The secret ring:: knowing asthma in Teeside's children

Alison Todd

THE SECRET IN THE RING:

KNOWING ASTHMA IN TEESSIDE'S CHILDREN

Alison Todd

Submitted for the degree of Doctor of Philosophy
University of Durham
Department of Anthropology
Centre for Integrated Health Care Research, School for Health
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ABSTRACT

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Asthma in children in Teesside in the north east of England is the subject of my research. Asthma is the most commonly diagnosed chronic health problem of childhood in the United Kingdom and its prevalence has increased markedly in recent decades. Previous research has identified it as being a particular health concern of people in Teesside.

'What is asthma?' is my central research question, and I seek its answer in how people talk about asthma. My data is derived from semi-structured interviews with children with asthma and their families, observation of their consultations with health professionals in asthma clinics, and unstructured interviews within, and participant observation of, their local community.

Asthma is presented as different modes of 'unhealth' – illness, disease, sickness and diagnosis, the last being a sub-category of, or the same as, sickness. Relationships are created between these different modes of asthma and other unhealths. Research focuses upon the contributions of biology, culture and history to asthma in Teesside's children. I show how relationships between the self and the other, the individual and the population, and the local and wider worlds contribute to how asthma is known in them. Throughout, a contrast is drawn between asthma as a thing and asthma as a word. Central to my argument is that the contribution of things and words to asthma is variable, and uncertainty over their respective contributions gives asthma its potency.

The dissertation is, however, also about researching asthma. Reflexivity guides my research and I discuss how my dual background in medicine and anthropology has influenced my approach to researching asthma and to writing about it. Disciplines, I argue, discipline the practice and presentation of research: what asthma was when I practised medicine is not what I have researched here as an anthropologist.

DECLARATION

The research cited on p.16 was submitted as part fulfilment of a Masters in Public Health in Developing Countries at the London School of Hygiene and Tropical Medicine in 1995.

STATEMENT OF COPYRIGHT

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ACRONYMS

ADHD	Attention defecit hyperactivity disorder
AHR	Airway hyperresponsiveness
BTS	British Thoracic Society
DLA	Disability Living Allowance
EBM	Evidence based medicine
FEV_1	Forced expiratory volume in one second
FVC	Forced vital capacity
GP	General Practitioner
HP	Health professional
ISAAC	International Study of Asthma and Allergies in Childhood
LFTs	Lung function tests
NAC	National Asthma Campaign
NHS	National Health Service
PE	Physical education
PEFR	Peak expiratory flow rate
RIU	Research and Intelligence Unit
SATS	Standardized Assessment Tests
SES	Socioeconomic status
SIGN	Scottish Intercollegiate Guidelines Network
THA	Tees Health Authority
UK	United Kingdom
WHO	World Health Organization

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Part 1 – Stages

Chapter 1 INTRODUCING ASTHMA

> [T]he professional thinker within us relates to our various other selves ... to the lover, parent and friend, to the citizen, poet or mystic, and to the social being living in close and committed relations with so many other people and things.
>
> Mary Midgley[1]

[1] Midgley (1989:29)

1.1 PRESENTING ASTHMA: BEGINNING AT THE END

> 6.552. There are indeed, things that cannot be put into words. They *make themselves manifest*[2]...
>
> 7. What we cannot speak about, we must pass over in silence.
>
> Ludwig Wittgenstein[3]

If so, I end here. If not, I begin with asthma.

Asthma can affect anyone but childhood asthma is my subject, and the United Kingdom (UK) has the greatest percentage of children with symptoms of severe asthma in the world (International Study of Asthma and Allergies in Children (ISAAC), 1998). In the UK it is the most commonly diagnosed chronic health problem of childhood (Rees and Kanabar, 2000), affecting around 1.5 million children (National Asthma Campaign (NAC), 2002). In 1997 when my research began 23% of boys and 18% of girls aged 2-15 years in England had a doctor diagnosis of asthma. It was twice as common as 30 years ago and six times as many children as then were affected at least once every week (NAC Asthma Audit, 2001). A quarter of children with current symptoms have at least one night of sleep a week disturbed by their asthma, a third miss more than a week of school each year, and two thirds are restricted in their everyday activities (NAC, 1997/8; NAC 1999/2000). General practitioners (GPs) in 1993 were four to five times more likely to give a child a diagnosis of asthma than in 1979 (NAC, 1997/8). Now it is responsible for 1 in 20 GP consultations with children, and our National Health Service (NHS) spends more than £250 million annually treating it (NAC, 2002).

But what is asthma? That is my principal research question, and to answer it now would, speaking metaphorically, be to reveal the criminal on the last page of the detective story. I have, however, introduced it above as a health problem or what Marinker has termed "an unhealth" (1975:83). Health and unhealth are, according to Boyd (2000), elusive concepts so my dissertation begins with asthma as a word. Asthma is what anyone says is asthma, and as it is what any one person says is

[2] Unless stated, all emphases are in the original.
[3] In Midgley (1989:222)

asthma, it is a single instance of that word. If I were to present you with the first instance of that word it would be with what Aeneas had when he emerged victorious from battle around 700BC in Homer's *The Iliad* (Marketos and Ballos, 1982). In reality, it was what he was doing – panting – rather than what he had. Asthma as a word, was born in the archetypal Greek hero, and conceived by an epic storyteller.

Asthma was not therefore conceived of as an unhealth, but in the writings of Aretaeus, a Cappodochian medical practitioner of the second century AD it became so (Sakula, 1988). Unhealth exists in multiple modes (Marinker, 1975; Boyd, 2000). Illness[4] is a "feeling, an experience of unhealth which is entirely personal, interior to the person of the patient" in contrast to disease which is a "pathological process". (Marinker, 1975:82). "[I]llness" then, according to Cassell, "is something a man has"; "disease ... is something an organ has" (1976:42). The word asthma might therefore signify a personal experience and/or a material reality – what Erikson (1964:220) has termed "an actuality"[5].

How are these known? Firstly, those who have it may feel it, and hence know it in themselves. Secondly, others might sense it in them, or it might be communicated to others, not via the senses, but via words. Communication of unhealth signals the entry of the other whose presence makes personal unhealth, social. "If illness is an interior and personal mode ... sickness is the external and public mode of unhealth" (Marinker, 1975:83). Sickness is diagnosed by the other, but according to which unhealth – illness, disease or both? Sickness is founded upon "possession of that much treasured gift, the disease" (Marinker, 1975:83). It is most certain when the diagnostician believes the ill person to be possessed by the disease claimed, because as Rosenberg (1997:39) adeptly states, "[w]e are most comfortable with ills that have a discrete, material and well-understood basis – a basis demonstrable in the laboratory and at postmortem".

[4] I use unhealth as a general term rather than ill-health because the latter shares its prefix with illness.
[5] Erikson (1964:220) distinguishes between the "world as a reality also perceived and judged by others and as an actuality within" which we interact with others. His actuality is more real to me.

Illness originates in the ill person as a state that in Middle English was difficult, unpleasant and hurtful if not downright wicked, harmful and immoral (Boyd, 2000). Originally, as a derivation from *illr* in old Norse it was also of unknown origin (*The New Oxford Dictionary of English*, 1998). Disease, by contrast, is given by the doctor, because illness is "what the patient feels when he goes to the doctor" and disease is "what he has on the way home from the doctor's office" (Cassell, 1976:42). Disease originated in Old French as *desaise*, meaning lack of ease, while pathology – its material signature – is derived from the ancient Greek knowledge of suffering (*The New Oxford Dictionary of English*, 1998). Does its word imply that it might once have been the feeling of dis-ease that now defines it as an illness? Boyd (2000) suggests not. "Dis-ease ... is literally the absence of ease or elbow room. The basic idea is of an impediment to free movement" (ibid:17). It belonged nevertheless to the bodily space of everyone before medicine transformed people into patients (Conrad, 1990) and confined disease to its own spaces.

Foucault (1963) documents medicine's confinement of disease to its spaces such that today it alone has the power to give disease to its patients. Disease can be so powerful that according to Richard Gordon, the author of the *Doctor in the House* series, medicine's ultimate personification "the consultant owned the patient's illness"[6]. Medicine's diagnostic authority by which it gifts disease is founded upon a body of specialized knowledge and a legally sanctioned right to practice it (Helman, 2001). I have democratized asthma. If asthma is what anyone says it is then anyone can diagnose it, gift it and thereby create, or attempt to create, sickness[7] in another out of the word asthma. Consequently, this dissertation begins by reducing asthma's medical diagnosticians and donors to their lay counterparts.

The diagnosis of asthma is central to my research. Like asthma, diagnosis was born as a word in Greece as a composite of *dia* 'apart' and *gignōskein* 'recognize, know' (*The New Oxford Dictionary of English*, 1998). Hence asthma is diagnosed or known

[6] Interviewed in *Reading the Decades*, BBC2, 6 April 2002, 1910-2010 hours.
[7] Sickness's literary origin is from the Old English *seoc* meaning affected by illness, although the mid nineteenth century added a temporary second meaning of setting someone upon, or pursuing, or accompanying another (*The New Oxford Dictionary of English*, 1998) reminiscent of the lack of elbow room brought by disease.

apart, if it is detected in the person who may or may not possess the word asthma. Thus some have cast the doctor as a detective (Hunter, 1991; Downie and Macnaughton, 2000). Here all are detectives, but the introduction of the detective transforms the disease of asthma from a gift into a crime – into the cases of detectives rather than of doctors. The distinction is not always clear. The Azande of the Sudan treat both unhealth and crime as misfortunes caused by witchcraft (Evans-Pritchard, [1937] 1976) while gift-giving among the native Indians on the northwest coast of America, might be a prelude to an attack by those bearing them (Rosman and Ruebel, 1979). More generally, gifts may be ill-received (Mauss, [1950] 2002).

Re-casting asthma as a crime introduces the criminal. Who has committed asthma? Detectives in stories are though, rarely satisfied with catching the criminal unless they can explain why the crime was committed. Their lay and medical counterparts are no different. 'Why asthma?' both ask, because explaining unhealth is therapeutic to its communication by patients/people (Kleinman, 1988) and by doctors/people (Hunter, 1991). Here, however, asthma's detectives leave the traditional genre because before they begin to solve the crime and catch the criminal, they have to know if a crime has been committed. 'Asthma' – a single instance of the word – has been uttered but 'is the word asthma?' they must interrogate of each case. Hence they must seek its material signature – how it makes itself manifest – in the person with the word. If asthma is an actuality distinct from its word, then it must speak for, and of, itself.

The person with the word is the crime scene, but it is no more than a series of historical coincidences that brought unhealth into the body of the sick person (Foucault, 1963[8]). Equally, a series of historical coincidences might cause a place to become characterized by unhealth (Bush *et al*, 2001). Asthma is common in Teesside (TEES Group, 1995), and Teessiders worry about it (Cornford *et al*, 1993; Cornford, 1998; Cornford 1999). Thus both Teesside and children as alternative or complimentary spaces follow asthma in the title of my dissertation, but my introduction to it so far has begun at the end. Asthma in Teesside's children was not the original subject of my research: to introduce it I have to re-present asthma to you.

[8] Foucault's (1963) analysis focuses upon disease, but is applicable to unhealth in general.

1.2 RE-PRESENTING ASTHMA: BEGINNING AT THE BEGINNING

> Neither I nor my image can see his face, it is enough to know that he is someone's back.
>
> Gao Xingjian[9]

I begin my re-presentation of asthma by introducing you to it as it presented itself to me. In February 1988 I was a final year medical student attached to the paediatric unit of a hospital in a Scottish town. On a Tuesday afternoon I accompanied a consultant paediatrician and his team on their ward round. There was at least one new patient in one of the four-bedded wards. On the left closest to the corridor, a little girl was sitting up in bed, a man to one side of her, a woman to the other. A mask was on her face attached to a machine called a nebuliser whose noise was the only bedside competition to the noise of her breathing. As the team gathered in silence around her bed the man and the woman silently walked to the window at the other side of the ward. All we could see of them were their backs.

Yet I have no memory of the team ever looking at their backs. A thick battered folder of notes was heaved from the trolley. 'Wheelbarrow syndrome' my lips moved silently; its principal diagnostic criteria at my medical school being the need of a wheelbarrow to transport the patient's notes. The consultant flicked to the most recent entry detailing his patient's admission during the previous night. Then silently, looking at his stethoscope, he placed it a few times on the front of the child's chest and on her back. 'Same as usual' was all I remember him saying to his team who remained silent throughout. Something was written in the notes and we moved on swiftly to the next patient and parents and to the noise of the usual greetings and chatter and banter that accompanied this consultant and his team on their daily ward round.

In this, my first remembered meeting with asthma, its modes of unhealth were one. It was as in Norway where there is only one word *sykdom* for illness, disease and sickness "which emphasises that it is researchers' needs which have subdivided the

[9] Xingjian [1990] (2001:313).

meanings rather than social usage[10]" (Wilkinson, 1988:37). It was simply asthma, and asthma simply was. It was an actuality, a material reality that had made itself manifest in the little girl who epitomized Foucault's (1963) space before the birth of modern medicine where things and words had not yet been separated. In her seeing (or more generally sensing) and saying were still one. True, it was a word – a diagnosis – but mainly I remember it as a sensory presence of a noise of breathing and of machines, of eyes on a stethoscope and on a chest, and of an imagined weight of notes in hands. More memorable was the sensory absence of the sound of words or cries or laughs, or of eyes, faces and people being looked at and into, of a hand touching the child or a handshake with her parents. The meeting was devoid of human interaction and it felt very wrong to me.

Presenting this meeting now I have cast the medical student that I was then as the anthropologist in the traditional role of participant observer (Agar, 1996; Hammersley & Atkinson, 1995). The meeting felt so wrong because of its cultural dissonance. Parents in my own society do not of their own accord usually leave young children alone with doctors, and in many other countries to leave an adult relative would be equally deviant (Stacey, 1988). Moreover, the consultant had ignored the patient's (or parent's) account of illness as the fundamental fact in clinical medicine (Hunter, 1991), although in India questioning the patient/parent might suggest lack of medical expertise (Stacey, 1988). What I had observed therefore, had significance only in its cultural context, which in this case I knew by personal rather than anthropological experience. However, like an anthropologist, through further participant observation, conversations with ward staff (though never the child's parents who would not talk to medical students) and consultation of medical records, I looked into this child and her family. Writing this now, I remember her fighting her asthma and her depressed, unemployed parents as they tried to treat it and her inside their cold, damp smoky high-rise flat in a run-down estate emptied of community places or green spaces. Yet, "their selfhood [was] dissolved by [my] gaze ... The human beings have all disappeared" (Helman, 1991:14). Sadly all I can remember of them now, are her asthma and her parents' backs.

[10] Researchers differ in the significance they attach to the terms, the meanings they attribute to them and how they use them. So did those I researched, and I retain their terms when quoting either.

I must have met asthma before then in lectures and textbooks, and in other patients, especially during a previous attachment to a respiratory ward, but I have no memories of it. Moreover, your re-introduction to asthma is retrospective because it began my research as the unhealth I would use to study relationships between living with unhealth and living in poverty. It was not, I had concluded, so much asthma that I had observed, but a family living unhealth – any severe chronic unhealth – in poverty. Asthma had therefore parked itself in my consciousness not as a subject – a destination – but as a means – a vehicle – with which to explore relationships between socio-economic status (SES) and severe chronic unhealth that today I know still as "someone's back" (Xingjian, [1990] (2001:313).

I have re-presented asthma to you because "the reality experienced in the field ... is not the unmediated world of the 'others', but the world *between* ourselves and the others" (Hastrup, 1992:117). Reflexivity guides my research and it requires a consciousness of self and of one's own experiences and their influences on it (Hertz, 1997; Davies, 1999). Consequently the autobiography of the researcher is relevant, integral even, to reflexive research because "[n]obody is only a specialist" (Midgley, 1989:29). Coser (1993), a sociologist and a German Jew, attributes his early life experiences of fascism as contributing to his decision to study social conflict and his rejection of theoretical perspectives emphasising social consensus. It is, however, not only a question of being reflexive or not, but of how reflexive. Revelations differ. Okely (1996a,b) is her own key informant in her analyses of girls' boarding schools and Krieger (1996) makes public her sexuality by revealing that she was a member of the lesbian community she studied. James (1999) by contrast, never returns to her own childhood in her account of her research experiences with primary school children though "buried memories fleetingly and painfully resurfaced" in her writing (ibid:99).

My partial autobiography[11], narrated below, has two aims. Its first is to show how my attitudes to, and experiences of, unhealth and other things have influenced my research. Though I begin with neither medicine nor anthropology they are my focus

[11] My partial autobiography is limited to past experiences that I consider to be of greatest relevance to my research, and that I am willing to make public.

and in particular the significance of the entry of the latter to co-habit with the former. Its second aim is to introduce some of the key literary influences[12] on my research and to relate them to my attitudes and experiences. I range widely because Stone and Lewondo-Hundt (1987) characterize anthropologists as interdisciplinary foragers for knowledge and ideas, in an allusion to the foragers (hunter-gatherers) that were their traditional research subjects. My basic intellectual diet of anthropology and medicine has been supplemented with other social sciences, and I have foraged sparingly from philosophy, especially from the moral philosopher Mary Midgley's (1989) *Wisdom, Information and Wonder: What is Knowledge For?*. Her answer that the "point of knowledge cannot be just to store it. Traditionally, the value of knowledge centred on *understanding* – on the power to see the connections of things, to wonder at them, and so to live wisely" (unpaginated) made it my academic bible long before this research began.[13]

I begin with a visit as a child to London to an exhibition about Pompeii because I left it wanting to be an archaeologist – a profession that like medicine values material reality. I cannot remember beginning to want to be a doctor, but when career choices had to be made, I had to choose between archaeology and medicine. My choice was essentially pragmatic as my wise headmaster advised me that it would be easier to move from medicine to archaeology, and only the latter could be a hobby. I entered medicine with the aim of specializing in tropical medicine and I remain fascinated by infectious disease. In medicine I added three more interests. The first, palaeopathology directed me to the material reality of disease in those who could no longer speak for, and of, themselves. The second, public health, introduced me to the complexity of relationships between the case/person in whom I sought "individualized evidence" (Downie and Macnaughton, 2000:46) and the population/society that was presented to me as statistical probabilities. The third, haematology, especially leukaemia, added to this interest in scale an urgency to master the "art of adjusting scientific abstractions to the individual case" (Hunter, 1991:vii). How to reconcile the survival statistics of the population in the medical

[12] As the literature is diverse it is presented throughout the dissertation rather than separately in a literature review.
[13] Hence I began with Midgley rather than with asthma.

literature with the new diagnosis in the hospital – a reconciliation that probably was even more challenging for the person with the diagnosis.

Haematology as it was clinically practised where I was a junior doctor was also my most potent introduction to the communication of unhealth. "All ill-health is a form of communication" (Marinker, 1975:82). It did not seem so then. Our unit valued communication with patients, with their families and friends, and with medical colleagues, but there were times when these blood cancers seemed to be among those things that Wittgenstein could not put into words. I could feel the enlarged lymph nodes but I felt always a sensory mismatch between this solid and fixed demonstration of disease and the fluid and mobile image of leukaemia as a cancer of the blood that I think I shared with many patients. More importantly then, the transformation of that demonstration/image into words was, I became increasingly to believe, a process both fraught with danger and imbued with healing. Thus I entered this research with a belief in the power of words. However, I entered it also with a belief in disease that echoes the old religious meaning of belief as taking "the reality of God as a fact of the universe" rather than its modern conversion to what might be little more than an opinion on an uncertainty (Smith, 1998:44).

Okely (1992:9) argues that "in an academic context 'the personal is theoretical'". My twin beliefs in disease and in words influence my theoretical perspective. I reject the extreme social constructivist position that converts "the stable realities of the human body and disease [into] 'inventions'" (Bury, 1986:137), and I second his (1997:14) assertion that "[m]edical sociology [or anthropology] would not be true to its task if it dealt with the suffering and pain that illness involves as if they were mere 'fabrications' of historically or culturally contingent 'discourses'". I do, however, follow a milder version of social constructivism that holds that social forces shape how we interpret our world, but rarely as in the stronger version, that they create it (Gasper, 1999). I am open to the possibility, probability even, that the medical knowledge I learned from textbooks and teachers has its social influences. Unhealth it has not usually invented, but it might have invented unhealths as they are known inside medicine and also beyond. A migraine in the UK might be a liver crisis in France, while low blood pressure earns revenue for the pharmaceutical industry in Germany and a reduction in medical insurance payments in the United States (Payer,

1990). Though I find certain social constructivist writings indifferent to biological processes, remote from social reality and "frustratingly abstract and 'data free'" (Bury, 1997:190) [14], they have contributed to this dissertation a distinction between the material reality or actuality of unhealth as a thing, and its cultural representation as words. "We are doomed," writes Foucault (1963:xvi) "historically to history; to the patient construction of discourses about discourses, and to the task of hearing what has already been said". If so, as asthma in my research has begun as what anyone says it is, has Foucault doomed my dissertation?

I hope not because Foucault's *The Birth of the Clinic* (1963) has been influential in that its diseases appear to my medical gaze to be actualities, even if to its author they are medical constructs. His historical account of what disease became to medicine penetrates the heart of medical diagnosis and the essence of disease as it is transmitted throughout medicine. It is revealing also of how the emerging principles of modern disease created tensions for its representation when the case in the clinic became transformed into the statistic in the population. However, I perceive disease differently from Atkinson (1995) whose *Medical Talk and Medical Work* discusses how doctors' interactions define the construction of medical knowledge and how their clinical opinions are socially produced and influenced by the increasing complexity of medical technology. His account of the haematology department where "[o]ne might be forgiven for believing that patients are there primarily in order to provide doctors with the opportunity to talk about them" (ibid:8), did not communicate to me the unhealth that I encountered in my haematology department.

By contrast, Hunter's (1991) *Doctor's Stories* communicates unhealth to me. It characterizes medicine as an interpretive activity more akin to the social sciences and humanities than to the physics, chemistry and biology with which my medical training began. She analyses how language transforms a patient's illness into a doctor's diagnosis and how language, by 're-storying' (ibid:141) patients, returns to them that diagnosis, now reified as a disease that appears to have at least the possibility of a reality to Hunter as well as to the doctor. Hunter, a professor of English and teacher of humanities in medical education, who describes herself as "an

[14] E.g. BwO (body without organs) cited by Fox (1993).

ethnographer among a white-coated tribe" (ibid:xiii), may therefore have gone native in that she writes as though disease is real to patients, to doctors, and to herself.

I left medicine after obtaining my registration with the General Medical Council. There were aspects of medicine I did not like, but archaeology that I had continued as a hobby pulled more than medicine pushed. I came to the University of Durham to study archaeology but as I thought I would encounter more paleopathology in anthropology I began both disciplines. All things biological were familiar but like Crapanzano (1990:145), I still find socio-cultural anthropology "subversive. By describing different social, cultural and psychological arrangements, it challenges commonly accepted ways of perceiving, articulating and understanding the world". In particular it challenged the scientific, quantitative and material dimensions of my medical and archaeological experiences. Socio-cultural anthropology was partly responsible for subverting my archaeological aspirations but also soon I realised that I missed the living too much to make archaeology more than a hobby. My most difficult career choice so far was whether to return to haematology, to embark on public health or to continue with anthropology alone. I chose the last as an anthropological road to health.

My relationships with medicine and with anthropology have an equally significant influence on what this dissertation is not about. It is not about the medical profession or medical discourse *per se* because I for one have not yet "forgiven" Atkinson (1995:8) because I respect the medicine I no longer practice and my friends who still practice it. I am not, I hope, impervious to the potential for medicine to be destructive, but unlike Armstrong, also originally a medical practitioner, I do not share his affinity for the political dimensions of Foucault's thesis. Foucault (in Armstrong, 1983) represents modern medicine as the Panopticon – Bentham's model of the ideal prison offering total surveillance, which Armstrong (1983:5) distils into "a creative arrangement of power which fabricated an individual body ... [as] the point on which repression could be exercised and into which ideologies could be inscribed". I am more comfortable with Hunter (1991) who I believe is humane towards the practice of medicine and its practitioners, and not at the expense of inhumanity towards its patients. There is in my research medical talk and medical work and medical power (and even patient power), but only as it pertains to asthma.

