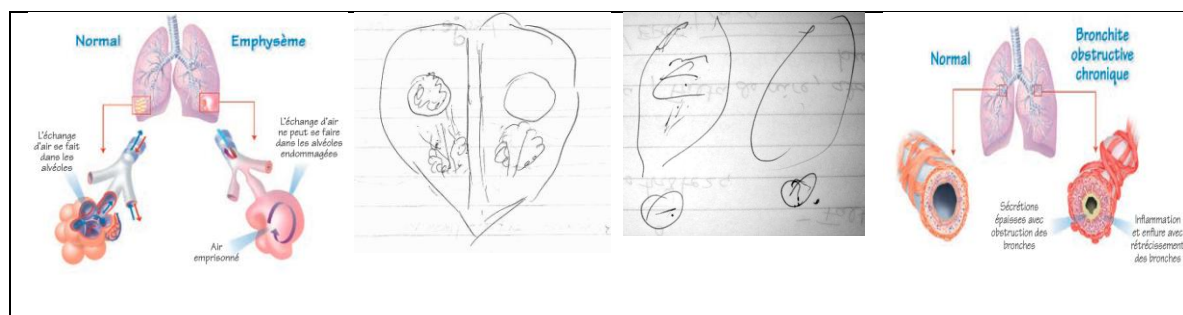


Figure 6.4: Comparison of participant and medical drawings

These images were chosen because they are the ones from which I learned about COPD when doing research at McGill University and are representative in style to other materials produced to teach COPD physiology to patients which I saw in Uruguay particularly in pulmonary

rehabilitation sessions at the public hospital which both Martín and Macarena attended. It is therefore entirely understandable how Martín had come to understand the bronchial tubes as being outside the lungs. The magnification of a small section of the body, implicit in these kinds of medical images, can be misinterpreted. So in both cases the participants clearly understand that their lung problems include two parts of the lungs: the bronchial tubes and the alveoli. However, where they are placed and their relative size or number remains less clear. Their visual and imaginative lens is that of magnification. Furthermore, many of the participants describe the alveoli as “sacs”, “bags”, “balloons” or “balls” which when healthy can inflate and deflate with ease but when diseased with COPD lose their elasticity. This is the common way for health professionals I shadowed, across institutions, to explain emphysema. The adoption of that discourse I would argue demonstrates its suitability for the lay audience. Martín’s image of the bronchial tubes outside the lungs supports his theory that asthma affects the tubes and COPD affects the lungs which in turn require different treatment.

The X-Ray Perspective

The co-construction of visual perspectives is also evident in the way in which some participants referred to x-rays. Take the following examples:

Tomás, 60, is the epitome of the ‘expert patient’. The second time we met at his doctor’s office, I stood back and watched him be invited by the doctor to come look at his X-rays, as features were being pointed out. In his home Tomás told me that he has learned to read X-rays, just as he has learned when he should start antibiotics and corticosteroids. He frequently uses the internet to look up information on COPD and medications. Interestingly, when I asked Tomás to draw his lungs, not only was he the only participant who drew them as a sum of five lobes (as indeed they are) he also coloured-them in black (Figure 6.5). This was not however in reference to dirty lungs, as I had heard others evoke the term ‘black lungs’. Rather, it is because, as he explained, in the X-ray the area with emphysema looks totally black.

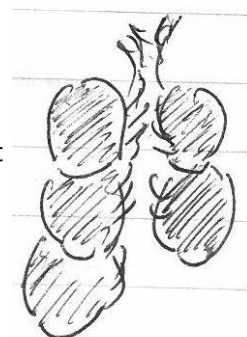


Figure 6.5:
Tomás’s lungs

Gustavo, 54, told me as he drew that he deliberately made the lobe on the right incomplete (Figure 6.6). He said that on his X-ray he can see that one lung is whole, whereas on the other side part of the lung is missing. He searches for the word for alveoli but cannot remember it so says “those little dots” or little “bags” “they don’t have any elasticity, they have nothing.” He then starts inhaling and exhaling deeply with his hands on his rib-cage to show me that his chest does not expand because of this loss of elasticity. He asks me to see, from the outside, this loss of internal elasticity.

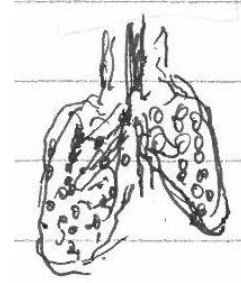


Figure 6.6: Gustavo's lungs

When Tomás and Gustavo drew their lungs they were seeing their lungs through the lens of an X-ray of Computational Tomography (CT). They expressed this in the following ways: that certain parts of their lungs are “black”, and that certain parts of the lung seem as though they are “missing.” In Figure 6.7 I have placed Tomás's and Gustavo's drawings next to images of emphysema produced by X-ray and CT scan taken from Midgley's edited book *Chronic Obstructive Pulmonary Disease: a Forgotten Killer* (2008). The caption under the image from Midgley (2008) explains that the arrows in Figure 5.7a point to darkened areas of the lung which represents trapped air called bullae caused by emphysema. Figure 5.7b, a CT scan, shows how the areas where there are bullae are transparent (*i.e.* as though there are parts missing) and arguably could be interpreted as looking black and not transparent. The comparison illustrates the way in which perspective, in this case a biotechnological perspective, might be taken up by some participants, which in turn shapes their understandings and imaginings of COPD. In this case, Gustavo and Tomás both are speaking, seeing and thinking from an X-ray perspective. In so doing, they make the non-reversibility of their COPD, in relation to the damaged structure of the lung, very clear to themselves. Gustavo in particular can feel that part of his lung “is missing” when he inhales and exhales and notices a difference in the expansion of the rib-cage on the right and left.

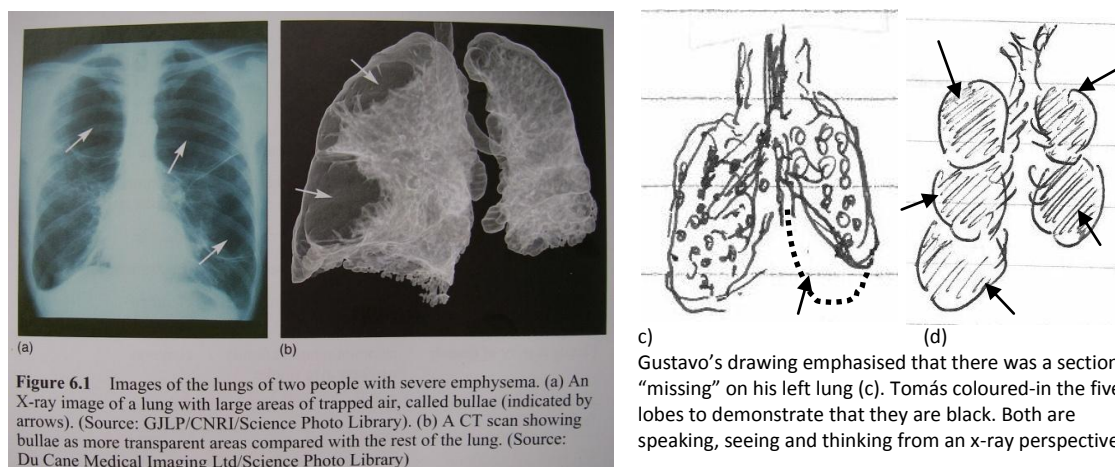


Figure 6.7: The X-Ray perspective: comparison of a) X-ray of the lungs with emphysema and b) a CT scan of lungs with emphysema (Midgley, 2008) with c) Gustavo's and d) Tomás's lungs drawings

Folk Representations of Reduced Pulmonary Capacity

In contrast to the previous two themes which highlight biomedical co-construction, the third highlights the lay or folk understanding of reduced pulmonary capacity. Participants in my study largely agreed that COPD was a disease of the bronchial tubes and the alveoli, and they understood they lost or were losing pulmonary capacity or respiratory capacity. In medicine, while X-rays or CT scans let you see emphysema, they cannot directly visualise a person's pulmonary capacity. For this, medicine uses pulmonary function tests (spirometry) which produce numerical and graphical representations of lung-function in relation to expected lung function based on age, gender, height and weight. The graph and table in Figure 6.8 are taken from a spirometry report. In Figure 6.8, the highlighted value next to FEV1/FVC for this person is 40%, whereas for a person their age, it should be around 84%. Similarly, the FEV1 is only 38% (also highlighted in Figure 6.8) of what it should be. Even though pulmonary function is measured by quantifying breath through a machine, some participants did visualise reduced pulmonary capacity in their drawings of their lungs. In each of the images and narratives below the idea conveyed is that there is a whole lung but only part of it is available for respiration and receiving air. Pulmonary capacity is associated with space for air in the lungs, in a literal sense. The sensation for the patient is that they cannot get a lot of air in or out, especially when being active.

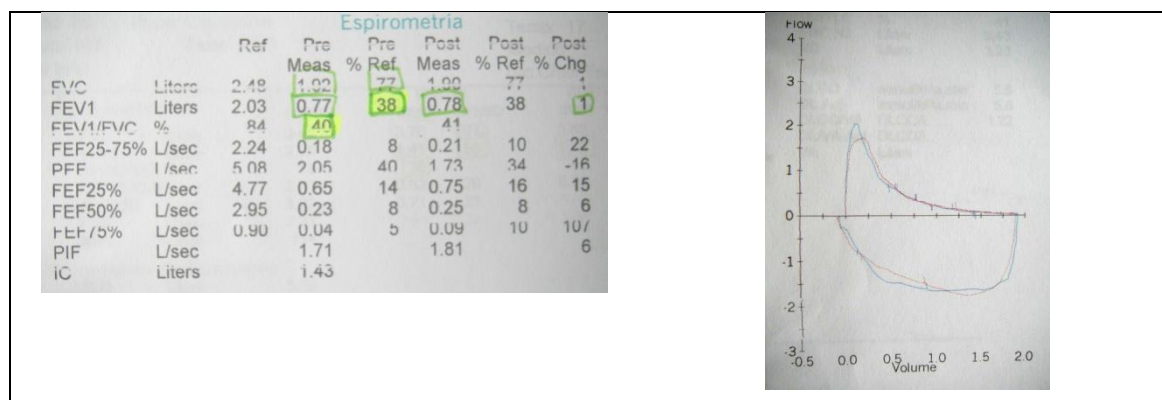
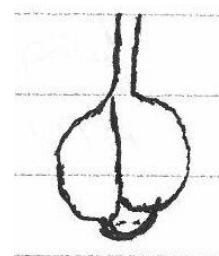


Figure 6.8: Spirometry results: Lung-function values and flow-volume curve

Sebastián, after saying he did not know how to draw lungs, produced the drawing on the right (Figure 6.9). He explained that the vertical line that seems to run between the lungs represents one lung being blocked off. He says this is the sensation he gets when *me falta el aire*, as though there is one lung that is working more than the other. I asked him how it is when he is not breathless and he said when he is sitting or not doing anything strenuous, it is open and he can feel the air in both lungs. The third lobe he drew at the bottom represents the stomach, in which he feels palpitations when he is breathless. He thinks maybe a regular person might have the same sensation when breathless because of exertion.



**Figure 6.9:
Sebastián's lungs**

Joaquín, 72, who, as we saw earlier, no longer considers himself ill, says he barely notices his COPD ever since he was diagnosed and has received treatment. He no longer exacerbates frequently like he used to which would require a home visit from a doctor or nurse. He understands his COPD in terms of a reduced pulmonary capacity. He was apprehensive about drawing but in the end produced this picture of two lungs with a line dividing each of them (Figure 6.10). He explained that the line represents having only a portion of one's original pulmonary capacity left. Interestingly this underlying state has not implied 'ill-health' since the control of his symptoms was achieved.



**Figure 6.10:
Joaquín's lungs**

Vivian drew her lungs and then coloured-in a dark circumference (Figure 6.11). The white space which remains represents the pulmonary capacity she has left or the space for air. She told me from what she understands she does not have very much pulmonary capacity and that “it’s a bit squeezed because of other stuff occupying the dark part.” She does not know what is in the dark circumference, *i.e.* what exactly is taking up space where air should be. She said, “Maybe it’s COPD or something from the cigarettes, but there is less space for the air.” She asked me, “Can you see COPD on an X-ray?”

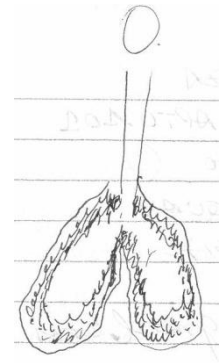


Figure 6.11:
Vivian’s lungs

Co-Morbid Lungs: COPD as Hope

José, who loves to paint, drew a more symbolic picture of his lungs (Figure 6.12a). He asked me, “Do you want me to draw it how *I see it*?” I said sure and so following from what I told him about imagining that he could open the body and see what is inside, he drew each lung as though it could be opened like a locket. He explained that he has fibrosis in one lung and COPD (emphysema) in another and that each represents a very different picture to him. The lobe on the left has fibrosis which he says is a symbol of death (the cross and setting sun) because surviving it is dependent upon his continued response to corticosteroid treatment, which is outside his and his doctors’ control. The lobe on the right shows a field with a tree, a sun, and a stream which represents life. He feels that his COPD is something he can live with. There were things he could do like stop smoking, take care of himself and take medication and that with this it can be controlled. Afterwards, I asked him what he thought his lungs looked like in a literal sense and he produced the picture on the right (Figure 6.12b) which includes a description of both diagnoses drawing on all the biomedical vocabulary he has come to know so well.

CONCLUSION: EXPRESSIONS AND EMBODIED MEMORIES OF BREATHLESSNESS

The story being told throughout this chapter is that COPD is expressed in many ways. Not only is it inherently a mix of at least two pathologies (chronic bronchitis and emphysema), it also has a multiplicity of ways of expressing itself and being expressed by individuals and families. The qualitative research published to date on COPD tends to miss out on this breadth of experience and ways of making sense of the sensations of breathlessness including emotional sensations. Hearing from a wide-range of people with COPD who experience it as a disease of

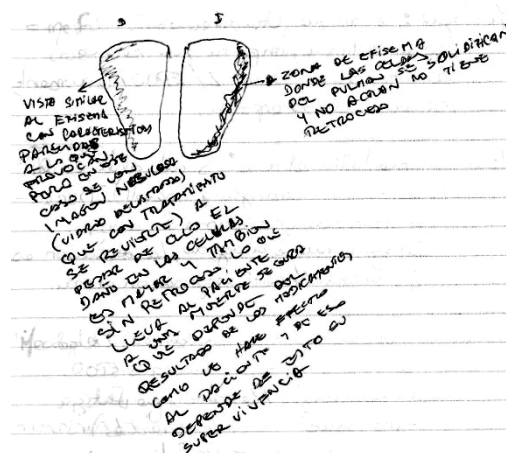
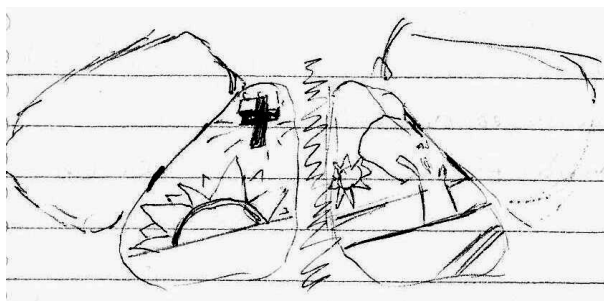


Figure 6.12: José's lungs. a) symbolic representations b) representation of pathology

the past, an invisible disease, a series of acute episodes, a daily disabling condition, or just one of many diseases which emerge in later life, is a novel contribution of this research. I have written the chapter so as to give the reader an embodied understanding of what it can feel like to have COPD. To return to questions described in the introduction of this thesis, posed by Banks (2007) and Bagnoli (2009), yes, the multimodal methods yielded new insight and yes, it permitted access to new ways of understanding and representing experience. By studying the language of COPD, the ways in which people understand their bodies and the ways in which the emotional and physical are inseparable in the experience of COPD, we come to a fuller, more nuanced and complex understanding of the lives of people with COPD as well as the ambiguities of the disease itself.

In terms of the anthropology of chronic illness these findings also support the critique of the chronic-acute dichotomy and contradict absolute definitions of COPD as incurable and irreversible (Smith-Morris, 2010; Manderson & Smith-Morris, 2010). Its medical definition is based on measurement of invisible air as it leaves the body (through spirometry) but its definition for individuals will be based on everything from their gender, the language they have to draw on and make sense of their sensations, their employment, their expectations and desires, their co-morbidities, their age and their identity. They may never come to define their experience by the nature and severity of the pathology itself as defined by medicine. However, they do come to understand and interpret their bodily sensations through a biomedical lens,

which they incorporate and remold within their imaginations and narratives and this shapes how they interpret their breathing sensations.

An emergent theme in my interactions with and observations of participants was what I define here as embodied memories of breathlessness. Prior research has shown how extreme breathlessness provokes the very real sensation and fear of dying in individuals with COPD and their family members who witness it (Bailey, 2001; Ek *et al.*, 2011; Heinzer *et al.*, 2003; Yu *et al.*, 2007). Almost all participants had had at least one experience of “acute breathlessness” outside the normal day to day chronic acute episodes of breathlessness upon exertion, *e.g.* making beds, walking to markets, trying to cut wood or tame an animal. These daily, chronic-acute episodes produced sensations evoked in the expressions they used: tired, agitated, attacked, breathlessness, lacking oxygen, frustration, sadness, anguish, and anger. It was not always clear whether feeling this way was related to a momentary exertion or an indication that one might be “coming down with something”. Coming down with something, *i.e.* having an acute episode like that described by Macarena and many others, who due to space constraints I could not include, evoked sensations of fear, anxiety, anguish, panic and imminent death. The words used by participants in my study such as attacked, drowning, suffocating, choking and chest closing, give an indication of the severe suffering such experiences cause. The fact that patients live with lungs which they imagine to be “black”, “missing parts”, “having sections blocked off”, “having less room in them for air” and being “all obstructed” also adds to vulnerability, panic and anxiety at the first signs that these damaged parts are under threat from triggers. These triggers may be, as we saw in Chapter 5, changes in air, temperature, humidity and climate, which can cause congestion, coughs, colds and flu. Previous experiences of factors outside the body triggering what occurs inside the body, are deeply embodied memories and explain why my participants would shut themselves up in their homes, miss appointments, and cancel engagements to protect themselves, for fear of coming close to such a horrific experience of breathlessness again. COPD changes their bodies, and thus changes their perception of the outside world. They become hyper-sensitive to their environments; not only in a psychological sense, but in a somatic sense too. The narratives, the imagery evoked by the terms and metaphors used to describe sensations, and way the disruption in the body is understood, all demonstrate how harrowing an experience losing control over such a vital, and normally taken for granted, function can be. Even in participants who felt they had recovered, they remain vigilant and on edge about provoking another acute episode.

It had not occurred to me before fieldwork and before really listening to and seeing what it is like for people to become uncontrollably breathless, that my experience of quasi-drowning at the age of 16 was a sensation and experience close to COPD exacerbation. While swimming in an Olympic-sized pool during a school trip, I started swimming under water with my eyes shut, making my way to the shallow-end of the pool to play ball with a friend. When I swam to the surface for air, I crushed my head into what felt like a cement block. I panicked and swam further and came up again, hitting my head again into this cement structure and was unable to reach the surface for air. I would only discover the next day when I was released from hospital that what I was stuck under was an adjustable portion of the pool floor (amounting to about one third the size of the pool), which was raised that day to create a shallow end. The panic and “desperation” described by my breathless participants soon overwhelmed me as my body screamed for air but I had none to give it. I felt as though someone was suffocating me by blocking my mouth and nose and I felt like I was dying, slowly, completely conscious of what was happening to me. I felt around with my arms to see if this cement ‘thing’ came to an end, but it did not. Eventually, I just had to breathe in and I lost consciousness instantly without pain, as the water surged into my airways. Only a few minutes later, I suspect, I began breathing and screaming on the side of the pool, having been dragged up from the bottom by the lifeguard who, luckily, brought my blue body back to life.

Months later, I took a SCUBA diving course, and while practising buddy-breathing techniques, where two divers share one regulator, five metres under the ocean, I did not clear the regulator of water properly and I breathed in water and began to choke. Instantly, I felt like I was back in the pool and became so overwhelmingly panicked that I could not concentrate on the Dive Master trying to give me the regulator again. I shot for the surface and ended up being towed into shore while I screamed. Anyone who experiences the need for breath which cannot be met has the memory imprinted in their bodies. It is an unforgettable sensation. For participants with COPD and their family members, breathlessness can ease, be controlled, and lived-with, but embodied memories of severe breathlessness rarely fade. In the words of Florencia, whose story of the chronic acuteness of breathlessness I told earlier:

“The doctors tell me not to panic, that I won’t die when I am breathless. But I can’t not panic, that’s what it feels like to me.”

Embodying Inequalities in COPD Care and the Role of Family

*“When I start getting a disability pension I will have
electricity in my house and I’ll buy oxygen...”
(Peter)*

*“The hospital is the village ranch (estancia) everyone can come and stay
here over the holidays” (Marta)*

INTRODUCTION

This chapter concerns the political-economy of COPD care in Uruguay at the time of my fieldwork. While the previous chapter focused on what it feels like to have COPD, this chapter argues that when and how COPD is experienced is shaped by wider inequalities in access to healthcare. Following the idea that healthcare systems are more than professional healing forms (Csordas & Kleinman, 1996), I also intend to discuss the customs and values shared by my participants when it came to caring for people who were ill. Often the line between family-member and health professional can be blurred, as will be seen. Studying COPD in a country like Uruguay with a split public-private healthcare system is implicitly a study of health inequalities. Health inequalities can be related to the unequal distribution of disease and its risk-factors or it can relate to unequal access to healthcare (Singer & Baer, 2007). This chapter focuses on the latter; however, the former is ever-present.

As described in Chapter 4, Uruguay was halfway into a major healthcare reform at the time of my study aimed at addressing inequalities in health and healthcare. Therefore, I recognise that the Uruguayan health system is currently in a state of flux. I heard time and again that healthcare had improved in the past few years, that all children now had free universal access to any hospital (private or public) of their choosing, that more medications were becoming available in the public sector and that salaries were rising for professionals in the public sector. I also heard occasional complaints about the healthcare reform but from my own perspective those who complained were those that needed the reform less and who did not suffer the burden of depending on an impoverished public sector. However, this chapter will show, indeed critically, that at the time of my fieldwork, healthcare in Uruguay was

exceedingly complex and fragmented. Chronic conditions like COPD, which are only beginning to appear on the political agenda, despite their prevalence, represent a category of affliction for which access to diagnosis, treatment and appropriate hospitalisation varied widely both within and between Montevideo and the Interior.

The chapter is divided into two sections. In the first, I present data on healthcare use and spending, gathered via a demographic questionnaire (Appendix D), to illustrate in broader, more general terms, the complexity of healthcare in Uruguay and who has access to what, when, and for how much. In the second part of the chapter, I delve more deeply into the topic of COPD care and inequality through the story of a participant, Marcelo and his family. Excerpts from field notes on this particular family's journey will provide the outline for a consideration of significant pillars in COPD care: diagnosis and medication, inpatient care, home oxygen therapy, approaching death, genetic-testing, homecare and going to hospital. The reason I focused on the story of Marcelo and his family is because it was the first time in six months of fieldwork that I had heard the word 'terminal' used in reference to someone with COPD. Furthermore, Marcelo was only 54 years old.

Over the course of five months I accompanied the family at home and in hospital, letting their experiences and frustrations guide my investigation into healthcare delivery and policy. This chapter embodies the way in which a sensorial approach to understanding the experience of illness experience at the individual and family level is a framework aptly suited to critically investigating how the social and political bodies are at play within the individual. The way Marcelo was clearly given the label 'terminal' encapsulates the way in which COPD as a diagnosis and a medical 'thing' is defined and delimited by medicine. Therefore, the chapter ends with a critical reflection on how the political-economy of health, in this case, has the power to frame COPD as a either a chronic or a terminal disease.

THE COMPLEXITY OF HEALTHCARE ACCESS AND SPENDING

In the demographic questionnaire I carried out with 29 participants with COPD, I asked about healthcare services used, spending and income and this data is presented in Table 7.1. Taking Javier (2nd row) as an example, the table indicates the following (column headings in bold): Javier has no **dependent children**, his **employment** status is that he receives a pension, and his **household income** is 84,000 pesos per month [Javier owns a working-ranch]. He receives care from a private **healthcare institution** and spends, every month, 3058 pesos on the

membership fee, 10,000 pesos on **medication**, 11,322 pesos on **oxygen**, 325 pesos for **emergency insurance**, 0 on **accompanying insurance** because he does not have such insurance (his wife and family visit him in hospital). Therefore, his **total spending** on healthcare is 24,705 pesos, *i.e.* 29% of his household **income is spent on healthcare**. It is important to remember that the household income also has to pay for other household members' healthcare costs not represented in Table 7.1. It is important to note that participants often gave estimates of costs and income and, therefore, while the data is informative, it cannot be taken as perfectly accurate. One participant warned me that "the rich will underestimate their income and the poor will overestimate it." Nevertheless, the columns of income and percentage of income spent on healthcare are useful for drawing our attention to certain themes in healthcare complexity to be explored in this section.

'Hidden' Spending

There are some important costs that are not represented in Table 7.1 because of the difficulty of generalizing them to a monthly cost, but which are nevertheless very significant. One is transportation. Getting to and from hospitals and outpatient clinics can be costly and this cost can be a significant burden to low-income households. Also not represented in Table 7.1 is the money spent on medicinal plants and alternative therapies. Of 29 participants, 10 responded that they had used medicinal plants and alternative therapies, of which six had used acupuncture. Probably the most important 'hidden' expense is the price of the notorious *tiqué* (ticket). Over and above the monthly cost of hospital-affiliation members normally also pay a fee, called *tiqué*, of around 100-200 pesos for each doctor's consultation, paramedical test, medications from the hospital pharmacy and emergency service-calls. The only *tiqués* represented in the table are those for medications. This is why patients with private or private mutual care generally have higher medication costs. All the participants in public healthcare had what they called *Carné ASSE* (*Administración de Servicios de la Salud del Estado*), or colloquially *Carné de Pobre* (poor card), which is a card that entitles the holder to an exemption from payment of *tiqués* based on being from a low-income household. In an interview with an economist in the Ministry of Public Health working on the health care reform, I was told animatedly about how impossible it was to negotiate getting rid of *tiqués* with private institutions. He said:

Table 7.1: Healthcare services and their associated monthly costs utilised by 29 participants with COPD in Montevideo and Tacuarembó. All values are given as Uruguayan pesos (20 pesos = 1USD) Acronyms: P: Pensioner; E: Employed; I-E: Informal Employment; Inc: fee included in Membership Fee; n/a: not applicable/does not have; F: Contributes to FONASA; P: included as part of pension; +: additional income from savings, investments or work income; M: Mutua; * Individuals' income depends on the financial support of family and friends. ** Allen also spent 400,000 pesos on oxygen machines of his own.