More generally, the conflict perspective that Bury (1997) identifies as a development in medical sociology in the 1960s and 1970s, conflicts with my continuing engagement with medicine. The conflict perspective rose to challenge the social consensus that underpinned the doctor-patient relationship of its functionalist predecessor. Ill people with a medical diagnosis of disease were permitted by society to adopt the sick role that relieved them of their social responsibilities, but only if they complied with medical efforts to relieve them of their disease, and thus enable them to return to their social roles (Parsons, 1951). Medicine and society, including its ill people who remain social beings, cooperated because they had common values. Its successor, by contrast, placed conflict at the heart of the doctor-patient relationship, its source being the protagonists' differing conceptions of unhealth. Patients bring illnesses; doctors diagnose diseases. Either doctors force patients to leave their office empty handed and defeated, or they become Greeks (or native American Indians) bearing gifts of disease that subordinate their patients. In both, disease wins out over illness in the struggle for unhealth. My academic disengagement with the practice of medicine and with its practitioners could, of course, be construed psychologically as denial or sociologically as avoidance. Sinclair (1997:7), a medical practitioner before he became an anthropologist as well, directed his doctoral research to his first profession because "I reasoned that it was a little presumptuous to try to understand what other people did before I understood what I had been doing myself". While admiring his ambition, I content myself nonetheless, with trying to understand asthma.

Like Sinclair, however, my social scientific background is primarily anthropological rather than sociological, and my anthropological background is in turn, primarily medical. Medical anthropology defies easy definition as it "lies – sometimes uncomfortably – in the overlap between the social and natural sciences" (Helman, 2001:4). In its socio-cultural dimensions it concerns itself with societies' beliefs and practices relating to unhealth and their relationships to their wider culture. It addresses also the social organization of unhealth in terms of how it is presented to and recognized by society, and how it is treated. Its biological dimensions overlap with many of the disciplines of the medical sciences including clinical medicine,

genetics, nutrition and epidemiology[15] (Helman, 2001), but with added evolutionary and ecological perspectives (Anderson, 1996; McElroy and Townsend, 1996).

Medical anthropology's diversity has, according to Good (1994:5) cast it as "our discipline's London, a metropole where diverse voices engage in substantial matters of the day". Certain anthropological landmarks aim to prevent this particular "city of organized thought and its town-planners" (Midgley, 1989:23) degenerating into the Tower of Babel. Firstly its portrayal of humans as biological, psychological, social and cultural beings gives it a holistic approach that its practitioners contrast with the reductionism of the medical sciences, and I would contrast also with the anti-biological stance of the strongest versions of social constructivism (Fox, 1993). At the core of holism is the concept that the whole is greater than the sum of all its parts (Anderson, 1996). Interdisciplinarity is a second landmark of medical anthropology, and one that according to Anderson (1996) takes it beyond multidisciplinary teamwork, thereby making its foraging more challenging. At its most challenging it creates "a new object that belongs to no one" (Barthes in Clifford, 1986:1), and it demands "a degree of mutuality" (Clifford, 1986:19) – a sharing among its diverse practitioners of core concepts such as holism, and of methods such as participant observation. The latter as its methodological gold standard distinguishes it from sociological research tools that typically maintain a greater distance between researcher and researched (Agar, 1996). Thirdly, anthropology began as the comparative study of societies (Anderson, 1996) that are small in scale and distant, both geographically and culturally, from the anthropologist's own society. Thus it contrasts with sociology whose subjects have traditionally lived at home.

The above has emphasised anthropology's distinctiveness from sociology, yet the differences between them are perhaps, and increasingly, more matters of degree than of kind (Van Maanen, 1988), and anthropology's collaboration with other disciplines is increasing (Agar, 1996). Anthropologists have begun to work at home (Fainzang, 1998; Frankenberg, 1990; Jackson, 1987; Messerschmidt, 1981; Okely, 1996a,b) recognizing that "home can be the most exotic place there is, the shoppers' faces as wrinkled and misshapen, as fascinating as the oldest babushkas in the remotest Uzbeki village" (Robinson, 1996:54). Participant observation is practised by

[15] The study of the distribution of disease within populations.

sociologists (Atkinson, 1995; Rock, 1979; Van Maanen, 1988) and as discussed above in relation to social constructivism, not all sociologists are dismissive of the biological natures of their subjects. Neither though, accept biology solely as a natural phenomenon, hence in their respective medical spheres, both disciplines have the power to "denaturalize disease and contemplate it as a cultural system" (Good, 1994:2).

As it was, however, anthropology not sociology I studied, I began my research within anthropology. Within medical anthropology's London, Good's (1994) map has been most influential. Good classifies the discipline into four theoretical approaches: empirical, critical, cognitive and interpretive. The empirical approach, also called ecological by McElroy and Townsend (1996) resembles most closely the positivist, reductionist perspective of scientific medicine, and is adopted most commonly by its more biological practitioners. Practitioners on the more social side of its socio-cultural dimension may adopt the critical approach, also called political-economic by Singer and Baer (1995), that focuses upon inequalities in relationships between health, wealth and power. Cognitive and interpretive approaches are generally the domain of the more culturally orientated medical anthropologists. The former addresses the role of language in structuring and classifying health and unhealth, but is according to Good (1994), difficult to separate from the interpretive approach that concerns itself with their experience and meaning to the person affected, and their communication to others.

The interpretive approach has been my principal influence because relations between biology and culture are central to its understanding of health and unhealth. Its practitioners including Eisenberg (1977) and Kleinman *et al* (1978) distinguish also between illness and disease. Their investigations of the meaning and interpretation of unhealth, particularly through the analysis of language used in their communication, has placed unhealth at the heart of society. Semantic networks map medical terms, lay descriptions, symptoms and treatments into symbolic pathways that are rooted in societies' most basic cultural values and organizing principles (Good, 1994). At a more personal level, the interpretive approach addresses the difficulties inherent in the representation and communication of bodily experiences by those experiencing them. It has "a special concern to produce 'experience-near' accounts which render

the body present" (ibid:55). It seemed right for my research but perhaps also it was right for me as when I read that the "practice of medicine is an interpretive activity" (Hunter, 1991:xvii)[16], I recognized it in my medical attempts to explain unhealth to myself, as well as to my patients.

The interpretive approach is moreover, indebted to Geertz (1973), whose concept of culture has inhabited me since undergraduate anthropology. His words express it beautifully as being

> "essentially a semiotic one. Believing ... that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning" (1973:5).

However, despite the cultural emphasis of the above, biology plays a significant role in Geertz's work and a synthetic analysis that treats biological, psychological, social and cultural factors as variables within a unitary system is his ultimate goal (Geertz, 1973). Engel's (1977) proposed replacement of a biomedical model that focuses upon disease to the exclusion of the ill person, with a biopsychosocial model of unhealth, attempts such a synthetic analysis within medicine. Hunter (1991), however, restricts the biomedical model largely to a social construct – a "straw horse" (Anderson, 1996:405) – because it "points to what scarcely exists in practice" (Hunter, 1991:21). Schwartz and Wiggins (1985) agree, claiming that the biomedical model existed "more at the level of mythical views of medicine than at the level of real medical practice" (ibid:334). All suggest that the impact of Engel's model has been largely theoretical as many medical practitioners practised it already.

I did not move straight from undergraduate anthropology to my doctoral research. First, I was asked on the stairs in the Anthropology Department to join a team studying the health and lifestyles of children in Nepal, especially homeless children in its capital, Kathmandu. Thus began by accident my interest in researching children, and hence my acquaintance with the social scientific literature on child-centred research[17]. On my return I completed a taught Masters at The London School of Hygiene and Tropical Medicine which I followed with textual research into global urban health inequalities

[16] I read the same later in Downie and Macnaughton (2000) and Erikson (1964).
[17] Such as Fine and Sandstrom (1988) and James and Prout (1990), and more recently Greig and Taylor, (1999) and Christensen and James, (2000).

(Todd, 1996; Todd, 1997). Black (1982) in *The Black Report* and Watt (1996) who reported on health inequalities in my birthplace of Glasgow did most to bring unhealth home. Engels's (1848) *The Conditions of the Working Class in England* and Harrison's (1983) more recent *Inside The Inner City* did the same for poverty, and honed my research interests to urban locations. All heightened also my concerns brought from medicine about relationships between poverty and health that are highlighted by Keesing's (1987:161) refashioning of Geertz's cultural webs into "webs of mystification as well as significance" as they "constitute ideologies, disguising human political and economic realities"[18].

However, as the attraction of the anthropological other continued to dominate, I began my original doctoral research into attitudes to health and health management among homeless children in Cape Town, South Africa. Participant observation was to be its main method as I had returned from Nepal believing like Thoreau and Geertz, that it "is not worth it, as Thoreau said, to go round the world to count the cats in Zanzibar" (Geertz, 1973:16). I returned home, anthropologically speaking, before ever leaving it because of unhealth in friends and family. Research into asthma was being conducted at my home, then London, that was both urban and poverty directed, and I remembered the little girl with asthma. I returned to my anthropological home in the University of Durham because the London research was primarily quantitative and I wished to be more qualitative, my concern being more with substantive than with statistical significance (Porter, 1994). I sited my research in Teesside about 30km south east of Durham because it has a lot of asthma and a lot of poverty (TEES Group, 1995). I had never been there – I knew it only as a word.

My reflexive journey to my research ends here. In the next chapter I continue it through my research, but I end this chapter with an introduction to my dissertation.

[18] Lock and Scheper-Hughes (1996) combine the critical and interpretive approaches into a "critical-interpretive medical anthropology" (ibid:44). In their perspective though, the critical would appear to come first; in mine it comes second.

1.3 THE DISSERTATION

> The anthropological dissertation, typically a straightforward analytical and descriptive account from fieldwork, is the ethnography that most anthropologists must write. Since the granting of professional credentials has depended on its evaluation, it has tended to be a conservative exercise.
>
> George Marcus[19]

Conservatism has influenced this dissertation in that it follows a relatively standard format (Phillips and Pugh, 2000), proceeding from this first stage to methods and research site, then three chapters of results and discussion, and finally a conclusion, although all are named differently.

[19] Marcus (1986:265).

Chapter 2 TRAVELS WITH ASTHMA

> [I]f you want to understand what a science is, you should look in the first instance not at its theories or its findings, and certainly not what its apologists say about it; you should look at what the practitioners do.
>
> Clifford Geertz[1]

[1] Geertz (1973:5).

2.1 THE MAP

> [A] research project is a journey, an intellectual journey.
>
> Annette Lareau and Jeffrey Schultz[2]

My research began in October 1997, though as the previous chapter has shown, my intellectual journey began much earlier. This chapter describes the routes my research has taken from my registration as a doctoral student until the submission of this dissertation. Its three parts narrate the research process before, during and after 'the field' because fieldwork begins before arriving in the field – a metaphor of the research site as like mine, it might be urban – and continues after leaving it (Van Maanen, 1988). Having completed my research process, it was not as Hammersley and Atkinson (1995) note, as simple as going and doing it, hence I make it "*public*" (Agar, 1996:14), to facilitate assessment of its findings. Essentially, as Agar (1996:2) puts it colloquially and perfectly, it "still boil[ed] down to the same old problem of one human trying to figure out what some other humans are up to".

The chapter's three specific aims contribute to this more general aim. Its first is to explain why and how I revised my research project during my early travels. "To say that my research question 'evolved is true, but this is far too passive a description" (Lareau, 1996:226), and I too, took "steps to produce a more focused research question" (ibid:226) such that I came to question the very nature of my research – a questioning that Lambert and McKevitt (2002) identify as one of the strengths of anthropology. Its second aim is to describe the epistemological and methodological baggage that has accompanied it, and to discuss its influence upon it. Its third aim is to explore the theoretical and practical implications of researching close to home, both geographically in relation to Teesside, and culturally in relation to my former profession of medicine.

[2] Lareau & Schultz (1996:195)

2.2 PREPARING FOR ASTHMA

> So you will not be traversing a set course laid out by others ... it is no use sitting around waiting for somebody to tell you what to do next or, worse, complaining that nobody is telling you what to do next; in the postgraduate world these are opportunities, not deficiencies.
>
> Estelle Phillips and Derek Pugh[3]

This first part begins with my preparations for my original research into relationships between childhood asthma in Teesside and SES, jointly registered with the Department of Anthropology and the Centre for Health Studies (now renamed the Centre for Integrated Health Care Research). As I have taught, and been taught, primarily in the Department of Anthropology, I have had greater involvement with medical anthropology than with medicine though medical friends have played a counter-balancing role in my personal life. My dual registration gave nonetheless a literary reality to my interdisciplinary aim, namely the integration of anthropology and medicine in the theory, practice and writing of my research.

2.2.1 Literary Influences

I begin with the literary route my research has followed. Its starting points were asthma as its subject, medical anthropology as its primary discipline and Teesside as its location. The previous chapter has shown how medical anthropology ramified into other disciplines, and Teesside is the subject of the next chapter. This chapter confines itself to searching for asthma in the medical and social scientific literature. As the former is vast and as my aim was to be systematic, I selected as most relevant

- prevalence (the proportion of the population with asthma).
- aetiology (its cause(s)).
- severity.
- patient/family management.

[3] Phillips & Pugh (2000:2).

Within these I gave priority to literature

- linking the above to SES.
- published within the previous five years.
- pertaining to the UK and the north east of England in particular.

The literature search had the additional aim of generating an operational definition of asthma that I could use to determine its prevalence in my study and investigate quantitatively its relationships with SES. I had begun this task at The London School of Hygiene and Tropical Medicine but asthma remained undefined and I became amazed and frustrated by the variability of asthma in the medical literature which moreover, appeared to have implications for its relationships with SES. Might medicine, I began to wonder, know asthma differently in rich people and in poor people?

My amazement reflected my belief that I knew asthma. Asthma in the little girl[4] (p.6) and my other memories of it were similar, but differed from much of the asthma in the literature. My frustration reflected my failure to define asthma to my own satisfaction. In retrospect I echo Lareau (1996:224) that "part of my problem was that the question I was framing [my research aim] was too heavily embedded in quantitative models" in which definition of research variables is a necessary prerequisite to researching them (Bryman, 1988). Gradually, and perhaps at first unconsciously, I began to treat the medical literature on asthma as texts to be *interpreted* as well as knowledge to be applied.

Thus I came to researching asthma *per se*, and I broadened my search of the medical literature in several directions. I included articles pertaining to the diagnosis of asthma. I studied descriptions of asthma in medical texts ranging from specialist texts on asthma to introductory paediatric texts containing an entry on asthma. As the social scientific literature on asthma is sparse by comparison with its medical representations, I added historical asthma since its birth in Aeneas, and Gabbay (1982) through his social constructivist account of its past treatment by medicine,

[4] Page numbers are given when the relevant material first appeared in a previous chapter.

played a major conceptual role in re-orienting my research. "The past is another country", Hartley (1953:5) observes at the start of his novel *The Go-Between.* Anthropology's other is separated by space, history's other by time, but relationships vary between time and space. Many traditional societies had a more spatial concept of time in which the present runs parallel to the past rather than following it (Lévi-Strauss, [1962] 1966), while Giddens (1993) describes their convergence in modern western society which frequently employs metaphors of space to describe time (Lakoff and Johnson, 1980). A final, if idiosyncratic perspective, on relationships between time and space is offered by Falliers. This physician of asthma attributes the death of Pelops, caused according to Greek mythology by the "'swiftness of the flight'" (1987:72) with which his winged horses drew his chariot across the Aegean Sea, to the first case of jet lag. Finally I extended my literature search beyond academic space into personal or family representations of asthma and its public representations in local newspapers and health information leaflets.

2.2.2 Informal Influences

None of the influences described in this sub-section occurred in relation to, or were in response to, the direct planning of my research. They were made possible by my research being located at or close to my geographical home – the UK and Teesside respectively – and by my interaction with professionals in my current and former disciplines – anthropology and medicine. They influenced the direction of my research in two ways. Firstly, they reinforced my interest in the diagnosis of asthma, and ultimately in the 'What is asthma?' question. Secondly, they stimulated a desire to produce an "experience-near" (Good, 1994:55) account of asthma.

Participant observation began before I began fieldwork in Teesside. I discussed asthma with medical friends and at medical conferences where I listened to, and talked with, health professionals with a particular interest with asthma. At a medical conference I saw paintings of what it felt like to have asthma and saw in their colours especially, a power equal to the power of words. Two doctors who have since crossed disciplines into the social sciences and humanities respectively made valuable contributions. One gave me medical advice about how to distinguish between what

was, and was not, asthma. The other told me that eventually I would grow out of thinking of asthma as a material reality. I have still to do so.

I spoke about asthma with friends, and with strangers during chance meetings especially at parties or on public transport. On the latter I listened into several conversations about asthma and observed one unhealth that I diagnosed as asthma and two self-treatments with inhalers[5]. Two anthropologists talked occasionally of their sons' asthma and one about his own complaints that had caused him to borrow his son's inhaler. I think also I heard asthma worsening in another anthropologist as we walked slowly uphill to *Boots* where she was collecting a prescription for an inhaler. During a presentation, an anthropologist questioned the relevance of the material reality of asthma to my research; another asked me whether a person who said she had asthma really had asthma. During another presentation about pleurisy, a social constructivist historian interrupted himself to assert that if ever he thought he had it, he would expect his GP to prescribe an antibiotic, not diagnose a social construction. Lastly, I noted media reports of asthma, and though I did not seek these actively, they indicate a continuous tuning of my ears and eyes to its word.

These informal encounters combined with my literary experiences of asthma to re-route my research journey into a totally qualitative study of asthma because I felt that "a preoccupation with statistical significance ... [would] have left no room for considerations of substantive significance" (Porter, 1994:393). Thus my research into relationships between asthma and SES became a qualitative exploration of their substantive significance that aimed to subvert (p.12) the dominance of the quantitative portrayal of their statistical significance in the medical literature. More generally though, my principal research aim became an exploration of how children and their families know their asthma, and how asthma is known in what I have titled the free garden and the pleasant land.

Finally, informal influences extended beyond asthma to the disciplines within which it was being researched. In meetings, often not about asthma, with health

[5] Medicines used to treat asthma and some other respiratory unhealths.

professionals, with social scientists, and with both, on different occasions I played, and was cast, as one of them, and as one of the other. I observed and experienced both consensus and conflict. Consensus was rewarding, especially if it had to be earned, and my belief in interdisciplinary research remains, but conflict challenged my desire to bring both disciplines into my research. Conflict was greatest when it raged inside my own head threatening to turn me into the two-faced Janus of Greek mythology (Latour, 1987), but most challenging when occasionally, I felt it went beyond the discipline to its disciples as both 'doctor-bashing' and 'social scientist-bashing' bashed me.

2.2.3 Formal influences

This section describes influences that I encountered in the context of the direct planning of my research. The first were my supervisors, who represent my dual background in anthropology and medicine. Hence, I looked to their respective disciplines as well as to my research when trying to interpret their responses to me, and to each other, during meetings and in their comments on my written work. My opening definition of asthma (p.2) was derived from my medical supervisor's suggestion that I define asthma as what 'we' (doctors I presumed, he meant, though I have made it anyone) say it is. My anthropological supervisor's comment that I could not see the wood for the trees in the most medical sections of my dissertation increased the reflexivity of my writing in case we were seeing different woods.

The second was a pilot study conducted in Durham in late 1998 comprising exploratory interviews with five families containing one or more children with asthma aged 11-16 years, the age range being selected as the transitional stage from child to young adult. The pilot study had as its aim the development of a semi-structured interview schedule for the subsequent study in Teesside. It identified areas I had overlooked, especially the role of schools, as well as raising reflexive and ethical issues that are discussed later. Unexpected benefits were advice from two of the mothers as to how best to present my later study to the Teesside families, and mechanical analogies to asthma drawn by the engineer father of a child with asthma.

I have included the pilot study in the subsequent analysis because most of its findings were similar to those that emerged later in Teesside.

During the pilot study I reflected upon my self-presentation to the families and to health professionals. My past as a doctor conjures a different image to my present as a student, and my former image is more powerful and might in consequence bias lay participants to give what they perceive to be the correct medical responses. I was, however, unwilling to conceal my medical past because it influences my attitudes to asthma and people with it, and it contributes to my aim to integrate medicine and anthropology. Most importantly, I believed it might be relevant to decisions as to whether or not to participate and if so, what to contribute. It would have been unethical (Richards and Schwartz, 2002) to conceal it prior to interview and potentially damaging if revealed inadvertently during interview. Thus I presented myself as the double-headed Janus of medical doctor and student anthropologist. Turning to the health professionals, were they to be subjects or colleagues? Colleagues, I decided for several reasons. Firstly, despite Lambert and McKevitt's (2002) appeal for greater inclusion of health professionals as research subjects in anthropological health research, my primary focus was on asthma in the family. Secondly, my medical past, however distant, cast me as colleague rather than as their researcher. Thirdly, and pragmatically, I thought they would be more likely to agree if they were approached as potential facilitators rather than as potential subjects.

The third formal influence comprised one example of the bureaucratization of academic research described by Okely (1987) in relation to her work with Gypsies, in that I had to obtain the approval of local health authority research ethics committees before I could recruit subjects from medical spaces. The pilot study was submitted to the Durham committee and the main study to the South Tees committee. Lux *et al* (2000) reported delays in response times to their submissions, but both committees to which I submitted met most months to consider submissions. These were either approved outright, or subject to minor changes being made and communicated to the chairperson, or they were rejected until resubmitted to the entire committee. My pilot study was twice rejected, hence more than three months elapsed between its first submission and its approval. The committees had also to be informed of any subsequent changes to the proposal, and if changes were deemed major, the study had again to be assessed at their

monthly meeting. Thus they had the potential to delay research. For this reason, my submission for my main study was more extensive than the research actually intended, and in particular it had more than one way of recruiting all study subjects, so that if the first approach failed, a second had already been approved.

The Durham committee's principal reservation regarding the pilot study exposed scientific differences between the committee members and myself. They disagreed with my choice of what they described as my objective measure of asthma[6] and recommended diary keeping of symptoms as an alternative. I rejected their alternative as it had the potential to conflict with the exploratory open-ended approach essential to the main aim of my pilot study. Their second rejection of my application was accompanied by the concession that I telephone a nominated member of the committee and discuss my reasoning with him. I decided to remove the offending objective measurement, but not to replace it with the committee's alternative, and after the required phone call my pilot study was passed but the committee's reservations about the absence of any objective history of asthma remained. Social scientific and especially qualitative approaches to research challenge, however, the very possibility of objectivity (Bryman, 1988; Silverman, 1993), and "[i]t is worth noting that these types of 'social' protocols seem to create the biggest uncertainty for ethics committees" (Alberti, 1995:639). The committee's objection raised also political issues regarding its power to patrol research as its scientific custodian as well as its ethical guardian if its role of "helping to ensure relevant research is done" (Savulescu *et al*, 1996:1390) sanctions it as the ultimate arbiter of relevance. More generally, the experiences of Middle *et al* (1995), While (1995) and Lux *et al* (2000), whose research was submitted to multiple committees and approved by some and rejected by others for various and differing reasons, impart a local and particular quality to ethical research.

Social scientific and especially qualitative, research was further subordinated by the application form for both committees being designed for research in the quantitative and positivist tradition of the medical sciences. Section headings included the following: subjects, controls, healthy volunteers, statistical analysis (or justification for its absence), drug and radiation dosages. I translated the section headings into the language of my qualitative research and then back translated my qualitative research, not into

[6] Peak expiratory flow rate, which will be discussed later.

standard scientific language, but in the form of 'Yes, in the sense that X are being included as controls in order to'. As interdisciplinary dialogue it was intellectually stimulating, and one which Stone and Lewondo-Hundt (1987) and Trostle and Sommerfeld (1996) recommend between anthropology and epidemiology. It was facilitated nevertheless, by my acquaintance with both, and I empathize with Oddens and De Wied's (1995) request that separate forms be devised for the social sciences. The dialogue benefited also from a course on qualitative health research at the Department of Sociology at the University of Surrey. Its structuring around an imaginary application to a local health authority's research ethics committee reiterated in its choice of subject matter their influence on social medical scientists.

The influence on me of the South Tees committee was increased further by it perceiving its involvement as extending beyond the clinic into the community. Advice was sought from it prior to submission of the proposal as to whether its consent was required for community sampling as committees vary in the extent to which they extend their remit to community research (Middle *et al*, 1995; While, 1995). As its reply was in the affirmative and emphasised the sensitive nature of community research, but not as in the experience of Bonell (1994) that it was unscientific, I delayed the community phase to a second submission. The first submission confining itself to sampling from medical lists was passed at its first hearing subject to my clarifying certain points with the chairperson. As with the Durham committee, comments were made regarding the scientific merits of the study but they were presented as suggestions and approval was not contingent on their being accepted. I accepted some, especially the suggestion that my study was biased towards the worst of asthma in those with it.

My second submission consisted of the community phase and changes I wished to make to my original submission despite the contingency plans above. It was passed also on its first hearing, but a sensitivity towards perceived ethical implications of qualitative research rather than to its scientific merits was evident in the committee's proviso that I assure the chairperson that I would not ask anything that was contentious or potentially embarrassing to my subjects. Remembering the section for radiation dosages on the application form I wondered if it were more acceptable ethically to irradiate subjects than to talk to them. Yet the former has officially defined safe limits, while as Richard and Schwartz (2002) rightly observe, interpersonal communication has the potential to

be unsafe, as made uncomfortably clear by Lee's (1993:5) anecdotes of "interviewees lapsing into embarrassed silences ... or needing to use alcohol as a prop while being interviewed". My preparatory work had suggested that asthma could indeed be contentious and cause embarrassment to subjects because of values or experiences that were unknown to me. The chairperson accepted my explanation and my assurance that I would never deliberately research in a manner that I thought could give rise to the committee's concerns because I was my participants' guest, and had, moreover, invited myself.

Finally, ethical requirements influenced the presentation of my study to potential participants in two ways. Firstly, the detail required in the information leaflet and especially in the consent form had generated letters that women in the pilot study had found complex and overly detailed. In the main study therefore, the consent form accompanying the initial letter committed those signing and returning it only to my visiting them to explain the study to them in greater detail. At that visit an information leaflet and consent form would be left for them to sign and return at a later date if they wished to take part. Secondly, recruitment had to be done on my behalf by clinic staff as ethical requirements regarding patient confidentiality prevented me from contacting patients without their prior consent. To emphasise to those contacted that their confidentiality had not been breached I decided to 'ghost write' letters for the clinic staff stating that they were asking the patient to take part and that I was not aware that the patient had been contacted.

The entry of the clinic staff signals the next stage of my research as they were its most regular companions.

2.3 DOING ASTHMA

> The present narrator has three kinds of *data*; first, what he saw himself; secondly, the accounts of other eye-witnesses (thanks to the part he played, he was enabled to learn their personal impressions from all those figuring in this chronicle) and, lastly, documents which subsequently came into his hands.
>
> Albert Camus[7]

This section describes my fieldwork. Like my research aims it evolved, though for reasons that were not theoretical or conceptual but dependent upon the 'doing' in the field. The journey is here, its destinations[8] are in the appendix.

2.3.1 Researching in the Clinic

From March 2000 to March 2001 I attended two asthma clinics run by nurses with specialist training in respiratory medicine, and occasionally by doctors. The first – a weekly half-day session – was held at a Teesside GP practice. Patients attended for regular review of their asthma or subsequent to GP referral or a self-referral. Appointments lasted 15 minutes. The second – a weekly all day clinic – at a local hospital was attended by patients following hospital admission or for regular review. Appointments lasted 45 minutes for a new patient and 30 minutes for a review patient. At the clinics I wore clothes that were, I hoped, smart enough to acknowledge their formal setting, but not so smart that I distanced myself from patients. I was aided by the relatively informal dress code of hospital paediatric clinics and at the GP clinics where the nurses were in uniform, I dressed as I did for the hospital clinic. Apart from doctors, clinic staff introduced themselves by their first names, and I was introduced likewise. Gaining access to the clinics was unproblematic. My anthropological supervisor had met a Teesside GP with an interest in asthma. He recommended I contact the consultant responsible for the hospital clinic.

Patients were given an information leaflet and consent form by the receptionist on arrival at the clinic. At the hospital clinic the signed consent form of patients willing to

[7] Camus (1947:8).
[8] Sample sizes, interview protocols, information leaflets etc.

participate was put into their hospital notes. As these were studied by the health professional before summoning the patient I was able to leave the consulting room before the arrival of patients who did not want to take part. At the GP clinic[9] patients brought their consent forms with them to the consulting room, but were asked by the nurse before entering whether they were willing to take part. If not, she asked me to leave before the patient entered[10]. My clinic role was usually that of non-participant observer in that apart from greeting and thanking the patient after having been introduced by the nurse, I took no part in the consultation. However, as nurses had to find a doctor to sign their prescriptions[11] often I had the opportunity to conduct a short interview with the patient and family. Further, as some patients who attended regularly began to involve me in their consultations, some observations became increasingly participant. They became participant also when I attempted to entertain children who were disturbing the consultation. Although data collection was compromised it seemed to me the most appropriate and direct way of realising the ethical requirement that my research would benefit its subjects. Notes were made during consultations and the short interviews, but the pace of both meant that they are only a partial representation.

2.3.2 Researching in the Home

The study proposed also a year long focus on 10 severely asthmatic children of varying SES aged 13-14 years and their principal carer(s). Methods comprised three monthly home interviews, diary keeping of symptoms, and drawings of what it was like to have asthma or writings about what it was like to care for an asthmatic child. On the advice of the GP practice severe asthma was defined as one or more hospital admissions in the previous year for asthma and/or four or more courses of oral steroids and/or a nebuliser for regular home treatment[12]. SES was, however, left to the discretion of the nurse rather

[9] The GP clinic, unlike its hospital counterpart, included adults with asthma. These patients were included if their asthma had begun in childhood.

[10] Unfortunately I did not keep a record of those not wishing to participate but I am confident that the number of patients attending the hospital clinic who excluded me was in single figures, and there was only one consultation at the GP clinic from which I was excluded.

[11] Most consultations generated prescriptions.

[12] Oral steroids are the strongest home treatment and nebulisers are usually confined to hospitals.

than being based on any formal criteria such as postcode or the Townsend Index (Townsend *et al*, 1989) as time considerations and data limitations precluded a more systematic approach. Recruitment was confined to the GP clinic as the practice was confident that its list contained sufficient patients meeting the study criteria. To broaden the study's depth 20 families with children with asthma were to be interviewed once at home. To extend the study beyond asthma in the family interviews were proposed also with 10 women without asthmatic children who were patients of the GP practice. Lastly, recruitment was to be extended to 10 elderly GP patients who were life-long local residents to provide a temporal dimension to the community perspective.

2.3.2a Seeking subjects

Recruitment began late and ended prematurely. Its planned beginning in October 1999 was delayed for several weeks by the practice's annual influenza vaccination programme. When recruitment began the practice nurse was unable to find 10 patients with sufficiently severe asthma, even after extending the age range to 11-16 years. To minimise further delay, severity criteria were abandoned, and severity, like SES, was left to her discretion. Recruitment was further postponed for several weeks by her unhealth. She promised to recruit immediately upon her return in early December but her workload delayed her sending the recruitment letters until the week before Christmas. No replies were received from the 10 families contacted and reminder letters sent early January generated only one positive response. Two shortcomings on my part might have contributed to the recruitment failure. First, I failed to follow up on the intended early December recruitment, and therefore did not request its postponement to January as Christmas approached when letters might be forgotten or lost in the festivities. Second, when the reminder letters were sent out in January, I failed to remind the nurse to include the original letter introducing the study to the subjects.

Ten more recruitment letters were sent the following month. Only one reply was received and reminder letters plus the original letter generated no more responses. This second recruitment failure suggested that the families contacted did not want to take part in the study as it was presented to them. The pilot study had by contrast received a 100% positive response. Perhaps people were discouraged by the much greater commitment requested of them, and my research might have been better received had I been able to present it to them face-to-face, especially if the traditional ethnographic practice of

participant observation while 'living in' had introduced us. My decision to recruit via medical lists precluded any prior relationship building and although easier in principle than community sampling, may not have turned out to be easier in practice.

Two failures of recruitment of the core sample from medical lists caused that part of the study to be abandoned. A third recruitment was considered but dismissed because 18 of the clinic's 20 most severe asthmatics in the target age range were no longer available. Also, although recruitment could have been redirected to the hospital clinic, re-submission to the ethics committee would have delayed research and as asthma may vary throughout the year, shortening its duration might have generated partial and biased findings.

2.3.2b Desperately seeking subjects

In literal desperation, recruitment shifted to the clinics via an addition to the observation consent form stating that I might write to the families requesting an interview at home. My initial target was 40 interviews – a doubling of the 20 single interviews in my original proposal, and I removed the lower age limit of the child with asthma because most attending both clinics were under 11 years.

Although born out of necessity the new recruitment strategy had several advantages. It enabled purposive selection of potential interviewees because of information revealed during the consultation on the basis of one of more of the following criteria: severity, SES, initial diagnosis, multiple child asthmatics in the family, family management and school management. Further, as I had observed the clinic consultation of those who did not agree to my interview request, I had limited but valuable data on non-respondents, and it soon became apparent that those living in poor areas were less likely to agree to interview. According to the criteria of the Townsend Index, most acceptors owned homes that appeared spacious enough for the family, and had cars, and at least one adult in full-time employment.

The main disadvantage of the new recruitment strategy was that still, only about one in five families contacted agreed to interview. Reminder letters were not sent as I considered the notification of a possible interview request on the clinic consent form as the first phase of interview recruitment, and as I might see them at a follow up

appointment, I was concerned that they might perceive reminder letters as harassment. Ethical concerns apart, harassed patients might refuse my presence at future consultations at which often I had the opportunity for the short interviews. No patient receiving an interview request refused my presence at subsequent consultations and though I did not mention my request at their next appointment, my presence prompted a few families to mention it and to agree to it.

My next strategy to try to boost recruitment was to explain in the interview request letter why I wished to interview the child and/or mother. In effect, I made my reasons for their purposive selection clear to them. As I had been present at their consultation, it seemed appropriate to write a more personal letter showing that I had been interested in, and had remembered, what they had said. Acceptance rates more than doubled yet they remained below 50% so reminder letters were added, but these generated only one more positive response.

Interview acceptors remained biased towards those of higher SES. Staff at the hospital clinic suggested that poorer families might be reluctant to be interviewed in what they perceived to be very poor homes. Discussions began about the possibility of holding interviews at the hospital (with travelling expenses provided), but were abandoned because of unhealth of the nurse who would have been responsible for recruitment. Instead I bowed to time constraints and reduced my interview target from 40 to 20, with the compromise that the remaining five then required would be purposively selected for low SES. Three recruits were achieved this way but the ever-increasing pressures of time and two new patients with severe asthma led to the final two subjects being purposively selected for severity and initial diagnosis instead.

2.3.2c Interviewing subjects

As data generated by interviews may be influenced both by the personal interaction between subject and interviewer, and by their social characteristics such as gender and class (Davies, 1999), this sub-section describes how data was collected, beginning with scenes from my home interviews. Some I set myself; my interviewees set others. My dress was more informal than in clinics because the home is more informal, and because I wished to minimise the formality of a taped semi-structured interview. Also, I wished to play my more informal student role. Families appeared to attach most significance to

my arriving by bus, and perhaps inadvertently I achieved my aim more by my mode of transport than by any of my attempts at informality. In order to try to ascertain how the families perceived me, I noted how they addressed me. No-one called me doctor, some called me Alison, others did not call me anything. I called parents by their first names only if they had already called me by mine, and if I felt the interaction up to that point had been sufficiently extensive and informal to earn such familiarity. I might have met them already several times at clinics, and because of rescheduling of appointments, had several phone conversations with them.

Interviews lasted from one hour to two and a half hours, though my longest visit was four hours because I was invited to stay for supper. If the interview reached the hour specified on their request letter, I asked if I might continue. Lareau (1996) is of the opinion that staying beyond the interview time stated on the request letter shows a lack of respect for the respondents. I can only hope I did not outstay my welcome and I ended the interview if I felt in danger of doing so because children were interrupting frequently or it was likely their bedtime was approaching.

I began by taping interviews whenever home circumstances permitted. Children, dogs, parrots, toys, televisions, gameboys, computers, phones and doorbells meant that sometimes they did not. Background noise interfered with recording quality; interruptions led to frequent recording stop-starts, and more importantly, to anxious apologies from parents and occasionally even to reprimands to their children. Lareau (1996), when faced with a home environment not conducive to taping requested the interview be moved to a room that was private and quiet or asked for the television to be switched off. I did not as I view such requests as more intrusive to respondents than staying a little longer than the time stated on my request letter. I took notes instead and data and relationships benefited. Eventually I stopped tape-recording altogether because repeatedly the richest data was emerging from conversations after the interview was officially over and the recorder had been switched off. All were initiated by the interviewee(s) and lasted up to an hour. With their permission I made notes or I requested their permission (always granted) to add later the conversations in note form to the recorded interview. Note-taking also introduced greater informality into the interviews, some of which became more like "conversations with a purpose" (Burgess,

1991:102), even approaching the informal and unstructured, but no less rigorous, interaction of participant observation.

Greater informality facilitated respondents interrupting the interview, often with positive consequences, as upon their return they might have remembered, or thought about something, or thought again, or wondered if. Greater informality culminated in role reversal in several interviews when I was questioned about my research, about their asthma, and more generally about medicine and health. Hudson *et al* (1998) encountered similar questioning and requests for information in the course of their qualitative research into public reactions to a major study of health and environment in Teesside. In their study as in mine, researchers' responses had the potential to bias subsequent data. Ultimately, I gave priority to honesty and equality, but I tried to delay my contributions until I had some idea of theirs, and overall this greater exchange of information and ideas embodying more of the give and take of everyday communication, added to the richness and depth of the data.

I turned off the tape-recorder reluctantly, however, because written notes have their drawbacks. Firstly, I might have recorded the data inaccurately. Thus I read, and if I trusted my memory, I altered and/or added to my notes after interview. Secondly, data was lost as not every word was noted. Phrases and sentences that impacted on me at the time because of their content or their delivery were recorded within quotation marks as fully and accurately as possible. The remaining content was recorded in note form. Strong emotions expressed by tone of voice, pacing of speech or change of demeanour or posture were also noted. Thirdly, note-taking ruled out analysis by formal techniques such as discourse analysis or conversation analysis (Silverman, 1993). More significantly to me, it added to my insecurity as it deviated from the taping of interviews that was recommended by all but the most ethnographic of the recent literature on qualitative research methods. Hence taping remained my preferred option until I acknowledged that I was acting in self-defence. Later, a woman and a health professional herself, in a silent and otherwise empty house, said spontaneously that she was very glad I was not taping as in previous taped interviews she had felt very rushed and had kept getting muddled and forgetting things. It was music to my ears and I illustrate how it could be without a tape-recorder with another interview purposively selected because it went well.

It began with a cup of tea with the mother of two asthmatic boys in a kitchen whose newly decorated appearance evoked genuine admiration on my part and questions about whether the home decorating had affected her sons' asthma. My praise led to a tour of the house to see and discuss other home decorating projects and the changes made to the boys' bedrooms because of their asthma. The boys aged seven and four played throughout the interview. Often they involved their mother, and more rarely me in their games. The oldest occasionally interrupted with something about his asthma. After about an hour their mother asked if I would mind if she invited the builder and family friend who was renovating her house to join us for coffee. She introduced me and my research and they began to talk about her sons' asthma and asthma in other children known to them. With their permission I continued to take notes and gradually I joined in, and began to guide the conversation onto how asthma is portrayed by medicine and the media, as the builder's spontaneous comments on such matters had been particularly interesting. He left us after about half an hour and the interview continued for about the same length of time with the family, followed for a while longer by conversation about other things, but interspersed with asthma. It ended with an invitation to phone or return if they could be of any help. I have not done so but I enjoyed seeing them again at the clinic a few months later.

After interviews I noted my impressions of our interactions during the interview. The scenes above contrasted with a family whose daughter with asthma opened the door and led me immediately into a room where her mother and father were waiting for me behind a table upon which I was told to place my tape-recorder. Finally, I speculated as to why families agreed to interview when so many had not, and concluded that the family around the table but not the mother in the kitchen had an agenda on asthma[13].

Interviews had as their primary aim the generation of valid data as it "is crucial to remember that the validity of the study results must always be the primary objective" (Hennekins and Buring, 1987:37). In qualitative research "[b]y 'validity' I mean truth: interpreted as the extent to which an account accurately represents the social phenomena to which it refers" (Hammersley, 1998:57). A particular topic might therefore be explored in depth if it was providing particularly interesting data or seemed of particular

[13] I identify the family around the table later.

concern to the interviewee. I aimed to record what Cornwell (1984:16) refers to as a private account that "springs directly from personal experience and from the thoughts and feelings accompanying it" as opposed to the public account that reproduces social norms and permeates everyday conversation.

Private accounts have, however, interesting implications for data reliability as "there are severe limits on the possibility and practice of replication in the social sciences, and especially in ethnography" (Hammersley, 1998:57). Occasionally while thinking and talking, interviewees changed their minds, as when one woman began to wonder if her brother had had asthma as a child. On these occasions I tried to minimize my potential to introduce bias by keeping questions non-directive or to repeat as a question the last thing the informant had said, and to use non-verbal encouragement such as leaning forward or nodding. However, as I agree with Ellis *et al* (1997:121) that "interviewing is a collaborative communication process occurring between researchers and respondents", issues of validity and reliability remain within the context of a reflexive research process (Davies, 1999; Hertz, 1997; Lareau and Schultz, 1996; Watson, 1999).

Finally, as parents of asthmatic children were the principal contributors, I am subject to the criticisms levied in the literature about much research being on children rather than with them (Christensen and James, 2000), or focusing upon interactions with their parents (Tates and Meeuwesen, 2001). I requested interviews with all children aged 10 years or older, though the youngest contributor who volunteered herself upon my arrival, was six years old. Children chose whether or not to have their parents present. Several children did not want to be interviewed and other children, as found also by Mayall (1999) and Gabe *et al*, (2002), wanted their mother present. The adult focus was increased further as I removed from the study children's drawings of 'This is me when I have asthma'. I should have, but had not, addressed earlier the issues raised by Bendelow and Pridmore (1998) regarding their interpretation by researchers and their emotive power on their artists.

2.3.3 Researching in the Community

As recruiting asthmatic families proved so difficult, recruitment of non-asthmatic patients via medical lists was not even attempted. Instead, the community phase relied upon women attending a community centre in a socially deprived area of Teesside, who if they had asthma in their family, also boosted low SES participants. Centre staff approved my research but I made my own introductions to the women. I introduced my dual background of doctor and research student, but I wore my student clothes. Usually I joined, and in the process interrupted, a group. I did not take notes though I had permission to do so, as I felt that the more informal my approach the more valid the data. Thus I wrote up my visits immediately afterwards. I was least sure of myself among these women. Biology facilitated access – I am female – and overtly I was accepted culturally in consequence. Biology apart, they remained anthropology's exotic other: my life seemed so different to theirs economically and socially that I felt a very different sort of woman. Though women began to greet me before I greeted them and to change subject or end conversations with me as they did with each other, at the end of my three months of weekly two hour visits, my insecurity remained. For that reason perhaps, increasingly I became a participant observer as I talked about, and more usually listened to, at least some of the things that the women talked about amongst themselves. In retrospect these have provided considerable insight into unhealth, and especially into lives, in difficult circumstances. In consequence memories of their everyday lives without asthma were added subsequently to my dissertation as their significance became increasingly apparent.

Secondly, elderly people attending a local day-care centre provided the temporal dimension to the community perspective on asthma, courtesy of sessions organized by its staff that were devoted to exploring the past. Initial visits were spent introducing my research and myself, in conversations about asthma, and in general conversation. During later visits unstructured interviews were held with six women and two men above 70 years – the oldest was 96 – who were willing, and in my opinion and that of the staff, mentally able to contribute to the study. We talked about asthma, about health in general and about Teesside, and whether these had changed, and if so how. We talked also about things they brought into the conversation and as with the women above, these on occasion were illuminating. Conversations lasted from 20-90 minutes. I took notes and

following a hunch gained during the initial visits, I tried to arrange the seating so that if they wished, they could read as I wrote. I made weekly two hour visits for three months and I dressed fairly smartly but conservatively and the elderly people appeared to appreciate it – cardigans were complimented. On my last research visit I said I would look in again to tell them how I was getting on with my study. As I came in a few weeks later a woman said to her neighbour, "See! She promised she'd be back". I have kept promising.

2.3.4 Data Analysis

A characteristic of qualitative research is that data is analysed as it is collected as well as after its collection has ceased (Bryman, 1988). During fieldwork, clinic and interview data were compiled into separate interim reports whose section headings represented both my original topics and emergent themes. Clinic data provided asthma's breadth, but its depth was limited by the medical structure of the consultation and the limited time available for my own questions. The interviews that were taped were transcribed professionally. Interviews were read repeatedly, both individually and as a sequence though in different orders each time. Notes made during conversations in the community were similarly read. CAQDAS (Computer Assisted Qualitative Data Analysis Software) packages were tested at training courses but were not used for two reasons. First, taped and noted data differed in quantity and quality and although such packages are capable of analysing both types of data, the greater length and completeness of the former might cause it to be over-represented in the analysis. Second, as noted by Fielding and Lee (1998), CAQDAS is based upon the principles of grounded theory (Glaser and Strauss, 1967) whereas my analysis is founded upon the interpretive approach. Yet I recognize in it affinities with the former, perhaps because its thought processes bear similarities to those of medical diagnosis (Hunter, 1991), and though I never consciously followed grounded theory, my interpretive analysis sought emergent themes which were incorporated into subsequent interviews. Ultimately however, as I was most interested in "the 'story' the respondent has to tell" (Conrad, 1990:1258), I gave priority to keeping the interviews whole rather than risking a coding and categorization that "'shatters' the data and disembodies it from the person who produces it" (ibid:1258). My data set was

moreover, small enough to manage without the organizational capacity of CAQDAS that I perceive as its greatest strength.

Of issue constantly in the analysis, was the representativeness, or lack of, of the data, and hence its generalizability beyond, and even within, those contributing to the study. Data collected varied according to method and its setting and priorities changed during the course of its collection because people with asthma differed, and because new themes were explored as they emerged. Moreover, as priority was given to depth rather than breadth, the interview schedule was not always completed. There is a "tendency towards an anecdotal approach to the use of 'data' in relation to conclusions or explanations in qualitative research ... [and] the representativeness or generality of these fragments is rarely addressed" (Bryman, 1988:77). Bryman is using anecdotal perjoratively but anecdotes are valuable as they play a significant role in communication and may be illustrative of more general themes (Hunter, 1991; Downie and Macnaughton, 2000; Macnaughton, 1998), hence they contribute to my results. Also, as Downie and Macnaughton (2000) warn against quantification of qualitative research, my results go no further than "linguistic hedges and quantifiers" (Agar, 1996:43) such as most, many, some, a few, rarely, as guides to relative frequencies within the asthmatic sample.

I claim no generalizability of the data beyond the asthmatic sample in the conventional usage of the word in scientific research (Bryman, 1988). I do, however, support Conrad's (1990) assertion that the generalizability of qualitative research is to be sought in its concepts, not its samples or the data they generate. The latter should not though, be entirely discounted as generalization is an interactive process in which its audience attempts to identify with the findings and to relate them to its own experiences (Downie and Macnaughton, 2000). Such qualitative generalizability is the route by which my research, through its interactions with medical and lay audiences, is most likely to meet its ethical requirement of benefiting its participants if it results in people with asthma being better treated by either or by both.