Participant	Dependent Children	Employment	Household Income	Healthcare Institution	Membership Fee	Medication	Oxygen	Emergency Insurance	Accompanying Insurance	Total Spending	% of income spent on healthcare
José	1	P	78 000	Private	5200	0 (Inc)	0 (Inc)	0 (Inc)	400	5600	7
Javier	0	P	84 000	Private	3058	10 000	11322	325	n/a	24 705	29
Tomás	0	E	80 000	Private	1600	2000	n/a	280	n/a	3880	5
Ignacio	0	P/E	160 000	Private	1000	4500	n/a	0(Inc)	1000	6500	4
Patricia	3	P/I-E	11 200	Public	0	0	n/a	n/a	n/a	0	0
Allen	0	P	50 000 +	Private	2000	14 000	4500**	400	500	21 400	42
Daniela	0	P	19 000	Public	0	0	n/a	452	n/a	452	2
Vivian	0	E	80 000	Private	3000	0 (Inc)	n/a	0 (Inc)	n/a	3000	4
Martín	0	P/I-E	16 000	Public	0(F)	0	0	n/a	n/a	0	0
Gustavo	2	P	30 000	Public	0	0	n/a	500	n/a	500	2
Lucía	0	U	0*	Public	0	0	0	n/a	n/a	0	0
Mauricio	1	P	n/a	Private(M)	4000	725	0	0 (Inc)	1000	5725	n/a
Soledad	0	P	20 000	Private	2600	3800	n/a	0 (Inc)	n/a	6400	32
Nicolás	1	E	24 000	Private(M)	635 (F)	426	n/a	220	n/a	1281	5
Lukas	0	E	17 000	Private(M)	510 (F)	900	n/a	n/a	n/a	1410	8
Macarena	0	U	12 000	Public	0	900	n/a	300	n/a	1200	10
Mateo	2	P/I-E	11 000	Private	0 (F)	2000	n/a	400	n/a	2400	22
Sebastián	3	P	8390	Public	0	0	0	195	n/a	195	2
Jessica	0	P	7000	Public	0	0	n/a	400	n/a	400	6
Sofía	0	E	13 000	Private(M)	1000 (F)	0	n/a	200	n/a	1200	9
Marcelo	0	P	5500	Public	0	0	5500	n/a	n/a	11 000	100
Bruno	0	P	16356	Private(M)	0 (P)	300	n/a	0 (Inc)	n/a	300	2
Bruno	0	P	12446	Private(M)	0 (F: R)	1700	0	140	387	2227	18
Joaquín	0	P	5027	Private(M)	0 (P)	500	n/a	0 (Inc)	n/a	500	10
Peter	0	U	0*	Public	0	0	n/a	n/a	n/a	0	-
Rodrigo	0	P	21660	Private(M)	1208	1700	n/a	0 (Inc)	494	3402	16
Florencia	0	U	0*	Public	0 (F)	0	5500	250	n/a	5750	-
Claudia	0	E	45 000	Private(M)	0 (F)	4000	0	140	440	4580	10
Nelson	1	P	7000	Public	0	0	n/a	n/a	n/a	0	0

“But then, what we couldn’t achieve through policy the market took care of. One big private provider, to attract members, cancelled all *tiqués* for children and other providers followed suit to remain competitive.”

Conventions within Conventions and Systems within Systems

Many people had a number of free *tiqués* per month included in their membership fees or simply had such fees waived, despite being in private institutions. The price people were paying for *tiqués* or membership varied widely based on the institution they were using, the retirement plan they were under or whether their employer had some kind of special agreement with the healthcare provider. For instance, Nicolás (Table 7.1) worked for a public hospital which had a contract with a private mutual hospital that entitled him to a number of free *tiqués* each month. Bruno, a retired police officer, received his private mutual care free of charge as part of his pension. If he were living in Montevideo, he would have received care from the publically funded Military Hospital, however, where he lived there was no such service. Vivian. worked for the Association of Notaries that provided its members with their own healthcare insurance entitling them to care in a private institution and separate rights and privileges.

Finally, some people in Uruguay have private health insurance through multi-national insurance companies, which pay out to the healthcare institutions their clients receive care from. Regular members of my private hospital site in Montevideo pay for their prescriptions and their oxygen use, as can be seen in the case of Allen and Javier who are paying 21,400 and 24,705 pesos a month for their healthcare, medications and oxygen. José’s insurance company paid for his care at the private hospital including his many medications and oxygen so that his monthly spending was 5600 pesos.

The Public-Private Divide within FONASA

As can be seen in Table 7.1, seven participants had joined FONASA, the healthcare reform’s centralised contribution plan. Under the program contributors can choose to receive state-funded care from a private mutual or a public hospital (or have their private hospital fee subsidized). Therefore, Mateo was able to join a private mutual institution through FONASA despite his low household income when he was employed. Once he retired because of illness FONASA continued to pay his monthly fees. However, the downside for Mateo is that if he

were at a public hospital he would receive a low-income certification (*carné ASSE* or *carne de pobre*, as mentioned earlier) and would not have to pay the *tiqué* price for doctors' visits, tests or medications. Because he is in a private institution he must pay *tiqués*, which amount to 2000 pesos a month in medication alone. Combined with the fee for the emergency insurance, he is spending 22% of his monthly household income on healthcare (11,000 pesos for a family of four). I was told on a number of occasions while in Uruguay that many low-income households had switched to mutual care under the reform because being a member of these providers offered the person a higher social status. They were accessing, indeed consuming, a product which had previously only been accessible to the middle class. However, if they were unable to pay the tickets a household's access to healthcare might actually be reduced. I asked a civil servant in the Ministry of Health about this and his response was:

"We knew this would happen; that there would be a rush of people out of the public institutions to the private ones, but that over time it would balance out. Also, although people need to wait two years before changing from one private provider to another, under FONASA, they can always return to the public system at any time."

Access to Oxygen Therapy and Medications: Not just a Question of Public vs. Private

You can see in Table 7.1 that all the participants receiving public healthcare were pensioners and should therefore be eligible for free medications. However, Macarena was spending 900 pesos a month on a medication which was not available in the public system. Generally, the more expensive and better medications for COPD were not available to my participants in public healthcare, although I heard, near the end of fieldwork, that this was changing with the purchasing of generic brands. The public hospitals I visited often tried to make do with pharmaceutical company samples, although this was precarious and frequent changing of brands was said to decrease patients' confidence in their treatments. Alvarez Pedrosian (2009), in his ethnography of the Maciel public hospital in Montevideo, states that using free samples of medications has been a strategy operating for over a decade in the public healthcare system. Generally, name brand medications, especially international brands, were seen as more effective, certainly by health professionals, and frequently by patients.

However, providing some kinds of medication for COPD and not others was not only a public-hospital phenomenon. Participants in private healthcare in Tacuarembó all complained to me about how one particular medication called tiotropium bromide was not covered by the

private mutual hospital *i.e.* it was not available to them at the price of a *tiqué* like their other medications. Bruno, Rodrigo and Claudia all have high medication costs (Table 7.1) because of having to buy this medication at its full-price, or at a slight discount with a voucher sometimes given to them by their doctor, who in turn receive these from pharmaceutical representatives. Even with a voucher, the medication still amounted to 1300 to 1600 pesos for just one inhaler that would only last a month. One doctor, working in a public healthcare institution, told me that the barrier to getting the right medications can sometimes be down to the individual directors of the hospitals. He said, “I’ve put in applications to the directors for different kinds of medications for COPD arguing that long-term they are cost-saving and better for patients and family, but they haven’t taken it on.”

Participants who attended the private hospital in Tacuarembó felt that the hospital’s refusal to include the medication as part of its normal coverage, was due to the fact that it was the only private institution in town, *i.e.* it did not have any competition. Near the end of my study, physicians reported to me that some patients in Montevideo were beginning to have access to a generic brand of tiotropium bromide. Therefore, it is clearly the case that medication cost and provision is, not only a case of private versus public, but also of the interior of the country versus the capital. Whereas some medications make their way onto a Ministry of Public Health list of ‘required medication’ and, therefore, must be provided in original or generic form across all institutions, medications specifically for COPD were not yet on that list during my fieldwork. Lastly, in Table 7.1 there is a star next to Patricia’s apparent nil medication cost because she explained that although she is meant to receive free medication, the pharmacy in her neighbourhood, situated outside Montevideo, sometimes does not have what she needs so she buys her medication on the black market, usually from a neighbour who sells inhalers. I was told on a number of occasions that prescription medications are frequently sold in street-markets.

Having given a general overview of the complexity of healthcare access and spending across my participants, I want to illustrate how these inequalities play out at individual and family levels. To do so, Marcelo’s story (Chapter 5, p.21) will be the guiding line of the rest of this chapter. The single-spaced texts headed with a date and location of fieldnote excerpts.

March 14th 2010 – In Hospital

Today was my first day at the hospital. I received a very friendly welcome from the internists and one told me “I’m writing in the file of a COPD patient at the moment. He is a young man, 54, and he’s in the terminal stage. He’s going home today.” We walked out to the ward and I was introduced to Marcelo and his wife, Marta.

I asked Marcelo how long he’d been in hospital. It had been 11 days. “I’ve had back to back attacks since December. We spend some days in the hospital and some days at home. I’ve had breathlessness (*falta de aire*) for 10 years.” Marcelo was very emaciated. His legs and arms were nothing but skin and bones and he had the barrel chest so typical of advanced COPD. When he breathed from the oxygen mask his thoracic cage expanded greatly and you could see his ribs. With each breath his abdomen was sucked inwards and spasmed. His breath was shallow, as though he could only fill the tops of his lungs and his breath had a strong fetid smell.

I spent most of the day at Marcelo’s bedside. A topic which emerged within minutes was that of home oxygen therapy. Marta told me that it has been very difficult getting oxygen. “The hospital doesn’t give it.” After a couple months of back and forth ASSE agreed to provide one oxygen tank per week. “But if he’s really *atacado* he can use one tank in a day. Then we have to buy them and they are 1200 pesos (\$60 USD) each. It’s very expensive and I can understand that the hospital can’t provide it, because that’s how much it costs them too.” I looked at the prescription for oxygen and from what I could read of the doctor’s handwriting it said “COPD exacerbation. Terminal Stage. Emphysema.”

Later the internist came back to chat at Marcelo’s bedside. Addressing me at the bedside, he said, “When this patient came to the hospital, we were looking for the cause of the exacerbation. Normally these patients are hospitalised for an infection or bronchitis or something but he didn’t have anything, white blood cells were normal, no fever. He had urinary retention that improved with treatment. We concluded, as I said to him, that this episode is representative of the natural progression of this disease. He is in a very advanced stage, almost terminal [he said this only slightly quieter]. These patients come in and they don’t drink, they don’t eat, they don’t walk. All they can do is breathe and with such difficulty that they can’t both breathe and eat. When they recuperate all that returns.” He spoke to Marcelo, “Isn’t that true? You weren’t eating and now you eat everything.” Marcelo responded, “Yes, I eat everything.” “Now he needs oxygen, he is oxygen-dependent like almost all end up being. These patients would

benefit from the backpacks [the portable oxygen tanks that can be worn in a backpack], which would enable them to walk. But here, you know, we're not the Third World, we're the Fourth World. If you need anything just let me know", and with that he left.

At first Marcelo seemed relaxed and in a good mood but after the doctor left he seemed more nervous. I didn't realise this immediately, but he began speaking less, breathing more quickly, and was clenching his fists. Marta said, "When he's home he doesn't want to come to the hospital, I need to insist, and then he doesn't want to go home. He gets really nervous if he knows he is running out of oxygen in the tank." Marta was running in and out of the room. A few times when she came back she came with an obvious smell of tobacco smoke. Once, while she was gone, I asked Marcelo about where he used to work. He said he worked for the tobacco plantation in Tacuarembó. He worked there for 15 years until it closed. He recently began getting a government pension for chronic illness. He said they've spent all that money on oxygen.

Marta said at one point that he had always been healthy. She doesn't understand how they never saw it coming. He'd been very bad for the past year since he had an experience in the Intensive Care Unit. Before that episode the diagnoses they heard were asthma and bronchitis, then it suddenly became COPD which they didn't understand. She said she'd heard that it is caused by poor oxygen levels in the blood and she couldn't understand why they'd never seen that in previous tests [before he started to get really ill]. She said she has told her daughters to go to the doctors and ask to get tested for that disease.

Shortly after, a nurse came by to say that the ambulance was there to pick them up. I helped carry out the electric fan they'd brought from home and a backpack to the ambulance. The male nurse wheeled him out. It was very difficult for him to get into the ambulance. His legs are like toothpicks. The nurse lifted him in. I gave them both a kiss and Marta said "Well, dear, come whenever you like".

Diagnosis and Medications

My first encounter with Marcelo and Marta clearly brought up two major healthcare issues concerning COPD. One is oxygen therapy which I will return to later in the chapter, and the other is diagnosis. Diagnosis is a critical topic in Uruguay. Despite the prevalence of COPD, it remains a disease at the margins of public and healthcare consciousness. The essential equipment for diagnosing it, a spirometer, is unavailable at many, if not most, hospitals across the interior, not to mention in most primary care settings across the country. Marcelo was

parachuted into the diagnosis of COPD via a serious acute episode, which resulted in being sent to intensive care, being hooked-up to a ventilator and spending two months in hospital. Others in my study had similar experiences, which resonates with findings from previous work I collaborated on regarding the experience of people with failing kidneys. In that study, some participants were aware of their deteriorating kidney function and were aware of approaching 'end-stage' whereas others were 'parachuted' into end-stage from an acute illness episode (Allen *et al.*, 2008; Allen *et al.*, 2011). Diagnosis at the point of emergency room attention, frequently followed by inpatient care, is a part of the majority of my participants' narratives, especially those receiving care from public institutions. Those in private healthcare varied. Health professionals labelling the symptoms of COPD as asthma is another common thread throughout my participants' narratives, whether they received care in private or public institutions, and is something discussed from the lay perspective in Chapter 5.

A frequently heard statement amongst COPD professionals in Uruguay and elsewhere is that "people with COPD seek help too late." Certainly there is truth in this statement. People with progressive lung deterioration can cope with a great deal of lung function loss (Carel, 2008). A few even explained they delayed consulting because they did not want to be told to quit smoking. Often by the time people feel like the symptoms are affecting their everyday life and see a doctor, the obstruction is moderate to severe (GOLD, 2008). However, there are those, like Marcelo, who present at emergency departments for years complaining of acute lung infections, such as pneumonia and bronchitis. I was able to witness what an emergency visit for an acute respiratory episode is like with a participant who also had an unclear diagnosis of COPD. I ran into Micaela at the hospital and she said she went to Accident and Emergency because all of a sudden she had trouble breathing. I was able to introduce myself and chat to the emergency doctor caring for her. I spoke about the unavailability of spirometry and he responded, "Yes, when we get a patient in emergency we treat the person's respiratory crisis but I don't know if I'm treating asthma or bronchitis or something else." I spoke about how Micaela has had no follow-up. He said, "Yes, that is a big problem here, outpatients does not work well." I mentioned how she is not on any kind of treatment. His reaction suggested this is not unusual. Another health professional shared the following thoughts with me:

“In hospitals in Montevideo they diagnose their patients earlier, they treat them earlier, they have more para-clinical tools like CTs and spirometry and they have access to thoracic surgery. Someone with very localized emphysema can have the section removed and their symptoms can improve a lot.”

This doctor also mentioned tiotropium bromide as being a good yet expensive drug but said he never saw anyone in the public hospital, where he also worked in Montevideo, on that medication because it is not available. From what I could ascertain from my participants experiences, this rosier picture of the capital city was both accurate in general but depended very much on the healthcare services accessed. I believe the issue of primary care and/or emergency care staff not having COPD on their radars, or not knowing how or to whom they should refer patients who they suspect might have COPD is a country-wide and global issue (Bednarek *et al.*, 2000; Lindberg *et al.*, 2006; Pena *et al.*, 2000; Shahab *et al.*, 2006; Takahashi *et al.*, 2003). Even when emergency doctors encourage their patients to go and see their own doctor for follow-up, patients may participate in delaying diagnosis because now, having managed the crisis, they ‘feel fine’ and do not feel they need to see a doctor. Chapter 6, which covered the Expressions of COPD and evidence from other studies, show that for some identifying as “ill” only occurs during acute episodes (Williams *et al.*, 2007). It is often the first major hospitalisation, like in the case of Marcelo, which leads to a change in perception of the seriousness of the symptoms (Bailey, 2001).

Where coordination between specialties and between primary, secondary and tertiary care is smooth, diagnosis seemed like an easier process among my participants. I shadowed a respirologist in the private hospital and observed the diagnostic process of two participants in my study. Both were ex-smokers of many years and, having complained of recurring respiratory difficulties, were referred to the respirologist, who then referred them for spirometry. Whereas in public hospitals you might wait months to see a specialist or to get an appointment for spirometry, in this private hospital appointments were made within a week. Although both had quit smoking they benefitted from being given vaccines to prevent lung infections in the winter, and from receiving information about the importance of not inhaling smoke and, in one case, pharmaceutical treatment to reduce the feeling of breathlessness. Clearly the rapidity of this diagnostic process is almost inconceivable in any public system and it shows how much more straightforward the diagnosis of COPD can be when there is an

informed opinion, a respirologist to refer the patient to, and a diagnostic test. In Marcelo's town, Tacuarembó, people who access the private mutual hospital are also referred to the only respirologist in town and can get a spirometry test by the specialist who visits the town once a month to do them.

March 28th 2010 – In Hospital

I went to visit Marcelo in the hospital and I met his 23 year old daughter, Melina, for the first time. She told me that last night Marcelo experienced a lot of pain in his abdomen and nobody gave a damn (*nadie dio bola*). "It's like they [the healthcare staff] are tired of us, we're here so much. The nurse-assistant didn't want to call a doctor and another nurse-assistant said he would pass by but he never did. We don't say much because if we start asking a lot they might come less." She explained how the family try to do as much as possible, giving him his medication, his nebulisations, and his personal hygiene. "We try to bother them [the healthcare staff] as little as possible."

March 29th 2010 – In Hospital

I popped in to see Marcelo around the time when Marta turned up to take over the position at the bedside from her 21 year old daughter, Victoria. What proceeded sounded like a conversation between the night and day nurses at shift-change. Victoria told Marta how the night had been, what the doctors had said, how she told them that he gets nervous they might send him home. Then one of the student nurses came in with a medication and Marcelo said, "Again?" [she had brought it too early]. She left and came back and said that she was told to leave the medication with them and he should take it at 12pm. After she left, Marta and Victoria told me they always double check the medication and call each other to remind the other of the medications that were taken in the morning or at night. Marta said she worries about giving him something he shouldn't have, or giving it to him too early which might hurt him. The daughter said if she gets given a medication she has not heard of before she doesn't give it to him.

Los Acompañantes (Companions) and Inpatient Care

Upon entering a hospital room to visit one of my participants the least likely scenario would be to find them alone or only in the company of other patients. People almost always had an *acompañante* (a companion), usually a family member, at the bedside. The custom is to accompany a person throughout their hospital stay, if possible up to 24 hours a day. Often elaborate rosters are organised, with daughters, sons, brothers, cousins, in-laws and neighbours each spending a couple of hours at the bedside. In most institutions, it seemed

every patient was allowed to have one companion at all times and during visiting hours there was no limit. It was not uncommon to see a group of six or more people surrounding their loved-one's bed during visiting hours. In Marcelo's case, his two daughters and wife carried most of the burden of his 24-hour hospital care. They bathed him, fetched and cleaned the bedpans, took his bowl they had brought from home to the canteen trolley that came by with the daily meals, gave him his pills, his inhalers, adjusted his oxygen, and called the nurse or doctor if something changed in his condition. They slept in an armchair next to his bed.

In my time in Uruguay I played the role of the night-shift companion once, to the 65 year old woman with whom I lived in Tacuarembó. Not long after I moved in, she fell in the town square one day and had to spend a few days in hospital awaiting surgery on her arm. I offered to stay with her the first night. I felt way out of my depth, having little to no experience in being a carer but when asked to help her shower, go to the toilet and get dressed the next day, I simply got on with it as it was an inherent part of my companion role. Sleeping one night in a chair left me exhausted, so I am sure that it is a challenging responsibility over longer periods. Families do these tasks in the public healthcare institutions, which in the UK or Canada we would expect nursing assistants to do. However, we can glean from the excerpts above that just because families in this public hospital were heavily involved in inpatient care did not mean they did not have expectations of the care provided by staff. Their expectations were for staff to 'care' but their sense was that because they were there so often staff were "tired of them" and they felt, especially because Marcelo was "terminal" that he was not high on their list of priorities.

Therefore, they tried to "bother" as little as possible and did as much as they could and became expert carers and knowers of medications, when to take them and which medication was to alleviate which condition. However, this also led to an air of non-confidence and over time I began to see them envisioning their role not only as companionship but as Marcelo's protectors. They narrated their role as protecting him from medical error or from the wrong medications at the wrong time, or worse, from care-decisions made at the hands of people who saw him as "terminal" and, therefore, whose life might have been seen as less valuable. Parallels with the Cuban system, described and analyzed by Brotherton (2005), are evident. Just as the individual practices of families in healthcare contribute to the functioning and successes of the Cuban welfare system, families in Uruguay are actors collaborating in the project of health for all in Uruguay.

Interestingly, while this family felt the level of care from nursing staff was decreasing in relation to the amount of time they were spending in hospital, the frequency of hospitalisation for José (Chapter 6 p. 151), a patient at a private hospital, led to a decrease in friends and family attention and not healthcare attention. Every time I visited José our conversations were interrupted by physiotherapists, nurses doing a check-up or insulin test, a doctor visit, a psychotherapy session or, a visit from a dietician. Staff-patient ratios at his private hospital were higher and there was a greater range of healthcare specialties available for patients. Only once in my 12 visits did I happen to arrive when he was accompanied, in that case by his sister. He told me: “People get tired, the longer you are sick, the less people come to see you.” Furthermore, his family was spread across a large city and his daughters all had full-time work and young families to take care of.

The custom of *acompanar* (to accompany) is to some degree threatened by modern urban living marked by faster-paced lifestyles and double bread-winner households in full-time employment. To accompany and visit people in hospital, one needs the time and the flexibility to do so within one’s work. The working class families in Uruguay I met seemed to uphold these family values with pride and at almost any cost. In response to my question, “What if the farm-owner said you couldn’t leave for 30 days to accompany your brother in hospital?” the brother of one of my participants with COPD responded, “I would go anyway, family first.” I found these values, part and parcel of a general Uruguayan value of solidarity, important to almost everyone I met. However, it seems work-responsibilities and time, make upholding it increasingly problematic. I found it fascinating that an industry of companion services was booming in Uruguay. Just like emergency insurance, if you paid companion insurance every month and had to spend time in hospital, you would be sent a professional companion to sit by your bedside and help you, relieving your family members of some of the duty, especially overnight. Figure 7.1 is a picture of such an accompanying service. The company name translates as “Watchfulness: Company and Nursing” and their motto reads: “We take care of yours, like you would do.”

This seemed to me a reconciliation of the value of accompanying a hospitalised family member and the reality that it can be increasingly difficult to do so, particularly in the case of chronic disease, which may require frequent and long hospitalisation. However, it is a strategy wedded to consumerism and ‘insurance-culture’, which means many will spend more money than they will receive in return, and yet for others, it remains completely out of reach. A



Figure 7.1: An accompanying business in an Interior town. Photo by the author.

government employee working on gender-equality issues, with whom I discussed the custom, criticised it for shifting responsibility for nursing care away from hospitals and into the hands of family members, especially female family members. She strongly argued that accompanying was an unfair burden on women and that if the government invested in more nurses, women would be relieved. Although I think she makes a very good point, it seemed to me that the issue was not only about not trusting that a nurse will be present to pick up on a crucial change in your loved-one's condition, but also it was about family values and community caring. While I met families who commended the private *acompanante* services, particularly small families who were utterly exhausted maintaining work and accompanying duties, I also met families who looked down on this out-sourcing of family-solidarity, love and care. I also met families who paid for the service but then were disappointed by the qualities of the accompanier, or by fine-print regarding number of days, hours and location of the accompanying, which they were not fully aware of until the moment of needing the service.

Having a family that is willing and available to accompany a person who is ill, particularly if they have a chronic condition, like COPD, requiring frequent acute care hospitalisations, is a form of social capital (Bourdieu, 1984). Williams and Bury's (1989) study

found that their participants in the UK with COPD did not have such forms of social capital or at least felt they did not want to draw on them as 73% of their 92 participants did not receive any help from social support networks. In Uruguay, drawing on social capital in times of ill-health is normalised, however, it is in a process of being replaced with financial capital. Private accompanying services in Uruguay represent an outsourcing of care by both family and healthcare institutions, in response to constraints of time, resources and possibly changing values. They are an example of a medical technology which, in the words of Biehl and Moran-Thomas (2009), is “increasingly constituted outside the clinical encounter” and which mediates the interrelations of kinship to “open up and relimit family complexes and human values” (p.274).

April 5th 2010 – In Hospital (Marcelo at Home)

I saw Marta today near the administration office at the hospital and she looked frustrated. She said, “I told them I would go on the radio and ask for help from the community to get oxygen but they don’t want me to do that because it would reflect badly on the hospital. We’ve been putting all our money together to buy oxygen. We got one [tank] yesterday but it will run out by 3pm today... I can understand that it is expensive for them and they probably don’t want to spend the money on a patient like Marcelo [a terminal patient].” I said, “It’s hard to believe because surely it must cost more to have him in hospital than the cost of the oxygen tanks.” She responded, “They aren’t even hospitalising him anymore. If we go to emergency they say he can’t be hospitalised just because he needs oxygen.” An employee showed up and said they were getting an oxygen tank delivery tomorrow, so she should come back in the morning. Marta asked what time because yesterday she was told to come back today. He just said the morning and she didn’t kick up much of a fuss.

Home-Oxygen Therapy

The issue of home-oxygen provision was the most emotionally poignant area of inequality I encountered in COPD care. Marcelo was not an exception; Florencia (Chapter 6, p. 145) was in exactly the same position as she and her daughters were also asking for oxygen tanks, getting them unpredictably and insufficiently, and having to spend very limited household income on them. Both families received donations either through radio-solicitations, through churches and the appeals of Mormon missionaries, or through the sale of *tortas fritas* (a fried bread snack sold for five pesos each). Furthermore, it so happened that while I lived with the young

single-mother in Tacuarembó, she was also battling to get an oxygen tank for her 94 year old grandmother to relieve occasional episodes of shortness of breath. Like the participants with COPD, she had been prescribed the oxygen by a physician in the public system. She also had to go to the hospital repeatedly and pester until she eventually got it. She always told me “you need a godfather [padrino, meaning contact] in these situations to help you get things.” Health professionals I spoke to also concurred it was a problem. A woman working in rural healthcare approached me after a seminar I gave and told me with much emotion that she had a story to tell me about a patient needing oxygen who could not get it and which she would one day share with me.

This situation was in no way limited to Tacuarembó, it seemed variable where and how patients in the public system could get access to home oxygen therapy in the interior. Even in Montevideo the situation was far from adequate. Participants seeking care from my public hospital site, for instance, were not given oxygen but had to be referred to another public hospital to receive it. This led to coordination problems in the referral process and increased the risk of patients getting lost in the system. The difference of course is that being a large capital city, individuals had the option of going to another public hospital nearby. In the interior, often only bigger towns have public hospitals and when they do there is usually only one.

From witnessing Marcelo’s family’s struggle, I began studying the topic of oxygen therapy from the bottom-up and calling oxygen-provision companies for information, making appointments with hospital directors and Ministry of Public Health officials, and simply speaking to anyone I could about the issue of oxygen provision. My meeting with officials at the Ministry led me to conclude that there were no binding decrees on the provision of home oxygen therapy, therefore, no country-level legislation was being broken by not providing it. They were surprised to hear the cases I presented to them and one reaction was,

“It must be a one-off, limited to this case. One of our next campaigns is ‘the right to health’ so that people are better informed of what care they have a right to.”