Yet in retrospect I have questioned during analysis and writing whether the quantitative framework that accompanied the early stages of my research had in fact, persisted conceptually throughout, and caused me to

> "ignore a rich array of meanings and connotations ... To quantify qualities abstracts away much of their conventional meaning ... like a report on travels through a new and interesting country by a correspondent who wrote down nothing but the times of arrival and departure of the trains" (Porter, 1994:396).

Unlike Porter's correspondent I as a qualitative researcher cannot revisit the country to record what I inadvertently, rather than deliberately, ignored. Nevertheless, Porter's correspondent needed tracks, trains and a timetable to record his new and interesting country and whether his travelogue would have been of any value to a cartographer mapping the landscape for the railway is debatable. Thus while I want you to interact with my research, I want you also to know the landscape in which it travelled. Relationships between quality and quantity – the substantive and the statistical (Porter, ibid) – have been the greatest academic challenge to my research[14] and are fundamental to its analysis of the risks of getting, and of having, asthma. Further, they have an ethical significance as interpretation of substantive significance as statistical significance, might swell perceptions of risk, or even create them.

2.3.5 Revisiting Research

In this final part of doing asthma I reflect upon experiences that caused me to learn by doing. It is a confessional tale (Van Maanen, 1988) as the spotlight is upon me rather than upon my subjects. I include it in the interests of reflexivity because the experiences influenced the data collected, and because doctoral research principally "concerns the learning of skills, not knowledge" (Phillips and Pugh, 2000:21). It is an apprentice-ship, and as "[d]oing research is a craft skill ... the basic educational process that takes place is that of learning by doing" (ibid:53).

I begin with research relationships. Paradoxically my most important relationships were not with my research subjects, but with clinic staff who I had decided to treat as colleagues. I had neither their permission, nor the ethics committee's approval to research them, and it had never been my intention to do so. Nevertheless, soon I had to face the fact that I had blinded myself to their relevance to asthma in the family. Moreover, the occasional remark about asthma begged for written posterity. I have tried

[14] The index records the respective contributions of all clinic patients to my dissertation.

to overcome this caveat by a dual approach. I have quoted clinic staff, but have rendered them anonymous amongst the other health professionals that I had access to thanks to my medical background. Secondly, I have restricted their contributions in clinic to that which is of direct relevance to their patients.

Turning to lessons learned from them, my greatest mistake was to question a woman during the pilot study about how she felt about her daughter's asthma in her daughter's presence. Her guarded response taught me to request separate interviews with parents and to exclude that topic if the small size of the house meant that privacy could not be ensured.

Secondly, an equally dramatic education occurred when feelings of dread stopped my pen as a woman described her son's asthma. I learned then that still I revere disease and that I am a doctor before I am an anthropologist. I had no doubt that her son had had two life-threatening attacks in the previous six months for which she had not sought medical help. I advised her immediately to contact the clinic, but her response added to my concerns. Thus, despite the dangers of blurring the boundaries between research and therapeutic encounters (Richards & Schwartz, 2002), my contribution over the next two hours was primarily therapeutic in intent. As after leaving I remained extremely worried, and as she had by coincidence a clinic appointment the following day, I breached her confidentiality and had a long discussion with the clinic staff on the grounds that my primary ethical responsibility was to her son's health. I breached confidentiality on one other occasion that was far less dramatic but more difficult for that reason. While interviewing a teenage boy alone I reached the conclusion that he had a second disease that was not serious, but was treatable, and I advised him to tell the nurse at his next clinic about certain symptoms he had not mentioned previously. When he had not done so after two more visits I raised my additional diagnosis with her.

The third learning by doing emerged early in the interviews when home treatment of a girl's asthma attacks was less than the clinic routinely advised. I suggested the family contact the clinic for advice, but advised them also of the clinic recommendations, while stressing my independence from the clinic and my research role rather than medical role. In this case I maintained patient confidentiality because the girl's asthma attacks did not appear to be life-threatening although they were distressing to her. Before my next

interview I discussed my experience with both clinics and obtained their consent to inform patients of their recommended protocols, provided I advised them first to contact the clinic.

My fourth introduction to the realities of research emerged during the pilot study when as soon as I switched off the tape-recorder, the woman said "Now! I want to ask *you* some questions" and asked me whether her daughter's asthma could be improved. I advised her to contact the clinic, but offered to talk through her concerns with her to help her prepare for her next clinic visit. After about an hour she thanked me for helping her with her "shopping list" for the nurse, but I left her very aware that I had imparted much information and advice in the process. Again, the clinics were happy for me to respond in this manner, and I answered to the best of my medical ability many questions about asthma in subsequent interviews – I stress medical ability, because in these situations I used medical texts as sources of knowledge, not sources for interpretation.

More problematically, I was asked on several occasions for my opinion on the medical management of the child's asthma, but only once about the management of the clinic at which I had met the child. On that occasion I suggested as usual that the woman spoke to the clinic about it. When she persisted I stressed that as a researcher I could not involve myself in medical management. However, I relented when she asked a third time because by then it was apparent that she was very worried about her son's asthma, and her concerns I assumed, arose out of a lack of knowledge and understanding. I assumed wrongly. During the next hour and a half my explanations of the clinic's actions, which in my medical opinion were standard practice, were dissected with a rapier sharp logic that is the envy of my dissertation and I left exhausted[15]. The more academic our discussion, the more my research would have benefited from it, but at the cost of being increasingly unethical because she was first and foremost the worried mother of an asthmatic child. Afterwards I sent her some patient information leaflets on asthma and the telephone number of the local branch of the NAC. On the other occasions interviewees raised medical management I was permitted to be as non-committal as possible.

[15] As we covered little of the interview schedule, she and her child appear infrequently in my dissertation, but of all contributors, she has had the greatest 'behind the scenes' influence.

I remember also entering a home where asthma was part of a much greater problem. In retrospect I had realised that at the clinic but I was seduced by a very interesting asthma. I listened for a while, kept the interview going with questions that, to echo the South Tees ethics committee were I hoped, neither contentious nor potentially embarrassing, and I left when the hour stated on the consent letter had elapsed[16].

I end with a near-miss. Had I not remembered at the last minute that I should not attend an asthma clinic with a cold I might have created asthma in my subjects. I turn now to how I have created their asthma in this dissertation.

[16] To give more detail would jeopardize the family's anonymity.

2.4 MY DISSERTATION

> You have only the desire to narrate... How is it possible to find a clear pure language ... able to give expression to the sufferings of life and the fear of death ... as well as just allowing whatever will happen to happen.
>
> Gao Xingjian[17]

When Van Maanen (1988:xii) returned from the field to write his dissertation he was told by his supervisors "to simply 'write up' what I had 'discovered' in the field as if what was then in my head (and field notes) could be uncorked like a bottle and a message poured out". Van Maanen's supervisors were not ethnographers, but ethnographers at the time of his writing up rarely, according to Geertz (1988:1), examined their writing, dismissing it as "an unhealthy self-absorption – time-wasting at best, hypochondriacal at worst". Despite the risk of introducing anthropological hypochondria into research about unhealth, this final section is about the writing of my "research *product* " (Agar, 1996:4). Its relatively conformist academic structuring introduced it conservatively in the previous chapter, but conservatism in anthropological writing is about much more than following the standard order of things. Its traditional aim is to convince its reader that its author has "truly 'been there'" (Geertz, 1988:5) so that with passport stamped the writer has ethnographic status, and the writing is a qualified account of the reality encountered. Unless the reader has also been there, or is there, words are the means to this end as they have to convey the writer's reality to the readers, and/or to create it for them.

But will readers distinguish between conveying and creating, and which meaning of qualified was intended? Such *double entendre* prefaces the entry of literary, fictive and artistic as adjectives that have been applied to anthropological prose in inferior opposition to the perceived factual accounts of natural scientists (Clifford, 1986; Geertz, 1988). The fieldwork that we report is influenced by how we write, and by how others read our writings (Atkinson, 1990). Thus the reality of my dissertation is as much as my fieldwork founded upon an interaction between researcher and reader,

[17] Xingjian [1990] (2001:350-1).

as between researcher and researched. Separations between that which is reported, how it is reported, and how it is read are ultimately false (Clifford, 1986). Geertz (1988:2) argues nonetheless that attention to how we write does not necessarily sentence it (and us) to "a corrosive relativism in which everything is but a more or less clever expression of opinion". Both the goals and the own goals of writing research are encapsulated in Clifford's (1986:6) observation that fiction has a dual derivation from the Latin *fingere* meaning to make, and to make up.

All writing is made; all dissertations are made up out of their research. Literary conventions such as the naming of, and reference to, sampling, bias and validity appeal to the ascribed non-fiction of the natural sciences. Such sciences claim their reporting of reality by reifying their research in conventions of study design, selection of variables and/or of experimental procedures, and of statistical or laboratory analysis. Atkinson (1990) and Van Maanen (1988) show how similarly realist tales are ethnographically manufactured by various stylistic conventions including detailed observations, emphasis on the native's point-of-view and concealment of the 'I' of the author both in the field and in analysis. Both natural and social-scientific tales claim the original meaning of art as something of use that has been fashioned with skill (Clifford, 1986), their aim being, to paraphrase Marinker (p.3), to secure the award of the 'treasured gift' of authenticity from their readers. Confessional tales that because of the reflexive ethos of my research categorize much of my writing so far, are according to Van Maanen (1988), an alternative route to securing such a reward irrespective of whether that aim is made explicit to the reader or is conscious to the writer. Their literary conventions give the fieldworker a starring and skilled role, a personal authorship that gives an authority to the writer, and a naturalness that convinces the readers of its authenticity despite, or perhaps because of, all its caveats that have been shared with them. This genre therefore pursues realism as doggedly as the realist tale and is even more deserving of the award of authenticity as it has confessed what its counterpart has concealed.

Words aim to represent research but they may also represent the discipline in which it is being conducted, and even the researcher conducting it. As I believe in the power of words I believe writing research and disseminating its words have the potential to be, and/or to become, a political act. Its ethical consequences are captured in the African

proverb "Until the lions have their own historian, tales of hunting will always glorify the hunter" (in Dahlgren, 1991:67). Asthma is my lion, specifically asthma in Teesside's children, and while Xingjian [1990] (2001) speaks poetically of my aim, politically speaking, I am Dahlgren's hunter. Hence, I make public (Agar, 1996) how I use words in my writing, beginning with the words of others. As one might expect historians or authors who write reflexively in relation to their fieldwork or their writing to be the most revealing, I was especially interested in literature of direct relevance to my research whose writers had produced also such reflexive texts[18]. Of these Okely (1996) in *Own and Other Culture* indicates by her inclusion of consecutive chapters on girls' boarding schools written for popular and academic audiences respectively, that one writes for an audience as well as about a subject. Wolf (1992) reinforces the contribution of the audience by presenting as *A Thrice-Told Tale*, popular, academic and field notes versions of an event observed during fieldwork but not recorded at the time as she perceived it as being irrelevant to her research.

The subject and subjects of their accounts are similar, yet their accounts are different. This is because words can be powerful and that power might be transformed if they are converted into other words, even if preservation of original meaning is the sole aim of the translation. Quotations therefore, make a major contribution to this dissertation. Words are preserved also because although rewriting aims to demonstrate understanding and disprove laziness it has the subversive implication that they can be written better – perhaps they cannot. Nor are all analysed explicitly or immediately as my analysis of them might be concealed in my selection of them. Further, my analysis might dilute the power with which they speak for themselves and/or of their author, as that power is derived from experiencing them for oneself, not from reading their academic dissection. Moreover, readers should have opportunities to conduct their own analysis unfettered by mine, and thereby to accompany my contributors and myself as diagnosticians and detectives of asthma.

As words can be powerful, the more I explain their use or their analysis, the more I risk diluting their power. On the other hand, the more abstract and vague I remain, the less the evidence base with which to attempt to substantiate their intended use. I compromise by citing *The Ethnographic Imagination* (Atkinson, 1990) as my most

[18] Paul Atkinson, Carolyn Ellis, Clifford Geertz, Allison James and Judith Okely.

influential academic guide to writing[19] and by confining my illustrations to the first section of 'Introducing Asthma' that forms the framework (Atkinson, 1990) of my dissertation. Hunter's (1991) detectives have been cast as all who seek the actuality of asthma, and Lakoff and Johnston's (1980) personification of metaphor has guided my writing about it as an actuality. The original meanings of illness, disease and sickness are the literary equivalents of their actualities. As they pertain to asthma, they form consecutively, the three chapters of the second part of the dissertation where their relationships to things, words, time, space, people and places are explored. My ultimate aim in using my own words is though, to write a dissertation that I believe to be true to its origins in the interaction between the researched and the researcher. Words should remain a means to an end, not become the end. They should not assume authenticity, but be authentic.

In trying to be authentic, I have been confronted by the need to preserve the anonymity of those who contributed it, especially as they and my dissertation live very close to each other. A dog apart I have not followed the well-trodden route in qualitative writing of pseudonyms, nor have I followed Scheper-Hughes's (1979) creation of composite characters. Both in my opinion challenge the uniqueness of the person, and the latter also anthropology's holism as the original not composite character was its subject. I have coded instead, because although a composite of letters and numbers might depersonalize participants, it prevents their 'repersonalization' as pseudonyms or composites. Participants may, however, be identified by others and by themselves (Richards and Schwartz, 2002), as much by what is said about them, as by whom they are said to be. In this respect I have been guided by the person who asked Scheper-Hughes when she visited again the Irish villagers that she portrayed as saints, scholars and schizophrenics

> "Why couldn't you have left it a dusty dissertation on a library shelf that no one would read, or a scholarly book that only the 'experts' would read? Why did you have to write it in a way that *we* could read it and understand exactly what you were saying?" (1979:vii)

Thus I anticipate that I have revealed more information in this 'dusty dissertation' than I will reveal in the reports that I have promised the families with asthma and the asthma clinics. Equally, I will be more restrictive in publications as these might not

[19] Whom I have not yet forgiven for his opinion of doctors (p.11).

be scholarly enough to deter a wider audience, especially as research can reach it by delayed and circuitous routes (Walt, 1994), especially those involving the media (Moffatt *et al*, 2000a; Phillimore and Moffatt, 2000).

In practice, however, as interdisciplinary foraging (p.9) has guided my research and my reading, my greatest written challenge has been writing a dissertation that is relevant to, and will, I hope, be understood in its entirety by any "well educated, attentive close reader of that text" (Hunter, 1991:12). My writing draws upon what I perceive to be the styles and conventions of the various disciplines in general, but my dissertation is written primarily for social scientists and health professionals as their disciplines are of greatest relevance to it. They are also of greatest relevance to me as they are mine. If forced to choose its library shelf it would be one labelled 'Anthropology'. Yet I feel a kinship with Bowker and Star who "would hate to have to assign a Dewey classification number" to their book on classification, and I share their "modest hope that it will not find its way onto the fantasy shelves" (1999:xii). Writing has proved most challenging when a discipline's discourse adds to or alters the meaning of a word. There is an entire anthropology of the person (Carrithers, 1996) who stands in a distinctive social scientific relationship to an actor (Barfield, 1997). The case that you met earlier (p.6) has added medical significance (Hunter, 1991) while GM-CSF which you will meet later requires specialist understanding (Kay, 1997). Xingjian who introduced 'My Dissertation' with what I want to do, warns me that I "create out of nothingness, playing with words" [1990] (2001:350). I have tried to create out of asthma, but I have played with words when I feared my disciplines were becoming my disciplinarians, and occasionally for the fun of it. What if my words are acceptable to no-one? Well, "[p]eople have spoken so much nonsense, so why shouldn't you say more?" (ibid:350).

Chapter 3 HERCULES'S MOOON

[H]ere is this world, make of it what you will

John Van Maanen[1]

[1] Van Maanen (1988:103).

3.1 INTRODUCTION

I never saw no place
Nowhere the like of it

Andy Croft[2]

Here I describe my fieldwork site. It is the new and interesting country that I, like Porter's correspondent (p.42) have travelled through, though I begin with the travels of others, leaving mine until its end.

[2] Extract from 'No Place Like Home' in Croft (1996:14).

3.2 THE CHILD HERCULES

> I took a boat and entering the Teesmouth ... I was fancying the coming of a day when the bare fields we then were traversing would be covered with a busy multitude and numerous vessels crowding to these banks... Time, however, must roll many successive tides ere the change is effected. But who that has considered the nature and extent of British enterprise, commerce and industry will take his stand at this spot, pointing the finger of scorn at the vision and proclaiming that it will never be.
>
> Joseph Pease [3]

Teesside is less than 200 years old. Before its birth it was salt marsh and bare fields that in 1801 were interrupted only by four houses and 25 people (Briggs, [1963] 1996). The hamlet was sited on the south bank of the Tees at the place where monks journeying between Whitby and Durham had ferried the river for several centuries (Bell, 1907). Its name Middlesbrough may originate from it being sited upon a 'middle place' or 'middle burgh' of solid higher land in the marshes that were there and then the river's south bank (Moorsom, 1993). Teesside's parents are its geology and its geography: its mineral reserves and their proximity to the Teesmouth where the river meets the North Sea. The river also located Teesside to its banks and named it accordingly. However, if the river gave Teesside its name, its minerals gave its name its significance. Clay was Teesside's first contributor, founding its pottery industry in 1820 (Lyth, 1952). Though important in reputation, its material contribution paled into insignificance beside coal. In the year 1830-31 more than 150,000 tons of coal left Teesside, fifteen times that estimated by Joseph Pease, the son of a local farmer and driving force behind the enterprise (Briggs, [1963] 1996). Pease, in his diary in 1828, had in fact grossly over-estimated the number of tides to effect his change, thereby pouring scorn on his own British vision.

Coal created Middlesbrough out of those four houses and 25 people. It began life as a port for the shipment of coal from the River Tees to London. In 1825 the Stockton and Darlington Railway, known colloquially as 'the Quaker's line' after the religious affiliations of its founders (Briggs, [1963] 1996), opened, and in 1829 was extended to

[3] Pease (1828), in Lillie (1968:47).

the hamlet of Middlesbrough where the sea was closer and the river deeper (Lillie, 1968). The plaque on the first new house (ibid:51)

ERECTED BY
MR. GEORGE CHAPMAN
APRIL 1830
BEING THE FIRST HOUSE IN THE
NEW TOWN OF MIDDLESBROUGH
UPON TEES

signified the importance of the river.

By 1841 its population had increased to over 5000 with a further ten-fold increase by 1881 and another near doubling by the turn of the century (Bell, 1907). So fast was its growth that one Victorian writer described it as a town that had "'won a name without history, an importance without antiquity'" (in Briggs, [1963] 1996:1). Pease, in association with various relatives by birth and marriage and a Norwich banker, as the *Owners of the Middlesbrough Estate* attempted to impose his history on Middlesbrough (Lillie, 1968). The Owners created its original plan in 1829 in which four streets led from a central square to the four key points of the compass. Yet the end result resembled

> "[t]hose ancient cities, which from being at first only villages have become, in the course of time, large towns, are usually but ill laid out compared with the regularly constructed towns which a professional architect has freely planned on an open plain ... When one observes their indiscriminate juxtaposition ... and the consequent irregularity of the streets, one is disposed to allege that chance rather than any human will guided by reason must have led to any such arrangement" (Descartes, in Midgley, 1989:177).

The vision of their professional architect was according to Lady Bell, the wife of one of their industrial successors, defeated by

> "[t]he unexpectedness of it ... a great rush from all parts of the country ... there springs, and too rapidly into existence a community of a pre-ordained inevitable kind, the members of which must live near their work ... A town arising in this way cannot wait to consider anything else than time and space" (1907:2-3).

Lady Bell, married to an iron owner, challenges the casting of Pease and his associates – the coal men – as Middlesbrough's obstetricians, citing iron not coal as fuelling the birth of the town. Certainly iron, according to Lillie (1968) saved the infant Middlesbrough, thus casting John Vaughan and Henry Bolckow, its first "*Iron Men*" (ibid:65), its paediatricians if not its obstetricians. Unlike Pease, both were strangers who were

persuaded by him to settle and invest in Teesside's next mineral as the iron industry was becoming one of the main driving forces behind the nation's Industrial Revolution. Contemporary descriptions of the first ironworks in 1841 evoke a more homely beginning to the revolution in which a "lump of iron ... was kneaded like an old woman working a loaf" (anonymous in Lillie (1968:71). Soon the otherness of industry entered in the iron squeezer, bestialized by the anonymous contemporary as "a huge crocodile" on which "someone had chalked an eye on each side and a row of large teeth in the jaw", to be alienated further into "a mighty monster chewing red hot iron for its food" (in ibid:71).

Iron was risky at first as local ironstone was invisible to its investors and it had to be transported some distance from Whitby at considerable expense, but "why it took so long to creep out" of the Cleveland hills is "[o]ne of the mysteries of the Iron Age" (Lillie, 1968:96). In 1850, their investment was realized and their fortunes secured when, after much careful searching Vaughan discovered large quantities of high quality ironstone in the Cleveland Hills (Nicholson, 1996). The alternative local and unofficial creation myth attributes his discovery to chance rather than care, ascribing it to a stumble over a block of ironstone while shooting rabbits. Nicholson (1996:41) likens this popular account to "the classic story lines of folk-tales and fairy-tales" unlike the official published accounts stressing the Victorian ideals of self-help, individualism, patience and above all else, sheer hard work that made the man, and made the man his fortune. Following the finding of the pot of gold/ironstone, iron production increased ten-fold in the next five years and by the last quarter of the nineteenth century the region was responsible for a third of national iron output, over two and a half million tons (Beynon *et al*, 1994).

Steel followed iron on the national stage but steel production initially required non-phosphoric iron ore, not the phosphoric Cleveland ironstone. Thus Middlesbrough remained iron bound during the middle decades of the nineteenth century and its steel production began in the 1870s with expensive imported ores that demoted it from the premier industrial league. During this period several firms went into liquidation and many jobs were lost. *Bolckow-Vaughan*, named after its founders, was the first to forge iron into steel, but its growth into a steel giant had to wait until the invention at the end of the decade of a method of making steel from phosphoric iron ores.

The industrial status of Teesside, and of Middlesbrough especially, during the second half of the nineteenth century created its own mythology, even more heroic than that of its ironstone. William Gladstone, then prime minister, during his visit in 1862 famously praised Middlesbrough as "[t]his remarkable place, THE YOUNGEST CHILD OF ENGLAND'S ENTERPRISE ... It is an infant, gentlemen, but it is an infant Hercules" (in Briggs, [1963] 1996:1). An unidentified contemporary extolled with equal enthusiasm the fame of Hercules's iron that

> "furnishes railways to Europe; it runs by Neapolitan and Papal dungeons; it startles the bandit in its haunts in Cilicia; it streaks the prairies of America; it stretches over the plains of India; it surprises the Belochees; it pursues the peggunus of Gangotri. It has crept out of the Cleveland Hills, where it has slept since the Roman days, and now, like a strong and invincible serpent, coils itself around the world" (in Briggs, [1963] 1996:1-2).

Middlesbrough's contribution to sea transport and trade was no less impressive. Ship building filled the river banks from the 1830s, and by the end of the nineteenth century over one tenth of the world merchant shipping production was launched from Teesside, and one half from the northeast as a whole (Beynon *et al*, 1994), thus realising the dream of its obstetrician.

Coal, iron and steel dominated the landscape they created. By 1871, 90 blast furnaces ringed the riverside, lighting it with flares by night and concealing it in a pall of smoke by day. Yet these furnaces give Teesside an enduring, uncompromising beauty in my imagination, and their smoke according to proud locals, symbolized its power and prosperity. As the mayor proudly if forthrightly declared at the opening of the new town hall in 1889 by the Prince of Wales

> "His Royal Highness owned he had expected to see a smoky town. It is one, and if there is one thing more than another that Middlesbrough can be said to be proud of, it is the smoke (cheers and laughter). The smoke is an indication of plenty of work (applause) – an indication of prosperous times (cheers) – an indication that all classes of workpeople are being employed, that there is little necessity for charity (cheers) and that even those in the humblest station are in a position free from want (cheers). Therefore we are proud of our smoke (cheers)" (in Briggs, [1963] 1996:20).

But was the mayor 'coming clean'? The "path of the ironworker is literally strewn with danger" warned Lady Bell (1907:35). Gassing, pneumonia, consumption, asthma, fevers, blood poisoning, eye complaints and above all else, accidents strew his path.

Bell's (ibid) description of the working and living environments of the workpeople, especially those in the humblest station in a society and culture of "blast-furnaces that are never allowed to go out" (ibid:27) echoes those of the dark satanic mills recounted more than half a century earlier by Engels (1848) and Gaskell (1855).

All portray the industrial danger to health counterpoised with the economic danger of unhealth. Bell's (1907) focus is predominantly upon the health of the men employed *At The Works* which by its subtitle *A Study of a Manufacturing Town* binds and subordinates the town to its industry. Despite her gender she says little about the health of women and children at home or in other employment beyond the dangers of childbirth and frequent forays into hygiene. Dirt and cleanliness feature also in Gaskell's (1855) novel in which the working health of the women millworkers in the 'North' is embodied in Bessy who "falls into a waste, coughing and spitting blood, because [she's] just poisoned by the fluff" (ibid:102). Engels (1848) multiplies the poor person into poor people who suffer typhus, influenza, lung diseases, digestive problems, starvation, 'rachitis' [rickets], arthritis, muscular weakness, nervous disorders and alcoholism, and especially among children, accidents. All narrate the impact on health of material threats in the present, and potential threats to the future. Such threats might have contributed to the escapism and oblivion of alcohol replacing faith in and obedience to God. The public house usurped the church as the town's core social institution, and the Quaker ideals of its first 'doctors' became the ethos of a frontier town of the American wild west (Briggs, [1963] 1996). The most direct contributors might, however, have been the cowboys themselves – male immigrants who by the end of the nineteenth century distinguished Middlesbrough demographically from most English industrial towns.

At the end of the nineteenth century a new industrial actor entered Teesside's stage. The first big chemical plant in Billingham on the north bank of the river started production at the end of the first world war but the merger in 1926 of several chemical firms to form *Imperial Chemicals Industry* (*ICI*) catalysed output. Thus, as with iron and steel before it, scenes on national and international stages were critical to the birth and growth of its latest industry. The chemical industry's attitude to its workforce originally mirrored the paternalistic intentions of its iron and steel predecessors, though with the aim, according to Beynon *et al* (1994) of promoting and maintaining low levels of unionization among its workforce. It built over 2000 houses for its workers transforming Billingham from a

one church, one pub hamlet to a one industry, one company town, and further reinforced stability by encouraging the recruitment of generations of the same family, often resident in its own houses. Thus *ICI* became a fact of life for Billingham's residents.

In 1945 Middlesbrough council aimed perhaps, to make the *Middlesbrough Survey and Plan* an equally factual reality. Its creator, Max Lock (in Beynon *et al*, 1994), harked back to the time when "Middlesbrough started to build with a 'clean slate'" praising the "almost aggressive faith of Joseph Pease" (in ibid:68). One might wonder, however, if he were mindful of Lady Bell when he applauded his collaborators for being "as great pioneers in the field of town planning as were the Middlesbrough Ironmasters in the mid-nineteenth century in the field of *industry*" (in ibid:68, emphasis added). Lock's plan projected the post-war reformist ethos that was founded upon a belief in the benefits of state intervention into individual lives and his reference to "[o]ur sociologists believe" (in ibid:68), incorporated a belief in the contribution of academia to good governance. One sociologist believed that "industry used to be the focus and the very *raison d'etre* of Middlesbrough", but had lost its power to weave the threads of its human fabric into a web of "social relationships, [and] Middlesbrough now lacks a focus" (Glass, 1948:14-15). Industry retained however, its power in the political corridors in Middlesbrough, and like the *Owners*' plan before it, the ideals of its creators were never realized (Beynon *et al*, 1994).

Yet despite industry's continuing local dominance its fortunes ebbed and flowed throughout much of the twentieth century. After the First World War *Bolckow-Vaughan* suffered a take over by its rival *Dorman-Long* whose superior economic health was founded in part at least on it having won the contract to build the Sydney Harbour Bridge. *Dorman-Long* prospered in the inter-war years acquiring a considerable interest in coal – its industrial predecessor in Teesside. Ownership began with several local mines, and subsequently extended nationally. By the outbreak of the second world war "it would be difficult to find a closer link between coal, by-products and all branches of the iron and steel industry than is represented by this well-knit Durham combine" (The Labour Research Department (1939), in ibid:30). Though it lost its minerals to the nationalized coal industry in 1947 it continued to expand, opening ten years later its second new coking works at the South Bank adjacent to Middlesbrough, but not without controversy. Local councillors drew "attention to the present nuisance existing as a

result of the emission of smoke and solid matter" (in ibid:66), thereby jeopardizing the spirit of local co-operation between industry and government, founded till then upon a common interest in job creation. Eventually they were over-ruled by the UK government following an appeal by the nationally renowned and influential *Dorman-Long* which was required merely to take "all practicable precautions, rather than *effective* anti-pollution measures" (Secretary to the Teesside Smoke Abatement Society, in ibid:67).

A decade later *Dorman-Long* had been nationalised into one fourteenth of the *British Steel Corporation* whose fortunes declined the following decade, again primarily because of events originating far beyond Teesside. National and local steel production was hit by the combination of the world wide global recession of the 1970s, the emergence of newly industrialising countries such as Brazil and South Korea as major producers of steel at lower cost, and a growing substitution of steel for aluminium and plastics. By the early 1980s jobs in steel production had fallen to almost one half of their peak levels and steel output was down by one third with knock-on effects for industries involved in supplying the steel industry and processing its product. The knock-on effect was made worse by the increasing severance of local links between the steel industry and allied industries in favour of more competitive national or imported alternatives – in 1979 imported coal replaced local coal in the steel furnaces. Moreover, the contraction of other heavy industries such as coal mining, shipbuilding, engineering and construction further worsened Teesside's industrial decline during the 1970s and 1980s. Maile (1987:71) in a publication supported by the Confederation of British Industry is revealing.

> "Old hands talked to me proudly of present records and shook their heads over past history. 'We've got seven and a half thousand men here now producing 3 million tonnes of steel annually – a few years back we had difficulty achieving that between Consett, Hartlepool and here with twenty-five thousand men or more...' *Admittedly*, the increased technology and massive investment have produced a more streamlined, efficient plant" (emphasis added).

Teesside's chemical industry suffered a similar fate. The world recession reduced the demand for its products while production increased worldwide due to the emergence of new producers, particularly oil and gas producers, whose competitiveness had been boosted by the price rises in these products in the early 1970s. Employment in Teesside's chemicals contracted from over 20,000 in 1979 to less than half that figure just over a decade later (Beynon *et al*, 1994).

Unemployment was perhaps particularly damaging to Teesside's working men, whose masculine culture was rooted in the frontier town of the nineteenth century and in the difficult and dangerous labour at the works. It has also since become stereotyped as a culture of place – of 'The North'. I remember the comedienne Caroline Aherne in her persona of Mrs Merton as the housewife of The North assuring us that its men are very receptive to feminism as long as it does not stop their dinner being on the table at 6 o'clock sharp. On the other hand men have, they might reply, been the traditional providers of those dinners since the Iron Age.

Unemployment rates in Teesside peaked at over 20% in the mid 1980s, but in its poorest parts over 40% were without work (Beynon *et al*, 1994). Further, work changed for those still in employment in the harsher industrial climate with the emergence of regimes of regimented flexibility. Employers asserted their "right to manage" (ibid:126), whether this be *British Steel Corporation*'s insistence on its exclusive right to determine and re-determine the shift patterns of its workforce or a Japanese employer's prohibition of talking on its factory production line. These new working practices, allied with reductions in fringe benefits, sub-contracting, short-term contracts, non-union agreements and job insecurity created atmospheres of fear and uncertainty reminiscent of the potential threats to the future if not the actual dangers of the present, of their counterparts of the previous century. A Teesside working man put it more bluntly: "[t]he authorities are pushing people into situations of anarchy. People just don't see justice being done" (in ibid:126). The rising levels of unemployment and of low-waged part-time employment in turn stimulated the growth of the informal sector, "the so-called 'black' or 'fiddle' economy" (ibid:125), often in collusion with employers who traded low wages and poor working conditions for a blind eye to any paperwork that would entail loss of social security benefits for their illegal employees. Those robbed by the informal economy were not, though, confined to the state and its taxpayers. According to the same Teesside working man "You can get anything you want knocked-off. It's the poor robbing the poor. The gear turns up at car boot sales, it's all the stuff that can't be traced" (in ibid:126).

Such was the fate of

THE WORKS OF GIANTS

Splendid this rampart though fate destroyed it.
Strange was its building, but fall was strangest.
Mighty the giants who must have made it.
Bitter the wind that blows through ruins,
Coldest the moon that hoops its shadows
Dark through rubble of best ambition,
Dark through the halls where rats are creeping
Over the faces of stone-dead builders.
Bitter the day when walls fell earthwards
Coldest the day that broke on ruin.
Long was the building, short the falling,
Gone are the builders, never returning.

Andy Croft[4]

Had the infant Hercules simply outgrown its strength, or had it been badly brought up? The question journeys far beyond the boundaries of this dissertation, but at the end of its next part I return to the significance of Hercules's childhood for childhood asthma in the adult it became. Now I continue its journey in the body of Teesside today.

[4] Croft (1996:11)

3.3 THE ADULT HERCULES

> Dying before your time is the ultimate social exclusion.
>
> Graham Watt[5]

The adult Hercules is poor and unhealthy. Its impoverished body is described in Townsend *et al's* (1986, 1989) study of poverty[6] in the north of England. Middlesbrough came second out of 29 districts in the proportion of its local authority wards ranked among the worst fifth in the northern region. Currently eight of its 22 wards are very deprived according to the Townsend score and unemployment rates are above the national average (Tees Health Authority (THA), 2001). However, Middlesbrough and its Teesside neighbour Stockton on the north bank of the river, differ significantly from other deprived areas in that both house many relatively affluent wards. Teesside is therefore characterized by social inequality, as much as by poverty. The adult Hercules is malnourished with starvation and obesity co-existing in the same body such that "[s]ometimes, locally, the highest and lowest areas are separated by no more than a few hundred yards" (THA, 1998:2.2.1). Child poverty estimated from numbers claiming income support is nearly eight times higher in the poorest than in the wealthiest wards (Johnstone, 2001).

Moving from its wealth to its health, death rates in Teesside are about 15% above the national average (THA, 1998) and have been so since the mid 1980s (Research and Intelligence Unit (RIU), 1987). Health went hand in hand with wealth in Townsend *et al's* (ibid) study and in the subsequent study by Phillimore *et al* (1994). As with wealth Teesside was home to some of the most healthy wards in the northern region but many of the most unhealthy[7], Middlesbrough having the highest proportion of wards ranked amongst the worst fifth (Townsend *et al*, 1986). The most unhealthy wards had a premature mortality in excess of 50% of the national average which translates temporally to the national mortality experience some thirty years earlier (RIU, 1987).

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[5] Watt (1996:1027)

[6] The study devised the Townsend Index constructed out of four indicators taken from the 1981 Census – unemployment, lack of car ownership or home ownership, and overcrowding – as a measure of poverty.

[7] The study devised also a health index measuring premature mortality, morbidity and delayed development recorded respectively as standardised mortality ratios (the ratio of observed number of deaths to expected number of deaths) for persons under 65 years, proportion of permanently sick or disabled adults and proportion of live births below 2800 grams.

The most unhealthy wards also have infant mortality rates double those of their healthiest counterparts (Johnstone, 2001).

Geographically, the south bank of the River Tees dominated the statistics of premature mortality. Moreover, the excess of mortality was not explained statistically by the combined effects of material deprivation and occupational class. It might, Townsend *et al* (1986:171-2) suggested, implicate the impact of the local environment on health, for

> "the deprivation caused by living in an area where exposure to various forms of environmental pollution is a regular feature of life is not something which it has been possible to incorporate in the analysis of deprivation ... But the very special industrial characteristics of the Teesside basin, based on the chemical and steel industries, and the fact that mortality is a product of a complex array of factors over a lengthy period, does raise the possibility that what we have evidence of here ... is the effect on mortality of long-term exposure to environmental pollution as well as other possible elements of material deprivation which are not covered at all or covered inadequately by the choice of indicators available for analysis".

Further support for these suggestions was provided by the comparison of rates of premature mortality in materially deprived wards in the industrial town of Sunderland which are considerably lower than those reported in the above South Tees wards. Also, Phillimore and Morris (1991) showed that the elevated death rates in the South Tees wards could not be attributed to a short-lived anomaly confined to the early 1980s – the years reported by Townsend *et al* (1986, 1989) – as they persisted from the mid 1970s to the mid 1980s. These findings raised the possibility that the differing industrial character of the two areas might have contributed to their different mortality experiences. Sunderland's coal mining and ship building, had the potential to pollute its largely male workforce at work, but Teesside's steel and chemicals had a greater potential to pollute all its residents all of the time. Mortality in Teesside from respiratory diseases was 25% above the national average, but the excess reached 40% in women in South Tees (RIU, 1987).

Unlike the sociologists contributing to *The Middlesbrough Survey and Plan* these academics' concerns about Teesside's industry were primarily over its environmental side effects, and they were not the first to air such views as local industrial decline in the 1970s coincided with a national rise in the environmental movement. According to Beynon *et al* (1994), local politicians initially contained the protests of local campaigners, portraying jobs as the inevitable and desirable trade-off for a polluted

environment, thereby echoing their predecessors in 1889. By the middle of the decade environmental campaigning against the reclamation of land for expansion of the chemical industry had spilled into the public arena. Avian not human health was promoted initially as its bird population had awarded the land the status of a site of Special Scientific Interest, prompting an allegiance of workers and employers in the industry to fight back under the slogan 'jobs not birds' (ibid:113). Yet over the subsequent decade a distinct shift in emphasis occurred because sacrificing the birds did not save jobs in the polluting industries. Also, concerns over the effects of pollution on human health became uppermost, particularly among the local residents, and among women especially, most of whom had been excluded from employment in the industries, yet lived in the environment they created. Thus "the priority of 'people over birds'" (ibid:118) reached centre stage.

The amalgam of lay suppositions and academic evidence in Teesside's furnace fuelled in the early 1990s a major three year investigation by researchers from the universities of Newcastle, Durham and Teesside as the aptly named Teesside Environmental Epidemiology Study (TEES) Group. The TEES Group (1995) compared the health and environment of residents in poor housing estates in Teesside living close to industry with those living in housing estates in Sunderland, equally poor, but without proximity to industry. The Teesside estates were further sub-divided into three zones according to their distance from the industrial complexes, thus enabling investigation of the health consequences of differing exposures to pollution.

The TEES Group (1995) concluded that on most indicators of air quality Teesside and Sunderland scored similarly and were comparable to other urban centres. Usually levels remained well within World Health Organization (WHO) guidelines, although fine particulate levels (PM_{10s}) occasionally exceeded these guidelines at one site in Middlesbrough. Elevated levels appeared to have little immediate health effects as GP consultation rates did not increase in Teesside on or after days of poor air quality. In comparison with national statistics residents in both Teesside and Sunderland were in extremely poor health but no statistically significant differences emerged between the study areas in mortality from doctor-diagnosed diseases or in morbidity from self-reported illnesses, apart from an excess of deaths from lung cancer among women living close to Teesside's industries. Rates of other respiratory unhealths were similar in

Teesside and Sunderland and between the Teesside zones, though in the previous 12 months, children and adults in Teesside living close to industry had reported a greater frequency of asthma attacks.

A second study of childhood asthma and wheeze in South Cleveland contradicted, however, the above as children living most distant from industry reported the most frequent attacks (Denn *et al*, 1995). Asthma and wheeze were very common, with 26.7% of the 2686 children reporting either at some time in their lives, and 13.5% reporting either within the previous year. As with the study above, there were no statistically significant differences in rates between the zones distinguished by their differing proximity to industry. Nor were there any statistically significant associations with poverty[8] though "unemployment was associated with reported asthma within the 12 months prior to the start of the survey" (ibid:178). Neither environmental pollution, nor poverty, therefore, had any statistically significant link with asthma in Teesside's children.

However, as I have said already my preoccupation is with substantive not statistical significance (p.24), and I have implied that Teesside is substantively significant in itself (p.5). Thus, I end this section by returning to anthropology at home (p.14)

AS WE CONTINUE OUR SEARCH FOR POMEGRANATES

the rain drenches the crowded market stalls
with all the descriptive detail it can muster.
Sometimes home can be the most exotic place
there is, the shoppers faces as wrinkled
and misshapen, as fascinating as the oldest
babushkas in the remotest Uzbeki village.

Today is not one of those days. Today
is a shop for fruit and get the hell out of day...
The pomegranates in their boxes nestle
in shredded raffia, hold more promises
than anyone could ever keep...

Today is one of those days the town seems
inhabited purely by stroke victims, ourselves
included. We poke each other in the ribs...
at the crossroads: we find ourselves stranded,
hold out our hands as if to check it's still raining

Mark Robinson[9]

[8] Poverty was measured by the Townsend Index.
[9] Robinson (1996:54).

Such is Robinson's (1996) Hercules, but it, and none of what preceded it, are mine as I have not yet described my fieldwork site. I do so now, but 'My Hercules' is written differently. Why, is within 'My Dissertation' as is why I do not tell you now, but in case you are not as accommodating of my travelogue as Xingjian (p.50), it is written under the influence of Lakoff and Johnson's (1999) concept of the embodied mind in which reason is not literal and dispassionate but emotional, imaginative and metaphorical.

.

3.4 MY HERCULES

> Imagine yourself suddenly set down by all your gear, alone on a tropical beach close to a native village, while the launch or dingy which has brought you sails away our of sight ... Imagine further that you are a beginner, without previous experience, with nothing to guide you and no one to help you ... Imagine yourself then, making your first entry into the village, alone.
>
> Bronislaw Malinowski[10]

I have begun in the Trobriand islands early in the last century with the founding father of ethnography because of the power of 'Imagine' on me. Imagination has contributed to scientific thinking since the Scottish Enlightenment of the eighteenth century (Downie and Macnaughton, 2000), and by commandeering my imagination Malinowski (1922:4) makes his "brief outline of an Ethnographer's tribulations as lived through by myself" more real. I too ask the imperative. Imagine yourself not in the Trobriands but in Teesside, and as I revealed some of my tribulations in the previous chapter, it, rather than I, is my intended subject of your imagination. Yet my purpose is equally authoritarian, as my words aim to recreate for you, Teesside as the place of my research, and as significant to it, as my experiential and theoretical influences discussed in earlier chapters.

You though, might have your own Teesside. If so will you "[e]mpty your mind of all its pictures" (Moorsom, 1993:1) and imagine[11] yourself suddenly set down, but where? In my reality Middlesbrough's bus or rail station, but imaginatively as its word. Teesside, like asthma, began for me as a word (p.17), a word that I translated into a place on the banks of the river. If The Tees is its beginning, where is its ending? The sea is to the east, but to the west, north and south I imagine it ending at the bare fields of Joseph Pease's diary. Industry is Teesside's place yet it is another country inside the modern shopping centres that line the pedestrian precincts of Middlesbrough, its first urban place. *The Terrace* restaurant on the top floor of one of the more traditional department stores images Italy in its name yet I come home to industry in its tall windows. Closer still are streets edged with smaller shops, self-effacing or strident, and the public buildings of any large town – the red brick and sandstone public library, the newer and

[10]Malinowski (1922:4).
[11] My Hercules is empty of pictures as it is contradictory to say 'Imagine' (figs. 1-n).

greyer police station and law courts, and a church with grilles guarding its stained glass windows. Its vicarage is in a modern tower block next to the *Future Steps* careers centre and a sign on the door directs ecclesiastical deliveries to the *Gold Centre* across the road.

Further away on *The Boulevard*, Captain Cook's *Bottle of Notes* sculpture by Claes Oldenburg replaces the Tower of Pisa that I might have imagined from *The Terrace*, but leans further. From *The Terrace* the bus station is closest to my eye, and a much more human place than the railway station, whose line once so dominant sits still elevated, but on the edge. Yet there is something strange about the centre of Middlesbrough as it never feels a place in which to linger, especially after the shops close. It has fast food outlets and pubs, but there are no restaurants now that *Pizza Hut* has closed. The library, open till 7pm most evenings was my favourite place to linger but it has no public toilets. Middlesbrough might have a central place spatially, but I have never felt it to be a community place.

I first encountered Middlesbrough after 7pm when I returned from an interview, so imagine yourself now, where most of the families lived. If you are familiar with my country you might think it has no need of words as its image is so ordinary, and mine might risk rendering the familiar exotic. There were rows of semi-detached houses, or newer small private, or less frequently council, terraces, or older and larger terraced houses with bay windows and high ceilings, or detached homes arranged on their own space and around others. Cars were outside them, or in driveways or in front of, but rarely inside garages. Gardens or green public spaces were close by, small clusters of shops, pubs, take-aways and bus stops, and streets, usually quiet, but sometimes within earshot of a busy road. Homes varied in size from two bedrooms and two public rooms to four bedrooms and at least as many public rooms, and two had no cars while several had two cars, and not all had front gardens. Yet my memories are of uniformity and conformity that contrast the mishmash in the centre of their town.

"Town centre" I said to the bus driver. "You're here" he replied. So I am. I am in the centre of South Bank, its capitals symbolic of its elevation to a bounded place, but the row of shops on either side of the bus stop seemed too insignificant to separate it from Middlesbrough town centre to which I was returning. I felt like Gertrude Stein in that

mid-western town in which there was no there there. Had the 'there' of this town become the shopping centre accessed by an underpass whose entrance was obscured by market stalls on my weekly Friday visits to the women's community centre? The underpass is lined either side by painted tiles. Cheerful murals of fruit traders (any pomegranates?), space ships and exotic locations clash thematically and blend stylistically, but the last on the left is different. The black metal struts of the transporter bridge penetrate the nondescript brown and faun buildings below yet never touch them. The sky behind the struts is a hot metal red.

In front of that sky a grey cob canters round its tether. Its skewbald companion walks expectantly towards a blue plastic bucket beside its anchoring stake but realises regretfully I am not its Gypsy. The grey quietens slowly and the skewbald loses interest. The grass verge with its spruce green vacuum cleaner bounds their apple green space. Two white and tan drawers – newcomers perhaps, because they are almost empty of the leaves on which they are lying – lie on the opposite verge. Cars line up in front of it on the edge of the muddy road. Most are more than a decade old and are tinged with dirt or industry. At the end of the road a metallic bridge shimmers in the sky behind the horses. Between them and the sky a spiky tower the colour of sand reads

DORMAN

LONG

as it spears the heavens above the horses and oversees a busily puffing hour glass grey chimney. Between the tower and the chimney intermittent white clouds and red sunsets fragment the sky with their smoke and flares.

At the other end of the road a small and unassuming red and white sign finally finds the railway station beneath the metallic bridge. The sign is positioned at a right-angled bend round which cars and buses irregularly swing. The right angle demarcates the car park of the shopping centre in which purchases, mostly more recent than those in the muddy road, await the contents of supermarket trolleys. A disembodied voice from the supermarket orders a name to the cold meats counter as I walk past the pub intruding between it and its equally modern carpeted neighbour – a furniture centre with an expensive leather reproduction suite in its window. Yet the publican *Barnacle Bill* looks the earliest resident. The star and cross on the probation offices guide me to the

underpass that is the pedestrian's gateway to consumerism. On its other side a smoking cloud is passing over a poster advertising Pink Floyd's *Echoes*.