Healthcare professionals tended to be of the opinion that the decision to provide home oxygen therapy comes down to decisions taken at the directive-committee level in each institution. A form of healthcare professional protest seemed to be to write prescriptions for treatments, oxygen included, which should be available, even if they are not. This puts the institution in a

precarious position when the patient shows up to the hospital pharmacy or administration offices demanding what the doctor ordered. A respirologist gave me an example of prescribing a test for one of her patients that the private institution in question was not providing. When the administration rang her up to reprimand her for doing so, her response was:

“I’m the doctor, you pay me to be a doctor, the patient needs this test so I prescribe it. Providing it is your responsibility. I’ll do my job, you do yours.”

During one of my first visits to Marcelo’s hospital I asked how many oxygen-dependent COPD patients they have and the answer was “Zero, we don’t provide home oxygen therapy.” It turned out that although there was no program, in some cases home oxygen was provided to ‘special cases’ and Marcelo and Florencia fell into this category. However, their oxygen-insecurity continued to the day they both received oxygen-concentrator machines, a positive step for the institution. Oxygen concentrators are electric machines which produce oxygen by taking air from the environment and concentrating oxygen for delivery through nose canula or a mask. The advantage is the machine is not filled with oxygen, like tanks, that gets used up and needs to be replaced. The disadvantage of concentrators is that they need some maintaining, and they can be costly to run because of the electricity required. However, if the energy supply is reliable they are the cheapest and most consistent source of oxygen and are particularly recommended for developing countries (Duke *et al.*, 2010). It has remained unclear to me whether there had always been a plan to get concentrators or whether my presence doing research prompted their purchase. All I know is that, all of a sudden, I was told they were awaiting delivery of some concentrators from Asia, which had been delayed due to the 2011 tsunami in Japan, demonstrating the interconnections of the local and global in the modern-day economy of healthcare politics. A small country like Uruguay does not produce its own oxygen concentrators. Other participants with the means bought machines from the USA which then they had problems servicing in Uruguay.

My discussions with directors of public healthcare institutions led me to the following understanding of some of their perspectives on the issue. They argued that in order to provide home oxygen, you need a homecare program because the patient needs to be followed-up in the home and their proper use of oxygen needs to be monitored. The public hospital in Tacuarembó and indeed most public hospitals in Uruguay do not have homecare programs (*i.e.* sending nurses and doctors to people’s homes). The other fundamental issue was that there

were no oxygen-tank producing or filling companies in the Department of Tacuarembó and oxygen-tanks were being sent to Montevideo for refilling at great cost. Figure 7.2 shows a truck full of oxygen tanks I passed while in a bus on my way to Montevideo from Tacuarembó. They would travel approximately 800 km just to be filled and returned. Within the hospital, oxygen is produced centrally for inpatients but they cannot fill tanks. Another issue with oxygen-tanks, according to the administration, was that they had problems in the past with staff stealing them because of the demand for such gas, especially in welding, and their expensive price tag.

Lastly there was the argument of cost, responsibility and priorities. The hospital Marcelo received care from had many surgical and intensive care responsibilities for the whole of the region, without a necessarily larger budget from the Administration of State Health Services (ASSE), and therefore the discourse was: “we cannot provide everything.” A physician with whom I discussed the hospital’s position rebuked this, by saying:

“The hospital is very good in some specialty services but how many people do you think suffer from those things as opposed to those who have COPD?”

I was concerned that Marcelo’s family had spent 12,000 pesos in a little over a month, had incurred a lot of worry and stress, and so I made some calls to the four oxygen providers in the country to learn more about how they provide services in the interior and what they charge. Only one provider would be able to service Tacuarembó and the monthly rental of the



Figure 7.2: Oxygen tanks being transported along Route 5 towards Montevideo, presumably to be refilled. Photo by the author.

concentrator, with maintenance, nursing follow-up and a spare tank in case of electrical shortage, would cost around 5000 pesos. This amounts to the monthly income of the family but since they were thinking of appealing for help on local radio, I suggested it to them as a less expensive and more secure option, one which they claimed nobody had spoken to them about. One paramedical shop in town also rented a concentrator very cheaply but there was only one and it was being used at the time. In Montevideo, oxygen-dependent participants in the public system all received their oxygen from a private company commissioned by the public healthcare institution to provide the tanks, assess the patient and maintain the equipment.

There is no denying that oxygen-producing private companies operate in parallel to pharmaceutical companies and are driven by profit like most businesses. A critical study of their operations in the developing world is crucial and deserves as much attention as the study of other kinds of drug-treatments in the global market. Unfortunately, an in-depth investigation of the medicinal gas industry was beyond the scope of this thesis but there is no doubt that with the increase of COPD across the globe this will become a crucial area of research. What the crisis of oxygen supply symbolises is how COPD was falling through the cracks in Uruguay's healthcare equality pursuit. According to Janes (2003), effective treatment of chronic illness requires three kinds of resources: long-term access to medications, diagnostic and treatment facilities and long-term respite or hospice care, which are not available through primary care. Oxygen, as a treatment for COPD requires affordable oxygen and specialist follow-up from both physician and specialist-nurse or other allied health professional, who is trained in COPD care.

April 18th 2011 – In Hospital

It's Holy Week, called *turismo* here, so the hospital is quite quiet with laboratories working only for emergencies and rural rounds and outpatient clinics are suspended. I went to the room and found that Melina was at her wit's end because Marcelo was wailing, babbling, and chanting and being aggressive. She said the doctor has said "that because of the lack of oxygen his neurons are dying off and he's becoming demented." Marcelo said things like, "I'm lacking oxygen" and "I'm in another world." She told me the doctor has told them he may only live for a couple months and they should think about morphine. I asked what for and she answered, "To kill him" (*para matarlo*). I asked, "Do they do that here?" and she said, "Yes." I asked whether they discussed it. She said her mother doesn't want to do it but in her view he's worse than he was, he's lost all autonomy, he's losing his

mind and he isn't going to get any better. I asked her if she thought he was suffering. She said she doesn't think he's aware. She said the doctor says he is saturating just fine. "He's not using as much oxygen, it was on very low today. Now that he's not so aware he's not so worried about the oxygen. He often takes it off. He seems to breathe okay without it." I mentioned that Peter [another patient with COPD on the wards] died. She said immediately "They killed him, you know, they gave him morphine. He was totally fine, walking, real happy and Monday he spent the whole day in bed. The rumour was he was dead for two hours before the nursing-assistants went to check on him. Since he didn't have any family with him, they decided to use morphine."

Approaching Death

Peter, who is mentioned above and quoted at the start of this chapter, died within a few weeks of agreeing to participate in my study. He was said to have unconfirmed COPD but also advanced lung-cancer. He was a man who worked on *estancias* (large homesteads or ranches) his whole life, he started smoking when he was 6 years old, was unmarried and had no children or close family. He was the subject of much conversation on the ward, not about his advanced disease, which people could not see but about how he was alone. This, to onlookers, was tragic. Consequently, people on the wards, particularly Marcelo's family, pulled together to help him, by keeping him company, getting him things, and helping him get his meals. When he died the rumours began. I had seen the bottle of morphine at his bedside last time I had visited him so I know he was receiving it. The effect such a death had on those in the ward was significant. The perceived imperative to not only accompany, but also protect one's family members, was recognisably stronger. Also, in Marcelo's case, the perception that morphine was a drug used "to kill" stood in stark contrast to the family's Catholic beliefs in the right of God, and only God, to take a life.

I spoke to the doctors about patients' perception that morphine was used to euthanise patients. I was told time and time again that morphine is an exceptional drug for reducing the anxiety caused by severe dyspnoea (Horton *et al.*, 2010; Rocker *et al.*, 2012). However, I was also told about the case of Dr Magga who, in 2006, was accused of killing his patients with morphine in Montevideo. It is easy to imagine how such a high profile case can travel quickly throughout a small country with good telecommunications, including very accessible internet, and shape the thoughts and feelings of the general population. Furthermore, I am sure it is not the first or last case. In fact, in 2012 the arrest of two nurses in Montevideo suspected of killing

50 patients with drugs or air in their IVs made international headlines and has without a doubt contributed to these fears (El Pais Digital, 2012). Both nurses in that case worked in both public and private hospitals.

April 22nd 2011 – In Hospital

It was amazing, Marcelo seemed totally himself today. He greeted me enthusiastically and spoke in his usual voice and was conversing. He wasn't wearing oxygen and it wasn't even turned on. I asked how he was last night and he said well. There was a woman visiting him whom Marta had known since childhood. I joined their conversation. Marcelo said that he was *loco* (crazy) the other day and saying all kinds of things. I asked him what it was like for him in those moments, whether he was aware of what was going on. He said, "I'm in another world." The woman sitting next to us began to say that it is a terrible disease and she wouldn't wish it on anyone. Marta said, "They treated it like asthma and allergic bronchitis before realising it was this disease COPD. It's a disease he's had since birth, a lack of oxygen, and after with smoking and other things it got worse and worse." Marcelo added, "I was born with this in my blood." Marta said that the disease runs in families, that siblings of Marcelo have the disease. She explained to her friend that Marcelo's sister has the same disease but doesn't spend all her time hospitalised. "She stays at home and has oxygen at home." The woman responded, "Ah, so it's hereditary?" and Marta replied, "Yes."

Genetic Testing

The family's belief that the disease was genetic or hereditary was mentioned several times during the course of fieldwork. Marta told me that it was a doctor who looked after Marcelo in the intensive care unit who first said that it was something he had "always had." While such an explanatory model helped the family make meaning out of their loved-ones suffering, it also felt to me like genetics was serving as a scapegoat for the more significant reason Marcelo was dying of such advanced COPD so young: being a poor person without the appropriate healthcare for detecting and treating such a chronic disease. Florencia, who I have mentioned before, was following a similar experiential path as Marcelo. Her daughter said to me:

"Her doctor says her disease was not caused by cigarettes, the cause is genetic. The doctor says you rarely have such a young patient with this disease."

Whether the doctor tried to explain that Florencia probably had a genetic predisposition to developing COPD or whether, she indeed said it was caused

exclusively by genes will remain unknown. The only *known* genetic cause of COPD accounting for 1- 2% of cases is the alpha-1-antitrypsin deficiency (Currie, 2011). However, it is agreed in the medical literature that there is a 'susceptible smoker', who develops COPD and the genetic contribution to this susceptibility is still unclear.

In Marcelo's case his doctors suspected he had alpha-1-antitrypsin deficiency, as did others I presented his case to, particularly on the basis of his age and that he had a sibling with the disease. Testing for this disease is another service that was not readily available in Marcelo's town and a blood sample had to be sent to Montevideo and only after requesting approval from hospital administration, *i.e.* the director's office. In June a blood sample was sent off to Montevideo, motivated in part, I am sure, by the fact that I was asking for the result after they had mentioned suspecting he could have it. A month later the result came back negative, he did not carry the known genetic cause. One wonders whether Florencia would be exactly the same and it puts into question the fairness of alluding to genetic causation when the only known test has not yet been performed and when the issues of smoking history, unaddressed occupational risk-factors, absence of diagnosis, insufficient treatment and general conditions of poverty, such as malnutrition and housing conditions, likely account far more for why a person like Marcelo at age 54, with no known co-morbidities, is so sick.

The study by Lock *et al.* (2007) on the narratives of Canadians and Americans who received genetic testing for Alzheimer's, found that people's causation theories were complex and they remained largely unchanged in terms of their embodied identity or lifestyle after testing. A consistent finding was that participants in their narratives considered family history to be a better predictor of future Alzheimer's than genetic testing, even in those cases where their genetic predisposition returned lower than they had expected. If families in Uruguay are similar, and they probably are, then I suspect Marta has not stopped thinking it could be "in the blood" or in the family, just because the Alpha-1-antitrypsin deficit test came back negative. In many ways she is right to not discount her theories because there may very well be other genetic causes of COPD not yet discovered and named. To say to a patient, "It's not genetic," just as to say, "In your case it is probably genetic" produce problematic consequences. The first is problematic because a more truthful statement would be,

“It’s not genetic so far as we know today, right now, in this place”, because there very well may be new discoveries in the future. In the second, alluding to genetics as cause may downplay the importance of environmental factors, such as inhaling tobacco smoke. Furthermore, tobacco smoking is important in the context of shared family environments of exposure, which can lead two people in a family to develop the same tobacco-related disease (Kalucka, 2006). Also, poverty and inequality within countries and between nations are inextricably linked to the likelihood of smoking and exposure to other risk factors (Mannino & Buist, 2007).

May 2nd 2011 – At Home

Marcelo’s home was about a 30-40 minute bike ride from the city centre along a paved road. The neighborhood is very much on the margins of Tacuarembó and feels much more rural. There are a few houses along the road and lovely views of fields and the surrounding hills. Houses are small and *humilde* (humble). I called Marta as I got near and her niece came and met me on her motorcycle to show me the way. The houses, connected by paths not big enough for cars (of which there were few, if any, in this neighborhood) were mostly made of cement blocks and wood with either straw thatch or metal roofs. Marta and Marcelo’s house was made up of two sections. One was the one-room cement block house, which had a fridge, some wardrobes and shelves, two single beds, a sewing machine and a small television. The other section of the house included the kitchen and bathroom which were in a less formal wood construction with plastic bin bags placed amongst the wood to keep the rain out (Figure 7.3). There was a toilet but the only running water came from a tap outside so buckets needed to be filled to flush. They had two dogs and four cats. Marta told me they keep the cats only because they hunt the rats and mice from the house. In the back was her daughter’s house, her fighting cocks (an illegal but existent pastime), her chickens and her rabbit. Surrounding the house were beautiful orange trees and flowers planted in cans and sectioned soft-drink bottles. Marta used to also work in the tobacco plant but now has some work cleaning houses and also mends clothing on her old sewing machine. Marcelo was lying in one of the single beds with two oxygen tanks next to him, although he wasn’t using any when I arrived. He looked well. He told me proudly, “I’m not using oxygen.” Marta said, “He hasn’t used it for two nights and I can’t sleep well and would like for him to use it but he doesn’t want to. I wake him up at night to see if he needs oxygen.” Despite her worry, he received a lot of positive comments for not using oxygen. His sister who was also visiting at the time said warmly, “You didn’t use your oxygen,” and he answered, “No, I’m better.” Marta added, “The doctors

said that the less he uses it, the better because his need for it is kind of psychological. They also said that an overdose of oxygen can cause just as many problems as not using enough.”



Figure 7.3: Marcelo and Marta’s Home. Photo by the author.

Conflictual Relationship with Oxygen

Almost every excerpt so far speaks to the conflictual relationship the person and the oxygen tank or machine can share; a relationship that is participated-in and shaped-by family members. Nobody wants to have to depend on a machine, however, many reported feeling better once they were using oxygen. At the same time, some participants felt that having to use it less and less was a sign of getting better and Marcelo, like at least one other participant in my study, received positive reinforcement for holding back from using oxygen. One of the first things I was told by a doctor in Montevideo was that oxygen therapy is seen by the lay population as end-of-life care and their challenge as COPD specialists is to help patients see that it is a treatment which will prolong their life and not a treatment for the end of life.

Generally speaking, the oxygen-dependent patients who received specialist respirology care (whether outpatients or in pulmonary rehabilitation) saw oxygen as a treatment and did not expect to ever be able to live without it, even though they would like to. Marcelo and Florencia, however, did not see their oxygen use as permanent. This may be because they were the most recent users of oxygen in my study and many other participants reported that there is a period of adaptation and reconciliation with the unfortunate fact of being tied to a machine.

In investigating the issue further, I took the issue to a health professional specialising in oxygen therapy and another layer of complexity was added to the story.

“I would say that out of 100 individuals referred for home oxygen, 40% are COPD, 20% are terminal patients, and then the rest are various pathologies. I think of the 60% [*i.e.* COPD and terminal illnesses], many don’t need to be on oxygen. I know this because people stop using the oxygen, or use it much less, which suggests that they don’t actually need it. But, if you try to take the oxygen tank away from the patient, they resist massively and start using the oxygen again, so that you don’t take it away. The person sees the oxygen machine as their lung, and as their lung it’s “theirs” and you can’t take that away. The psychological dependence is impressive and doctors are partly to blame because they have a habit of prescribing it without thinking it through carefully. Sometimes you are referred a patient for home-oxygen who hasn’t had the necessary tests and we don’t get all the information we need from the doctor. We’ve been improving this with better guidelines and referral procedures.”

I shared with him an alternative interpretation, which he found interesting. I felt that patients get blamed and criticised for their psychological dependence on oxygen, whereas I see that the health professionals in in-patient settings are complicit in the production of this dependence. He agreed with this. I also found, as the case above illustrates, that there was a lot of conflicting perspectives on oxygen use. The same person who’ll fight to the death to receive and keep the oxygen they feel they need, might begin to use it less because using it less symbolises getting better and this is positively reinforced by family members. This is concerning considering that some people with COPD who are prescribed oxygen for the treatment of chronic hypoxia or Cor Pulmonar (a heart disease) should be using oxygen at least 16 hours a day to prevent heart problems or slow its deterioration. Being aware of how the individual and family interpret oxygen-use and reinforce certain behaviours is clearly an important part of long-term follow-up of oxygen users. The embodied memories of breathlessness discussed in the chapter 6, easily account for how possessive a person can be about their oxygen-tank, particularly if they fear needing it again and facing difficulties getting it. Similarly, Janes’ (2003) research on the experiences of Mongolians with chronic conditions found that because medications were not reliably accessible, one strategy for individuals was to ration their treatment, thus taking inappropriate doses of medication.

May 17th 2011 – At Home

I called Marta to see if I could pass by, and she said, “We’re here, struggling” [*luchando*]. When I arrived, she said, “He’s not been well for a few days, his blood pressure is high.” I sat down next to Marcelo’s bed and he said, “Marta says I’m going to have to be hospitalised. I don’t want to, if I need oxygen, I have it here, why would I need to go?” He told me he turned 54 in December and that he’d like to live well into his 70s. At that moment he looked at the cross on the wall next to him and ran his fingers over Jesus’ legs a couple of times and told me, “I asked Jesus if I could live until 70. I don’t know why but recently living into my 70s is something that is on my mind a lot.” We spent a few minutes in relative silence and when Marta returned she brought Marcelo a bowl of soup. He had a few spoonfuls and then, suddenly, he became very hot and he began purse-lip breathing and was complaining of being hot. We helped him take off his sweater and he asked that the window be opened. Marta immediately fetched the blood pressure machine, which finally gave a reading on the third try that was normal and everyone calmed down. Marta asked him if he wanted to see a doctor and he said no. She said, “I’ll give you a nebulisation like they do in the hospital.”

Later, as we ate our soup in the kitchen, Marta told me, “I’d like to take him to the doctor’s because he’s not been well for a few days but I know they’ll just give him a nebulizer and maybe a diazepam (a sedative). It’s always the same, I feel like I do more for him at home. They don’t even take his blood pressure.” At one point she said, “Poor thing. He wants and thinks he will get better, but that’s not the way it goes, does it?”

May 26th 2011 – At Home

I went in and sat by Marcelo’s bedside. He was back to looking like a scared boy in his bed. Last time, he was more himself, his voice was deeper and louder and he would smile. Today he stared off into the distance, his arms tucked up above his chest, his voice faint and sad and full of anguish. He said, “Last night I had an attack, I was breathless and I needed to use oxygen. It had been days since I needed oxygen.” He had been using it since 10pm the night before and was concerned about running out and having to go to the hospital. “If I go, I won’t come out,” he said.

Homecare and Deciding when to go to Hospital

Over and above continuing to demonstrate the conflictual relationship Marcelo had with oxygen therapy, these entries illustrate the turning points when a person with COPD goes from being stable to having an exacerbation. In these situations, the family are the healthcare professionals and, in this case, have learned what to do by observing healthcare professionals each time they go to the hospital. Their sense of the limited capabilities of the hospital to do anything, the disruption hospitalisation causes to the whole family and the unwillingness of Marcelo to go, all influence the family's decision to care for him at home, as best that they can. In this state, participants with emergency medical insurance can call a physician to the home and, if needed, the patient can be started on a course of antibiotics and stay at home or be transported to the hospital. As is evident in Table 7.1, a number of research participants could afford this service and it is possibly one of the greatest advantages that Uruguay has in terms of COPD care. When I interviewed people with COPD in Québec, I found that the impossibility of being seen at home by a physician when they first started to feel unwell, delayed them from seeking care, especially if the snow and ice made going outside a risky business. In response, respiratory care teams were trying to incite patients to call the specialist nurse at the hospital when they felt unwell. That a person with COPD in Uruguay can phone and within hours be seen by a doctor, who may start them on a course of antibiotics, do some nebulisations or send them to the hospital, is a useful resource but again, you have to be able to pay the monthly cost and the *tiqué*. In Marcelo's case, the family either uses taxis to get him to hospital or if the hospital ambulance service is available they will call it.

Occasionally, they have been able to ask the doctor, who attends the local clinic in the neighbourhood, to pass by the house to see Marcelo but in the moment of crisis this is not always possible. Some participants in the private systems in both the interior and the capital had access to 'home hospitalisation' through their institution, meaning that if they needed hospital care they could stay at home and a nurse would be sent three times a day and a doctor once a day to administer treatment and monitor them. Verónica, an 88 year old non-smoker with severe COPD, was always cared for by home hospitalisation if possible because her doctors felt she was at greater risk of picking up a virus in the hospital. However, being a member of the private hospital did not guarantee you homecare either. You had to be within a 'zone' of care covered by the hospital, which was usually restricted to urban areas. Again these kinds of services, highly valued by users and cost-effective for institutions, are available to

some but not others. In the case of COPD I can see home hospitalisation, like mobile emergency services, as a resource for patient-care. Uruguayans were always shocked to hear that in the 'First World', as they commonly referred to Canada or England, you could almost never get a doctor to come to your home like you could in Uruguay.

Marcelo and Marta were not unusual for being equipped with an electronic blood pressure cuff and a nebulizer machine. Nor were they alone in engaging in what Csordas (1990) might call an embodied language and ritual practice. As Marcelo complains of a sudden rush of heat in his body, Marta engages in repeated rituals such as undressing him, opening a window, and swiftly reaching for the blood pressure cuff. The blood pressure machine is highly symbolic of 'good care' in their story. The fact that health professionals no longer took Marcelo's blood pressure was symbol for the family of his abandonment by the health system. The importance of blood pressure as an intervention was pervasive and I suspect this is linked to the public health campaigns surrounding hypertension.

Another illustrative example of these kinds of ritual practices comes from a conversation I had with Patricia, a 45 year old single-mother of three with very severe COPD in the spring. She described how she home-hospitalised herself over the winter to deal with exacerbations. She used the words *internacion domiciliar* which is the official term used for this service when provided by private health care institutions. However, as a patient in the public system, she did not have access to this service and simply did it herself. When I met her in the spring, shortly before I left Uruguay, she told me:

"This winter, I did home hospitalisation all winter, why? Because I have my nebuliser, I have my medication, and if let's say I wake up, there's humidity, I go to the bathroom and I can't breathe, I start doing what it would be like if I was hospitalised, the same thing: the nebulizer, in bed. The kids can manage, of course they are older now too [11, 13, 17]. I manage myself, they make the meals and bring them to me, and if I have to, I get them out of school, so we can manage. I prefer being here than being in hospital because then they have to go stay with their grandmother, everything gets disrupted. If what they will do to me in hospital is what I can do for myself here? Except of course if it is a big lack of breath [*falta*] so that a nebulizer won't be enough, then yes, I need to go to the hospital for the big tanks [oxygen tanks]."

The custom of accompanying patients, adds a tremendous financial burden to the already emotional burden of caring (Kleinman & Hall-Clifford, 2010) because poor households may become increasingly impoverished by missing work opportunities by being in the hospital at the bedside. Therefore, a consideration of the feasibility of providing home-hospitalisation in the public sector is a worthwhile discussion, in order to reduce the financial and emotional burden. In Patricia's case, her disease requires the informal care of her children, which may also interfere with their schooling and, in turn, their chances in life. COPD in this case resonates with Nichter's (2008b) idea of the syndemic relationship between chronic illness in an adult and the predisposition of children to acute and later chronic illness. Although it was not clear whether Patricia's children were in any way more likely to get an infection, they were occasionally being taken out of school, they had added responsibilities in the home, and overall the household could be impoverished by Patricia's inability to maintain work during the winter months when she exacerbates most frequently.

June 3rd 2011 – At Home

"I've got little time left. I'm here between four walls", said Marcelo. "Before I could walk, I could go out to the forest and countryside, now I'm useless. This isn't going to get better, get that idea out of your head girl [referring to me as *muchacha*]. I'm 54 years old, and I've got little time left."

June 13th 2011 – Text Message from Marta

"Hi, how are you? We're pretty okay, Marcelo for the moment has a bad chest but nothing too serious. Today they brought us the oxygen codifier [oxygen concentrator machine], we just switched it on. We'll see how we go with it, x."

Sadly for Marcelo and his family, the solution to his oxygen-scarcity problem was short-lived. The following day he went into hospital where he died on June 16th. At his wake that night³, his eldest daughter explained how he died. He started feeling like he was in pain all over and asked to be taken to the hospital. He was kept in emergency for a day and a half because there were no ward beds. They found he had a bit of congestion but was without fever or cough. But then he had a kind of seizure. It passed and Marcelo came to and was conversing with Marta and

³ It is customary in Uruguay to hold the wake as soon as the body is released from hospital. In Marcelo's case we stayed with his body in the closed coffin all night in the funeral parlour as family members arrived by bus from various parts of the country. He was placed within an above ground cement grave rented from the municipality, within 24 hours. In two years the family will be called to be present while the grave is opened, his bones removed and washed and then placed in a small urn (a practice called *Reduccion* –Reduction) to be left above ground in either a large shelf or on the ground in the open air of the cemetery. Wealthier citizens have their own mausoleums however, they also practice reduction.

asked for a glass of water. By the time she got it and stood up, he was dead. Marta said,
“He was a good colour and went peacefully. He had been telling me that he was going to go.”

Marta recounted how the doctor cried and they embraced each other.

“He’s a very humane doctor, he cared about Marcelo. Every time we’d cross each other in the halls he would put a hand on my back and say “be strong” [*fuera, fuerza*].”

However, the next few times I met Marta she told me that thinking back, she wonders whether they used morphine on Marcelo. “Maybe that’s why the doctor cried”, she said. I asked her how she would feel if she were told they had used morphine. She responded, “Helpless.”

Kaufman’s (2005) research on the shaping of death in American hospitals resonates with Marcelo’s experience of end-of-life and dying in hospital. In Kaufman’s words:

“Death is shaped, known, defined, and disputed through the varied forms of human activity that surround it. Thus death is not a natural phenomenon; it is made. And the ways in which death is made vary tremendously culturally and historically. There is no such thing as a death that occurs beyond the boundaries of society and historical moment, social norms and expectations, tradition and cultural innovation.” (p. 63).

CONCLUSION: INVESTING IN COPD AS A CHRONIC OR TERMINAL DISEASE

Investigating the ways in which healthcare systems shape the experience of chronic illness is a rich topic for anthropologists, primarily because participant-observation offers opportunities for seeing aspects of illness or entire groups who may normally be ignored (Lock, 2001).