Houses. The biggest have the best industrial view, but it is not their size that classifies them. Grilles, boards, panes, double glazing, decorative stained glass. Some have no numbers; others have painted or metallic numbers on the doors, a few doors have numbered and decorated plaques beside them. If I were not a stranger, might I "open two doors side by side into houses of identically the same accommodation, and find one of them a bright and seemly home and the other an abode hardly fit to be entered into by human beings" (Bell, 1907:5)? In one street of double glazing and decorative stained glass in bay windows almost all the houses have wooden or enamel number plaques beside the doors. A man and a boy play football outside one of them while women and another man are talking in the garden before another. A couple of streets away panes are interspersed with boards, and grilles soon replace both, but then double glazing returns, and mingles with boards and panes. Material remains litter pavements. A few of their canine producers pass by, not all accompanied. Over the garden fence one greets the few passers-by on foot or in push chairs. Houses flank other pavements, some protected on the outside by burglar alarms. In certain streets all houses advertise the same alarm; in others different manufacturers compete. In a few streets the curry factory wins the competition for the senses, but in a street with an industrial victor, a similar though more aromatic smell emanates from an open doorway framing an Asian woman.

As I write I imagine that suburb of Manchester whose streets and houses were classified separately into three categories by Dr Holland (in Engels, 1848). Mortality rates in streets of the second category were nearly 20% higher than those in the first and highest category of streets, while mortality rates in the third and lowest category of streets were almost 70% higher. Mortality in houses of the second category was about 30% higher, and in the third category nearly 80% higher, than in houses of the first category. Here as there, now as then, might I, like Dr Holland, conclude that "*hundreds of our immediate neighbours* are annually being destroyed" (in ibid:136) and thereby suffering Watt's (1996:1026) "ultimate social exclusion". But until then in

EGERTON STREET

One more dark, wet, orange night to inhabit,
Walk down, splash through, soak up, at last admit.

One more defeat to bite on, chew on, swallow.
There's still worse to come, more rain to follow,

Like this helpless anger, this year's new dismay,
Which blows relentless, blows its strength away.

So many torrential defeats, such dark weather,
Pressing down and through the leaking leather

Of my boots, vulnerable as faith, or love.
You cannot be gloomy enough. Enough.

Andy Croft[12]

On the other side of the main road a more prosperous looking pocket of uniformity, or almost, settles and soothes my eye in the Netherlands. Locals call them Dutch houses because of their roofs, but I see church bells and old-fashioned policemen's helmets. Their earthy rustic colours are nostalgically rural, but one with a steel grey roof and paint the colour of the sandy tower emits their industrial backcloth. Back to the star and cross on the probation offices – my town centre – and a second pocket of uniformity overlays the disparate streets and houses. It would be ordinary in another place, but it is not ordinary here. A modern estate of small terraces of, I estimate, three bedroom houses, set in green. Low fences and gates, many without padlocks, bound their front gardens, some of which contain the coloured remnants of autumn. Garden gnomes beaming at their wishing well create the most brightly coloured tableau of all but they are becoming dwarfs as images intrude of Grumpy's House on a wooden sign, handmade I am sure, duelling with its only written rival

DORMAN

LONG

on that sandy spike in Hercules's moon.

[12] Croft (1996:60). Egerton Street is in Middlesbrough and outwardly more prosperous than many streets in South Bank.

3.5 CONCLUSION

> OK, I lied, I made it up. I never saw no place
> Nowhere the like of it
>
> Andy Croft[13]

Belonging to the Emperor, embalmed, tame, sucking pigs, sirens, fabulous, stray dogs, included in the present classification, frenzied, innumerable, drawn with a very fine camelhair brush, etcetera, having just broken the water pitcher, that from a long way off look like flies. DORMAN LONG, leather suites, looking over the garden fence, push chairs, the disembodied voice, a curry cooking in an Asian home, stray dogs, windows, a Gypsy's grey cob, burglar alarms, the transporter in the underpass, smoking fire, a vacuum cleaner and garden gnomes. Two lists of things. The first in a Chinese encyclopedia entitled the *Celestial Emporium of Benevolent Knowledge* (Junger, 1990)[14]. The second in Teesside. Despite "the stark impossibility of thinking *that*" (Foucault, 1970:xv) the classification of animals was presumed by its believers to have made sense to the Chinese classifier. Can any sense be made of my Teesside in "the country of the mind" (Gunn, 1956:47)? In it, like Gunn's (1954:65) anthropologist "I found myself lost somewhere between symbolism and actuality" in *The Other Landscape*[15], situated "behind the physical one I looked at" (ibid:68).

I leave it as a question because although I try to make sense of Teesside, its children and their asthma by the end of the dissertation, it remains insensible in my imagination. It never entered my notebook, hence its narration out of, and as, images not words. Here, it is an impressionist tale, drawing upon how an impressionist painting aims to capture what was there then, and deliver it thus, to its audience (Van Maanen, 1988). As it was to be imagined, not abstracted academically, it had no analysis and scarcely a citation with which to claim academic authenticity and authority. Analysis could, as my fictional peer observes, have gone "on forever and ad nauseam, but 'the other landscape' remains

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[13] Extract from 'No Place Like Home' in Croft (1996:14).

[14] Junger (1990) cites Franz Kuhn as his source who in turn is cited by Jean Louis Borges in the context of discussions into how to create a general language in which words are replaced by a numerical classification. The encyclopedia has yet to be found and has been attributed to a construct of Borges to illustrate the classificatory principles of his "language of numbers". (http://lists.village.virginia.edu/lists_archive/Humanist/v04/0309.html, p.2)

[15] The novel's title.

at least a useful label. To put it naively for the moment, it stands for something" (Gunn, 1954:68).

Does it stand for my fieldwork site? Like Xingjian (p.46) I had only the desire to narrate Teesside, yet I have not narrated it, and the moon over it acknowledges that its place has defeated my words. The poster advertising Pink Floyd's *Echoes* reminded me of their *Dark Side of the Moon* where "[e]verything under the sun is in tune, but the sun is eclipsed by the moon".

'O No'! The mooon, because coming from London (p.17), Middlesborough was the capital of my fieldwork site. Naturally,

> [t]hey've quite lost their manners in Loondon...
> The UKO's a long way to go,
> So please take a hint from a Teesside mis-print:
> That Middlesbrough's only one O...
>
> Andy Croft[16]

[16] Extract from 'O No', in Blackburn *et al* (1996:38).

Part 2 – Acts

> "One minute he'd be fine in my arms. Then the next minute ... he'd be fighting for his breath. ... It just used to literally stop him. ... He'd flop and go blue. You could see every muscle working. He used to swell [his chest] and cough till he choked. ... The time he was in hospital for eight days he just laid. I {long pause} It took all it did for him just to breathe".

Several years later, tears stopped her, and after apologizing to me for her distress she changed to the present tense, explaining it still upset her to think about it because "it's scary".

Her son had started coughing when he was a few months old. His GP had told her he was "just chesty" but one day he was diagnosed with asthma after he became very breathless and was admitted to hospital. It was the first of many visits to what became her son's prison as inside his hospital cot he panicked, and his panic made his asthma worse. Eventually his mother persuaded her consultant to let her try to treat him at home with a nebuliser. His visits became less frequent, but still there were times when she rang the hospital to say "we're on our way", and at home his asthma remained. Steam soothed him so when his asthma was bad she sat with him in the bathroom beside a hot shower, reading stories. Many nights were spent this way and sleep became cherished.

She always knew the local weather forecast because the slightest change in temperature could trigger an attack. "If we had him out on a summer's day and a cloud crossed the sun {she feigns a shiver}, I used to panic, and say 'Get a cardigan on him. Get him inside!'". In summer she always carried with her long trousers, a jumper, thick socks and a coat. If it started to rain "it was a nightmare", so her son only walked outside if they had the push chair with a rain hood with them, and "if the wind changed he was ill". Even on the best of days he could only walk a little way before getting out of breath, and he rarely played outside in case he got cold or wet. But overheating was just as dangerous, so layers had to be removed with equal haste. Inside he had to be protected from other dangers: nobody was allowed to smoke or spray air fresheners in his home or use deodorants or nail varnish remover in the same room as him.

His whole life revolved around his asthma. Sometimes he breathed so fast she was afraid to leave him in case anything happened, and always he was watched because if he

sneezed or his nose began to run, his asthma was on the way. He never went anywhere without someone who would know what to do if he went "downhill in minutes". Family life also revolved around his asthma. Family outings often meant splitting up the family. She and her son did what he could manage while her husband, daughters and older son did something more adventurous or went further afield. Their first family holiday was at a centre where a doctor was available at all times and a hospital nearby. She introduced him to the doctor as soon as they arrived and he had "a bad do" while he was there. The family car was a lifeline, and when her marriage ended she was "devastated" at the loss of her husband but "panic stricken" at the loss of the car and its driver. Her eldest daughter who lived at home immediately bought a car to replace it, and she, her sister and even his brother who was only a few years older than him, helped look after him and look out for his asthma. He was "totally mollycoddled ... very wrapped in cotton wool", though they tried "still to have fun with him [because] if you're not careful you can make them feel different in a negative way. Like an invalid and it's not good for them ... He's a little boy".

His asthma had begun to improve by the time he started school. Now, aged seven, "people wouldn't know he has asthma ... he's rough and tumble ... out in the wind and rain ... a well-rounded little boy". Nonetheless, his mother is still "quite frightened" to let him out of her sight, even though his school is close by, and she stays at home as much as possible during the school day. She works in the evenings but makes sure one of her grown up daughters is at home with her son, but "its not so horrendous now if we hear him cough. Before the alarm bells went off". Yet if he coughs once they all start listening and counting. "I must admit" she concluded, "we still do watch him like a hawk" [MI1].

Chapter 4 ASTHMA IN THE FAMILY

4.1 INTRODUCTION

I have begun my account of asthma in Teesside's children with the family that made the greatest impression on me[1]. It was immediate and emotional, and why it was so, I am still not sure. It was not only the woman's tears at home, as unusually I can remember her son entering the clinic a few weeks earlier, a few steps ahead of his mother. He seemed very at home there – his smile was welcoming. He answered the health professional's questions with a composure and comprehension that belied his seven years, and she asked more of him than was usual. He was a little professional: a child embodiment of the *Expert Patient* (Department of Health, 2001), yet he was most definitely not a medical construct. When the nurse's questions turned to his mother he left them to play quietly and self-sufficiently with the clinic toys as befitted the "well-rounded little boy" of his mother's interview.

His asthma has been described from the perspective of a child with asthma and from the perspective of his family, particularly his mother. As such it is asthma as an illness. Illness has been introduced briefly already (p.3), but Helman (2001:83) offers a more expansive definition of it as

> "the subjective response of the individual and those around him, to his being unwell; particularly how he, and they, interpret the origin and significance of this event; how it affects his behaviour, and his relationship with other people; and the various steps he takes to remedy the situation. It not only includes his experiences of ill-health, but also the *meaning* he gives to that experience".

This chapter focuses on asthma as an illness, and its structure follows Eisenberg's (1977:11) simpler, if more restrictive, definition of illnesses as "*experiences* of disvalued changes in states of being and in social function", that is striking in its resemblance to the earlier meanings of disease as lack of ease and inconvenience (p.4). The opening presentation focused on just these two dimensions of illness in one child and one family. This chapter aims to present them in all children with asthma and their families. It does so in the next section 'Experiencing Asthma' by reducing the totality of

[1] It was not the first interview, but I have called it [11] in acknowledgement of its impact.

asthma in the opening illness narrative into its constituent parts or atoms[2], and contrasts are drawn between quantitative and qualitative contributions. 'Experiencing Asthma' distinguishes also between atoms that are witnessed as well as experienced, and those that are experienced alone, and it distinguishes between the children who experience the atoms and the adults who witness them. The section continues by showing that asthma does not end with its atoms, as its experience goes beyond that which children and their families described as their asthma. How asthma is experienced has the potential to impact upon how life is lived with asthma. The following section 'Living with Asthma' structures the lives of asthmatic children and their families within a framework of time and space, and within the latter a second framework of external and internal spaces. In so doing it introduces agents that stimulate asthma and those that repress it, and describes their potency to both order and to disorder time and space. To highlight particular features of asthma's personality, comparisons are drawn throughout, with other illnesses, and the final section 'Beyond Asthma' expands the place of childhood asthma in the worlds of illness (Radley, 1993).

I have begun with asthma as an illness, but many accounts of the modes of unhealth begin with disease, even if either or both of its other two modes are the primary subject(s). Those I quoted in the introduction to the dissertation (Boyd, 2000; Cassell, 1975; Eisenberg, 1977; Marinker, 1975) began with disease, but I re-ordered them to put illness first. Illness has ontological primacy because the person has first to recognise that he or she is "unwell" (Helman, 2001:83). When the urine of many teenage boys of the Bozo tribe in Mali turns red, it is a bodily sign of approaching manhood akin to menstruation, not of the infectious disease schistosomiasis (Dettwyler, 1994). Intestinal worms are essential for the health of Guatemalan villagers as without them they would not feel hungry, and would be in danger of starving to death (Barrett, 1997). Moreover, *a priori* distinctions must be made between illness and other changes in states of being. In the western world, the secularization of the Enlightenment reclassified possession by God or the Devil as mental illness, thereby creating it in the social constructivist sense (Foucault, 1967). Further, Illich (1976) contends that contemporary western society has

[2] I name them atoms because of Midgley's (1989:186) attribution of the atomism of the philosopher David Hume, as an aid to the empiricist philosophers in their quest for the "ultimate units of *experience*" (emphasis added). The term atomism is, however, more usually associated with the logical atomism of Bertrand Russell, himself greatly influenced by Hume (Midgley, 1989), who made the reductive proposition that certain things are basic and from them all other things can be constructed by logical means (Griffin and Martens, 1999).

via the aegis of medicine created illness out of normal individual and social experience, and out of pathology whose origin is not within the human body, but within the social body. Stress originated as a mechanical property of a material (Fusé, 1975), supermarket shoppers suffer trolley rage (Helman, 2001) and antisocial children are transformed into unhealthy children by attention deficit hyperactivity disorder (ADHD) (Elliot and Place, 1998).

I have begun with asthma as an illness because illness in the family is my primary focus, and putting it first increases its status as such. Order is significant because that which comes first has no comparison until there is a second. By contrast, what comes after is always comparable to what has gone before. Accounts that put disease first implicitly relegate illness to an inferior status, however much the explicit purpose of the account is to give it primacy. The inferiority of illness is further augmented by it belonging to the category of lay beliefs that Moffatt *et al* (1995:883) perceptively note

> "only has currency in the context of an explicit contrast with the views of a more powerful group who can claim expert or authoritative status – scientists, the medical profession, the legal profession, or of course the church. Thus views of 'lay people' by definition lack authority – and the term 'lay beliefs' can easily function as a euphemism for 'popular misconceptions'".

By beginning with illness I aim to increase the authority of asthma in the family as its contrast with asthma in medicine can come only afterwards.

Asthma's primacy as an illness is further reinforced in this chapter, firstly by avoiding language that explicitly or implicitly devalues the status of asthma as an illness in comparison to asthma as a disease. Words and their derivatives such as 'belief', 'opinion' and 'perception' are avoided, and 'said' is used for narrative purposes only. In contrast to its traditional and modern social meanings (p.10), "the term 'belief' as it is employed in anthropology ... connote[s] error or falsehood, although it is seldom explicitly asserted" (Good, 1994:17). Belief is devalued in comparison to knowledge: "[k]nowledge requires both certitude and correctness; belief implies uncertainty, error, or both" (ibid:17). Secondly, no distinction is made between lay and medical terms and there is no assessment of the medical correctness or otherwise of the illness narratives. Thirdly, as its intention is to describe asthma from the emic (participant) perspectives, it emphasises these by frequent use of quotations and often by presenting them before my etic (researcher/author) analysis that "converts them into the second-order constructs of

an observer" (Kelleher, 1988:142). My primary aim here, is to present a biography of asthma in the children and their families, but my perspective is included where my observation supplemented or contradicted participants' accounts – their autobiographies – of their asthma.

Story tellers want to tell interesting stories, hence their biographies of illness risk sensationalizing illness by focusing upon the dramatic and the negative. Some of what I describe below is remembered for that reason, including the asthma presented above, but it was not unique. On the contrary, the asthma in that family represents other asthmas in other families, and I emphasise the dramatic and the negative only if they illustrate more general aspects of asthma. Further, although individual portraits of illness, can be analysed powerfully and revealingly, as in Good's (1994) account of a young man's experience of chronic pain, the following account aims to be representative of the asthma in all the families who participated. Nonetheless, in quantity of text, that which follows is clearly biased towards the dramatic and the negative. "Finally", Burton (1975:186) ends her account of cystic fibrosis – usually a more severe illness than asthma – that is similarly biased, "lest I paint too gloomy a picture of the stresses imposed by a chronic disease, may I emphasise that despite all the stresses and handicaps imposed by it, most children cope remarkably well". For the same reason I end my introduction by counterbalancing the opening presentation with an asthma that

> "never really has been a problem. ... [She's] never really had an attack. ... On a day to day, week by week, month by month, year by year... it's never been ... she has never been really bad. ... I've never been really overly concerned ... I might notice she is a little bit husky and maybe a little bit tight chested but not sounding [wheezing], just by the way she is breathing ... Apart from that {pause} I've never been with her or I've never been called to school, or there's never been any illness with her chest ... it has never been a big thing you know" [MI15].

Her daughter agreed. She was no longer the fastest girl in her class but she did not blame her asthma and was hopeful that soon she would return as Achilles, if not Aeneas.

4.2 EXPERIENCING ASTHMA

> As an old Jew put it (and old Jews have a way of speaking for the victims of all nations) ... my bowels are sluggish, my feet hurt, my heart jumps – and you know ... I myself don't feel so well either.
>
> Erik Erikson[3]

This section describes children's experience of their asthma and their families' experiences of their children's asthma, and continues with others' experiences of asthma and related illnesses. It begins with the atom of asthma that was most common.

4.2.1 Atoms of Asthma

4.2.1a Cough

"Cough, cough, cough, cough, cough, it's like having a different kid" [HR39a][4]. Cough was frequently described as multiple coughs, most usually dry, but sometimes phlegm made it wet: children felt the difference, their families heard it. There was a great variety to its sound. Occasionally it was a "something stuck in your throat cough" [HR89], or it turned children into barking dogs or little old men. When noisy, it could be "embarrassing like. You're in McDonalds and he's coughing away like a little old man. You feel everyone looking at him ... 'Can't you stop that child doing that?'" [MI9]. Others like C15 above, mimed no more than a quiet and occasional catch in the back of the throat. Asthma's cough varied also within, as well as between, children – "she's been cough, cough, cough, cough. Now she's only little spells of coughing. She's not coughing much at the moment, but she could suddenly start again" [HR100]. Some children had coughing fits when they "coughed like mad" [CI12] and young children especially, vomited. Away from home, one woman used to carry spare clothes for her daughter, plastic bags for soiled clothes, and wipes [MI4]. At their worst, children like C1, coughed till they choked.

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[3] Erikson (1964:51).
[4] See Appendix – 'Codes and Categorizations'.

4.2.1b Noisy breathing

Asthma changed many children's breathing, adding most often a constant noise on breathing out, usually described as a wheeze, but occasionally as a whistle or sounding. One girl "screech[ed] like a cat" and was teased by the boys in her class [CI21]. Also common was a "rattle" or "rattly chest" on both breathing in and breathing out, like a "diesel engine" [MI14] or like "people chattering in her chest" [HR97], or like "an old man. He rattles" [HR47]. Wheeze tended to accompany a dry cough, a rattle a wet cough, but some children both wheezed and rattled, while others did neither. Parents could feel asthma's rattle but not always its wheeze, when they laid a hand on their children's chests or when they cuddled them. Occasionally noisy breathing changed speech, causing one girl to "squeak at the end of every word" [CI21]. Sometimes there was also the added noise of children gasping for breath when their asthma was severe as when "she sounds like she's being strangled" [HR104], but in the most severe asthma, breathing became silent.

4.2.1c Difficulty in breathing

Being unable to breathe, breathless, short of breath, gasping for breath, out of puff or puffy were also frequently atoms of asthma. Occasional allusions were made to an obstruction: "the air goes into my mouth, then it gets stuck" [HR58] or it is "as though his chest is closed" [HR109]. Breathing was hard work when asthma was bad, and a few children drew analogies between breathing in asthma and breathing at the extremes of physical exercise – in both they were "whacked ... my body starts to feel like its collapsing. I start to shake" [HR43]. Parents saw their children's chests heaving or moving fast, the muscles of their rib cage, stomach and neck standing out, and being sucked in and out or up and down. Occasionally, their throat or windpipe moved up and down as well. A few parents felt their breathing altering in sympathy with their children's asthmatic breathing. When breathing was at its most difficult walking, eating and speaking took children to the limits of their physical endurance. It was asthma's most frightening atom for children and parents alike, hence qualitatively, it was its most important experience. C21 embarrassed by her wheeze, and M9 embarrassed by her son's cough both became afraid when breathing became difficult.

4.2.1d Changes in colour

Children might cough till they were red or purple in the face. Usually their colour returned to normal when their cough subsided, but a night of violent coughing left one young boy with a red rash on his face and neck from broken blood vessels beneath his skin [MI7]. Conversely children might lose colour when their breathing was noisy or difficult, becoming pale or pasty. At their worst, the lips of a few children turned blue. Children did not see their blueness, but it frightened their parents[5], though the mother of [HR1] spoke so matter-of-factly about her son regularly being carried home by his friends from football games blue and gasping that I wondered if she had got used to it.

These were the principal audible and visible – sensible – manifestations of asthma. Putting them together

> "[w]hen he's at his worst he couldn't put two words together. It's just cough, cough, cough. He finds it very difficult to get a breath in between sometimes. His lips have actually changed colour because he's been coughing so much ... he goes a bit blue" [MI17].

A further presence of asthma was, however, neither audible nor visible, but it was as, if not more, significant to children experiencing it, perhaps because it was insensible to all but them.

4.2.1e Chest pain

The pain of asthma is in the chest. It is communicated clearly and directly by the young girl who points to her chest and cries "'Mummy, it hurts!'" [HR73]. Most often a restricting or constricting pain, usually a tightness or tightening of the chest, but also a squeezing of or pressing on the chest. A teenage girl evoked the metaphor of an elephant sitting on her chest. Her family would ask her, "'How heavy's the elephant?' Really heavy and we know she's not feeling too good" [MI16]. Less frequently, children felt a sharp pain like a stitch in the centre of their chest. Less frequently still, the pain was erosive, "like something is scraping it [the chest]" [HR51]. Chest pain and breathing difficulties went hand in hand: the harder children had to work at breathing, the sorer they became. Older asthmatics had not grown out of its pain – a teenage girl regularly arrived home from school in tears when her asthma was hurting [CI14] and a young man

[5] Some paintings of what it felt like to have asthma (p.23) were strikingly blue – blue people in blue spaces.

always he slept through the nocturnal disturbances of three asthmatic children [FI11]. Often however, fathers were up as well when their children's asthma was severe and they were disturbed too, when children ended up in the parental bed.

4.2.1g Reluctance to eat

The cough and breathing problems of asthma made chewing and swallowing food difficult. The chest pain and tiredness of asthma made it undesirable. By contrast, children were frequently thirsty and drank more.

4.2.1h Not themselves

"When his asthma's bad he's quiet. It's not normal for him" [HR61]. Children were frequently described as quiet however noisy their asthma. They said little and did little, even when their asthma permitted. Young children neither played nor demanded their parents' attention. Older children favoured passive entertainment such as television and videos over friends or going out. As well as, or instead of, becoming listless and apathetic, children also became nervy, irritable and easily upset. As some children became not themselves before they became obviously asthmatic, some families had developed an early warning system. Wanting "a carry all the time" was for one man a sign that his young daughter's asthma was on the way [HR83], while the mother of C17 became vigilant rather than reproving when he became bad tempered. Colour change could also precede asthma. The boy who became bad tempered also developed a "high colour" [MI17], but other children became pale. The most common visible warning sign, was a darkness or heaviness around the eyes, or becoming "baggy eyed" [HR42a]. Another warning sign for a few children was an itchy chin – her son or daughter rubbing or stroking their chins alerted one woman [MI21]. When some children became not themselves, asthma always followed, but a few children sometimes became themselves again without becoming asthmatic.

One such girl often

> "seems to be in a state of limbo ... she becomes very tired and can't be bothered. ... she just has no energy, she needs a boost ... you can't say that she's poorly ... you can't say what it is ... it's just she's not her usual bouncy self. ... her eyes go black and she gets a terrible bad breath and very pasty {pointing to her own face} and she gets very weepy and silly" [MI10].

Usually asthma followed, but not always, and at the time of interview she had not been herself for a few days, but without any other signs of asthma (and I observed none during her interview). Thus, like the old Jew, Teesside's children might feel ill as well as, or even instead of, experiencing the atoms of asthma by which the majority identified its illness personality.

Asthma as described in the family ends here, but if "the body is a part of the mind" (Hunter, 1991:xxii), it has not completed the account of illness as defined by Eisenberg (1977) as a disvalued change in state of being. That is because it has not yet described the fear that asthma might cause.

4.2.1i Fear[7]

When a young girl's asthma is bad she tries to hide from it by curling up on the floor in the corner of her bedroom [MI4], while a young boy tries to escape, crying "'Mummy, help me!'" [MI7]. In his sleep asthma is a nightmare to another young boy who screams and fights his mother as though he is having "a fit ... he's shaking, out of it ... it takes several minutes to bring him round" [HR39]. Usually fear abated with age but a few remained afraid, especially of asthma at night. The teenage girl, C14, who was upset by the pain of her asthma slept with the light on and her bedroom door open, and a boy was afraid to go to sleep when his asthma was bad [HR51]. One man's night time asthma had left an emotional legacy long after it had settled. As a child his asthma was worst in the early part of the night and he used to stay awake deliberately to avoid the fearful fight between sleep and suffocation when his asthma bore down as a wet cloth on his nose and mouth. He has suffered since from insomnia [GP10].

Asthma's emotional presence lingers also in an anecdote told by C6. While at a park with her father and some friends she had asked him if he had her inhaler. She had no need of it, and she had rarely needed it for years, but she wanted to know that it was there. When he admitted he had forgotten it, "I told him", she said, " 'well, you'd just better go back and get it!'". Her father ran the half mile back to their home and when he returned "he was puffing and panting worse than me with my asthma!". At this point her father told me that "we've got inhalers all over the place, but I've never seen her [need

[7] The paintings of asthma conveyed fear in the vividness of their colour – the acute blue of a sudden attack and the hard grey of a persistent siege.

to] use them". Her mother added that she needed them as "a comfort thing", and her daughter nodded in agreement [I6].

Asthma had the potential also to frighten its witnesses – C6 had had a bad attack in a restaurant and alarmed a waiter. Unlike tiredness, fear was often mentioned spontaneously by parents and was an emotion some had not got used to. Asthma that frightened parents was usually described as an attack, but occasionally as an outburst, a spasm or a bit of a do. Mothers described sitting up all night with the child.

> "He was so quiet, so lethargic. He just whimpered ... It was really frightening. He would let you do anything to him. He wasn't speaking. He wasn't moving. He just didn't have the will to do anything. He was too tired to cry ... he was just coughing and coughing. Mum and I were up with him all night" [MI7].

Fear that her son would stop breathing in his sleep caused another mother to sit beside her sleeping son and nudge him if he paused too long between breaths [MI9]. Another potent indicator of parental fear was one woman saying that if she heard any noise at night, her first thought was that it was her asthmatic son rather than her baby [HR39]. When another boy's asthma was bad his parents took him into their bed, and during his most recent bad night his mother "was getting a bit worried then thinking, 'Crumbs! What if he's going to die?'" [MI20]. The 'what if' scenario was similarly enacted by a man who, even when his sons were well and were "playing football outside, I'm watching at the gate, anxious like", and he mimed his hands shaking [HR42].

Fear at the time of an attack had therefore the potential to leave a legacy of worry between attacks, such that the family of C1 might not have been alone in watching him like a hawk. Fear persisted for a few parents long after the last severe attack. One woman had found it difficult to sleep for a year after her son's only severe night time attack and would "fly out of bed" at his slightest sound. Still, six years later, she has a disturbed night if she hears her son coughing in his sleep before she goes to bed [MI8]. Such illustrations of parents' fears about their children's asthma reveal a double edge to it. Witnessing the attacks was frightening but more frightening was the possibility that they would not wake when their child had a night time attack, and that their child would be too ill to wake them. Although noise characterises asthma, and children's emotional response might also be noisy, a few parents were afraid that neither would be noisy enough.

Some parents feared most of all an asthma attack when their children were out of their reach. Symbolic of parental worry over asthma attacks was the *Medic Alert* chain worn by one boy saying that he had asthma and asking whoever found him to call an ambulance [HR101]. Like M1, some parents worried when their child started nursery or school, while the added separation imposed by school trips was particularly disconcerting. One mother was "absolutely terrified" at the prospect of her teenage son going overseas with his school [MI22]. Another woman remembered a breathless and panicked overseas telephone call from her daughter saying that her teachers were not taking her asthma seriously. Though she had managed to calm her daughter and was satisfied with her teachers' response, worry that began with that phone call had remained despite school trips since being asthma free [MI23].

A few mothers did not verbalize their fear, even on direct questioning, but they revealed it in other ways. Twice one woman said, "I've just got used to it. I've learned to cope", but each time she tensed and grimaced and her voice became contained [MI4]. Another woman joked with the health professional that when well her daughter missed visiting the hospital ward, then stopped as though she too needed to catch her breath saying "I don't want to come in here anymore. I can't face it. Last time I got me mam to take her" [HR90]. Most revealing of all was a woman's farewell to me. Throughout her interview she had neither spoken of, nor signalled, any fears or worries about her daughter's asthma. I stopped as I was going out the door, when she told me that most people do not take asthma seriously, but parents of children with asthma never forget that asthma can kill [MI10]. Her daughter had never had a severe asthma attack, but what her mother's farewell revealed to me was her fear that it might happen some day. She echoed other parents' explicit worries that were compounded by a fear that their unfamiliarity with asthma attacks would prevent them from recognizing that this asthma was attacking their child. A few parents questioned health professionals about the differences between asthma and asthma attacks, and I was similarly questioned in one interview. Fear of the unknown had therefore, the potential to be more frightening than fear of the known.

It was of note though, that overall, children appeared less afraid of their asthma than were their parents of their children's asthma, especially when it had always been there. A young boy who had no memory of life without asthma handled his night time attacks

with equanimity. "It's part of his life", said his father, "he's growing up with it" [FI11], while the asthma of the boys whose father watched them from his garden gate was "second nature to them" [HR42]. The contrast between children's reactions and their parents was most evident in the differing memories of a boy and his mother of his asthma at its worst [I8]. The boy described coughing a little at night and by day getting a little more out of breath than usual. By contrast, his mother remembered a night when woken by a noise from his bedroom she found him on his hands and knees on top of his bed coughing and gasping for breath. By the next morning her son had no memory of his night time experience and as she told it he smiled at me and shook his head. His mother's reaction to her night time experience six years ago has been described already.

4.2.2 Distinguishing Asthma's Biographers

The above has introduced distinctions between children's narratives and those of their parents. In general, children, when asked what their asthma was like, tended to respond with its single atoms – coughed like mad, screeched like a cat, or was whacked. Their parents were more expansive and merged asthma's atoms into a whole.

> "Well, she's got no energy really and she's breathless and wheezing. She's just not herself at all. {pause} It's hard to explain really. {pause} She doesn't eat that much either. She stops eating her food. It's the cough. She's just generally out of sorts you know with it" [MI16].

And, the mother whose son opened this section with a "cough, cough, cough, cough, cough", also had "a different kid" [HR39a]. But "lest I paint too gloomy a picture" (Burton, 1975:186) other children's asthma was according to their families, as well as to them, no more than a single atom of experience, most usually a cough.

4.2.3 Distinguishing Asthma's Biographies

Deconstructing asthma into its atoms highlights its spatial distribution locally in the chest and generally within the body. Asthma is, however, distributed also according to time, and its patterning, like its atoms, differs both between and within children. When C17 whose asthma was described above at its worst, was at his best he had no asthma,

but even when C20 is "fine, he can be running around, he'll be coughing ... [and] you can hear him [wheeze] when he goes upstairs" [HR107/C20]. Á young man who had had asthma since a child had rarely felt totally free of it, though often its presence created minimal disturbance [GP80]. Children varied therefore, both in the severity of their asthma at its worst, and in whether its presence was intermittent or persistent.

For some parents, asthma's greatest threat to their children's lives was its unpredictability – the variability within them of its pattern. The young girl [HR104] who during an asthma attack "sounds like she's being strangled" could be "like she is now [well], then you'd find her lying on the floor – she can't breathe". A second young girl's asthma emerged from the following exchange between a mother (M) and a health professional (HP) as similarly unpredictable.

HP "the cycle's been broken..."

M {interrupting} "Well {pause} I'd say for now. But I could come out of here today and she'd be poorly. That's the sort of child she is" [HR100].

Other parents clearly contrasted these severe, sudden and unpredictable attacks with a more gradual worsening leading to a prolonged spell of asthma.

> "There's been a couple of outbursts when I've thought, 'Oh my God!'. I've phoned the doctor and said 'I can't get the *ventolin*[8] into him ... He's been sitting there with his little head propped on the table. He couldn't even get 'mam' out. ... When it hits him, it hits him like a ton of bricks".

By contrast, "when he's bad, he's like a little old fella ... He's very lazy, he just lies around" [HR108]. Other parents stressed the variability of their child's asthma above all else. "His asthma's up and down like a yoyo" [HR61a], and a twisting movement of the wrist demonstrated the same [HR63a].

Asthma as an illness in space – its distribution in the body – and in time – its patterning in a life – varied therefore, in Teesside's children. The following sub-sections compare and contrast their asthma with that of other asthmas and with other illnesses.

[8] Medicine for asthma that the person breathes in.

4.2.4 Asthma's Other Biographies

As noted by Gabe *et al* (2002), few studies have allowed children or adults to describe their asthma or their children's asthma in their own words, but one study concluded that "children almost unanimously described asthma in very negative terms (it's horrid ... it's a nuisance)" (Eiser and Havermans, 1994:103). In a study by Colland (1988, in ibid) German children's descriptions of what it was like to have asthma included often being ill, the embarrassment of being audibly ill, and particularly, fear of dying. As in Teesside, Eiser *et al* (1988) reported asthma at night, and being unable to breathe in asthma as children's most frightening experiences of it. Tiredness and weakness especially on exercise, and also before and/or after their asthma, but lasting for a maximum of 24 hours only, were described by some 11-16 year olds with moderate to severe asthma (Gabe *et al*, 2002). All referred to "problems with breathing" (ibid:1623), though their distinction between wheeze and difficulty in breathing does not appear to be as clear-cut as in my study. However, attacks provoked a similar fear that "'I am never going to breathe again'" (ibid:1623), and though fear eased for most as they gained experience in managing their asthma, severe attacks still had the power to panic some respondents.

The experiential dominance of the breathing difficulties in asthma is suggested also by *Breathless: An Asthma Journal*, the title of De Salvo's (1997) account of her and others' asthma, despite on its first page attributing her breathing difficulties to coughing attacks. Children and adults studied by Nocon and Booth (1989) described drowning or suffocation with a pillow as the metaphorical means by which breathing might be stopped in asthma. Their combination evokes the wet cloth that bore down upon GP10, but more generally of the force of asthma as coming from the outside. "[S]omeone's clenching them [my lungs] ... there's a load of carpet in them", an adult told Sweeney *et al* (2001:22). The same themes with the addition of an animal metaphor reminiscent of

C16, characterize De Salvo's (1997:3) intense and intensely self absorbed[9] description of her asthmatic breaths.

> "Inhale (Can't get enough air into my lungs. Feels like I'm suffocating, feels like I have a tomcat sitting on my chest and that I'm breathing against its weight. Feel, too, like I'm drowning in mucus.) Clear my throat. Choke. Exhale. (Better this time, if it were always like this I could take it.) Clear. Swallow. Exhale. Inhale. (Shit. Tomcat's back.) Drowning. Mayday. Mayday".

A woman in Nocon and Booth's (1989) study also needed rescuing as she "wouldn't be able to stand it if it came on again" (in ibid:96) and another "'wouldn't wish it on my worst enemy'" (ibid:96). An adult interviewed by Drummond (2000) had always to say to him/herself "I must sit down and be calm" (in ibid:241), while the following shows the immediacy of the fear, but is suggestive also of psychological coping mechanisms that confine it temporally to the attack itself.

> "You forget what it is like when you are in an asthma attack but if it is really bad, you think 'Oh God is it never going to stop?'. You would virtually lie down and die. But when it passes you think 'Thank God', and it is just put down to another attack... You've got a memory loss, the memory is that it's nae really as bad as it is" (ibid:242).

By contrast, Kleinman (1988:125) describes a man for whom the fear of drowning in, or being smothered by, asthma has led him to conclude that "[m]aybe they should just take me outside and shoot me".

Severe attacks of asthma are liminal experiences (Van Gennep, 1909; Turner, 1974) in that they remove those under attack from normal social life and place them in a special state that is dangerous, and in which they are vulnerable. However, unlike *rites de passage*, to which the concept of liminality was first applied by Van Gennep, asthmatics wish to return to normal social life unchanged.

Turning to the parents who witnessed their children's asthma, Sutherland's account of her daughter's asthma begins with its title, "'Help me, Mummy, I can't breathe'", and continues, "a small child gasps desperately, and you stand there totally swamped with

[9] De Salvo has calculated her average number of breaths per day, counted her coughs stopping one day at 347, and thought of eight different ways to communicate her asthma before settling upon "I am asthmatical" (1997:73).

the knowledge of your own inadequacy" (1987:1). Though Sutherland was describing her daughter's first attack that might be expected to be the most frightening because it was unknown, children in Teesside had similarly asked for help, and their mothers had felt similarly frightened and helpless during subsequent attacks. Local fears of night time asthma are highlighted by Cornford's (1999:129) description of how a mother whose child had been "diagnosed as having mild asthma 'was a bit panic stricken that ... one night I might go in and she'd had difficulty and just stopped breathing'". Nonetheless, the matter-of-factness with which the mother of HR1 narrated her son being carried back blue and gasping for breath from football games suggests that parents' fear may subside as their children return each time from their liminal state unchanged.

Sutherland's account emphasises also the pain asthma inflicted on her child and is suggestive of its suffocating presence as her daughter grabbed

> "frantically at the neck of her pyjamas, whose slight pressure was sufficient to cause her extreme discomfort ... she was too distressed by her inability to breathe for us to cover her mouth even for an instant by trying to pull the top over her head" (ibid:24).

Like many children in this study her daughter was not herself before attacks: "It was so unnatural for [her] to be so still. She was sleeping as if drugged" (ibid:23). Sutherland is, however, at her most arresting when describing the impact of her daughter's asthma on her marriage, and on her feelings for her daughter as "the object of our discomfort" (ibid:34). After seemingly endless nights of disturbance "absolutely at the end of my tether ... I began shaking her as I screamed and cried, begging her to please let us have some sleep" (ibid:35). By contrast, parents in Teesside had just got used to the tiredness. Though they might have been reluctant to express emotions that might be unacceptable to them or that they thought would be unacceptable to me, it might be significant that none had a child with severe night time asthma at the time of interview. Fading memories might therefore have contributed to the normalization of their tiredness.

By contrast, asthma was much less dramatic for most in Prout *et al*'s (1999) study of children with asthma and their families. One child's asthma was "an everyday thing" (in ibid:45), while another child had never had a "really bad asthma attack, what I call a *true* asthma attack. He gets tight chested and I think he finds it difficult to breathe, but

not to the extent that it's really stopped him" (in ibid:46). Prout *et al* (1999) recruited their participants from a general practice, while Nocon and Booth (1989) recruited recent hospital inpatients. My account has stressed the variability in asthma's severity, and if patients and their doctors are in agreement about illness severity, then the latter study might have recruited those experiencing more severe illness. Consultations with hospital patients make a greater contribution to my study, but bias towards the severe is reduced by approximately two thirds of the families interviewed being recruited via the GP clinic. The clinic setting of part of the fieldwork may, however, have biased it towards the negative. Patients might be expected to bring asthma's problems to the consultation; during it they were asked about its potential medical problems, and my medical past might have similarly influenced those who were interviewed at home (p.26).

4.2.5 Asthma's Analogous Biographies

In previous local research cough was in itself distressing for some adults if it interrupted sleep, rendered them tired and jaded when awake, and embarrassed them while talking (Cornford *et al*, 1993). Parents feared children who coughed might choke to death, suffer permanent lung damage or develop asthma (Cornford, 1998; 1999). Nocturnal disturbances rendered children grumpy the following day, but even if they slept through their coughs, their mothers might lose sleep from fear that they might die in their sleep. In this study daytime cough transformed a few children, all boys, into little old men [MI9], who might also rattle [HR47] or simply lie around [HR108]. Although the last is perhaps most suggestive of his mother's opinion of old men, or all men even, they draw implicit comparisons between asthma and chronic obstructive pulmonary disorders which target adults, men especially (Williams, 1993), though usually with a wet cough. Their attacks cause a man to "frighten meself I'll be so breathless, I'm literally fighting for me breath then" (in ibid:13), and they have the same external force as asthma: "[y]ou're gasping for air and you feel as if you're suffocating, as if a vacuum is sucking the air right out of you, you know" (in ibid:12). Williams (1993:1) opens his account with the essence of the attack: "the ability to breathe is the *sine qua non* of life ... an elemental fear is soon aroused". In his own words one of his respondents says the same: "'*it threatens your very existence*'" (in ibid:12).

Ellis (1995) in an ethnography of her partner's chronic obstructive pulmonary disorder writes as an adult witness. "[He] is coughing uncontrollably ... he's choking and now turning grey ... The coughing continues, the mucus that thwarts his breathing rattles. He works – cough, cough, clear the throat, gag" (ibid:23). Though one assumes the following quotations were recorded retrospectively, her interruption of his words communicates the disturbance of his breathing, as well as a fear that projects the pathological constriction of airways into a psychological restriction of space. "'No' he heaves from the chest ... 'I'm getting better now [gasp] with the door [gasp] open. I felt claustrophobic' [gasp]" (ibid:92). Thus attacks of asthma and its allies threaten not only to suck the breath of life out of the body, but also to squeeze the life within it.

4.2.6 Asthma as Metaphor

Many times thus far I, and asthma's other or analogous biographers, have written metaphorically[10] of our respective illnesses or quoted the metaphors of the ill people themselves and their witnesses. According to Sontag (1991), we thereby risk stigmatizing illness by its semantics, as metaphors have the power to influence perceptions of illness by its sufferers and society alike. Moreover, she devotes considerable attention to the negative imagery surrounding military metaphors in relation to cancer and AIDS, and Martin (1990) develops a similar argument in respect of representations of the body's immune system. As military metaphors are integral to our accounts of the asthma experience, all of us are, it would seem, literal war mongers. When attacked in the opening presentation C1 was "fighting for his breath" [M1] while Sutherland's daughter had "tightly clenched fists rammed deep into the mattress ... as she fought the interminable fight for breath" (1987:61), and I ended the sub-section above with the asthma that attacked. Military metaphors featured also in the accounts of

[10] I restrict metaphor to the literary sense in which Sontag (1991) uses it to say that something is a thing that it is not. Lakoff and Johnston (1980) expand metaphor into a basic principle that influences how we perceive our world, and in consequence how we think and speak about it, and how we act within it. Their proposition that "[o]ur ordinary conceptual system is fundamentally metaphorical in nature" (ibid:1) influences my writing (p.49). An alternative expansion of metaphor emphasises its performative consequences. It defines metaphor as "a strategic predication upon an inchoate pronoun ... which makes a movement and leads to a performance" (Fernandez, 1986:8). For example, in "We are Christian soldiers" (ibid:21), the strategic predication 'Christian soldiers' upon the inchoate 'we' makes a psychological movement in them – the members of the Apostle's Revelation Society in Ghana – such that their church activities are a performance of their fight against the devil.

Williams (1993) and his respondents, one of whom was "literally [metaphorically] fighting for his breath" (ibid:12). Other military metaphors – guard against, vigilance, combat, battle and kill – also permeated the illness descriptions of his respondents while in a different, but still military context, is the woman whose worst enemy would not be deserving of her asthma attacks (Nocon and Booth, 1989).

Military metaphors risk, however, misrepresenting the asthma that attacks Teesside's children. Firstly, warfare, or modern technological warfare at least, is impersonal in that the attacker and attacked are unknown to each other and often invisible as well. The asthma attack was more personal in the sense that for some, the fortunate ones, it could be predicted and often avoided by diplomatic measures that will be discussed later. Military connotations are perhaps most appropriate for the asthma whose attacks could not be predicted – for the asthma that ambushed – and these were the most frightening and the most feared. The greatest unknown was the attack that might happen, but had never happened yet: the attack that, according to M10, prevented parents of children with asthma forgetting that asthma can kill. Asthma has therefore, the potential also to attack, and even to lay siege to, the imagination.

However, while attack is asthma's most dramatic metaphor it is only a partial representation of its illness personality. Other metaphors that have been named already such as pipes, tubes and rattles, though mechanical, are more evocative of civilian than military life. They shift asthma from the engines of war to the diesel engine that C14 became, and even to central heating or plumbing systems that are vital to modern family homes. Mechanical metaphors are according to Sontag (1991) not stigmatizing in that they bring with them neither responsibility for, nor disgrace in having the illness – they are impersonal but not the enemy. Also, they locate the illness in familiar structures and thereby suggest familiar ways to treat the illness: one can clear pipes, drain central heating systems, and service engines (Radley, 1993; Lupton, 1994). Further, asthma's civilian metaphors locate it inside structures, in contrast to its military metaphors that advance from the outside. Apart from the occasional reference to an outburst from, or spasm within the person, the attack of asthma came from outside. Some children had, however, no memory of life without asthma, and as it has always been there inside them – psychologically as well as physically – it cannot attack from the outside, but rather

than being the enemy within[11], it was part of them, and not an enemy at all.

Asthma has been represented above as relating to both the body and the psyche. The following metaphorical analysis casts asthma as a character, or given its variability, as a cast of characters, with the aim of both portraying and classifying the illness experience of asthma within children and their families. The asthma that "was part of his life ... he's growing up with it" [FI11] illustrates asthma that was a part of the child himself. For C6 who did not like to be without her inhalers, it was like a boisterous and perhaps hyperactive or even antisocial big brother who could be kept under medical control. Asthma as an unwanted but unavoidable lodger characterises its relationship with the young man who stated that "I always know I have asthma but sometimes it doesn't bother me" [GP80]. When children had long spells untroubled by their asthma, it became the occasional visitor, and if it did no more than disturb the odd night or day it was merely the harmless, and probably elderly, relative or neighbour. Asthma was such for C8, but for his mother, still haunted by her memory of his only asthma attack six years before, it was the intruder who had violated the family home. Sontag (1991:5) writes of cancer as "the disease that doesn't knock before it enters". Whether or not asthma knocks, or indeed has to knock, is, it is suggested, one key to its emotional impact on children and their families.

4.2.7 Asthma in Performance

Illness as Sontag (1991) argues above may be stigmatized by its semantics. It might, however, be stigmatized also by its performance. Stigma, "an undesired differentness from what we ['normals'] had anticipated " (Goffman, 1968:15) did not emerge in this study as a significant dimension of the experience of asthma, perhaps because the self is preserved in asthma, unlike epilepsy in which stigma has been particularly documented (Scambler and Hopkins, 1988; Weinbren and Gill, 1998). As "[b]y definition, of course, we believe the person with a stigma is not quite human" (Goffman, 1968:15), the performance of asthma is less stigmatizing than that of epilepsy. Alternatively, asthma might be too common to be stigmatizing (Gabe *et al*, 2002). By contrast, Williams

[11] Cultural parallels can be drawn here with auto-immune diseases such as rheumatoid arthritis whose pathology is derived from the body being attacked by part of itself, namely its immune system.