Becker’s (2004) study of the experiences of uninsured Latino and African Americans with chronic diseases, found they delayed treatment because of the cost, were under-medicated or un-medicated, and avoided the health care system altogether. “The statements of uninsured people in this research attest to how concerns associated with their chronic illnesses are exacerbated by the hit-and-miss care they receive in this system” (Becker, 2004, p.271). COPD care in Uruguay was at the time of my study a hit-and-miss affair. Similarly, Gibson (2001) looked at the effect of healthcare reform in South Africa on thirty acutely chronically ill persons and their families. His article poignantly focuses on the stories of five of his six participants who died while trying to access care for an acute episode. He argued that the fragmented system, increasingly focused on primary care, is ill-prepared to deal with acute episodes of long-term,

chronic conditions. His participants died as a result of transitioning between institutions, being sent home, receiving limited treatment and sent away, or simply while waiting to be seen by a doctor. Having access to specialised acute care in South Africa, as in Uruguay and indeed anywhere else, is not only a question of having the appropriate personnel but also having appropriate means of transporting patients to hospital. Janes (2003, 2004), similarly, looked at the effect of healthcare reform and fragmentation on chronic illness sufferers in Mongolia. He found that the increasing focus on primary care pushed by global funding institutions, like the World Bank, lead to the production of “poor medicine for poor people” particularly for the chronically ill whom he found could not afford long-term medications, repeated analyses and tests (p.43).

Currently, access to care for COPD (from diagnosis to medications, to oxygen, to home and inpatient care) varies tremendously from one person to another in Uruguay. Where you live and what primary, secondary and tertiary healthcare you have access to, will shape whether you have a chance of being diagnosed before the disease is advanced. The hit and miss healthcare some participants with COPD received exacerbated their disease. Other chronic diseases such as diabetes and hypertension have been explicitly addressed with protocols for diagnosis and management, but COPD remains a disease on the margins. COPD is a complex disease; some patients, who do not get acute exacerbations but get progressively more breathless, may not feel they have to see a doctor until the breathlessness makes daily life a struggle. Also, an early diagnosis does not mean that the person will quit smoking, use treatments, or get vaccinated. Even if they do, there are always those who will get worse more quickly than others for reasons we do not yet understand. Uruguay does have some distinct advantages. The mobile emergency services and home-hospitalization services are impressive and would be the envy of many in England and Canada. However, unequal access to them contributes to healthcare inequalities in the context of COPD.

The underlying question some institutions, like the one in which Marcelo was treated, are facing, is whether to open the door to COPD or not; to name and address the elephant in the room or ignore it. When institutions open the door to diagnosis, *i.e.* by giving it a name, the cough, the breathlessness, the frequent chest infections become something *more*— they become part of a chronic disease. If there is diagnosis then the door, *i.e.* the expectation and indeed obligation, is opened for treatment, including smoking cessation, expensive medications, possibly oxygen, and qualified staff. Oxygen therapy, especially, requires

specialist evaluation and tests, a supplier of the medicinal gas, the expertise to maintain the oxygen concentrator equipment, and the staff to monitor and manage its use. Even in the UK, there is evidence to suggest that the prescribing, monitoring and follow-up of home oxygen therapy is insufficiently, and even inappropriately, carried out according to guidelines (Hungin *et al.*, 2003). However, if the door is kept closed for as long as possible, COPD progresses in silence and patients and healthcare staff suffer the consequences of suffering, and the institutions face the consequences of expensive and recurring inpatient care (Devereux, 2011; Mannino & Buist, 2007; Sullivan *et al.*, 2000). According to the head of the ward at Marcelo's institution who analysed re-hospitalisation data in 2006, the majority of cases of rehospitalisation within 30 days post-discharge were for COPD exacerbation.

Living with COPD frequently leads to what Sharon Kaufman (2005) terms "the revolving door pathway" common to "...patients who are repeatedly admitted and discharged for recurring chronic ailments that cannot be cured..." (p.98). The same process has been described for people with COPD (Yu *et al.*, 2007). In the poignant stories Kaufman presents, the revolving door pathway was a result of interlinking factors, such as the fears of the person, the panic of the family, the failure of doctors to approach the topic of death and the Medicare payment policies, which she argues bear most of the responsibility. She presents the cases of patients whose transitions in and out of hospitals, nursing homes and their own homes were the product of health insurance policies regarding criteria for access and length of stays. In the case of Marcelo, the major factor affecting his ability to spend his last few months in his own home was the undependable provision of home oxygen therapy.

Being someone with the label COPD may be short-lived, just as 'being HIV positive' or having AIDS can be experienced as an acute disease of imminent death or a chronic condition of uncertain duration (Kendall & Hill, 2010). Marcelo lived with the label COPD for a year, although his family knew he had COPD much longer than that but they did not know how long. Other participants, in their 70s, had been living with a diagnosis of COPD, or emphysema, for decades. Turning COPD into a chronic disease is expensive for healthcare institutions and governmental social welfare programs but as long as it remains a terminal disease, the associated human and economic costs are greater. This chapter has taken the sensorial experience of breathlessness, exacerbation and the need for oxygen of Marcelo and his family as the guiding narrative to an investigation of the political-economy of COPD care in Uruguay. By comparing and contrasting his experiences with others, I have argued that his lived-

experience of the disease was not a natural part of COPD but one greatly shaped by inequalities in healthcare he experienced. I have also shown the crucial role of the family in caring for and helping to interpret the sensations of their family members. There are two other forms of care which do not feature in Marcelo's story but which are crucial for COPD prevention and care. These are Pulmonary Rehabilitation and Smoking Cessation which are the topics of the next chapter.

Reclaiming the Breath: Sensorial Work in Pulmonary Rehabilitation and Smoking Cessation

INTRODUCTION

So far we have seen the ways in which breathing is disrupted with COPD. I have presented very visual, metaphorical and descriptive examples of how the sensation of breathlessness can disrupt lives, disable, and when severe, equate sensorially with death. However, breathing is not always experienced in such negative terms. Chapter 6 demonstrated how some people with COPD may have only mild symptoms of breathlessness. However, even those with very severe COPD can experience breathing in more ways than simply as a struggle. Philosophers of health and illness, like Havi Carel (2007), remind us that health within illness is possible and it is important to explore this and not simply focus on suffering. I want to give space and time in this thesis for an exploration of the spaces dedicated to improving people's breathing and overall health. This chapter draws on fieldnotes gathered in two contexts where I witnessed attempts to reclaim the breath and experience breathing in socially-supported and potentially therapeutic ways. These were a pulmonary rehabilitation unit and smoking cessation services.

In these contexts sensations felt in the body were discussed, interpreted and made meaningful, socially, in groups. I refer to this process of interpretation and meaning or sense-making as 'sensorial work', which, in the context of a group, is a highly intersubjective process. Group members' subjectivities interact and create a space where 'sensorial work' happens. Nichter's (2008a) premise that "...the sensorial is not just experienced individually, but 'dividually'" (p.166) is useful here. He uses the term "...'dividual' as a heuristic to emphasise that one's experience of sensations is often dynamic and transactional..." and that "...one's experience of sensations is rarely solitary..." (p.166). Group-work makes the dividual experience of sensation explicit through verbalisation. As I was a participant-observer in both contexts over the course of the year, I too was part of the intersubjective process. In the words of Gillespie and Cornish (2009), in relation to their review of inter-subjectivity and ethnography, "...the researcher does not study intersubjectivity "out there" but rather enters

into the inter-subjective web, and through being part of that inter-subjective world, comes to understand it" (p.32). As such, I contend in agreement with Throop (2010) that the knowledge which is produced through ethnography is an intersubjective achievement in this case.

Elsewhere, it has been argued that a future area of development in the anthropology of illness is in collaborations between anthropology and occupational and rehabilitation sciences (Frank *et al.*, 2010), and so the present chapter is a preliminary step towards such collaboration.

There are many angles one could take towards analysing and comparing the large body of fieldnotes I have on smoking cessation services and pulmonary rehabilitation. In all I attended 18 pulmonary rehabilitation sessions, and 57 smoking cessation sessions. You could say it makes little sense to compare them. After all, one context is all about encouraging people to incorporate a practice into their lives (exercise) and the other is about encouraging people to withdraw a practice from their lives (smoking). Furthermore, in smoking cessation the main activity is conversation, whereas in rehabilitation exercise is the main activity, although conversation is a central component. Also, in one context everyone has diagnosed COPD and in the other only three people within the seven groups I followed were known to have COPD. Nevertheless, everyone in smoking cessation could potentially have or develop COPD and the ways in which they describe their breathing sensations can give us insight into how changes to one's breathing are interpreted. Therefore, despite these differences, I took an exploratory approach to comparing the two while I immersed myself in my fieldnotes and asked myself "what might emerge from a comparison of the intersubjectivity of pulmonary rehabilitation and smoking cessation?"

I focus here not on how they differ, but on how they have certain things in common. This ethnographic data is also strategically placed in this chapter because in the next chapter, I will return to the topic of smoking cessation services. In the first section of this chapter, I will describe both the smoking cessation and rehabilitation contexts, including the medical theory behind them, and give a snapshot of their enactment in practice through an ethnographic description of two sessions. Then the chapter will discuss two emergent themes on the topic of sensations.

PULMONARY REHABILITATION

Theory behind Pulmonary Rehabilitation

Pulmonary rehabilitation is an intervention designed for people with lung diseases who are disabled by their conditions. By disabled, what is meant is that their breathing difficulties are interfering with their ability to carry out everyday activities. A common occurrence in people with COPD is that their breathlessness leads them to avoid physical activity, which in turn leads to a loss of physical fitness and greater breathlessness (Booker, 2005). Rehabilitation programs usually include a variety of components generally addressing the need for greater exercise support, dietary advice, psychosocial support and education (Currie & Douglas, 2011). It is often provided in group format, creating a space for patients to provide each other with mutual support. Members of the team will vary from place to place. In England the team is considered multidisciplinary and frequently made up of physiotherapists, specialist nurses and doctors. The group I followed in Uruguay was led by a doctor with the occasional intervention of a social worker who saw patients individually, most frequently helping them to receive subsidised transportation to the rehabilitation sessions. As mentioned in Chapter 4, Uruguay has a large number of doctors, which means that they often take on the work that in England would commonly be done by nurses or physiotherapists.

Pulmonary rehabilitation has been shown to significantly improve functional ability, exercise capacity, and quality of life as well as reduce breathlessness and healthcare use including hospital admissions according to quantitative assessments (Booker, 2005). However, it does not influence disease progression, how many exacerbations a person has or even long-term survival (Currie & Douglas, 2011). Typically, the program runs for two to three months or longer, two to three times a week (Currie & Douglas, 2011). In the UK, pulmonary rehabilitation is currently not sufficiently available or accessible to those people who could benefit from it (Currie & Douglas, 2011). Uruguay was much the same. To the best of my knowledge it was not available in the interior of the country and I knew of only three healthcare institutions of more than 20 healthcare institutions in Montevideo with such programs. There were also some private rehabilitation clinics and home-based care from privately-paid professionals. The only other service publicly available which shared the breathing component of pulmonary rehabilitation was the free pulmonary physiotherapy consultations provided by a drug-company's social responsibility venture, the Centre for Pulmonary Attention (CAP). However,

the physiotherapist, who I observed, worked one-on-one with patients and there was no exercise component to the consultation.

A central component of any program is: "...assessing and advising on dysfunctional breathing" (Currie & Douglas, 2011, p. 26). That breathing can be dysfunctional yet malleable is an important premise of rehabilitations. Certain kinds of breathing are considered helpful and are frequently taught and practiced in pulmonary rehabilitation. Other kinds of breathing are considered unhelpful and discouraged. Table 8.1 from Currie and Douglas (2011) represents the diversity of breathing techniques that are said to be beneficial for people with COPD. As one can see the breathing techniques are not just about breathing but about body-placement too. The theme of breathing will be returned to later in this chapter. What follows is a descriptive example of a pulmonary rehabilitation session.

Table 8.1: Different techniques which may reduce breathlessness and allow more efficient ventilation. Reproduced in-full (including title) from Currie and Douglas (2011, p. 27)

Technique	Instruction and Effects
Pursed Lip Breathing	May reduce respiratory rate and air recovery during periods of increased activity
Relaxed, Slower, Deeper Breathing	May allow more effective ventilation during exertion and avoid rapid shallow breathing
Paced Breathing	Timing inhalation and exhalation with every other breath may help reduce symptoms during activity
Positioning	Passive fixing of the shoulder girdle (<i>e.g.</i> elbows resting on a table or ledge) may reduce breathlessness. Patients should also be encouraged to adopt the forward lean sitting position.
Energy-Conservation Technique	Home adaptations (such as a hand rail) or sitting to perform household chores.
Exhalation on Effort	Advise patients to exhale when they perform an activity (such as standing up, lifting the arms)

Pulmonary Rehabilitation at a Public University Hospital

One of my first field sites in early October 2010 was the pulmonary rehabilitation program at a public university hospital in Montevideo. The hospital, which now stands as a hotchpotch of modern and decrepit spaces, is an epic example of the wealth and vision of ‘the best healthcare for all’ policy of Uruguay in the 1930s. Graffiti-covered stairwells and blocked toilets were contrasted with freshly renovated wards boasting beautiful murals (Figure 8.1).



Figure 8.1: Contrast within the Public University Hospital. A freshly painted mural on a renovated ward (a) and the graffiti-covered stairwell with cracked and broken windows (b) Notice the no-smoking signs. The size of this hospital has made it very difficult to enforce the no-smoking policy amongst patients and staff in hidden corners like stairwells. Photos by the author.

The hospital had a very distinct charm despite its run-down feel; a particularly poignant example of the consequences of 12 years of dictatorial rule. All of the participants in my study who received care there, spoke highly of the inpatient and outpatient care they received here despite the lack of hot water, the abysmal quality of the ablutions and the need to bring bed sheets, cutlery, and toilet paper from home. I was repeatedly told by participants “it is full of the best professors of medicine.” Respiriology and the Pulmonary Function Laboratory were poorly signposted, as were many other departments. After walking down a long, fluorescent-lit, water-damaged hallway with only some select sections re-painted, one encountered a door on the left marked *Funcion Pulmonar* (Pulmonary Function). The door opened into a room where the cardio-pulmonary technicians busily carried out their tests with patients, namely spirometry. From this room, filled to the brim with ancient medical equipment and medical records, was a door leading to a small office where the respirologists shared two rickety desks and chairs with the secretary. The pulmonary function lab was the only example I experienced

during fieldwork of an interdisciplinary team who shared a physical space. In this physical space patients were discussed, tensions emerged and dissipated, all while *mate* was sipped and cakes, crackers and pastries were eaten. For the first three months of fieldwork, I would walk in to this space three times a week, enthusiastically greet and be greeted, and chat and share *mate* with the whole team who used the space while awaiting clinics, team meetings and pulmonary rehabilitation. Conversations were frequently interrupted by knocks on the door from lost patients. If you were not lost in the hospital, it was because you were not looking for something.

Dr. S carried out the great majority of the rehabilitation sessions, two to three times a week. Five people were regularly taking part in pulmonary rehabilitation and I got to know them all very well over the 12 months of research, as they all became keen participants (Sebastián, Macarena, Lucía, Martín and Mateo). The group was small, reflecting a lack of resources, possibly a lack of coordinated referrals and the lack of physical space and equipment. On my first day at pulmonary rehabilitation I sat in on Dr. S's consultation with a new patient joining rehabilitation. A physical examination was carried out by Dr. S as well as a structured psycho-social interview by the social worker. Dr. S always apologised about the rehabilitation room and said that it embarrassed her. It was in need of a paint-job and some window cleaning but otherwise had the essentials: chairs, very old but functional exercise bikes, a couple of oxygen tanks, a small desk and some mats. Macarena (Chapter 6, p.144) was the only patient that day and so Dr. S walked her through a typical session. She stood up and walked to the cupboard, turned to me and said, "We're a developing country so we use these," and showed me used water bottles which had been refilled to be used as hand weights. She told Macarena that, for all the exercises, the idea is to breathe in through the nose and out through the mouth because, "It will help you get the air out." (Table 8.1, "Exhalation on Effort"). Dr. S began explaining that there is a natural deterioration of respiratory capacity in humans but that only around 18% of smokers end up developing COPD. She drew a graph which showed that the respiratory capacity of a susceptible smoker will deteriorate quicker than a non-susceptible smoker or non-smoker but that the rate of decline will go back to the rate of a non-smoker or non-susceptible smoker when the person quits (Table 8.2).

To this Macarena exclaimed, "*Que alegría*" (I'm so happy to hear that). She said she was afraid it would keep getting worse and that one day she would need oxygen. Dr. S explained that there are people with advanced COPD who need oxygen and others that do not.

While looking at an illustration on the wall, printed by a pharmaceutical company (similar to Figure 6.4, Chapter 6), she explained what COPD was:

“Bronchitis is coughing, phlegm and mucus. As for emphysema, the alveoli work like a paper bag with COPD. You can blow the bag up but it’s not so easy getting the air out. Why is Forlan [the famous Uruguayan footballer] the best? Because he works out a lot, he goes to the gym, so he can run all over the place. Here we will do the same thing. If you are in shape you will be in a better situation to face this disease. If you do nothing, you lose muscular strength. With exercise, your body will be able to resist more and you’ll be better off, it is fundamental.”

After a long conversation Dr. S ended with:

“This part of pulmonary rehabilitation has to do with education and the psycho-social support, it is important, it is not a waste of time.” [said as justification for why they had not done any exercise yet].

Macarena responded, “No, no I completely understand.” and with this they began exercising. The exercises consisted of: a) flexing the arms while holding the water bottles as weights above the head and back down and out to the side of the body and down; and b) resting a weight (this time a 1 kg bag filled with rice) on the top of the foot while flexing the leg out straight and holding for six seconds. Water bottles and bags of rice were household items

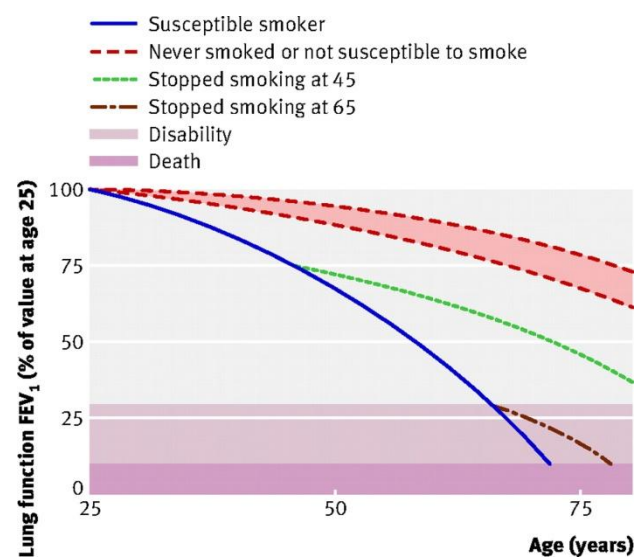


Figure 8.2: Example of a typical pulmonary capacity graph which Dr. S sketched to demonstrate that a susceptible smoker’s lung function will deteriorate at a far faster rate than a non-susceptible smoker or non-smoker, but that quitting smoking stabilises the rate of deterioration. The message is: it is never too late to quit. (Taken from: Parkes *et al.*, 2008)

easily available to participants, so that they could carry out the exercises at home. Another exercise tool sometimes used for upper body exercises were broomsticks. Macarena was explained that after she had some heart and lung tests she would start training on the bicycle too.

In the subsequent pulmonary rehabilitation, the routine was very much the same except that if no new patient were present, less time was spent on explaining the disease and more time was spent on exercising. In the majority of sessions to follow at least two of the five patients enrolled in the program were present. Attendance was an issue. One fundamental reason why patients missed rehabilitation was because of the weather (cold, rain or humidity) (Chapter 5) or because they were acutely ill with a cold, flu or lung infection (Chapter 6). The doctor encouraged them to stay home if they were unwell, so as not to infect others and it was generally assumed and agreed that pulmonary rehabilitation would be cancelled if it was raining. Most of the participants had long journeys to make, which included walking to bus stops. Getting wet and cold was not an option for people with COPD in this group.

SMOKING CESSATION

Smoking Cessation in Uruguay

Another important pillar of COPD care is smoking cessation. Whereas rehabilitation programs were scarce in Uruguay, smoking cessation services had become part of basic healthcare for about 67% of the population, although access was still a problem for those living in small villages and remote areas (Proyecto ITC, 2012). This was the result of the Ministry of Public Health making smoking cessation a priority area in Uruguay's healthcare reform. In 2009 two national guidelines were released on the topic of smoking cessation. One was *El Guia Nacional para el Abordaje del Tabaquismo* (The National Guide for Approaching Tobacco-Use) (Muñoz *et al.*, 2009). The second guideline was designed specifically for primary care (Muñoz *et al.*, 2009). Both outline the responsibility of every healthcare professional to ask about smoking, to advise patients and help those who want to quit. This included asking a patient each time they are seen whether they are smoking, advising them that it would be a good idea to quit, and then referring them on to a more specialised service if appropriate.

In Uruguay, like everywhere, most people who quit smoking quit by themselves, or at least without medical intervention (Chapman & MacKenzie, 2010). Within the groups I attended there were many smokers present who expressed that without support they could

not quit or, that after so many quits and restarts, they need something more to help them sustain a smoke-free life. Also, there are those smokers who find it difficult to quit because they are under significant time-pressure to do so. For example, having to quit for an upcoming surgery or because they were recovering from and still at high risk of strokes and heart attacks. Smokers who find it very difficult to quit, or are at a critical stage for quitting are those for whom specialised services for smoking cessation, called *Unidad Especializada en Tabaquismo* (Specialty Unit for Tobacco-Addiction), were designed for. These units were made up of professionals who had been trained in providing specialised smoking cessation support to people finding it difficult to quit and, in theory at least, any person belonging to one of the following groups: pregnant and lactating women, kids and adolescents, hospitalised patients, pre-operative patients, users of mental health services, patients with other addictions and patients who have started smoking again after having quit (Muñoz *et al.*, 2009). In practice, at the time of fieldwork, the requirement that each institution have a specialised unit was not fully being met. For instance, in my interior field site, the public hospital did not have its own smoking cessation service. Rather, the private hospital's was open to both public and private users.

The typical way of delivering smoking cessation support was in a group format. However, it was widely agreed that ideally a one-on-one service should also be made available for individuals for whom a group setting was not considered appropriate. This might be because the individual did not like the idea of a group or because their other addictions, co-morbidities or, simply, personality might derail group dynamics. The typical format was for a group to meet once a week. The groups were led by one to three people; one always was a physician, because they are the only ones with power to prescribe the medications available for smoking cessation. The number of participants in the groups I followed ranged from three to 12 and in the case of the church, closer to 25.

The approach to quitting in Uruguay is more flexible than in the UK. While in the UK most smoking cessation programs run for a pre-determined number of weeks and a quit date is determined in the curriculum (Smokefree, 2012), in Uruguay the norm was for individuals to reduce the amount they smoke gradually, at their own rate, and eventually establish their own quit date (Esteves *et al.*, 2011). If the group was a 'closed-group', *i.e.* it was a group composed of a set number of individuals for a pre-determined number of weeks, participants would be encouraged to try and quit within the program because quitting with the support of the group

might be helpful to them. However, there was a sense that being too authoritarian or deterministic and drastic with quit-dates was un-Uruguayan. One physician even told the participants in her group that while some places used nicotine patches, not only were they not available in private mutual institutions and public health pharmacies, but that they involved an approach to quitting which was un-Uruguayan. In her words:

“The nicotine patches are a really good product but they are expensive and so the private mutual institutions can’t provide them. Also, from the moment you wear the patch you have to stop smoking. Us Uruguayans, we aren’t so rigid. We do things in a more Creole [*Criollo*] way, more River Plate style [*Rio-Plantense*]. In other countries and cultures they use the patches. Here we have nicotine gum.”

Thus the approach to smoking cessation in Uruguay was wrapped-up in a kind of cultural identity, which favoured gentler more gradual forms of behaviour change. This fits with the *todo tranquilo* (everything easy-going) mentality of not being too rushed and the general dislike of authoritarianism, which permeates this post-dictatorial society (Chapter 4). Also, experts in Uruguay argue that setting a quit date causes a lot of anguish in smokers who are highly dependent on nicotine, which makes it difficult for them to stay in the program (Esteves *et al.*, 2011). Those who stay in the program are more likely to quit and remain smoke-free for up to a year (Esteves *et al.*, 2011). The use of nicotine gum allowed participants to carry on smoking as they gradually cut down and replaced the cigarettes with a piece of nicotine gum. The other medication commonly used was bupropion, an anti-depressant which helps improve smoking quit rates independent of its anti-depressive properties (Britton, 2011). The effect of the medication is delayed and normally it is not taken for longer than a few months. Both drugs are aimed at reducing the likelihood of unpleasant nicotine withdrawal symptoms, so that the user is more likely to tolerate smoking less and sustain a quit attempt.

The professionals providing the service normally had at least one of two possible qualifications in tobacco-cessation. The qualification came from participating in a multi-week professional and interdisciplinary training program provided by either the Honorary Commission for the Fight against Cancer (CHLCC) or the National Fund for Resources (FNR). The FNR is a national para-governmental organisation that subsidises highly specialised medical services. 657 health professionals have been trained in the FNR program, ranging from medics to psychologists, nurses, social workers and orthodontists. After completing the course, health

professionals either went on to simply incorporate their expertise into their clinical work, or worked in or set up their institution's specialised tobacco units. Those who taught and developed the training programs were the pioneers in tobacco-cessation (physicians, social workers, psychologists) and had close to three decades of self-acquired expertise. The cost of nicotine gum is very high in Latin America, which can be a barrier to access (Muller & Wehbe, 2008), just as the high price demanded by pharmaceutical companies for COPD medications is a barrier as seen in Chapter 7. However, Uruguay is among a select few countries that provides free nicotine gum and bupropion to over 130 services that meet the criteria of the FNR (Esteves *et al.*, 2011).

The Smoking Cessation Groups

Groups were normally held in a private room with chairs set out in a circle with one or three health professionals present. The sessions I witnessed normally began with participants being asked in turn to tell the group how they were doing with cutting down on how much they had been smoking since the last session. The person speaking almost always directed themselves to the health professionals, however, in the example I am about to give, the format was that of an open-group, meaning people could join the group at any time and this program ran continuously once a week by either a psychologist and a doctor or a doctor and a nurse. Normally the physician would lead the group while the psychologist took notes and filled out the standardised forms required by the FNR. Occasionally the psychologist would intervene or would be asked for her perspective. I asked the psychologist about the role she plays during one of the focus groups and she responded that she saw her role as supportive to the physician. In other groups psychologists did not see their role as supportive but rather took a more leadership role or at least shared equal responsibility for the conduct of the sessions. The following is an example of a dialogue between a participant and the health professionals taken from my fieldnotes. In this case, the participant was someone who had been going to the group and who had quit smoking but who had recently started again. He was a man in his thirties who, until his turn, had sat quietly, looking pensive and uncertain with his arm hooked through his motorcycle helmet.

Psychologist: "It's been a month since you last came."

Doctor: "What's happened?"

Man: "I have a karate class."

Doctor: "Are you smoking?"

Man: "Yes, I smoke, yes."

Psychologist: "You were smoking three a day?"

Doctor: "So have you loosened the reins a bit?"

Man: "Yes, my mother smokes in the house and the last time I came here there was no nicotine gum. I was told at the pharmacy that they didn't have any and they weren't sure when they would get some."

Doctor: "And your own willpower, your mind? We've always said the gum is just a tool. We also have other tools we can use."

Man: "When I didn't have the gum everything got on my nerves. I don't know if that was the withdrawal?" [his question was left unanswered]

Doctor: "Okay, you used to smoke a pack a day, then three, then zero and now 11. How do you feel?"

Man: "I feel unwell. I get short of breath (*me agito*). I feel a lack of oxygen (*me falta el oxigeno*) when I do exercise."

Doctor: "So you feel your lung capacity decreasing?"

Man: "Yes."

Doctor: "The important thing is that you've come back. Don't think of the cigarette in terms of something you are losing. You are gaining, in health and in wellbeing."

Man: "And in my wallet. I deny myself other things so I can buy cigarettes, it's crazy!"

Doctor: "Yes, the economic part is very important. We need to bring awareness to the action. It's not that you can't. You've quit before. You were not smoking. And yes, it might be that you are nervous. What strategies can you implement to cut-down how much you're smoking again?"

The difficulty with providing an example of a smoking cessation group is that they are so heterogeneous. Some were almost exclusively sequential and consecutive dialogues between the health professionals and participants; others included more spontaneous dialogue among participants. Much depended on the style of the health professionals running the group and the time available. Furthermore, participants were more likely to exchange ideas and stories

once they knew each other, making this more common in groups that were fixed over an intervention period, versus an open-group style, where new people can join a continuously running group. However, even in the open-groups, participants came to know and trust each other over time. In some open-groups, some participants had been attending for six months or more.

What rehabilitation and smoking cessation have in common is that they are made up of people with a shared goal (improve their experience of living with COPD and quit or at least reduce their smoking) and who look to health professionals for help in doing so. They are two relational and very social forms of COPD care. While drugs might be administered, such as inhalers, oxygen, nicotine gum, or anti-depressants, the 'care' being administered was dialogical, inter-subjective and largely experiential. It was also, for the majority who had no known tobacco-related diseases, care that was preventative.

INTERSUBJECTIVE SENSORIAL WORK

In keeping with a medical anthropology of sensations and experience of chronic illness I have selected two themes around which to organise the rest of this chapter. The underlining framework explored through ethnographic examples is the notion that sensations are experienced and interpreted socially in these spaces. The first theme is about the way the spaces were used to exchange stories and interpretations, particularly in the 'in-between' spaces of waiting rooms and 'in-between' moments when health professionals leave the room. The second theme is about the ways in which sensations of breathing were intersubjectively negotiated, interpreted and given meaning. In pulmonary rehabilitation participants were guided through a program aimed at getting them to understand, sense, and interpret their breathing in new ways, with the hope of improving breathing. In smoking cessation, a recurring theme was the experience of changes in breathing as a result of reducing the number of cigarettes consumed per day. Descriptions of these changes and new sensations were shared with the group and responded to by health professionals.

Sharing, Scaring and Comparing: Patient Interactions

One of the theoretical underpinnings of therapeutic group work of any kind in healthcare is that group members provide each other with mutual sharing and support. However, Jackson (1998) warns that intersubjectivity – as part of what occurs in groups - should not be

misconstrued as synonymous to shared empathic experience. Rather, he contends that intersubjectivity has two complementary poles. One is compassion and affirms shared identity and the other is conflict and confirms difference. As participant-observers, anthropologists are well suited to observing and recording the ways in which group dynamics are played out across this spectrum. However, it is important to recognise that participant-observers, as part of the intersubjective spaces, are equally subject to the cooperation, openness and tutelage of participants, as they are to possible uncooperativeness, deception or concealment (Prus, 1996).

Anthropologists are, however, in a different category to health professionals as we traverse the boundaries between the therapeutic spaces of consultation rooms and the in-between spaces of waiting rooms and hallways. In these latter spaces, we can build rapport with patients outside a healthcare professional – patient dynamic. In pulmonary rehabilitation, a lot of group interaction occurred in the hallways awaiting rehabilitation or when the doctor would step out of the room momentarily. The same was true for smoking cessation, except that health professionals tended to be there the entire duration of the session and so most of the informal, peer interaction occurred in the corridors. Health professionals are aware of some but not all of the interactions that occur within a group, which adds value to this kind of research. It is the intersubjectivity of these health professional-free spaces that I want to discuss in this section. In both contexts what stood out were examples of tense interactions alongside supportive ones. While patients were there for one another to offer words of encouragement, there was equally a sense of competing over who was ‘worse-off’ and, therefore, who had ‘to work harder’, either to quit or to carry out an exercise program.

In the following fieldnote, I was seated with my participants in pulmonary rehabilitation and, as always, I was doing the exercises alongside them.

The doctor went to look for the social worker and told us to continue with arm and leg exercises. Very quickly, they just began discussing amongst themselves. They began by comparing lung function parameters, how many blocks each could walk with, or without oxygen before getting out of breath; how much oxygen saturation they have; and what they feel like when they feel *atacado* (attacked). Mateo, who is awaiting the transplant comported himself as the expert, sharing lots of information authoritatively. He had a bit of a macho way of conducting himself and walked around and did things as though he owned the place. He told everyone “I only have 15% of my lung capacity, in both, that’s it.” This raised the question from another participant, “How much oxygen do you have in your blood?” and spurred a dynamic conversation filled with such declarations as, “I was only 74%”, “Without anything [oxygen] I can be 80%” and, “When I was really

bad I had 70%, and that's really bad." There was obviously some mystery about why some of them were oxygen-dependent and others were not. For instance, Mateo is awaiting a transplant, has only 15% of his lungs working, yet is not oxygen-dependent. Sebastián does not know what his capacity is but is on oxygen 16 hours a day. Lucía is on oxygen at home. Macarena is not on oxygen and is worried about having to be. They also asked each other how far they can walk. "How many blocks can you walk before you have to stop?" This question had to be answered by Sebastián in terms of both with and without oxygen. Mateo said you just have to learn to walk more slowly and stop and catch your breath. He says he always leaves the house with lots of time.

Lucía asked Mateo what it felt like to go into respiratory crisis. He described how the health professionals had to push on his rib cage to help get the air out and then described how in their disease the problem is getting the air out of the lungs. He described his traumatic hospital experience in very matter-of-fact terms, which left Lucía with a look of horror on her face. "How horrible", she said. Sebastián was told that his only option is pulmonary rehabilitation or a transplant and that he's had to increase his oxygen level from three to four because he feels out of breath. Mateo asked him lots of questions about his oxygen use and said that he thinks his oxygen level is too high. Mateo explained that he has emphysema because of smoking and his work. He said he lives in a place where there is a lot of humidity and he doesn't like going out at humid times of the day. Then the doctor came back in and asked if they had done the leg exercises. Everybody answered, "No, we were chatting." She asked what we had been chatting about and we all laughed and said, "Everything." She sat down and carried on with the exercises and explanations.

In smoking cessation, smokers compared each other on the basis of how much they smoked. I arrived at one session about 10 minutes before the start and sat down in the waiting room. I made the following field note about the waiting-room conversation. Two people were also waiting and within no time one woman asked an older gentleman if he was there to quit smoking.

They began to chat and compare smoking histories. The man said he was hospitalised and had COPD and so had to quit. The woman asked him what it was. He explained that it was a lung disease. She asked what caused it and he said the cigarette smoke. He said he has to quit because if he continues, it will get worse. The woman mentioned that she is soon going to be a grandmother and that luckily, she doesn't have anything like him yet. She said she had an X-ray done and they didn't find anything, "They said my lungs were dirty, and of course they are, but there is nothing wrong." The man mentioned nicotine and tar as toxic substances in cigarettes. One of them mentioned price and the woman said she smokes the national brands [more expensive]. The man said he did too and that contraband cigarettes [less expensive] were made of bad tobacco. The woman commented that she cut down to 10 cigarettes a day but one day she had a problem and let herself smoke more. She said, "The decision to smoke occurs in a three second window," and that, "We look for a way to smoke." The man

responded, “I’m old, I’ve smoked for many years.” She asked him how old he was. He said he was 61. She told him she started smoking at 11, but back then she didn’t smoke two packs a day like she does now. “If I could reduce to 10 cigarettes I’d be happy because from there it will be easy.” Another elderly man who had recently arrived at the waiting room spoke up in exclamation saying, “10! Easy?” She quickly responded, “Yeah, but I’m smoking 40 now.” He expressed his surprise. He was smoking eight a day but clearly didn’t find the idea of quitting those eight very easy. She explained that if she reduced to 10 that would be a good start. The elderly gentlemen commented, “So many people die of heart attacks and have never smoked, and so many people smoke and never get anything.” The woman said, “Tabaré [the previous president who implemented many of the smoking laws] wasn’t a gynaecologist! [a sarcastic joke in reference to the fact that if he had been a gynaecologist, and not an oncologist, smoking might not have become the public health priority it is today]. She continued, “I eat healthy, no fat, no fried foods, no flour because I don’t like it, just natural. Maybe I won’t quit entirely, maybe I’ll only smoke five a day.” Then the physician leading the group arrived and we all entered the room for the start of the cessation group.

In both excerpts participants are, in the in-between spaces of waiting rooms and healthcare professional-free space, comparing themselves. There are examples of how patients can mutually support each other with advice and information. For instance, Mateo is concerned about Sebastián’s use of oxygen. He thinks it is too high and, indeed if oxygen is too high it can lead to serious adverse health effects, such as hypoventilation and acidosis (too much acid in body fluids) (Douglas & Currie, 2011). Sebastián did not turn it down but at least he may be aware that there is such a thing as too much oxygen. In the smoking cessation group, by chatting and sharing, the woman finds out what COPD is. The fact that the man attributes his COPD to smoking and she considers herself lucky to not yet have any such problems may support her in her quit attempt, even though she is considering not quitting completely. They are also able to share their reservations about the risks of smoking by, for instance, affirming that they are smoking ‘better’ tobacco and that the speciality of the former president was a driving-force for focusing on smoking as opposed to other causes of ill-health. These expressions of common sentiments, which I heard repeated in many everyday contexts, were rarely expressed in the groups in the presence of health professionals.

What I find more intriguing, however, are the examples of when the group went from being supportive and encouraging to tense because sharing becomes scaring, or comparing turns to disagreements. In the above excerpts this occurred with Mateo sharing his experience of crisis and when the man practically jumped out of his seat on hearing the woman claim quitting from ten cigarettes would be easy. These comparisons sometimes became

confrontational when there was disagreement about “how tough it would be to quit” and “how bad your COPD is next to mine.” A similar example in another smoking cessation group came from a woman who smoked multiple packs a day. In response to another participant’s declaration that she smokes eight cigarettes a day, she interrupted and said: “Eight! If I was smoking that little I wouldn’t be here, I’m smoking 40!” If health professionals were present during these exchanges, which they sometime were, they would intervene with something like, “It is often the last few which are the most difficult to quit because they are the most addictive and engrained,” or, “Every person’s dependence on cigarettes is different.” Some groups included people who smoked as little as four or five cigarettes on a daily basis or even regularly went days without smoking. The other group members’ feelings towards these individuals were frequently ambiguous. There was a feeling that ‘those smokers’ should not be in the group. When, over the weeks, some people cut back more than others, this also caused some rupture. In one group, the men were cutting down more quickly and the women were having more difficulty. One woman commented a number of times:

“Well, compared to these guys I didn’t do too well this week. Men must have a different chip in their brains.”

The men seemed as though they were competing with each other week by week. However, this gender division was not noticed in other groups. The point being made is a more general one, and that is that the group dynamics can motivate and support smoking cessation but if differences arise in amounts smoked or amounts cut down, then divisions and tensions may arise.

Similarly, in rehabilitation, one patient, Macarena, joined rehabilitation because she felt very affected by her COPD and wanted “...to learn anything I can so as to have the best quality of life possible.” However, a health professional told me her case was an example of when the interpretation of the patient and the health professional differed. She felt disabled by the disease but the biomedical measurements of her disability (using a standardised breathlessness questionnaire) did not suggest she ‘needed’ rehabilitation. As seen in Chapter 6 Macarena has frequent exacerbations of her COPD. However, she was the only person in the group who was not oxygen-dependent and, from my observations, she was able to do far more exercise at far higher intensities than anyone else in the group. I observed how her ability alienated other participants who clearly felt at times that she was too healthy to be there.

Although this was never verbalised explicitly to me, when Macarena would really put a lot of effort into the cycling there were indirect comments made to me like, “She’s crazy.” The tension was sometimes palpable and on at least one occasion culminated in a passive aggressive interchange between her and Sebastián. Sebastián was not only younger than Macarena but also had worse spirometry readings and was oxygen-dependent. One day, Macarena was speaking of how horrible it was to be breathless and her experience with a cold recently. Sebastián snapped at her, “Listen, a cold doesn’t do anything to you.” Again, if a health professional were present they might explain that although Macarena does not have as bad a spirometry reading, she demonstrates an exacerbatory phenotype, *i.e.* someone with COPD who experiences frequent worsening of symptoms. Later, Macarena had her comeback when Sebastián became too breathless on the bike to converse anymore and so she said to him, “The biking is good, when you’re breathless you can’t talk anymore.”

In this case, the social and subjective nature of disability for people with COPD reported elsewhere (Williams & Bury, 1989) might not only be overlooked by physicians but also by patients themselves. Similarly, the subjective nature of tobacco addiction can also be missed by smokers themselves, who put everything down to how many cigarettes somebody smokes a day. These tense interchanges in addition to the scaring and comparing did not make up the majority of interchanges but they were frequent enough to warrant consideration. In these cases, sharing experience and sensation with peers did not always lead to supportive environments that boosted confidence; instead they could produce the opposite. Nevertheless, it is a kind of sensorial work they engaged in and it allowed these participants the rare opportunity of interacting with people who have the same disease and to exchange information.

Making Sense of Sensations: Patient-Health Professional Interactions

‘Techniques of Breathing’: Re-Scripting Embodied Memories of Breathlessness

As seen in Chapter 5, breathing and the breath has not been a topic taken up widely by anthropologists. However, the work which has been done on the experience of breathing demonstrates how it is given different cultural and symbolic meaning in different therapeutic or spiritual contexts (Edwards, 2006, 2008; Ekerholt & Bergland, 2008; Mehling *et al.*, 2011; Mehling, 2001; Morley, 2001). For Csordas (1994b), “Bodily processes like breathing (not as a technique, but, for example, as the sigh), blushing, menstruation, birth, sex, crying, and

laughing are of interest in their cultural variation" (p. 5). I would argue that breathing can indeed be made up of techniques which will vary cross-culturally and contextually. In the case of pulmonary rehabilitation, in the face of a taken for granted bodily process which is disrupted, breathing becomes a series of techniques (Table 8.1). Exercises for strengthening muscles are taught alongside the appropriate techniques of breathing. Techniques of breathing, to emulate Mauss' (1992) 'techniques of the body' are shaped by the social and cultural circumstances and are taught, learned and implemented (or not) in social contexts, which will vary. People with COPD need to learn to use and move their bodies differently so as to get the most out of their breath. They also need to get used to feeling breathless and know what kinds of breathlessness are out of their control and require emergency care and which forms of breathlessness are controllable, given that the proper techniques of breathing are learned.

Dr. S attempted to guide her patients to reinterpret and give new meaning to their sensations of breathlessness:

"The thing with your disease is that you are not going to die from being short of breath when you do physical activity, you need to know that all you need to do is: stop, relax, breathe. It can be difficult to do certain kinds of work with this disease but work is possible. The breathlessness you feel when you do exercise can be controlled by doing various activities and by breathing deeply and calmly [Table 8.1 Relaxed, Slower, Deeper Breathing]. However, if the breathlessness comes on when you are not being physically active, consulting a physician is best."

On one occasion Dr. S invited Ana, who had completed the rehabilitation program the year before, to speak to the group about her experience of rehabilitation. For Mauss (1992), such people help others to imitate techniques of the body because their successful performance of the techniques gives them authority and helps others have confidence in them. While the doctor was out of the room, she spoke to the group:

"I did the course last year and I quit smoking three years ago. Rehabilitation gave me a better quality of life. I learnt that everything takes its time. I can do twice as much as I used to be able to do, but things happen at their own pace. I can do the same as before but it takes me more time."

Dr. S not only wanted her patients to learn not to fear breathlessness but to experience their breathing in different ways. As discussed in Chapter 5, awareness of breathing and, equally, research on breathing emerges in situations where breathing is disrupted through illness or physical exertion, or when breathing rhythms are harnessed for the purpose of meditation and relaxation. Dr. S tried to help her patients experience breathing in this alternative way. One day I was in rehabilitation with two participants, Macarena and Martín (Chapter 6 p. 157) and while Dr. S was out of the room, I found a ball in the cupboard and we naughtily began passing it to each other like a volleyball. Very quickly they both got quite breathless and I felt guilty that I had caused them to be short of breath. However, the mood was nothing other than childlike fun and joy. We got rid of the ball before Dr. S came back in and within minutes she had Macarena and Martín lying down on their sides on mats on the ground and was guiding them through some breathing exercises and relaxation. She said:

“Relaxation is central for people with COPD. It is a disease which causes a lot of anxiety.”

She had them place a hand on their abdomen to feel it rise and fall with each breath as she guided them through the relaxation of each part of their bodies (Table 8.1: “Relaxed, slower, deeper breathing”). They laid on their sides because lying on one’s back increases the sensation of breathlessness (Table 8.1: “Positioning”). At the end, she asked them to open their eyes, but they had both fallen asleep.

From my observations what I saw Dr. S doing was trying to re-script a sensation (Hinton *et al.*, 2008, p.153) to help her patients experience the sensation of breathing in a controlled way, to increase their confidence and self-efficacy and positive engagement. In this interaction, breathlessness was re-scripted as relaxing and therapeutic. In rehabilitation breathing goes from being an automatism to a practice. Through guided and supervised awareness of bodily sensations of breathing, breathing as breathlessness is transformed from a sensation of fear and anxiety to a sensation under one’s control. Just as Lande (2007) in his fieldwork in a military training program, relearned to breathe in ways acceptable to a military habitus, so people with COPD, in rehabilitation, learn to incorporate different kinds of breathing to cope with breathlessness. Like the soldiers Lande (2007) embodied in his ethnographic study, participants in rehabilitation learn these experientially and intersubjectively. Crossley’s (2004, 2005) notion of Reflexive Body Techniques and particularly

his analysis of circuit training is useful here. He argues that phenomenological accounts often miss out on the sociality of body maintenance and argues that it is a form of symbolic interaction (Prus, 1996). In pulmonary rehabilitation, while there is a degree of body modification going on (*i.e.* strengthening and building muscle mass in the arms and legs), it is the experience of the sensation that is also the object of change.

Crossley's (2004) circuit trainers are confronting pain and extreme exertion but they are not confronting embodied memories of breathlessness (Chapter 6). Circuit training and rehabilitation are similar in that both are enacted within a controlled environment in the presence of an authority figure (instructor or doctor). However, for people whose COPD has become symptomatic enough to warrant a rehabilitation program, incorporating techniques of breathing is not uniquely a question of being physically and psychologically willing, they need to come to see their breathing as something that they can control. This control is seen by professionals as the key to managing acute exacerbations as well as the daily problems of breathing caused by exertion. However, achieving this means re-making one's sensorial experience of the body and working against embodied memories of breathlessness. Dr. S attempted this by providing a context of sociality where breathlessness could be experienced positively. People were breathless on the bicycles but they were also enjoying themselves and conversing with one another. Although medicine would not describe it in such terms, attempts are being made to re-script the memories of breathlessness laid down in the body and replace them in part with new memories of control, awareness, and enjoyment.

Breathing Sensations Before and After Quitting Smoking

Although breathing was not an explicit topic of smoking cessation, sensations of breathing were frequently described and interpreted socially in the group, particularly between the patient and the healthcare professional. Many became aware of changes in their breathing and sometimes it was unclear to them whether these changes were good or bad. One smoker, who had cut down from 40 to three cigarettes a day and was planning to try a day without smoking, had the following interchange with a doctor:

Participant: "My body is eliminating the nicotine. I have a lot of cough and expectoration."

Doctor: "That happens to all smokers, you will also notice changes in smells and tastes. Your lungs were deadened; they didn't have the sensitivity to react against the

cigarette smoke. When you quit, the lungs recuperate. That is a good sign. You will get better.”

Similarly, in a different group, a woman who had quit smoking had the following interchange with the doctor and psychologist:

Participant: “I have a lot of phlegm.”

Doctor: “Everything is loosening up. You seem to have a cold.”

Patient: “No, I’m congested, I have yellow phlegm and it comes out when I cough.”

Doctor: “That is all part of the process. For the moment, we won’t start antibiotics.”

Psychologist: “It’s cleansing.”

Similarly, a smoker asked in another group, “Is it true that you can start coughing after you quit smoking?” to which the physician responded:

“Yes, yes, it is a sign that your lungs are cleaning themselves and eliminating the effect of the cigarettes. You need to get it out. It’s important to drink a lot of liquid.”

The last two quotes make reference to notions of purification and toxicity. The health professionals put a positive spin on the symptoms, which might otherwise be distressing to smokers quitting. The symbolism of purification was a common theme across services. I heard professionals use metaphors such as “gas chambers” in reference to smoky bedrooms. I heard them advise patients to drink lots of water and not be surprised if their urine smelled of tobacco. In the words of one psychologist speaking to a smoker trying to quit: “Cleansing the body of nicotine is like washing penguins after an oil spill, the animal is cleaned feather by feather.”

Health professionals, in this context, are interacting with patients in ways which resonate with other forms of symbolic healing. They are encouraging patients to engage with the changes in their bodies with all their senses and to ascribe them positive meaning. Smell that your pee is full of the expelled toxins, see and smell the toxins in your home and release them as you release them from the body, and listen to and feel your body cough out all the loosened-up toxins. The discourse on purification was most explicit in the Seventh Day Adventist smoking cessation course, where detoxification was one of three main principles of the five-day program. The other two principles were affirming one's choice and exercise. Even exercise was seen as a way to help eliminate toxins through sweating. Interestingly, the

Adventist smoking cessation group included talks from the pastor, a medical doctor, a psychologist and a personal trainer. On the first night, the doctor said the following:

“You should drink a lot of water. The more, the better, but at least eight glasses a day. Water eliminates nicotine from the body. The more you drink the more quickly you eliminate the nicotine. It is good for circulation and elimination. Water therapy is also helpful, you should take a shower or a bath two or three times a day if possible in which you alternate between hot and cool water, as well as use an exfoliation accessory on the skin to stimulate circulation.”

The pastor on the third day of the course said, “The key is to eat well and drink lots of water, to walk and to do breathing exercises.” Convincing their patients that this elimination of toxins from their bodies, in the words of Douglas (2002), is “...a positive effort to organize the environment...” (p. 2) of their bodies, is also a way of trying to keep people in the program. Over the course of fieldwork, I heard a number of times smokers express their fears of stopping smoking because of a belief that their bodies may have become used to smoking and stopping could cause more harm than good. A discourse of detoxification was aimed towards re-scripting the unnerving symptoms of cough, congestion and changes in breathing as purifying and healthy changes, not threatening. In this case, we can “...see in the body a symbol of society” (Douglas, 2002, p. 116); a society in the process of eliminating tobacco smoke from public spaces as well as the spaces of individual bodies.

Sometimes smokers reported other kinds breathing sensations, which posed a problem for health professionals. On a couple of occasions in group cessation, smokers reported becoming breathless since quitting or while cutting down. In one case, the comment was ignored, in the other the doctor responded:

“No, it’s the opposite, your breathing should be better. The breathlessness you feel isn’t because you’re quitting smoking. It might be a withdrawal symptom.”

Otherwise, smokers sometimes reported that their breathing improved after quitting. In these cases, breathing better accompanied feeling fit, and less physically tired in everyday activities. The following quote comes from a woman who was asked to tell the group what was positive about having quit smoking:

“I like that that my fingers don’t smell of tobacco and that I don’t get as easily tired when walking. I also always seemed to have a kind bronchitis in the morning and have noises in my chest. I can’t believe that now I don’t have those noises.”

Another woman, trying to quit her last four cigarettes a day, reflected back on her breathing and said:

“I was something else. I used to smoke while I showered! I smoked almost two packs a day. At night I couldn’t breathe.”

These kinds of descriptions were welcomed by health professionals in the groups because they affirmed the medical perspective that breathing should improve when one has quit smoking. Again, in these social spaces sensations are shared and socially interpreted. Health professionals try to offer reinterpretations of the meaning of certain sensations, such as coughing or breathlessness, which are distressing, in order to keep patients’ confidence in the treatment. It was not possible for me to assess to what degree patients were convinced by the explanations of the physicians but this could be an interesting topic of investigation.

CONCLUSION

Pulmonary rehabilitation and smoking cessation are two fundamental pillars of COPD care. However, very few people with COPD in Uruguay have access to pulmonary rehabilitation, whether they are in the public or private system. Some healthcare professionals stated that cost was the barrier to providing a pulmonary rehabilitation program. Apart from having the necessary tests to evaluate patients and their needs and contra-indications for certain types of exercise, what the service presented here demonstrates is that water bottles, broomsticks, bags of rice and old bicycles are not luxurious, nor expensive, but they work. With more resources, one could have swimming pool rehabilitation or better stationary bicycles but in the end, it is the group and the bond between patients and the health professional that creates the space for the sensory work and re-scripting of embodied memories of breathlessness, which makes engagement in physical exercise possible. Although smoking cessation services are far more widespread, they are still not in every service and, as will be discussed in the next section, are not particularly tailored to or targeted towards people who have COPD. However, my observations do suggest that breathing is an important sensation for smokers before they

quit, while they quit and after they quit and support is sought for interpreting changes in breathing.

I have shown that, just as Dr. S tries to re-script breathlessness, smoking cessation professionals try to re-script and co-script changes in breathing such as coughs, congestion, and shortness of breath within a discourse of purification and detoxification. This chapter has also shown how these spaces provide participants with the opportunity to interact and share experiences and learn from each other's sensations. These sensations are experienced individually as participants engage in exercise or arrive at the course craving nicotine, struggling not to smoke and feeling changes occurring in their bodies. The intersubjectivity does not necessarily equate with empathy in all circumstances (Jackson, 1998) and sharing and comparing sensations can lead to disagreements, competitiveness and struggles over whose sensorial experience has authority over someone else's. However, this does not speak against the therapeutic benefits of these social spaces. It is the intersubjective aspect of healthcare that I argue will need developing in order to achieve the many public health goals envisaged for COPD, something I turn to in the subsequent and final chapter.

Taking Breath: A Fresh Perspective on COPD Care and Prevention

INTRODUCTION

In this final data chapter, I want to explore how a multi-modal sensorial ethnography of COPD in Uruguay, such as this, can contribute to current debates and thinking in public health. As mentioned throughout this thesis, COPD was only beginning to enter popular and media discourse in Uruguay at the time of my fieldwork. Headlines, such as “*COPD deaths increased by 153%*” (Herrera, 2009) and “*COPD: The fight to revert rates of diagnosis*” (Espectador, 2010), appeared in Uruguayan newspapers and on news websites. Chronic disease, in general, was within the context of the healthcare reform, beginning to be focused on in a specific way. Indications of this include the implementation of special programs for diabetes and hypertension and the implementation of *Carné de Salud de Adulto Mayor* (Older Adult Health Registry), a booklet the patient keeps which is used to list health conditions and medications and screen for chronic diseases. Although COPD was not an explicit priority of the healthcare reform, preventing all smoking-related diseases was. Indeed tobacco-control policies are a primary indication of the preventive turn in Uruguayan healthcare. Prevention is no easy task for a healthcare system that is diverse, fragmented and has only recently had such a thing as family medicine offered as a specialty in the Faculty of Medicine of the University of the Republic.

Biomedical researchers in Uruguay and Latin America are attempting to raise awareness of COPD which, despite its high prevalence, remains poorly diagnosed and treated in many healthcare settings (PLATINO, 2012), particularly outside the capital and in public institutions, to which this thesis attests. The healthcare reform is aimed towards closing the gap between private and public healthcare (*Ministerio de Salud Publica*, 2010). This ethnography indicates that, at least in terms of COPD diagnosis and care, the divide not only between private and public but also between interior and capital remains wide. This chapter remains sensitive to the fact that there are a number of important health issues in need of time and resources in any country, let alone Uruguay, and every country makes investments in

some issues as opposed to others, sometimes justifiably and sometimes less so. However, on the basis of COPD's prevalence, the investment the government has made in smoking cessation since 2005, and the continued aim of the *Frente Amplio* government to reduce inequalities in health, this thesis advocates for a fresh look at the challenges and opportunities Uruguay faces in confronting COPD.

The chapter is structured around consideration of three public health goals regarding COPD, which can be extrapolated from national and international clinical guidelines and WHO materials. These suggested health goals are 1) to diagnose COPD, especially diagnose it in its earlier stages, when it has not yet reached a level of severity which is disabling to the person, 2) to prevent already diagnosed COPD from getting worse, and 3) to prevent COPD altogether by raising awareness and implementing policy to reduce exposure to risk-factors. I do not reject these goals. Like other medical anthropologists, I am in this case "...committed to the public health project..." (Parker & Harper, 2006, p. 3). Nonetheless, I consider them critically in the light of the ethnographic findings and interpretations presented thus far and suggest ways in which the goals might be re-evaluated, re-articulated and re-applied, drawing on resources Uruguay already has available while encouraging investment in what it lacks.

Three recommendations are made for further exploration, debate, implementation and evaluation. One is that smoking cessation professionals be given the opportunity to be more involved in COPD screening for earlier diagnosis, the second that smoking cessation be framed more clearly as a 'treatment' for COPD and thirdly, that wider awareness campaigns focus on 'clean, pure air' as the driver for preventive action among individuals, including not taking up or quitting smoking, taking greater precautions in the workplace and considering environmental factors, such as wood smoke, more carefully. The focus on clean air also highlights the national and the local governments' roles in reducing risk-factors through regulating and monitoring policy.

DIAGNOSING COPD EARLIER

The Predicament of (Early) Diagnosis

COPD is under-diagnosed around the world, according to the literature and clinical guidelines (Bednarek *et al.*, 2008; Broekhuizen *et al.*, 2010; Lindberg *et al.*, 2006; Peña *et al.*, 2000; Shahab *et al.*, 2006; Takahashi *et al.*, 2003). In Uruguay, according to an epidemiological study,

of an estimated 250,000 people with COPD, only 5000 received a diagnosis (Menezes *et al.*, 2008). Why are so few Uruguayans diagnosed? At a basic level, there is a lack of awareness of COPD and spirometry is not widely available outside the capital, nor is it widely available in primary care settings across the country. If a person consults for cough, breathlessness and has a history of exposure to risk-factors but there is no spirometry or specialists to refer to, it is less likely that the person will be diagnosed with COPD. If, in those circumstances, they are diagnosed with COPD, it is more likely that the person will receive a false diagnosis of COPD, something which is also a problem in Uruguay (Menezes *et al.*, 2008). Despite not receiving a confirmed diagnosis, and, therefore, possibly a false one, the sufferer may nevertheless receive treatment in the form of an inhaler, corticosteroids or antibiotics but the identification of oneself as someone with COPD is unlikely. As we saw with Marcelo's story in Chapter 7, keeping the door closed on COPD diagnosis and treatment supports the likelihood of COPD becoming a terminal disease because it is only diagnosed when symptoms are intractable and hospitalisations frequent. Where the diagnostic equipment is not available, COPD at advanced stages becomes a category of exclusion or a negative diagnosis, *i.e.* when all other explanations are discounted, what may remain is a diagnosis of COPD.

However, the way in which the disease is experienced also plays a role in delaying seeking healthcare, outside of acute care episodes. Before it progresses to that stage, it might simply be thought of by the patient as asthma or bronchitis, or a normal part of life for a smoker or for a person getting older. In the words of one participant:

"I had a cough, like normal, like any other cough. I am a smoker. As a smoker you always know that at some point in time you're going to cough, you're going to suffocate at some point."

Not only may smokers expect to cough, but there is a readily available, socially acceptable and common explanation: asthma. As discussed in Chapter 5 and seen throughout excerpts in other chapters, the existence of asthma as a household term also, to some degree, normalises respiratory symptoms. Asthma is no normal condition but the use of the term is used liberally in Uruguay, from my observations. Guidelines recommend that a COPD diagnosis should be considered in any person above the age of 35 who presents with symptoms of shortness of breath, chest tightness, wheeze, cough, and sputum production, especially during exertion, and has a history of risk-factor exposure, especially smoking (Currie & Chetty, 2011). But how

many people will actively seek out care for what seem like benign symptoms of shortness of breath upon exertion and a bit of cough and phlegm? Like the participant above notes, smokers expect to cough. Producers of international guidelines recognise this issue. GOLD (2012) states, on the patients' section of their website, that "Many people think common COPD symptoms like coughing and breathlessness are just a normal part of getting older, but this is not the case."

It is unfair, however, as Marcelo's case also demonstrates, to blame patients because they 'consult too late'. Many who were seeking care at their local clinics or in hospital emergency rooms for lung infections, particularly in the winter, were treated for them in emergency care but coordination with follow-up care or referral for a suspected case of COPD was either non-existent or problematic. From my observations, there are several reasons for such a lack of coordination. Firstly, COPD is not well known, even among health professionals *i.e.* a 40 year old smoker or ex-smoker who coughs, is getting progressively more breathless and who has frequent chest infections, is not necessarily setting into motion a screening process involving referral and adequate tests. Sometimes those tests and specialists simply are not available and, despite some health professionals advocating for better technology and human resources, directors and directing committees may not consider COPD worthy of investment, or not as worthy as other problems. This is clearly an area in need of further advocacy and awareness-raising. At other times, coordination between departments is inefficient or convoluted making referral a problem; something that has been studied in the case of COPD in Spain (Castro, 2008). It has been argued that an overall disregard for COPD, leading to its treatments being poor, despite it currently being the fourth highest cause of death in the world, is because it has been viewed as a self-afflicted disease (Barnes, 2007).

If there is nowhere to send the patient for diagnostics, whether it be for spirometry, a CT scan, blood gases or for specialist evaluation and follow-up, then the health professional may make do as best they can. This may involve prescribing medications to try and deal with symptoms and care for exacerbations with antibiotics, inpatient care and other interventions like oxygen and non-invasive ventilation, if and when acute episodes happen. While some people in my study saw their respirologist for regular check-ups, others received some form of specialist care only during acute episodes, leading to crisis-to-crisis care and not management. The opportunity for early (or even mid-stage) diagnosis is lost, as is adequate prevention of the condition worsening. The more hospitalisations a person has, the longer they are, the more

they are likely to lose physical strength, especially in the case of people like Marcelo, who do not have access or only very limited access to in-hospital physiotherapy. By sitting motionless in a bed for weeks losing muscle mass and strength, both their experience of breathlessness and prognosis are worsened (Evans, 2010).

Beyond the need for greater investment in spirometers and professional training, the expressions and metaphors used to describe symptoms (Chapter 6) could help health professionals' pick-up on the problems facing their patients who have breathing difficulties. It is difficult to say without a comparative study of asthma, but I hypothesise that when people use the terms on the right side of Figure 6.1, they are speaking of a kind of disruption to breathing that is more suggestive of COPD than of asthma. The importance of being aware of these terms and considering how the words patients use can reveal clues to what pathology lies within the body has been shown in other studies and reviews (Caroci & Lareau, 2004; Harrison, 2012; Scano *et al.*, 2005; Williams *et al.*, 2008). To explore some of the complexities surrounding the goal of early diagnosis, *i.e.* diagnosis in early stages when the person may be symptomatic but may not interpret those symptoms as indicative of 'illness', I turn to Valeria's story.

Valeria's Diagnosis: Exemplifying the Issues

I met Valeria in a smoking cessation group at a public hospital. She was a 53 year-old single mother of six and grandmother of a dozen. She lived with her two youngest children and was barely making ends meet sewing and doing other kinds of *changas* (odd jobs) like selling band-aids on the city-buses. The group was meeting for the first time, and so the doctor and psychologist asked each participant to introduce themselves and say why it was they wanted to quit smoking. When it came time for Valeria to share, the following interchange occurred:

Valeria: "I am smoking three to four packs a day and want to quit because I don't feel well. I get out of breath a lot. I suffer from asthma because of smoking."

Doctor [immediately jumping in]: "Let's just clarify one thing. You don't have asthma, you have COPD. It is similar because both cause breathlessness but asthma is reversible and COPD is not. Asthma occurs more for genetic reasons and normally as a child, COPD starts later in life and in more than 90% of cases it's because of smoking."

Valeria: "Nobody in my family has asthma. I have osteoporosis, back problems, I'm on very strong medications, I have renal problems and an asthma problem [she again

referred to her breathing problem as asthma]. I don't have willpower; I'm coming here because I need help."

Psychologist: "Cigarettes are a very strong enemy. We can give you the tools but you need to work at it too."

At the end of the session I asked Valeria if she would like to participate in my study and she agreed. My attendance at smoking cessation group was, as already mentioned, originally envisioned as a way of meeting people with COPD, even though, as it turned out, Valeria was the only participant with COPD I recruited to the study in this context. There were probably many like Valeria who had COPD without knowing it, but Valeria was the only one I saw being diagnosed and it was partly my questions and curiosities about her care, and my participant-observation within the group that drove her diagnosis implicitly. As she had been outwardly referred to as someone with COPD, I went to her file to find her spirometry results but discovered that she had not had spirometry and, therefore, the clinical diagnosis had not been confirmed. When I asked the smoking cessation team about this, they explained how they did not have a clear referral protocol to spirometry from smoking cessation. They were not sure whether they had to send the person to a respirologist first, which would take months to get an appointment, or whether they could send patients, who are not yet under the care of respirologists, for spirometry directly. They decided to send Valeria for spirometry and I continued to follow her journey through the healthcare system. We met a few times at the hospital while she waited for various appointments and she told me about her smoking and her desire to at least reduce how much she smokes.

Five months later I met Valeria in the waiting room while she awaited her spirometry test. I believe the long delay did not have to do only with waiting times but also with the fact that Valeria attended her appointments sporadically because of the unpredictable nature of her multiple co-morbidities and home life. I chatted with her until she was called-in to do the test. When she came out, she told me to check her results and if I could to let her know. I went into the office and had a look. The FVC and FEV1/FVC showed that she had COPD. One of the respirologists was in the office, so I went over and double checked with her and mentioned that Valeria was being seen in smoking cessation. The respirologist confirmed she had an FEV1/FVC of 66% in contrast to the predicted value of 84%. These readings showed no significant change after being given a bronchodilator and, therefore, the obstruction was

diagnosed as “moderately severe”. The respirologist wrote the report on the spot and told me to run it down to the tobacco-clinic. Normally, the patient would return to pick up the result 10 days later and would be told to make an appointment with their doctor. I asked what I should tell the smoking cessation team and she said tell them they can refer to respirology.

By the time I walked down the hall, Valeria was just being called in. I gave the doctor and psychologist a kiss on the cheek and sat down. The doctor said “Oh, you have the result.” Valeria asked me, “How is it?” I said, “It shows you have COPD and not asthma, but you are quitting smoking so that’s the most important thing.” She was a bit shocked. I felt uncomfortable about having delivered the diagnosis, as normally this was not part of my participant-observer role. The doctor read out the result, “Moderately severe obstruction,” and Valeria asked how bad that was. The doctor said, “This is the time to quit, if you don’t the next step is the oxygen tank.” The psychologist, speaking calmly and tenderly, said it was OK that she had increased how much she was smoking because of the death of her brother but now they would get back into it. The doctor said not to worry, that it would get better without smoking and that she should get the flu vaccine and needs to use her inhalers. Valeria said she’d stopped using her inhalers because she’d been feeling good. The doctor said, kind of under her breath, “Well, this isn’t my role as doctor in tobacco addiction, but...” and proceeded to say that she should take her inhaler twice a day, and wrote her a prescription. Valeria responded that that particular inhaler was hard to get and was expensive. The doctor told her she could go to the Centre for Pulmonary Attention (CAP) and with the prescription, they give out a free one and a spacer and will teach her to use them. Valeria looked at the address and said she knew where it was, it was right next to the hospital where her brother died. She waved the paper and looked at me and said she would pin it up on her wall. She mentioned the man who lives near her and uses oxygen. The doctor assured her it would not come to that in her case. They also gave her a referral to respirology. Valeria then got up and left and they agreed that she would come the following week on Wednesday. The doctor turned to me and said, “It would be so great to have someone like you who delivers the results like that to our hands.” The doctor and psychologist discussed their frustrations with having to make referrals and for having to spend time in a smoking cessation clinic talking about inhalers, because already they have so much to do in so little time and with so few resources. “But I have to because she won’t get an appointment with a respirologist for a couple months” was the doctor’s justification for doing so.

Early diagnosis is a complex goal for COPD prevention and care. It is, however, supremely important if one wants to see fewer cases of advanced COPD in the future, particularly among younger cohorts of the population (Park & Sin, 2011; Zielinski *et al.*, 2006). Valeria's case exemplifies some of these issues. Firstly, Valeria clearly thought of her problem as being asthma, which I have argued is a common, normalised, non-stigmatising and household term in Uruguay that is used generally to describe breathing difficulties. The terminology used for COPD and asthma symptoms overlap (Chapter 6), as do the sensations they provoke which is one reason why COPD may be under-diagnosed. If health professionals mis-diagnose COPD as asthma (Marcelo in Chapter 7) and asthma is such a common household term and experience, people with COPD may interpret their symptoms as "a bit of asthma" for a long time and not consider it serious enough to seek medical attention.

We know from Valeria's account that she had been prescribed inhalers at one point but she was no longer taking them because she felt better. It is possible that the healthcare professional who prescribed the drug believed the problem to be asthma, or it was simply the diagnosis Valeria associated with inhalers. In any case, 'feeling better' as explored in Chapter 6 of this thesis, represents the way in which COPD is, for some, a series of acute episodes and not a chronic disease, particularly in earlier stages. None of my participants liked taking medication every day. There was a lot of scepticism over inhalers, their side-effects and whether they made your lungs weak. I frequently heard people tell me that inhalers were bad for the heart. When I explored this with health professionals they lamented this belief and assured me that although inhalers could cause palpitations if too many puffs are taken, they did not damage the heart. This was a clear point of tension in the doctor-patient relationship. In contrast, people who experienced disturbing everyday symptoms of COPD were more likely to be accustomed with having to use the inhalers and medications every day if they wanted to stabilise their symptoms. Differentiating asthma from COPD in public consciousness is a challenge for Uruguay if it is going to tackle under-diagnosis of COPD. Whether there will be resistance to applying a chronic disease label to symptoms otherwise not considered to be a chronic problem, is an important topic for further exploration.

A second issue Valeria's case exemplified was co-morbidity (having multiple chronic conditions) and the relative importance of cough and breathlessness for people struggling with other serious health problems, like renal failure, diabetes or heart problems. An interesting observation from my participants was that the more pack-years someone had, the more likely

they were to have other chronic diseases, but pack-years as a factor was not as obviously related to severity of obstruction. To explain this, Table 9.1 draws data from Table 3.1, and lists the five participants with the highest pack-year smoking history and the five with the lowest and includes data such as their age when they quit smoking and other chronic conditions. A couple of noteworthy comparisons can be made. Some participants with higher pack-years are the eldest (Soledad and Allen are in their 70s). Advanced age is associated with the appearance of chronic illnesses; so that the older one is, the more likely one is to be diagnosed with chronic diseases, including COPD. What is striking is the FEV1/FVC of the participants who were younger and who had a lower pack-year history. This is the mystery of COPD. Could it be that they share some kind of predisposition, such as having an unknown gene or having had multiple-lung infections in childhood, and have been exposed to other risk-factors, such as smoky or dusty work-environments and general conditions of poverty? One cannot say for sure. What is less mysterious is that having both a lower pack-year history and being younger meant the person had fewer other chronic conditions. Therefore, while their limitations were severe because of their diminished respiratory capacity, they did not (except for Macarena, who is also older and quit later in life) have the additional burden of coping with the effects of other chronic diseases. Whether they will go on to develop other chronic diseases as they age, or whether, by remaining non-smokers with relatively low pack-year histories having quit at relatively young ages, they will avoid the trials of co-morbidity, remains to be seen.

Suffice to say that the issue of co-morbidity adds complexity to the issue of motivation to quit, particularly if the smoker is older and has other diseases to manage, especially diseases which require other kinds of behaviour changes, *e.g.* changes in diet to control blood sugar. Contrary to the idea that more co-morbidity might be a motivating factor to quit, it may not be. For example, 61 year old Daniela smokes and her spirometry showed mild obstruction of the small airways. Dr. S encouraged her to see this as the opportune moment to quit, in a clinic I attended. She had quit smoking for a few months but started again and explained to me that she gives more importance to her diabetes and cutting out sugars as opposed to cutting down on cigarettes because sugar levels in the blood that are too high or too low could have very serious consequences like coma. “That scares me [coma], the COPD is just there,” she told me. Coma and possibly death were considered far more disturbing and frightening, and ultimately motivating, than coughing, sputum and breathlessness. Furthermore, her inability to

Table 9.1: Co-morbidities of the five participants with the highest pack-year history and the five participants with the lowest pack-year history.

Participant	Age	Pack-Years	Age when quit smoking	FEV1/FVC (%)	Co-Morbidities (chronic)
Valeria	53	140	Still smokes	55	<ul style="list-style-type: none"> • Osteoporosis • Back problems • Renal Disease
Soledad	72	125	66	44	<ul style="list-style-type: none"> • Obstructive artery disease • Diabetes • Gastritis • Arrhythmia • Hypertension • Heart Disease (previous heart attack)
José	53	120	51	n/a (very severe)	<ul style="list-style-type: none"> • Fibrosis • Diabetes • Chronic Pain • Hypertension • Congestive Heart Disease
Allen	72	96	62	24	<ul style="list-style-type: none"> • Heart disease • Diabetes • Fluid Retention
Tomás	60	80	60	70	<ul style="list-style-type: none"> • None
Patricia	45	28	42	29	<ul style="list-style-type: none"> • None
Claudia	50	26	40	30	<ul style="list-style-type: none"> • None
Mateo	43	20	33	30	<ul style="list-style-type: none"> • None
Macarena	59	17	53	56	<ul style="list-style-type: none"> • Hypertension • Hernia • High Cholesterol • Thyroid problem
Sebastián	36	14	26	34	<ul style="list-style-type: none"> • None

walk any further than down the path from her front door to the end of her building was the result of her painful legs due to obstructed arteries not breathlessness (see the case of William, Chapter 6 p. 142).

Other chronic diseases, like heart disease, can be almost symptomless before they manifest in a life-threatening attack, and these can provide a lot of motivation to make a quit attempt. This was the case for another participant named Lukas, a 48 year old with mild obstruction. Juan had been encouraged to quit smoking for years by his physicians, but only did so when he had a heart attack during the course of my fieldwork. It scared him and it gave him the motivation to quit. A serious respiratory event, often including hospitalisation, invasive or non-invasive ventilation, and being sent to intensive care, were frequently referred to as turning points and frightening events which motivated a change in attitude towards ongoing smoking for other participants. However, the fear associated with these events had the tendency to wear off. Two participants in particular had quit after a scary respiratory episode, but within a few months had started smoking again because they felt better, had a cigarette, did not feel any different, and so continued. The word *feel* here is paramount. Attention was being paid to sensations and the interpretation of sensations in order to reconcile a conflicting position on smoking.

Thirdly, Valeria's case highlights how coordination is not straightforward. If people at risk of having COPD are identified in primary care settings like outpatient clinics and smoking cessation groups, let alone emergency departments and other specialty services, how is one referred to screening for COPD? Whose responsibility is it to prescribe flu vaccines and inhalers and when? Who is responsible for delivering the diagnosis? Furthermore, referral does not necessarily mean that the diagnostic process will be put into motion. Valeria's five month delay to spirometry also had to do with her ability to maintain appointments amidst her tumultuous home life and many responsibilities. Even in healthcare settings where coordination and referral processes are very efficient, diagnosis is further complicated by participants refusing to accept a referral to a respirologist because of not wanting or not feeling able to quit. For example, Ignacio, who received care in a private hospital in Montevideo had been told for many years by his physician that he should really see the respirologist (who would have made a quick referral to spirometry) and offered to write him a referral. He refused for a long time, until his symptoms got much worse. When I asked why, he said, "I knew he would tell me to quit smoking." As was seen throughout this thesis, COPD is not a straightforward disease and participants often complained to me about how difficult it was to explain what their problem

was to other people. I now go on to suggest that improvements could be made in this area and that smoking cessation services offer an opportune context for exploration of early screening and detection of COPD.

Smoking Cessation as a Context for Exploring Early Diagnosis

A very recent report produced by the International Tobacco Control Policy Evaluation Project, the Faculty of Social Sciences at the University of the Republic and the Centre for the Investigation of the Tobacco Epidemic (CIET) has outlined that there are still improvements to be made in smoking cessation in Uruguay (Proyecto ITC, 2012). In particular, they report that only half of smokers who consult a physician are asked about their smoking and given quit advice. The national guidelines released in 2009 state that a patient's smoking status must be recorded in the medical history at every visit and outlines a care pathway for smoking cessation advice (Muñoz *et al.*, 2009). The fact that 71% of smokers in Uruguay have tried to quit and the majority regret having started, is what has driven policy for investment in smoking cessation (Proyecto ITC, 2012). Since 2005, 100 new smoking cessation programs were established in healthcare institutions across two thirds of the 19 departments which were subsidised by the FNR for nicotine gum and bupropion. From 2004 to December 2011, 24,735 people began treatment for smoking cessation through a FNR subsidised program (data provided by FNR).

I was surprised by how many people I saw in groups who wanted to quit “because of health” and who were symptomatic in terms of reporting cough, chestiness, and breathlessness. According to the ITC Project (Proyecto ITC, 2012), of survey respondents ($n=1411$ in 2011), 79% of those who reported having thought of quitting in the past 6 months were motivated to do so because of being concerned for their health. Those who go to smoking cessation services are thought to be those who have found it the most difficult to quit by themselves, the most addicted, or the heaviest smokers (Esteves *et al.*, 2011). I wonder whether they might be motivated to get help quitting because they have become aware of the impact smoking is having on their breathing and I think back to the descriptions of breathing difficulties presented in the previous chapter. Esteves *et al.*'s (2011) study found that 91% of a representative sample of 578 people who used the smoking cessation services subsidised by the FNR, had a tobacco-related disease. The study does not say what these are but it suggests the motive for quitting, “health”, was based on experiencing the negative effects of smoking.

Might there be a high percentage of people attending smoking cessation groups in Uruguay who have undiagnosed COPD in addition to other diseases? Might they be symptomatic? Chapter 8 showed how frequently sensations of breathing interpenetrate smokers' descriptions of their quitting experiences. Could having COPD confirmed or refuted support them or motivate them in their attempts to quit? Stratelis *et al.* (2006) found that their participants who received spirometry and advice and who had COPD were more likely to quit than those who did not. Furthermore, Parkes *et al.* (2008) found that getting a normal spirometry result or an abnormal one were equal in terms of their ability to motivate participants to quit smoking.

Following from Valeria's experiences, the smoking cessation group asked me to organise a joint-meeting with respirology at their public hospital, which I did and chaired. The two teams discussed the processes of inter-referral, criteria for pulmonary rehabilitation and how spirometry is scheduled. Some healthcare institutions have better coordination between smoking cessation and respirology than others. There are many factors which make referral complex. For example, one service I attended was (as were all services funded by the FNR) open to anyone regardless if they are affiliates of that particular institution. As such, the doctor informally screened for COPD using a short questionnaire produced by GOLD. However, if the patient was not an affiliate of the healthcare institution the doctor could not refer them for spirometry there. All she could do was recommend that they make an appointment with their doctor in their institution and ask for a spirometry test. However, as mentioned in the previous section, many people are not aware or concerned by breathlessness and coughing before it begins to make a noticeable impact on everyday life, and so if it is left up to the patient, it is less likely that they will be able and willing to negotiate complicated referral systems and may not pursue a possible diagnosis. If they are motivated to do so, they still have to go through the channels which will vary in complexity and time from one institution to the next.

There is also the question of cost. A concern among health professionals was that the institution would not be pleased with the financial cost of sending all suspected cases of COPD for spirometry. Many other questions remain. If spirometry is performed, how does the smoking cessation professional learn of the outcome? And, if the person does have COPD, should the approach to their smoking cessation be any different? This is the next topic I turn

to. Is there scope and possible benefit to re-framing smoking cessation as 'treatment' for COPD?

As a first step it would be useful to know how prevalent COPD is in populations that attend smoking cessation services. At the meeting I coordinated, such a study was discussed and since returning from the field it has been carried out. The smoking cessation team recently presented their results at a conference in Chile (Parodi *et al.*, 2012). In their study, all patients attending the clinic between 1st June and 30th April 2011-2012 were referred for spirometry. Of those who agreed to have a spirometry test and whose results were available for initial analysis ($n=74$), 38 people were found to have COPD and over 60% of this group were previously undiagnosed. They also found that over 60% were symptomatic of COPD and when spirometry was performed, they were confirmed to have it. The percentage of people with COPD may be consistently higher in populations seeking help to quit than in the general population. This suggests that of the 24,735 people who attended smoking cessation services subsidised by the FNR from 2004 to 2011, alongside those that operate outside the FNR program, thousands may have undiagnosed COPD. This suggests that smoking cessation could be a very fruitful setting in which to screen for COPD and diagnose it, and be one possible strategy for addressing, as we've seen in the case of Valeria, a very complex goal of early diagnosis.

PREVENTING DIAGNOSED COPD FROM GETTING WORSE

There is little doubt that the cause of COPD and its progression are multi-factorial. To take a stance on COPD diagnosis and treatment, more needs to be done than simply focusing on smoking. Reducing poverty, preventing childhood respiratory infections, investing in the expertise and equipment necessary, providing the appropriate treatments including medications, oxygen and rehabilitation, protecting the population from occupational and environmental risk factors, supporting people's emotional and mental health and vaccinating against flu and pneumonia are all critically important as has been emphasised throughout this thesis and elsewhere (Brehm & Celedon, 2008; Currie, 2011; Midgley, 2008). Smoking cessation once COPD has been diagnosed, however, remains the one currently known intervention that unequivocally can change the natural course of the disease (Britton, 2011; Midgley, 2008; Viegli *et al.*, 2007; Zielinski *et al.*, 2006). It has been argued elsewhere that people with COPD need more information about the effects of smoking, as well as more

support for stopping smoking (Kanervisto *et al.*, 2007). Since most of my participant-observation data concerning the risk-factors of COPD was gathered in smoking cessation, I focus on smoking in this section without taking away from how important an integrated, overall approach to reducing inequalities in health is.

In this section, I build on my suggestion that smoking cessation services may be an untapped resource for early diagnosis and argue that the smoking cessation specialists within them could develop their professional role further by becoming part of the care-team for people with COPD. I propose that smoking cessation be reframed more clearly as a ‘treatment’ for COPD. But first, in order to make that argument, I must provide some important background. First, I will show the inconsistent position smoking cessation has in guidelines and textbooks on COPD. Secondly, I describe how smoking cessation in Uruguay is already medicalised as a ‘treatment’ for a disease called *tabaquismo* (tobacco addiction). Thirdly, I discuss how health professionals in smoking cessation view their role and how their professional-development may make them akin to taking a more active role in COPD care. With these three background topics covered I end with a synthesis of my argument that the chronic disease model of smoking cessation reflects the reality of the smoking cessation journey of my participants and could therefore be transferred to routine COPD care in an explicit way.

The Inconsistent Position of Smoking Cessation in COPD Guidelines

While the literature has sometimes referred explicitly to smoking cessation as a treatment for COPD (Gilljam, 2007; Muhlig, 2008; Strassmann *et al.*, 2009; Stratelis *et al.*, 2006; Willemse *et al.*, 2005), this is neither widespread nor consistent internationally in terms of the position of smoking cessation in practice guidelines for COPD care and management. For instance, in the 2011 Latin American Thoracic Society guidelines for COPD (ALAT, 2011), smoking is defined as a chronic disease that is treatable. Although it appears in the schema for treatment, medications such as inhalers are foregrounded and smoking cessation figures as a “general preventative measure” (p. 21). In the UK, in the Managing Stable COPD section of the National Institute for Health and Clinical Excellence (NICE) Quick Reference guidelines for COPD, Smoking Cessation and Treatment appear separately (NICE, 2010). In the guidelines from Spain, smoking cessation falls under Primary Care Interventions alongside physical activity, vaccines, hydration and self-management (semFYC & SEPAR, 2010).

The word 'treatment' seems to be reserved for drug-treatment for treating the symptoms of COPD (inhalers, corticosteroids and antibiotics). When the word treatment appears with smoking cessation it is where smoking cessation medications such as nicotine replacement therapy and bupropion are discussed. As the GOLD, semFYC/SEPAR and ALAT guidelines are all fully or in-part subsidised by pharmaceutical companies, it is perhaps not surprising that they stress pharmacological management of symptoms. However, I wonder what a subtle reframing of smoking cessation as a treatment could have on health professionals' efforts to support their patients in quitting smoking and how patients understand the importance of smoking cessation. Bolman *et al.* (2005) found that pulmonologists (respirologists) were unsure of the effectiveness of their smoking cessation advice to patients and lacked experience assisting their patients to quit. In Uruguay, this could be the case as well but there already exists a rich resource of health professionals who could receive referrals of COPD patients needing assistance to quit smoking in a more systematic way. These health professionals have already defined what they do as 'treatment' for a chronic disease and I now turn to this topic.

Tobacco-Addiction as Disease and Smoking Cessation as its Treatment in Uruguay

One sunny afternoon in Tacuarembó, I was in the plaza as a participant-observer during an awareness raising campaign for smoking cessation. A loud-speaker on the top of a car bellowed out, "*Tabaquismo* is a chronic disease caused by an addiction to a drug which is called nicotine." By this time, I had listened to, with much curiosity and scepticism, the discourse of "smoking is a chronic disease", hundreds of times. Whether in conferences, on television, or in smoking cessation services, the medical and Ministry of Public Health discourse on smoking included the disease of tobacco-addiction, aptly called *tabaquismo*. The national guidelines for approaching the topic of smoking with patients in Uruguay define tobacco use as,

“...an addictive and chronic disease for which relapses are part of its evolution.

Nicotine, which acts upon the central nervous system, is the substance responsible for the addiction” (Muñoz *et al.*, 2009).

Esteves *et al.* (2011) state that in Uruguay *tabaquismo* “...is an addiction disease which is socially acceptable, despite the fact that in the past few years the population has become

more aware of the risks of the behaviour” (p. 78). Unfortunately for this English-language thesis, there is no single English term for Spanish’s *tabaquismo*. Even French has *tabagisme* and as nouns they certainly facilitate the reification of tobacco-use, which in turn lends itself more easily to its medicalisation. A search through various online Spanish-English dictionaries suggested such wide-ranging English translations for *tabaquismo* as nicotine poisoning, tobacco addiction, smoking, smoking habit and addiction to tobacco.

When I asked a number of my health professional participants where the notion of smoking as a chronic disease came from, I was told repeatedly that it was the World Health Organization (WHO) that defined it as such. However, while searching WHO websites confirms that they translate *tabaquismo* as ‘tobacco-use’ and cast it as an epidemic, the explicit definition of tobacco-use as a chronic disease is nowhere to be found. It is instead referred to as a risk-factor and a cause of other diseases. However, tobacco-use as a chronic disease was an integral component of smoking cessation discourse at the time of this study. For example, a social worker addressing a patient in a smoking cessation group said, “*Tabaquismo* is a type of chronic disease, that is why smokers have a propensity to relapse.” A physician addressing a group of patients in smoking cessation said:

“Smoking is not a vice [*vicio*]. It is a disease, an addiction. It’s in and of itself, a disease. And it’s like any other addiction: marijuana, cocaine. But it’s easier to become addicted to tobacco. But being a disease means that there is a treatment. The state is spending a lot of money on trying to help people quit. It is a disease and the nicotine gum [*chicle*] is a treatment.”

The professional community agreed that treatment not only consisted of medication but also of psychological and social support frequently delivered in the form of cognitive-behavioural therapy. There is more disagreement about the way medication should be used in smoking cessation, than most of the authorities on the subject would like to admit. Some professionals gave more importance to the biological addiction to nicotine and others gave more importance to the psychological dependence. The definition of tobacco-addiction (I believe this translation is more accurate in the Uruguayan context than the WHO translation ‘tobacco-use’) as a chronic disease was widely shared although some were more nuanced in their interpretation of ‘chronic’ as the vulnerability to relapse.

Bianco (2003), a Uruguayan cardiologist and director of CIET, makes reference to the WHO in his paper *Tobacco-addiction: A chronic disease to be treated*. The reference is that of

the International Statistical Classification of Diseases and Related Health Problems (WHO, 2010). Tobacco-use appears as a Mental and Behavioural Disorder due to Use of Tobacco. This falls within the category Mental and Behavioural Disorders due to Psychoactive Substance Use, alongside alcohol, cannabis, hallucinogens and even caffeine. It is the addiction element of tobacco-use, particularly its effect on the brain, which accords it its disease status. The lay term in Uruguay for being addicted to tobacco in Uruguay is *vicio* (vice). While smoking is frequently referred to as *un habito* (a habit), *vicio* tended to be chosen to connote being unable not to smoke. Such a person is *vicioso*. In this way vice seemed to me to be the equivalent to addiction in lay language. However, health professionals saw the rampant use of this adjective as a barrier to recognition that smoking is an addiction and they actively tried to change their patients' use of the term by overtly replacing vice with addiction. Once tobacco-use is established socially and medically as an addiction, its inclusion into the category of disease is possible. Figure 9.1 is a representation of the process of medicalisation in relation to terminology.

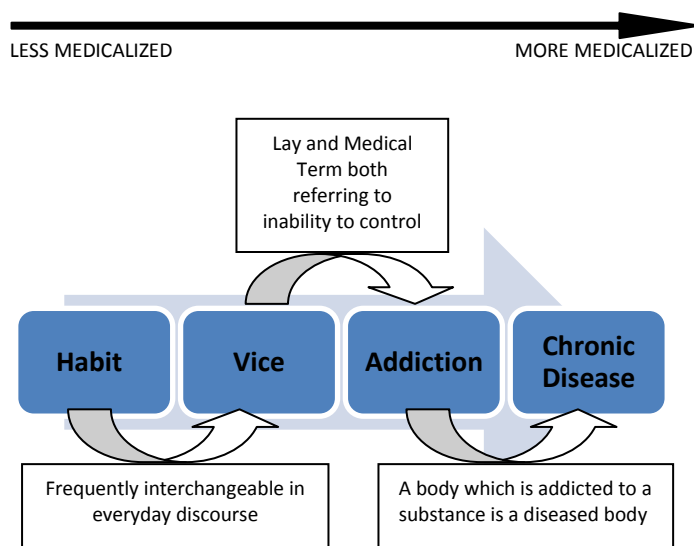


Figure 9.1: Terminology for tobacco-use from less medicalised to more medicalised

Although there is a long history in medical anthropology of critiquing medicalisation, it is also important to self-reflexively question, “Is medicalisation always a bad thing?” In Uruguay, medicalisation of smoking is wrapped up in the medicalisation of wider society and the power of medicine. This thesis, however, is not about evaluating medicalisation in everyday life in Uruguay, although descriptions of the pervasiveness of medical consumerism

has been emphasised as a fundamental context within which COPD care is situated. Like Rose (2007), in his writings on biopolitics, I take an approach to medicalisation which lends a critical evaluation but does not simply reject it on that basis. Rather, I am interested here in medicalisation in context, and in terms of the individuals involved in the process and their own understanding of their actions. I am less interested in analysing smoking cessation as an attempt by the state and by doctors to medicalise aspects of everyday life to control and exude power over bodies and people. Yes, there is a clear medicalisation of smoking occurring, however, those professionals who work in smoking cessation see themselves as working largely outside the standard medical model, which affects their ability to become accepted and valued within the system.

It has been argued that de-normalising is a process which stigmatises the smoker and that this stigma, which is thought to be a public health strategy can in fact be counter-productive for the goals of tobacco-control (Bell *et al.*, 2010). Chapman and Mackenzie (2010) make the good point that unassisted smoking cessation is under-researched and the medicalisation of smoking cessation may make smokers think it is impossible to quit otherwise. Within Uruguay, I found that the medicalisation of smoking was seen, at least by professionals, as a way of relieving the smoker of some of the moral stigma associated with making choices that harm them and others through second-hand smoke (Bianco, 2003). A Ministry of Health employee working for the national tobacco program put it the following way:

“It’s a disease, and as a disease what do we do? Do we blame people for being sick?
No, we help them, we provide them with treatment.”

This approach is not only supported by the WHO but also one put forth in the academic literature. In their article “*Smoking as a chronic disease*”, Steinberg *et al.* (2010) argue that “Instead of viewing smoking and tobacco use as a “bad habit” that can be cured with willpower, a more practical model describes smoking as a chronic relapsing condition that often requires ongoing medical and behavioural treatment” (p.413). Cessation specialists Muller and Wehbe (2008) similarly argue that “To control the tobacco pandemic in Latin American countries, nicotine addiction must be recognised and treated as a disease” (p. 285).

Smoking Cessation, Professional Development and Identity

Through interviews and focus groups I discovered that smoking cessation professionals, particularly those who were the pioneers in Uruguay, perceive themselves to be the 'black sheep' of the medical profession. Take, for example, the following excerpts from focus groups, where I asked, "How are smoking cessation professionals seen by colleagues in medicine and by society more generally?" Brackets contain the number of years the professional has worked in smoking cessation.

Physician (7 years): "Like something unimportant." [everyone laughs]

Physician (7 years): "Some colleagues boycott us. There was an increase in activity during the Vazquez government, but now it's losing importance."

Physician (17 years): "Our colleagues take an ambiguous position. They consider smoking cessation treatment as outside of medical assistance, but when they have a patient who's a smoker they run to us for help because they don't know what to do with them. They saw smoking cessation work as an opportune way for some doctors to make some money without too much work."

Physician (23 years): "There is an idea within healthcare institution administration that it's a job that anybody can do, without any training. But the vision has changed and they see the need now for the work."

Physician (unknown): "Most of the advance is due to political changes and to professional training. It's not seen as strange as it was before."

Psychologist (5 years): "I trained in the FNR. The training was devalued, even I devalued it. It was "a little course" that implied work for anybody who did it. But once I was doing it, my own perception changed."

Psychologist (19 years): "People working in tobacco cessation were seen like 'strange creatures' [*bichos raros*]."

Physician (16 years): "It is not considered important. What's important is the cardiac surgeon. The one working on the periphery [the poor areas of Montevideo] getting their hands dirty isn't seen well. It's the same with all professionals working in prevention. You have to have a lot of self-esteem to not become demoralised. My experience was of people telling me 'with the training you have, you're going to dedicate yourself to smoking!?'"

The point I am making is that the tobacco cessation specialists I spent time studying in clinics, at professional meetings and at political and community events, were highly dedicated to prevention, empathic towards their patients and saw themselves as working against the grain. I also see the medicalisation of smoking as a chronic disease as something they have drawn on and actively promoted in order to increase their status and acceptability within their professional circles, especially the physicians. If smoking is a disease and there is a treatment then they 'fit into' the biomedical model. Most felt they were underpaid because they worked in prevention, a few had worked for free for many years, and all were concerned about the importance of maintaining tobacco-control on the political agenda. I suggest that these professionals have the institutional infrastructure, skills and motivation which could be harnessed for the purpose of COPD prevention, diagnosis and, as I will discuss in the following section, treatment.

Smoking Cessation as Treatment for COPD

So far I have made the argument that smoking cessation has an inconsistent position in COPD guidelines; that in Uruguay, tobacco-addiction is seen as chronic disease and smoking cessation services as providing a treatment; and finally, that health professionals working in smoking cessation are committed to prevention but concerned about their position in healthcare and the future of preventive care. I have covered all of these topics in order to support my recommendation that smoking cessation treatment be explicitly framed as a treatment for COPD; something which would require better coordination between respirology and smoking cessation services across institutions.

Smoking cessation is always recommended in COPD guidelines and patients are always told they should quit, but the subtle difference in writing a prescription for smoking cessation treatment from a multidisciplinary team alongside prescriptions for medications must be explored. Smoking cessation is the most cost-effective intervention in COPD (ALAT, 2010; Britton, 2011). Low-income and middle-income countries, like Uruguay, are placed at a real disadvantage in the global pharmaceutical economy when it comes to purchasing inhalers, medicinal gases and oxygen-equipment. This clearly needs global political action, as has been taken in the realm of HIV/AIDS treatment (Farmer, 2005). However, it is equally important to consider ways of avoiding the need for medications and medicinal gases at all. While long-term oxygen and assisted ventilation can help people live longer, this comes with huge suffering and

cost and so major efforts in prevention are needed (Viegi *et al.*, 2007). My proposition is why not explore how reframing smoking cessation as a treatment could affect people's understandings of the causes and evolution of the disease, and their likelihood of sustaining a smoke-free life to help stabilize the disease and avoid severe stages?

Among my participants some did not quit after being diagnosed, or only quit years later, some still smoked, others took up smoking during my fieldwork and probably others will take up smoking again in the future. Many did not clearly understand what their diagnosis meant and how smoking was implicated. The WHO Report on the Global Tobacco Epidemic concludes that, globally, most users of tobacco are unaware of the harms it causes (WHO, 2011). COPD is one such harm that is under-recognized (GOLD, 2008). Mateo (p. 152, 170 and 213) related his experience of coming to understand his disease in the following way:

"When I had another crisis, a medic came to the house and he said, 'Do you know what you have?' I said, 'I have COPD.' and he responded, 'But do you know what it is?' and I said, 'No.' And what he told me was, 'Look, what you have are broken lungs, that's why you can't breathe, it's a progressive disease and ends with a transplant or you die, and you have to quit smoking.' And that's when I started to try and quit. And it was really tough, because I didn't smoke a lot but I smoked for many years, 20 and a bit years, for me smoking was a huge psychological crutch."

Not understanding the relationship between smoking and progressive lung function loss was one thing but not understanding how smoking cessation led to a stabilisation of the disease was another. Participants seemed to experience coming to terms with the idea that 'the damage is done' as a significant part of coming to terms with the disease itself, which is defined as incurable. Yet, as the anthropology of chronicity implies, the biomedical definition of irreversible damage as incurable disease does not always match individuals' experience of illness. For example the narratives of people diagnosed with schizophrenia presented in Good *et al.* (2010) "...contradict absolute biomedical definitions" (Manderson & Smith-Morris, 2010, p. 37), because some demonstrate recovery. However, defining schizophrenia medically as lifelong and degenerative implied that one would face a lifetime of psychosis and disability, which in turn contributed to hopelessness, despair and stigma. With COPD, as we saw in Chapter 6, the subjective sense of health can dramatically improve after diagnosis and treatment, leading to almost an entire rejection of any kind of 'chronic' label. But, when illness

did not improve after diagnosis and the understanding that it was incurable was internalised, hints of fatalism could be heard in participants' narratives.

My experience having seen patients be shown and explained the graph in Figure 9.2 is that its message is very powerful. The idea that there is always something worth saving can be more difficult to ascertain than the 'coming to terms' with irreversible loss. I think smoking cessation professionals can incorporate this message into their work and if they were referred patients with COPD in a systematic way, they would have the interpersonal skills and time necessary to help reinforce this. Also, the model in Uruguay for smoking cessation is a chronic one. It is seen as completely normal for smokers to quit and take up smoking again, and they reinforce the idea that the door is always open to return for help to quit again. There are no strict quit dates; participants determine when they will reach zero cigarettes per day. Once again, this approach to smoking is highly appropriate for people with COPD, like my participants, who had many quit attempts.

Taking on the issue of under-diagnosed COPD and the poor support people with COPD receive for smoking cessation could help health professionals continue to develop their professional status. This will require coordination with respiratory departments and may involve careful task-delegation, so as to not over-step professional boundaries. In Valeria's case the health professionals were ambivalent about having to take on the added responsibility of explaining COPD and prescribing treatment. If they could easily refer to respirologists, or if there was a slight re-conceptualisation of their role, more training in COPD could be incorporated into the curriculums of the CHLCC and the FNR. I presented this idea during a seminar I gave at the Sociedad Uruguaya de Tabacología (SUT) monthly professional meeting of cessation experts on September 2nd 2011 before leaving Uruguay. They were interested in my proposition, and time will tell whether anyone takes the idea forward. One thing is clear, and that is that people who have COPD and want to quit need access to support for doing so (Kanervisto *et al.*, 2007).

RAISING AWARENESS OF COPD RISK-FACTORS: SUGGESTIONS FOR PUBLIC HEALTH CAMPAIGNS

Jonsdottir and Jonsdottir (2007) remind us that "Although smoking cessation is the most important treatment for COPD, the benefits of quitting do not lead to the eradication of the disease" (p.297). Importantly, in order to eradicate the disease in the long-term, it is

imperative that efforts be made to reduce people's exposure to the risk-factors in the first place. One strategy I propose is for public health to draw on the symbolism of breathing 'pure, clean air' outside the home, inside the home and in the workplace and that such an approach is more consistent with my participants' explanatory models.

Public health measures and strategies for ensuring that populations can breathe clean air are central to COPD prevention in any country (Liu *et al.*, 2008). To date, few studies have looked at the long-term effects of air pollution on COPD prospectively, but there is a wealth of evidence to show that changes in the atmosphere in terms of carbon monoxide, ozone and particulate matter correlate with hospital admissions for acute respiratory trouble (Liu *et al.*, 2008). Fluctuations in atmospheric pollution affect morbidity and mortality of COPD and, therefore, require an environmental prevention approach in public health (Amiot *et al.*, 2010). A study in London found that the symptoms of COPD and exacerbations were associated with raised levels of air pollution, particularly particulate matter, black smoke and nitrogen dioxide (Peacock *et al.*, 2011). I could not find any such data for Uruguay, which suggests that monitoring such trends is an area in need of development.

In the case of COPD, indoor air pollution has been studied less than outdoor air pollution, despite the fact that pollution caused by biofuels, like burning wood, produces particles small enough to end up deep in the alveolar region causing damage to it (Bruce *et al.*, 1998; Liu *et al.*, 2008). Kurmi *et al.*'s (2010) systematic review and meta-analysis found that of all fuels (including coal), wood smoke presents the greatest risk for developing COPD. People who use solid fuels are at twice the risk of developing COPD than people who use non-biomass fuels (Kurmi *et al.*, 2010). Liu *et al.*, (2008) suggest that programs to replace biomass fuels for cooking with improved cooking stoves is one strategy for reducing indoor air pollution, but wood used for heating is another matter. The 2011 census in Uruguay found that 37% of all Uruguayan households use wood to heat their homes. I observed in my winter in Tacuarembó, the thickness of the evening air due to people heating their homes with wood. While the sight of fog to Uruguayans may have signalled humidity, to my senses of smell and sight it also signified an accumulation of chimney smoke. Furthermore, I observed repeatedly, in various households, the practice of throwing plastics and foil wrapping into fireplaces which would release strong smells and coloured fumes. However, there was little regard for the potential of these sources of domestic pollution to affect the respiratory system.

There is already sufficient evidence to causally link dusts, gases and fumes produced in occupational settings and COPD (Eisner *et al.*, 2010). A recent review confirms that approximately 15% of COPD is linked to occupational exposure, and this kind of exposure may account for 40% of cases in never-smokers (Blanc, 2012). However, in Uruguay, occupational health is a relatively new sub-field of medicine and there are clear links to be made between respirologists, general practitioners and occupational health professionals to prevent lung diseases like COPD, and prevent the exacerbation and worsening of already diagnosed lung diseases. While shadowing respirologists, I observed a number of young men consulting for breathing difficulties who worked in the forestry industry but who did not wear protective masks. Although the masks were available if they wanted them, they did not have to wear them and so did not. A participant's son worked in the forestry industry and when I asked him about wearing a mask, he just shrugged and suggested they were uncomfortable and nobody else wears them. Similarly, a number of participants were exposed to toxins in their workplace, whether it was from fumigation, tobacco-production, working with resins and glue, factory work or harsh cleaning products, and they also had no protection for their airways. More awareness raising and more stringent policy is clearly needed, especially because these risk-factors, like all the others seen so far, will disproportionately affect people with fewer economic resources. It is the people from the working classes who are more likely to be exposed to toxins in the workplace, who are more likely to heat with wood, and more likely to smoke (Layte & Whelan, 2009). The fact that individual inhalation of tobacco-smoke is only one of many factors implicated in the cause and worsening of COPD makes it clear that responsibility also lies with employers, industries and government to implement preventative measures.

People with COPD have altered bodies and I have argued that as such, they sense the world differently. They are aware of subtle changes in air which people with normally functioning lungs might not be. Throughout this thesis, I have shown how participants drew sensorial links between outside air and environment and their respiratory symptoms. Similar connections were drawn in the narratives of participants around the world interviewed about their experiences of COPD (Chen *et al.*, 2008; Gullick & Stainton, 2008; Jeng *et al.*, 2002; Nicholls, 2003; O'Neill, 2002; Small & Lamb, 1999). Generally, Uruguayans who I met were more concerned about volcano ash, humidity, changes in temperature and the bad air of modernisation and urbanisation than they were of more household airborne substances, like

cigarette smoke or burning wood and household items in the fireplace. However, perceptions of the risks of cigarette smoke were clearly changing. Based on the fact that people with COPD appear to be hyper-aware of 'air' I wonder whether they could be valuable collaborators in awareness-raising campaigns about the importance of breathing clean air. They could draw on their hypersensitivity to communicate, in vivid sensorial terms, the effects of different airs on breathing and the body. Furthermore creative technologies such as the GPS device placed on inhalers to track their use, designed by medical anthropologist David van Sickle (Asthmapolis, 2012), could prove exceptionally useful for gathering data on the way Uruguayans use their inhalers in response to environmental threats such as humidity, cold, temperature change, dusts, chemicals and tobacco smoke.

CONCLUSION

Janes and Corbett (2009) have argued that the "...the ultimate goal of anthropological work in and of global health is to reduce global health inequities and contribute to the development of sustainable and salutogenic sociocultural, political, and economic systems" (p.169). Clearly achieving the public health goals for COPD requires a multi-factorial approach. I have drawn on my ethnographic findings to provide a realistic understanding of why early diagnosis is a complex goal. I have drawn attention to a number of complicating factors including the pervasiveness of asthma as a household term, the normality of breathing difficulties and changes in breathing in Uruguayan discourse (Chapter 5), coordination issues between departments, and co-morbidities competing for priority in peoples' health behaviours. Nevertheless it is clear that investment in basic technology and expertise is needed in Uruguay, if the health inequality gap is to be addressed. In recognition that the Uruguayan government has a number of priorities requiring limited resources, I have also suggested a sustainable avenue for working towards earlier diagnosis and slowing the progress of the disease once it is diagnosed. I have recommended that Uruguay consider smoking cessation services and the professionals within them as a resource for screening for COPD among smokers wanting to quit and for providing support to people with COPD to quit smoking or remain smoke-free. This goes hand in hand with the Chapter 7's recommendation that mobile emergency services and home-hospitalisation be considered already existent resources which could be capitalized on more concretely.

Currently, in guidelines and textbooks, smoking cessation has an inconsistent position within COPD care and management. I have theorised on the possible benefits and challenges to explicitly repackaging smoking cessation as a treatment for COPD, alongside prescriptions for symptom-control drugs and ideally before these are necessary. This is not about prescribing smoking cessation medication but prescribing smoking cessation treatment as it is currently organised in Uruguay, *i.e.* interdisciplinary teams using psycho-social as well as pharmacological interventions, on a long-term care model, for people who want to quit or avoid relapse. At a public health level, raising awareness among the general population, health professionals, employers and policy makers is also crucial. There is sufficient evidence to warrant greater attention be paid to non-smoking-related risk-factors for COPD while continuing to support tobacco-control policy. Acknowledging that the cause of COPD is multi-factorial, and designing campaigns and policy to address other types of indoor, outdoor and occupational pollution, is not only sound in accordance with the most up to date literature on COPD but is also more in line with popular beliefs about the effect different properties of air have on the body and the multi-causal explanatory models of people with COPD reported here and elsewhere (Barnett, 2005; Hansen *et al.*, 2007; Nicholls, 2003; Schofield *et al.*, 2007).

Conclusion

INTRODUCTION

This thesis has drawn on a wide breadth of data gathered over 13 months of fieldwork in order to weave an ethnographic account of how COPD was being lived-with and cared-for in two cities in Uruguay in 2010. My predominant focus was on diagnosed COPD and what happens to people once they are diagnosed, as this was the period of their illness journey that I could directly observe. From shared conceptions of air, climate and breathing to illness narratives, inequalities, and opportunities, this thesis has made a unique contribution to both the anthropology of chronic illness and to the qualitative health literature on the experience of COPD. It attests to the importance of ethnography in the study of chronic illness. Ethnographic ways of researching and presenting material can help fill the gaps left by less contextualised and more uni-perspectival contributions in the health sciences.

In this thesis, each chapter can stand alone as they handle particular topics each with their own guiding argument and contribution. Together, they represent pieces of a puzzle drawn together to construct a representation of what living with and caring for COPD looks like in a developing country context. It gives an inside view into the complexities of COPD for healthcare institutions, health professionals, patients and families from which one can theorize on appropriate and sustainable avenues for addressing inequalities in care and preventing and treating the disease. In this concluding chapter I want to revisit and synthesise the original contribution of each chapter. There is always more to explore and in recognition of this I will also suggest areas and topics for future research.

REVISITING THE CHAPTERS

Chapter 1 introduced COPD as it is understood medically and described why Uruguay was chosen as an important site for carrying-out this research. COPD is a complicated disease to understand and communicate. Underneath its simplistic definition as ‘a mix of emphysema and bronchitis’ lies a far murkier picture of spirometric value cut-offs, reversibility, and distinguishment from asthma. COPD remains a mysterious disease. Not only has it been called many things but it is also equally unclear why some people develop COPD – the so-called

susceptible smoker - and others do not. Recent epidemiological research across five South American countries found Montevideo to have the highest prevalence of COPD and most cases encountered had not been previously diagnosed (Menezes *et al.*, 2008). Such findings, in addition to Uruguay being an equally enigmatic country one hears little about in both daily life and the anthropological literature, motivated my fieldwork there.

In Chapter 2 I ground my work within the anthropological literature on chronic illness. I review the contribution anthropologists have made in this area and outline some of the principal theoretical frameworks that have been drawn-upon; including expalantory models, narrative theory and critical perspectives. Then I turn to outlining my original theoretical framework for this research which was to combine a sensorial medical anthropological approach with a political-economy of health perspective. I track the development of sensorial medical anthropology as it is defined by Nichter (2008a) from its phenomenological roots and argue that Scheper-Hughes and Lock's (1987) three bodies and Merleau-Ponty's (1958) *Phenomenology of Perception* bridge phenomenology and sensorial anthropology. I contend, however, that my approach stems from a slightly different interpretation of the three bodies. I argue that if one sees the individual sentient body as the location for the expressions of the social body and body politic, then a phenomenological, or sensorial, approach to their investigation is possible. The theoretical framework underpinned the way I organized fieldwork and my choice of methods. The research responds to a call in the literature for more sophisticated forms of phenomenological research (Desjarlais & Throop, 2011), which draw on different methods and highlight factors in play outside the individual body.

In Chapter 3 I describe the study as multi-modal and multi-sited for I incorporated a multitude of visual and creative methods into my ethnographic approach and engaged in repeated participant-observation in a wide variety of sites frequented by my participants including homes, outpatient clinics, hospital wards, smoking cessation groups, professional meetings and organizations, community-awareness activities, the Ministry of Public Health, ambulances and rural medical rounds, among others. My multi-sited approach to fieldwork meant that I could participate-in and observe a wide variety of healthcare contexts such as inpatients, outpatients, rehabilitation, rural care, homecare and emergency care, as well as comprehend the perspectives of those working within them. Because of this breadth I was able to detect where coordination issues were a problem, where departments could improve their communications and how particular health professionals, like smoking cessation specialists,

could be mobilized to work towards better prevention and treatment of COPD. The chapter takes the second of Sanjek's (1990a) pillars of ethnographic validity, 'the ethnographer's path', seriously and provides a more transparent rendition of a methodology section than is usually the case in ethnographies. This description includes how I met the people I met, how I accessed the institutions I accessed and what kinds of information were gathered and from whom.

In Chapter 4, the reader is introduced to the history of Uruguay in terms of its citizenry and its healthcare system. The chapter presents an alternative structure to a historical narrative by focusing on the question "who are Uruguayans?" Drawing on Uruguayan authors and literature, it highlights how ethnicity discourse has been attenuated, and even written-out of history in Uruguay. Although there is little mention of ethnicity in the rest of the thesis, as it was a topic infrequently discussed by participants, I argue that recent data demonstrate how poverty is an ethnic issue in Uruguay and as the poor are more likely to use the public institutions, so too is healthcare. At the time of my fieldwork the country was prospering and recovering from a devastating economic crisis in 2002. The leftist coalition party was embarking on its second term under the leadership of a new president Pepe Mujica, which meant the party's healthcare reform, begun in 2005, could continue. The reform is aimed towards addressing the growing gap between public and private healthcare and was tackling risk-factors for chronic diseases such as smoking.

Chapter 5 explores the sensations of breathing and breathlessness by drawing on fieldnote data on the topic of breathing, air, weather and climate. The qualities of air, whether humid, dirty or cold, are perceived to interact directly with the body and produce health-effects, namely congestion, coughs, colds and flu. Breathless sensation is therefore a form of environmental embodiment. The narratives from some participants with COPD suggest that the qualities of certain kinds of air not only cause acute breathing difficulties but overtime, exposure to air that is humid and cold or changing in temperature, could contribute to the development of COPD. Social practices to avoid such risks are incorporated into daily life, such as avoiding drafts, avoiding drastic changes in temperature, staying indoors and covering one's mouth. The chapter draws together the literatures on the phenomenology of breathing and the anthropology of weather and wind and argues that ecological concepts such as sensory ecology (Shepard, 2004) are important for sensorial medical anthropologists undertaking research on illness experience. Placing breathing in social and cultural context is necessary background for the interpretation of illness narratives presented in Chapter 6.

My approach to fieldwork as already described focused on including participants with wide-ranging experiences of COPD. The qualitative literature on COPD tends to miss-out on the breadth of experience because it includes participants from inpatient or rehabilitation settings who are symptomatic and who have moderate to very severe airflow obstruction. My study included participants in outpatient settings which widened the breadth of illness experience captured, by essentially making it possible to recruit people with mild or stable COPD. The aim of Chapter 6 is to explore the diversity of ways in which COPD is “expressed”. Expressions of COPD as hope, as something of the past, and as acute episodes are added to the medical literature’s primary definition of COPD as incurable, degenerative and disabling. It is argued that the language of breathing difficulties helps one understand the embodied experience of the sensation and can help differentiate expressions of the disease. Lastly the ways in which COPD in the body is imagined are discovered to be co-constructed amongst my participants and these images of their lungs help frame the interpretation of sensations. Whereas regular interviewing would have led more quickly to data-saturation, multimodal methods provided the opportunity for participants to approach the topic from a different angle, generating rich data which led to new insights. Importantly the chapter situates COPD as a prime example of a disease which blurs the boundary between acute/chronic, curable/incurable and infectious/non-infectious, locating it among a growing body of literature in the anthropology of chronic illness (Manderson & Smith-Morris, 2010).

While Chapter 6 looks for the diversity of ways COPD can be expressed, Chapter 7 demonstrates how these expressions can be deeply shaped by the political-economy of healthcare. The first section provides an overview of the complexity of healthcare and shows how spending on healthcare varies depending on factors such as the availability of medication or oxygen at one’s institution, or the conventions employers have signed with their employees’ healthcare providers. In the second section of the chapter I explore, via the story of one particular family struggling with COPD, a number of pillars of COPD care, such as diagnosis, inpatient care and the role of families, homecare, end-of-life care, genetic testing, and home oxygen therapy. By comparing Marcelo to other participants I uncover not only what is lacking in care for COPD but also the resources Uruguay has at its disposition within family and state care. It is argued that COPD is something created and can be made into a terminal or a chronic disease. The chapter clearly illustrates inequalities and the contextualized lived-experience of COPD expressed through the individual, social and political bodies of patients and families. This

adds a unique perspective to the current qualitative literature on COPD which has focused predominantly on de-contextualised, high-income countries.

In Chapter 8 I take an exploratory approach to comparing two other pillars of COPD care to which access is also inconsistent: pulmonary rehabilitation and smoking cessation. I contend that as intersubjective forms of care, they create space for ‘sensorial work’ to occur. This work is comparative amongst participants and can lead to sharing information which can be supportive or occasionally distressing or confrontational. In these spaces sensations are made meaningful socially and with the participation of healthcare professionals sensations which can be distressing, such as embodied memories of breathlessness (a topic recurring throughout the thesis), are re-scripted through guided ‘techniques of breathing’. I show that smokers are also aware of their breathing and experience different sensations as they cut down and quit. These sensations are explored intersubjectively in the group context and health professionals attempt to guide participants towards re-scripting their changed breathing sensations by drawing on images and metaphors of purification.

Chapter 9 draws the previous chapters together by considering how the ethnographic data presented in this thesis can critically inform public health goals in COPD care, namely 1) to diagnose COPD and diagnose it earlier, 2) to prevent already diagnosed COPD from getting worse and 3) to prevent COPD altogether by reducing exposure to risk-factors. I recognise the complexity of the first goal but suggest sustainable avenues for working towards it. I argue that the current organisation of smoking cessation services, and the professionals within, could be capitalized upon to screen for COPD among smokers and to repackage smoking cessation explicitly as a treatment for COPD, on a par with other treatments such as inhalers, corticosteroids and oxygen-therapy. Furthermore, the importance Uruguayans place on the qualities of air suggest that focusing on the symbolism of “pure, clean air” in public health awareness campaigns would fit cultural and explanatory models. Furthermore, such an approach would take into account the growing body of research on the risks posed to lung health of indoor, outdoor and occupational pollution, in addition to tobacco smoke.

DIRECTIONS FOR FUTURE RESEARCH

Because this study was on diagnosed COPD, I focused on specialist outpatient services and hospital in-patient services as a way of meeting people diagnosed with COPD. However, an equally interesting approach might have been to explore COPD in primary care. For the

timeframe of my study this was not deemed feasible or desirable as the means for diagnosing COPD (spirometry) are scarcely available in Uruguay without referral to a specialist. However, a study which focused not on diagnosed COPD but on symptoms of breathlessness alone, at the primary care level, could uncover interesting information about what COPD may look like at even earlier stages or uncover more information on how referrals can be delayed. I was able to uncover some of this information through the retrospective accounts of my participants, but first hand observation could be useful.

Furthermore, my focus on diagnosed COPD at the hands of specialists also meant that the contexts I circulated in led me to focus far greater attention on physicians than on other health professionals. I have already demonstrated how prevalent doctors are in Uruguay and how they frequently occupy the posts which in the UK would be occupied by nurses or physiotherapists (such as pulmonary rehabilitation and smoking cessation). Nevertheless, because my focus after recruitment was on people with COPD and their families in the home context, I had little time to spend engaged in participant-observation in nursing stations. When I observed nurses it was generally from the patient and family's point of view which was not always positive towards these professionals as could be seen in Chapter 7. This also made me wary of appearing 'too close' to the healthcare professional staff and therefore I made a conscious choice to align myself more firmly with families and friends visiting at the bedside than with nurses or physicians located in their offices or stations. However, nurses spend a lot of time caring for people with COPD when hospitalized and manage their inpatient care. Therefore, investigating their work more closely would make an important contribution to future research on COPD in Uruguay.

The medicinal gas and inhaled-medication industry is also a fruitful area for further research. People's struggles for oxygen were some of the most poignant examples of suffering with COPD I witnessed. While I investigated the issue in terms of provision within Uruguay, costs, and any policy enacted at the government level, I could not, within the scope of this study, investigate oxygen-therapy or pharmaceuticals from a global perspective. While inhaled medications succumb to the same rules of global markets as any other medication, it would be interesting to see whether the medicinal gas industry is simply an extension of the pharmaceutical industry or whether it operates differently. Furthermore, understanding the development of oxygen-concentrator technologies, who produces them, and where they are used, is also a fascinating and important topic for future research.

FINAL THOUGHTS

This thesis has achieved the aims for which it was set out. It has contributed an original ethnography on a little known disease in a little known place. The methods and theoretical framework supported an approach to fieldwork, interpretation and presentation of the data which was novel in its achievement of the aims and objectives set forth in Chapter 1. It has come to a richer understanding of the experience of breathlessness; found that such a sensation has a cultural and social context in need of exploration; analyzed how the political-economy of healthcare expresses itself at the family and individual level; and demonstrated that ethnographic approaches to the study of chronic illness can support the analysis of challenges and opportunities for improvements in healthcare delivery and health policy.

As COPD climbs its way to the position of the 3rd most important cause of death globally, its name will go from being a relative unknown to a term as pervasive as diabetes or heart disease. With countries in the global South doubly burdened by the risk posed to their citizens by being exposed to both cigarette smoke and to occupational and household pollution, rates of COPD will continue to rise there. As such, healthcare demands, particularly for hospitalization for acute exacerbations and for oxygen-therapy, will also rise, as will the number of people disabled by breathlessness and unable to work, particularly people who make a living through manual labour. So much depends on the interpretation of a sensation: breathlessness. How breathing and breathlessness are conceptualised and interpreted in local cultural contexts, how it expresses itself in language and narrative, the social response it elicits and the emotions which go hand in hand with it will drive or delay both healthcare seeking on the part of the patient and detection on the part of healthcare professionals. The time is ripe for ethnographic studies of the sensorial experience of COPD, in diverse settings, across the socio-economic spectrum. Such research can pre-empt the need for creative public health approaches to prevention and treatment of COPD in developing countries, where it is currently, the elephant in the room.

Appendix A

Qualitative Research Publications on the Experience of Chronic Obstructive Pulmonary Disease. QHR = Qualitative Health Research

Author	Topic	Journal Type	Sample	COPD severity	Methods	<i>n</i>	Country	Analytical Framework
Rocker <i>et al.</i> , 2012	Use of opioids	Medicine	Patients, family caregivers physicians	Advanced	Semi-Structured Interviews	8 patients 12 caregiver 28 physician	Canada	Interpretive description
de Sousa Pinto & 2012	Experiences of care-givers	Public Health	Family carers	Not specified but enrolled in pulmonary rehabilitation	Ethnographic interviews and participant-observation	6	Brazil	Contextualized semantic narrative analysis
Hynes <i>et al.</i> 2012	Informal care-giving	Nursing	Family care-givers	Advanced	Semi-structured interviews	11	Ireland	Hermeneutic Phenomenology and Thematic Analysis
Ek <i>et al.</i> 2011	Illness Experience and living alone	Nursing	Patients	Advanced	Repeated interviews (4-5 each) telephone calls and field notes	4	Sweden	Phenomenology
Ek <i>et al.</i> 2011	Experience of couple-life	Palliative Care	Couples	Advanced and oxygen-dependent	Interviews (19)	4 couples	Sweden	Phenomenological-Hermeneutic
Williams <i>et al.</i> 2011*	The Experience of activity and air	QHR	Patients	Moderate to very severe	Semi-Structured interviews and field notes	18	England	Grounded Theory
McMillan Boyles <i>et al.</i> 2011	Disability	QHR	Patients	Advanced	Focused eth	15	Canada	Narrative Analysis
Crawford 2010	Experiences of health professionals with EOL life	Nursing	Nurses (5) and Doctors (2)	Advanced	Interviews	7	England	Phenomenology Thematic Analysis
Lohne <i>et al.</i> 2010	Pain Experience	Medicine	Patients	Moderate and Severe	Semi-Structured Interviews, Pain Questionnaire, Medical Records	16	Norway	Thematic Analysis and Descriptive Statistics
Spence <i>et al.</i> 2009	Experience of providing palliative care	Medicine	Health and Social care Professionals	End-Stage	Focus Groups (2) Interviews (6)	23	Northern Ireland	Thematic analysis
Hasson <i>Et al.</i> 2009	Experiences of bereaved carers	Palliative care	Carers (not spouses)	End-Stage	Semi-Structured interviews	9	Northern Ireland	Content Analysis
Wilson <i>et al.</i> 2008	Care needs at home	Aging	Patients	Elderly/Advanced oxygen	Interviews (3) and field	12	Canada	Ethnography Constant

				dependent	notes			comparative thematic analysis
Gullick & Stainton 2008	Illness experience and management	Nursing	Patients and Family	Severe (had elected surgery)	Interviews (58)	29	Australia	Phenomenology
Chen et al 2008	Self-Management Behaviours	Nursing	Patients (men)	Mild, Moderate and Severe	Interviews	18	Taiwan	Grounded Theory
Habraken et al 2008	Illness experience and help-seeking	Medicine	Patients	End-Stage	Semi-Structured Interviews	11	Netherlands	Thematic Analysis
Hasson et al 2008	Palliative Care	Nursing	Patients	Advanced	Semi-Structured Interviews	13	Northern Ireland	Thematic Analysis
Lomborg & Kirkevold 2008	Nurse-Pt interactions body-care	Nursing	Patients and Nurses	Severe	Participant-Observation, interviews, questionnaire	12 dyads	Denmark	Grounded Theory
Ek & Ternestedt 2008	EOL experience	Nursing	Patients	Severe (6 on oxygen)	Interviews (open-ended)	8	Sweden	Phenomenology
de Sousa Pinto et al., 2008	Illness experience of urban poor	Public Health	Patients	Not specified (but enrolled in pulmonary rehabilitation)	Interviews and participant-observation	6	Brazil	Ethnography Thematic and semantic analysis
Curtis et al 2008	Desire of prognostic info	Palliative Medicine	Patients, family, physicians and nurses	Severe COPD (also included cancer)	Open-ended Interviews	55 patients 36 family 31 physicians 25 nurses	USA	Grounded Theory
Goodridge et al 2008	Experiences of caring for critically ill	Nursing	ICU clinicians	Acutely ill COPD	Focus Groups (3) and Interviews (3)	15 Nurses 2 Respiratory Therapists	Canada	Thematic analysis
Castro, 2008	Continuity of care	Masters' Thesis	Patients and HCPs	Moderate to severe	Semi-structured interviews and patient records	4	Spain	Narrative Analysis
Horton 2008	Telecare evaluation	Nursing	Home care teams	Varied	Focus Group (1) and Case Studies	4	England	Thematic analysis
Gruffydd-Jones et al 2007	Medical, social, psychological are needs following discharge	Medicine	Patients	Varied	Focus Groups, questionnaires, records and structured Interviews	25	England	Thematic analysis Interpretive Phenomenology Descriptive Stats
Jonsdottir & Jonsdottir 2007	Women and Smoking	Nursing & Social Science	Patients (women)	Severe	Interviews	7	Iceland	Interpretive Phenomenology

Schofield et al. 2007	Smoking health beliefs	Nursing	Patients	Elderly	Semi-Structured Interviews	22	Scotland	Health Belief Model
Kanervisto et al. 2007	Illness experience	Nursing	Patients and Spouses	Severe	Interviews	9	Finland	Content-Analysis
Hansen et al. 2007	Smoking health beliefs	Sociology	Patients	Varied	Semi-Structured Interviews (30)	19	Australia	Grounded Theory and Narrative Analysis, Explanatory Models
Yu et al. 2007	Recurrent hospital admissions	Nursing	Patients	Severe	Unstructured Interview	5	China	Thematic Content-Analysis
Williams 2007*	Illness Experience and social aspects	Respiratory Medicine	Patients	Moderate to Severe	Semi-Structured interviews	6	England	Thematic Analysis
Odencranz et al. 2005	Experiences of eating	Nursing	Patients	Various	Interview and self-report diaries	13	Sweden	Content Analysis. Descriptive Statistics
Barnett 2005	Everyday experiences	Nursing	Patients	Moderate and Severe	Unstructured Interviews	10	England	Phenomenology
Robinson 2005	Illness Experience	Nursing	Patients	Severe	Unstructured Interviews	10	England	Mind-mapping
Monnikhof et al. 2004	Experience of Self-management programme	Counselling	Patients	Not Specified	Semi-structured interviews	20	Netherlands	Grounded Theory
Cicutto & Henderson 2004	Experience of self-care	Counselling	Patients	Symptomatic (daily)	Focus Groups (7)	42	Canada	Constant comparative thematic analysis
Seamark et al. 2004	Illness experience	Medicine	Patients	Severe	Interviews	9	England	Interpretive Phenomenology
Bailey 2004	Anxiety-dysnea relationship	QHR	Patients, family, nurses	Not specified. Long-term with history of exacerbation	Interviews and medical records	10 (triads)	Canada	Narrative Analysis
Nicholls 2003	Experience of breathlessness	Physiotherapy	Patients	Varied (in pulmonary rehabilitation)	Life-History Interviews	10	New Zealand	Phenomenology
Heinzer et al. 2003	Emotional aspects of acute breathlessness	Nursing	Patients	Not Specified (hospitalized and not newly diagnosed)	Semi-Structured open-ended Interviews and questionnaire	41	USA	Content Analysis
Jeng et al. 2002	Experiences post-hospitalization	Nursing	Patients	Not specified - elderly and recently discharged	Interviews	9	Taiwan	Constant comparative content analysis
O'Neill 2002	Illness Experience (women)	Nursing	Patients	Varied	Interviews Symptom diaries (4)	21	USA	Common-Sense Model Thematic Analysis
Bergs 2002	Quality of life of	Nursing	Wives of men with	2 years and no-longer	Unstructured Interviews	6	Iceland	Phenomenology

	female carers		COPD	working	(10)			
Guthrie et al. 2001	Illness Experience	Medicine	Patients	Severe	Repeated Interviews	20	England	Content Coding
Bailey 2001	Experience of acute exacerbation	Qualitative Health Research	Patients, family and nurses	Hospitalized long-term sufferers	Interviews	10 family- nurse units	Canada	Narrative Analysis
Small & Lamb 1999	Fatigue	Nursing	Patients	Varied	Semi- Structured Interviews	17 (COPD) 19 (asthma)	Canada	Thematic Content Analysis
Leidy & Haase 1996	Functional Performance	Nursing	Patients	Moderate to Severe	Open-Ended Interview	12	USA	Thematic Analysis
DeVito 1990	Perceptions and feelings of dyspnea and care	Critical Care	Patients	Not specified – Symptomatic and 1 hospitalization	Semi- structured Interviews	96	USA	Content Analysis
Total: 47								

Appendix B

Study Information Sheet



Discursos sobre la Enfermedad Pulmonar Obstructiva Crónica (EPOC), el Tabaquismo y su Cesación en el Contexto Cultural y Político del Uruguay

Investigadora:

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Supervisores Académicos:

Dr. Andrew Russell, Dr. Peter Collins, Dra. Susana Carro-Ripalda, Facultad de Antropología, Universidad Durham, Inglaterra

Soy una estudiante Canadiense de doctorado en antropología en Inglaterra. Esta investigación etnográfica se propone investigar los aspectos sociales, culturales y políticos de la enfermedad de obstrucción pulmonar crónica (EPOC). Quiero hablar no solo con personas con EPOC y sus familias, sino también con fumadores corrientes y fumadores que dejaron o están dejando de fumar, así como con profesionales de la salud, políticos, y trabajadores en organizaciones locales. Me interesa conocer las diferentes opiniones, experiencias y percepciones que expresan las personas acerca de las leyes sobre el tabaquismo y el sistema de salud. También estoy interesada en entender cómo se conforma la relación paciente-profesional de la salud a lo largo de una enfermedad crónica. Todo la información que comparten conmigo y lo que observaré, informaré la tesis que voy a escribir por mi doctorado. Pero voy a proteger su anonimato en mi tesis y otras publicaciones.

Elegí Uruguay por varias razones. Por ejemplo, el sistema de salud tiene muchos puntos en común con el Canadiense y el Británico, dando la posibilidad de establecer comparaciones relevantes (aunque estas comparaciones no van a ser parte del proyecto del PhD). También, la existencia de una clase media, de un sistema mutualista y público y la nueva reforma hace posible que muchas personas tengan acceso a alguna forma de cobertura médica. Uruguay une mi interés en culturas latinoamericanas y el estudio de enfermedades crónicas, como la Obstrucción Pulmonar, ya que en Uruguay esta enfermedad tiene muchos casos si se compara con la realidad de otros países de América Latina. Para terminar, la relativamente reciente ley anti-tabaco aporta interés desde el punto de vista político y sanitario a un estudio sobre enfermedades relacionadas al consumo de tabaco. Por supuesto, quiero conocer las percepciones de fumadores sobre la ley y sus percepciones de salud y enfermedad y también la importancia de tabaco en su vida.

Si tiene preguntas sobre la investigación, o, si quiere participar o si conoce una persona que quiera participar, puede llamarme o escribirme un correo. ¡Muchas gracias!

Appendix C
Consent Form



CONSENTIMIENTO DE PARTICIPACION

Discursos sobre el EPOC, el tabaquismo y su cesación en el contexto cultural y político del Uruguay

Investigadora:

Megan Wainwright, MSc, Estudiante de doctorado en Antropología, Universidad Durham, Inglaterra. E-mail: m.j.wainwright@durham.ac.uk Movil: 094214507

Por favor responder “si” si estas de acuerdo:

¿Has leído el documento que describe el proyecto? Si No

¿Has recibido información suficiente sobre el proyecto? Si No

¿Has entendido que todo lo que puedes compartir con la investigadora alimentara su tesis y trabajo académico futuro y podría utilizar algunas citas acerca de tu entrevista? Si No

¿Estás de acuerdo que las entrevistas sean grabadas? Si No

Algunas aclaraciones: Responde “si” para afirmar que las has leído:

- Puedes dejar de participar en la investigación o dejar una entrevista en cualquier momento, y sin la necesidad de dar una explicación. Si No
- Citas y otra información no serán identificadas con tu nombre, en caso de ser necesario se utilizara un seudónimo. Si No
- Todos los datos de la entrevista serán protegidos por password, lo que significa que únicamente la investigadora puede tener acceso a ellos. Si No

Muchas gracias por el aporte que realizas a esta investigación para continuar contribuyendo para al desarrollo del conocimiento acerca de esta temática.

Signed..... **Date**.....

PARTICIPANTE – **Aclaracion**.....

Signed..... **Date**.....

INVESTIGADORA – **Aclaracion**.....

Appendix D
Demographic Questionnaire



INFORMACION GENERAL

Muchas gracias por su participación en mi investigación. Estoy solicitando a todos mis participantes que responden a las preguntas siguientes para ayudarme a mejor entender las experiencias de cada uno. Responder es voluntario y tienes el derecho de no responder a cualquier pregunta. Su anonimidad será protegida en mi proyecto lo más que pueda y muchos de los datos siguientes serán discutidos de manera general en el caso de utilizarlos. Sería un placer discutir cualquier duda o pregunta que tuvieras.
Megan Wainwright – Estudiante de Doctorado en Antropología Médica -
094214507

DATOS DEMOGRAFICOS

1. ¿Fecha de nacimiento? ¿Y donde naciste?

2. ¿Estado civil?

3. ¿Si tienes hijos, cuántos hijos?

4. ¿Cuántos personas viven en tu hogar? _____

5. ¿Vives en?:

- Casa
- Apartamento

6. ¿Cuánto otras propiedades inmuebles? _____

7. ¿Cuánto habitaciones tiene la casa?

8. ¿Tiene calefacción? Que tipo?

9. ¿Tiene agua caliente?

10. ¿Cuál es tu profesión?

11. ¿Trabajas en ese momento? ¿Si no, hace cuanto tiempo que estas sin empleo?

12. ¿Cuál es su ingreso familiar mensual después de los impuestos?

13. ¿Tienes una religión?

14. ¿Eres practicante?

15. EDUCATION

EDUCACION	PUBLICO	PRIVADO
Primaria		
Liceo (secundaria)		
Universidad (licenciatura)		
(sujeto)		
Universidad (postgrado) (sujeto)		
Técnico (sujeto)		
Terciario/Otro:		

HISTORIA FUMADOR Y SALUD

16. ¿En general cuantos cigarrillos fuma(aba) y por cuantos años?_____

17. ¿Si dejaste de fumar, cuando dejaste?

18. ¿Dejaste solo o con ayuda de algún servicio?

19. ¿En que año fuiste diagnosticado con EPOC?

20. ¿Eres oxígeno dependiente? ¿Desde cuándo y cuantos horas por día utilizas oxígeno? ¿Qué cantidad?_____

21. ¿Cuántos veces estuviste internado por problemas respiratorios y cuando?

22. ¿Qué medicamentos tomaste por el EPOC?

23. ¿Tienes asma?

a) ¿Desde cuándo?

b) ¿Hiciste un espirometria (soplar en una machina) por diagnosticarlo?_____

24. ¿Tienes otras enfermedades? ¿Cuáles?

25. ¿Tomas/Tomaste yuyos? ¿Cuales son y porque?

26. ¿Utilizas otros tratamientos naturales o alternativos por cualquier problema de la salud?

SERVICIOS DE LA SALUD

27. ¿Eres en el

FONASA? _____

a) ¿Desde

cuándo? _____

b) ¿Cambiate de hospital/sanatorio con el

FONASA? _____

28. ¿Donde recibes servicios de la salud (nombre del hospital, sanatorio, mutualista o sociedad

médica)? _____

a) ¿Desde

cuándo? _____

b) ¿Cuánto te cuesta por

mes? _____

c) ¿Pagas tickets? ¿Cuánto salen?

d) ¿Cuánto gastas en medicamentos por mes?

e) ¿En oxígeno?

f) ¿Tienes un medico tratante? ¿Si llamas a tu médico tratante cuanto tiempo esperas para una consulta?

g) ¿Tienes un médico de cabecera (general o de familia)? Si llamas a tu médico cabecera cuanto tiempo esperas para una consulta?

h) ¿Si llamas para ver un medico en policlínica cuantos días esperas para una consulta?

i) ¿Si te presentas en la puerta de urgencia cuanto tiempo esperas para ver un medico? _____

j) ¿Tu hospital/sanatorio tiene un servicio de medico al domicilio? Cuanto demora para llegar? _____

29. ¿Tienes seguro de emergencia móvil? _____

a) ¿Cuál? _____

b) ¿Desde cuándo? _____

c) ¿Cuánto cuesta por mes? _____

d) ¿Cuánto veces utilizó el servicio de emergencia en un año? _____

e) ¿Utilizaste cuantos veces por el EPOC? _____

30. ¿Tienes un seguro de acompañante? ¿Cuál, cuánto cuesta y cual es la cobertura? _____

Fecha: _____

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