(2000) reported male teenagers with asthma frequently attempting to pass (Goffman 1968) as normal, though many female teenagers incorporated their asthma into their social identities. Adults with asthma studied by Adams *et al* (1997) differed yet again, in that some of either gender felt stigmatized by their asthma. Participants in the latter two studies were older than most in this study, and perhaps more self-conscious in consequence, but on the other hand, those studied by Williams (2000) were of similar ages to the unstigmatized majority interviewed by Gabe *et al* (2002).

The unstigmatized majority should not though, distract our attention from the minority of children who were embarrassed by their cough and noisy breathing and were teased by their peers, and the minority of parents who were conscious of their children's asthma attracting attention in public places. Certainly I was aware, and not I think only because I study asthma, of a woman's coughing fit on a train that the inhaler with which she tried to silence it, made me suspect was asthma (p.24). I observed also glances in her direction from fellow passengers and a child asked what was wrong with the lady. I did not know how to interpret the response of the man who accompanied her. He moved down the carriage to fetch I thought, a glass of water from the buffet, but returned with a complimentary magazine which he read till her coughing subsided. The embarrassed minority – inclusive or not of the lady's companion – might empathize with the public performance of respiratory distress that interrupted Ellis's (1995:56-7) academic dinner party.

> "In the middle of dinner, Gene begins coughing ... I place my hand on his arm and continue the conversation with our guests. "A little cold," Gene explains, pointing to his chest, and then coughs until he chokes and turns bluish-gray.
>
> "What can we do?" asks our guest.
>
> "Nothing, I'll be fine. Yes, I think the department politically has become more polarized." He says ... then coughing again.
>
> "It's OK," I say to quizzical looks, and we sit silently. The scenario repeats itself several times ... finally I relax".

Fear of embarrassment and of being stigmatized by one's illness performance may be sufficient to impair social function – the second half of Eisenberg's (1977) definition of illness. More significantly though, the social world is full of agents with the power to stimulate an attack that might restrict children with asthma.

4.3 LIVING WITH ASTHMA

> What is clear is that chronic illness is an ongoing process in which personal problems constantly emerge to challenge technical control, social order and individual mastery ... Few of us are heroes in the grand sense; but in a small, quiet way and in a moral rather than a military sense, there are real heroes among the chronically ill.
>
> Arthur Kleinman[12]

This section begins by describing how asthma interrupted the lives of children and their families and how they altered their lives to try to prevent its interruptions. It presents the agents[13] imbued with asthmatic potential within a framework of time and space, and within the latter, distinctions are drawn between external and internal spaces. It concludes by discussing asthma and its management as agents of disorder, but also, and therapeutically, as agencies for restoring order. It focuses again upon the children with asthma and their families in Teesside, but it returns also to asthmatics in the literature, and it continues the comparisons and contrasts with other illnesses.

4.3.1 Agents of Asthma

4.3.1a Asthma in time

Asthma had ended time for the brother of C18, and for childhood friends of F6 and M13. It had interrupted it for two days for the uncle of C7 when he was on a life support machine from which liminality he returned partially sighted. Repeated hospital admissions featured heavily in the lives of a minority of children such as C1, though the worst of his asthma was hopefully in the past. By contrast, another child whose entry into the consultation is equally vivid was as asthmatic now as she has ever been. Aged nine, she seemed tense, focused and closed; a regular patient who barely acknowledging the health professional's greeting and sat staring ahead of her. I was in her stare but not I felt, part of it. As soon as the pleasantries between her mother and the health professional were over, her mother began the consultation by saying that her daughter

[12] Kleinman (1988:144-5).

[13] The term agent is used for two reasons. Firstly, and irrespective of those warning against military metaphors, because some agents, often hidden or undercover, trigger attacks of asthma. Secondly, because agents act as material equivalents of Fernandez's (1986) metaphors to effect a change upon an person that will either induce or terminate/prevent a performance of asthma.

had made her promise not to say that she was any better, because she was no better. As she said it, her daughter became "a different kid" [HR39], though in contrast to him, she became a normal kid. Her asthma attacked night and day, in all seasons, in her bedroom, in her home, in friends' houses, at school, in the streets and on holiday. The enemy's presence remained in between attacks such that she would "stand beside me [her mother] whinging that she can't breathe" [HR33a]. When asthma permitted, she did not whinge. To continue the military metaphor, she had been living under the siege of her asthma. The transformation wrought in her when her mother's revelation of her suffering and the health professional's sympathetic response, lightened the psychological burden of her asthma, served only to reinforce the weight of its persistent physical presence. Her asthma would have been a contrasting candidate to C1[14] for my opening presentation but my request for interview was refused, perhaps because she and her family were living too much with asthma, or even being lived by it, to want to relive it in interview.

HR33's day to day school attendance had been severely curtailed by her asthma. School absences featured heavily in the illness narratives of a minority of children – the severest impact recorded was one full week's attendance in the last three months [HR11]. Many more children missed the occasional day or few days particularly in the winter – C12's asthma had kept her at home for approximately a week a month over the preceding winter, despite she and her mother describing her asthma as mild. Parents were often telephoned to collect their children from school, usually because of the impact of their asthma on them, but occasionally children were sent home because their cough was disturbing their class. Children might also miss school, and occasionally be sent home because they were so tired from their asthma of the previous night or nights. Asthma's socially destructive potential was as the regularity of the entry "on a night time" in my field notes testifies, increased by many children experiencing most of their asthma at night. "Illness," Sontag writes metaphorically "is the night side of life" (1991:3). For many children, asthma was the night side of life in an all too literal sense. Moreover, day might add insult to the injury of the night, if all that remained of asthma was tiredness: being inaudible and invisible to teachers and classmates alike and even to parents, it was not always accepted as proof of asthma's legacy.

[14] C1's asthma I imagine as vivid blue; HR33's as dull grey.

As well as varying from night to day, most children's asthma varied also with the seasons. Winter was particularly unwelcome for many. The asthma attack that had left the teenage boy partially sighted had occurred outside in winter [GMI7]. "The cold weather knocks him for six", said a father, who several weeks later was able to date his son's last severe attack to a sudden drop in temperature. "He gets upset", added his mother, "because he can't go out to play. He says to me, 'Mum, am I going to be like this forever? How long is the winter going to take?'" [HR101]. For some children, wind or dampness aggravated the cold of winter. On a cold foggy day, a boy, late home from school, was found by his mother kneeling on the pavement a short distance from his house clutching his chest [HR51], while it was on cold windy days that C14 was most likely to arrive home from school crying with the pain of her asthma. Winter was also the worst season for children whose asthma was sensitive to indoor heating or whose asthma might be worsened by sudden shifts in temperature – from indoor warmth to outdoor cold or *vice versa*. Finally, children's asthma might be worse in winter because colds, flu, and chest infections were agents of many children's asthma[15]. So common was the link between such agents and asthma that an entry in my notes reads "diagnosed with a chest infection, but interestingly, doesn't seem to have worsened her asthma" [GP72].

By contrast, summer was spoiled for a minority of children. A few found hot weather – hot and dry, or hot and humid, or both – aggravated their asthma. More blamed pollen as summer's chief culprit, and though infrequent, certain attacks were pinpointed to specific parks, gardens or other green spaces. One woman was admitted to hospital after her husband cut the grass in their garden [GP36]. Other children were particularly affected by changes in outdoor air temperature. Spring and autumn were usually their worst seasons, but sudden cold or warm snaps at any time of the year might affect them. Consequently MI might not have been the only parent for whom the weather forecast was unmissable.

4.3.1b Asthma in space

Other agents might trigger asthma in all seasons. For them space rather than time defined their potency. The father of the teenage boy whose worst attack had left him partially sighted blamed industrial air pollution as well as the cold weather as the

[15] Had I attended the clinic (p.45) when I was beginning a cold I might have become an agent myself.

weather had been cold for some time, but the air had looked particularly polluted that day [GFI7]. One family were even wondering if they ought to move house because their son's asthma had worsened since he had started walking to school along a busy road whose high verges trapped vehicle exhaust fumes [GP55].

The most commonly cited agent of asthma was, however, dust inside rather than pollution outside. Dust's potency was brought home to one woman when suddenly she heard her young son coughing violently in a clothes shop. He was invisible but when she followed his cough she found him lying under a rail of clothes on a dusty carpet [HR108]. Convection heaters that blew dust into the air also aggravated asthma, but it was dust in children's bedding that was its greatest provocateur and the main cause of its nocturnal presence. The only dissenting voice came from a woman who attributed her sons' night time asthma to mould in their bedroom where "it's black on the walls" [HR18]. Certain household or personal products, especially aerosols, such as air fresheners and polishes, perfumes and deodorants triggered children's asthma, and it might be worsened by cigarette smoke, especially in indoor settings. A minority of mothers interviewed smoked but cigarette smoke was encountered most frequently in other people's houses or in restaurants. Some teenagers were exposed to the cigarettes of peers, and a few were smokers themselves. Animals spanned the outdoor/indoor divide. A young boy was admitted to hospital after playing with a cat in the street [GMI7], while another young boy had his worst wheezy night for months after the family dog had slept on his bed during the day [MI7].

Thus far the internal/external dichotomy has been founded upon walls of buildings, but the surface of the body provides a second separation as asthma might also be provoked by changes in children's internal states. Exercise brought on many children's asthma and aggravated asthma that was already there. At their best, two brothers were regularly wheezy on walking to school [HR42], while when their asthma was bad, a teenage boy had to be driven to and from school [CI22], and another "comes up the stairs on his hands and knees" [MI17]. The drama of the boy being carried home by his friends from football games in the street, gasping for breath and unable to speak, with his chest heaving and his lips blue has been enacted twice already. If he was having a particularly bad attack one of his friends would run ahead to warn his mother [HR1]. Less dramatically, children were simply unable to keep up with friends, but with friends this

was rarely a problem. Friends "don't say now't. They stop with me. I've got good friends" [HR5]. Friends might also have asthma, and stop together as when a teenage girl on a school outing "had to climb this proper mountain. I get half way and I was like I can't go on. There was about five of us had to stop and we all sat in this little thing and had to take our inhalers" [CI16].

Children experienced more problems with keeping up, or even taking part, in school sports and a woman praised her daughter's school for staging separate events for asthmatic children on sports day [HR118]. By contrast many children and some parents complained that schools did not take sufficient notice of their pupils' asthma, particularly during physical education (PE) classes. Letters from parents exempted children from taking part, though "I try to tell my PE teacher I've got asthma, but he makes me do it anyway" [GP70], summed up the experience of some children when participation in PE triggered their asthma. The mother of a teenage boy had written several letters to his PE teacher, protesting that he was not allowed to stop when his asthma started, and once she had telephoned him after her son came home from school still breathless after a PE lesson earlier in the day. Neither writing nor telephoning had had any effect because his PE teacher thought her son was faking his asthma [GP21]. No child in clinic admitted to faking their asthma to avoid PE, but one girl interviewed said, with a smile and a glance at her mother, that occasionally she did so [CI21]. The firmness with which the mother and older sister of a teenage boy chastised him for often forgetting to take his inhalers to school on PE days was also suggestive. The boy replied in an aggrieved tone that he could not be expected to remember them all the time [I5].

Emotion was the other change in internal state that aggravated children's asthma. Moreover, asthma triggered by emotion added to the upset of the emotion. A young boy wheezed whenever "he gets into a paddy" [HR87], while when a girl gets upset "she cries and cries and coughs and coughs". When she was younger, her mother had been too afraid of her asthma to scold her [MI2]. Positive emotion could also end in, and be ended by, asthma. The same girl remembered a particularly bad coughing fit when she "got really excited playing musical bumps" at a children's party, and laughing was as likely as crying to cause a teenage girl to have a coughing fit [GP58]. Both sudden upset and prolonged worry worsened the asthma of the boy who often left his inhaler at home on PE days, and the patterning of his asthma mimicked the patterning of the stress. He

had had his worst attack in a foreign airport during an argument with a relative, but regularly, he noticed his everyday asthma was worse if he was worrying about something, usually at school [CI5]. Several parents mentioned that their children's asthma worsened during stressful periods at school, and a girl's asthma had been diagnosed initially as panic attacks as they occurred always at a new school in which she was unhappy [MI4]. Finally, twice asthma started soon after the death of a close relative [GP74b, HR65].

4.3.2 Expanding Asthma

Children's lives and those of their families might therefore be interrupted by their asthma and altered by avoiding its aggravating agents. Many parents spoke of how they tried to minimize the disruption caused to their children's lives, but children with severe and especially unpredictable asthma, were faced with alterations as alternatives to interruptions. Also, and importantly, in comparison to their peers, their lives were less independent of their families, especially their parents. Significantly, asthma's social consequences for children were also future oriented as it had the potential to impact on career choices. It had caused all the teenage boys interviewed to change their plans. One had wanted to be a vet but animals worsened his asthma [CI22], the other two wanted to enter the armed forces but knew already that their asthma would exclude them [CI5, CI17].

Asthma's disruption extended to the parents of such children. I was surprised when M4 could remember the exact date of a recent severe but not out of the ordinary asthma attack experienced by her youngest daughter. It had occurred, she explained, just after she and her husband had returned from their first meal out together for over a year. Equally revealing was a woman's contribution to a noisy conversation during a late night bus journey. In between shouts and laughter I caught the word asthma. Its speaker continued by saying that she would not have been able to go out a year ago, and certainly not to drink, and others agreed that his (her son's I assume) asthma was so much better. Asthma had thwarted the plans of a few women to return to work once their children had started school. M1 described herself as being fortunate in that her employment as a youth worker enabled her to work in the evenings. but she was acutely

aware that her continuing employment depended on her grown up daughters taking it in turns to have evenings at home. One of the women who stayed at or close to home had a teenage daughter who had both asthma and eczema. Her daughter's eczema had the greatest direct impact in terms of restricting family activities, time taken to apply ointments and bandages and the time and cost of frequent hospital visits, but it was her daughter's asthma that had dissuaded her from looking for a job. Her eczema could always wait, her asthma could not, and she could be alone with her eczema, but she could not with her asthma [MI16].

Asthma's potential to impact on families was therefore, economic as well as emotional and social. Its economic impact was especially significant if it threatened the car ownership or access that MI was "panic stricken" at losing when her marriage ended. Though mediagenic car journeys to the nearest Accident and Emergency department were rare, descriptions of them were vivid. A father's car was "vital" when his young son suddenly went blue, started grunting, and stopped crying [HR72], while a visit to his GP that began with a few metres walk to the family car, left a boy gasping for breath [MI20]. The bus stop would have been out of reach, hence an expensive taxi or the availability and goodwill of family and friends the only alternative to a medical call-out. It was only proximity that enabled a woman without a car to run to her child's school after being telephoned with the news that he was having an asthma attack [HR52].

Even everyday outings when asthma was troublesome might be a greater undertaking if a car was unavailable, and they might trigger an attack if they exposed children to its agents. Children might have to walk along busy roads and to wait at bus stops in air that was too cold or too hot. They might become upset if their asthma troubled them, or because they were tired or not themselves because of their asthma. Or they might become upset if reprimanded by their parents if behaving badly, if tired, or not themselves, or in dispute with siblings. Their upset might in turn worsen their asthma, thus renewing the asthmatic cycle. Not infrequently, one or more of the siblings might also have asthma that might be responsive to pollution, exercise, air temperature or emotion. If not a literal lifeline under such circumstances, a car could perhaps be a 'sanityline'.

The above hypothetical worst case scenario ended with the introduction of siblings. Asthma had the potential also to impact on their lives. The older sisters of C1 stayed at home to watch him and his brother worried about him, but others were irritated rather than worried, especially when sharing a bedroom with an asthmatic sibling. A girl shouted "Shuddup!" when her sister's asthma kept her awake at night: her sister took her inhaler to bed with her [GP69]. Removing a coughing young boy from the bedroom he shared with two brothers took priority over treating his cough [HR39a]. Siblings might also resent the extra attention paid to an asthmatic child. A boy protested about going to school when his sister was staying at home, and when at home was "a nightmare" [HR103]. Also, children might be scolded for persisting with rough and tumble play when their siblings' asthma was troublesome [HR108]. Finally, their activities and excursions might be curtailed if asthma kept the family at home [MI1, MI17].

Not surprisingly children of relatively affluent families experienced the least disruption. Bedrooms at the opposite end of a large house enabled the brother of C17 to avoid disturbed nights, while two parents and two cars enabled most of his daytime activities to continue as planned even if his mother and one car had to stay at home. Two adult carers at home or close by was also very important if the child had to be taken to hospital. One woman, whose husband worked away from home, and who had no close family living nearby, had to take her two younger children to hospital, usually in the middle of the night, along with her asthmatic son [MI20].

4.3.3 Restricting Asthma

By contrast, other children and their families lived life normally because certain agents they possessed, and certain activities they performed, successfully restricted their asthma. Their management of their asthma was both material and psychosocial.

4.3.3a Asthma's material management

Medicine breathed in from inhalers or puffers that were called usually by the colour of their container, or of its base, was the first of the agents with which asthma was materially managed. Spoken of most often was a "blue one" that all children took if

their asthma troubled them, and often also about 15 minutes before exercise to prevent it triggering their asthma. Most children or their mothers carried it with them or kept it at school, but the teenage boy whose asthma attack had left him partially sighted had left his blue inhaler at home that day. When younger he had worn it on a cord around his neck [GMI7]. Most children had also either a brown or an orange inhaler, and some had a green as well, while the remainder had a purple one. They took these colours every morning and evening to try to prevent anything stimulating their asthma.

Inhalers varied in their size and appearance, and the differences mattered to their owners. The most common type, L-shaped and less than 10cm long, fitted into one end of a clear plastic chamber, usually of 750ml capacity, into which its contents were fired. Children put the other end of the chamber into their mouths and took five breaths, or if young (usually under 3-5 years old), a mask was attached to its other end and put over their mouths and noses for 30 seconds. If more than one puff was taken, the inhaler was detached, shaken, reattached and the process repeated, and it had to be repeated for each puff of each inhaler. Taking inhalers took time: one boy and his mother had to find an extra 15 minutes every morning and evening for two puffs of green and four puffs of brown [HR91]. Increasing inhaler strength reduced time. By changing from the weakest to the strongest brown, a young boy's puffs were reduced from eight to two: before "he was worn out! I was worn out!" before the day had even begun [MI19].

Children, and their parents were, however, most likely to be worn out when children did not want to take their inhaler. A few young children were frightened of the mask, perhaps because it added to asthma's feelings of suffocation, leading to painful battles at inhaler times. It is "a nightmare" for a young girl and her parents because she "freaks out" and her father has to "pin her down" while her mother applies sufficient force to the mask to keep it on her face [HR40]. When there was only one parent, a relative or friend might be called to help, but often, and especially for single parents the struggle proved too demanding, and inhalers were abandoned. To my relief, for others, inhaler time was a happy time. "How long does 'Twinkle Twinkle Little Star' last?" a woman replied when asked how long she kept the mask to her son's face. He joined in [HR47], while another young boy put inhaler time to good use by practising his numbers as he counted his breaths [HR3]. Most telling of all, children as young as three years of age reminded their parents at normal inhaler times. Older children were not afraid of their

inhaler, though several found the chamber's mouthpiece obstructive when they were coughing and having difficulty breathing. Nevertheless many disliked the chamber because it was bulky, despite being in two parts. It was not only a nuisance to carry around, but also it was ridiculed by their peers. "I'd never take it to school. It makes you look like a spaceman. I'd be hammered!" [CI5]. A few older children and most adults had dispensed with it and squirted the inhaler directly into their mouths.

The size of the chamber by attracting attention to its users might have been partially responsible for their ridicule, but the principle reason was probably an age-related hierarchy of inhaler acquisition. Older children (the youngest was six years old) had other inhalers that were used without the chamber, and were small enough to fit into a pocket or small bag. Thus chambers were ridiculed because they were childish: most older children wanted to graduate to pocket inhalers. Trouser pockets accommodated the cylindrical *Turbohalers* better than the round *Accuhalers* and tended to be preferred by boys, especially older boys. On the other hand, *Accuhalers* were "posher" [HR35] and more attractive to some girls and younger boys, being two-toned (dark and light) and two-textured (gloss and matt). Also they were more gadget-like than *Turbohalers*. Their cap flipped neatly to one side and their drug was released by clicking a lever while *Turbohalers*' caps had to be unscrewed and their bases twisted to release the drug. C5 had broken several of his *Accuhalers* through excessive clicking, and GP13 kept losing the cap of her *Turbohaler*. She had refused to use one after it had rolled under her bed, a decision her mother professed to understanding. Both were subject to fashion. A boy chose an *Accuhaler* over a *Turbohaler* before trying either because his friend had one [HR51], and another boy's expression changed from disappointment on being told he could not have his friend's inhaler to pleasure on learning that the health professional's choice was much newer [GP61]. Though health professionals marketed them primarily on their appearance, the time saved was an added bonus as the five breaths into and out of the chamber were replaced by a single inhalation.

Some children were though, faced with a practical dilemma, especially when troubled by their asthma, because at those times "I'm not very good at the round one ... it didn't work" [GP57], while another boy had "tried all the others but can't get them in" [HR77]. A few children had put function before fashion and returned to their chambers, but a common compromise was a chamber inside the home and a pocket inhaler outside

it. The distinction was though not so much spatial as social, as C5 hid his chamber when friends stayed overnight, and squirted all the colours directly into his mouth. Occasionally no inhaler was fashionable enough for use in public. A few girls did not like using any inhaler away from home because it attracted attention to them. A teenage girl arrived home from school, breathless and tearful with her worst asthma attack for several years, rather than use her inhaler in the street [CI16]. Another girl was teased by the boys in her class if they saw her using her *Accuhaler*, so instead of taking it in the classroom 15 minutes before PE, she waited until she had reached the girls' changing room. Consequently PE and asthma often began together [CI25]. A few boys, especially older ones did not like using any inhaler when they did not have asthma, and used only their blue inhaler when it troubled them. The man whose asthma attack had left him partially sighted still only uses his blue inhaler though he has not forgotten it since [GMI7]. Usually it relieved them of their asthma, but not always. One teenage boy said that often his blue inhaler did not work, but his mother told me that he would not take his other inhalers unless she made him, despite being rarely asleep before 3am and being unable to play football or cycle with his friends [HR105/MI18].

A minority of parents did not want their children to take inhalers regularly. Some did not want their children to take any medicine regularly, especially if they had long spells without their asthma, but others worried that the brown, orange and purple inhalers that contained steroid would stunt their children's growth. Some parents were similarly worried about the steroid their children swallowed for a few days when their asthma was particularly troublesome, though usually more approving of its boost to their child's appetite. A few parents wondered if it had an emotional impact on their child. A young boy's temper tantrums had got much worse since his steroid inhaler had been increased [HC39a], while a few children had nightmares, were sleeping poorly at night or had become hyperactive.

Some schools restricted children's ability to control their asthma[16]. Most children in senior school kept their own inhaler, but in many junior schools they were kept in the child's classroom, in the medical room or in the school office. Usually children had access to their inhaler at all times, though until recently some schools had locked up the

[16] Local schools have protocols for managing asthma and the overall impression from parents was that school management was improving though certain schools were still causing concern.

inhalers and children had had difficulty locating the teacher with the key. Some schools, however, would not assist children with their inhalers, and children below about six years of age were rarely competent in their self-administration. The mother of HR52 who ran to his school when phoned to say he was having an asthma attack, ran to give him his inhaler that was kept at school, but which the school refused to administer because "his teachers are useless and won't do anything". Another mother had complained to the headmaster, but had been told that as there was no school nurse resident in the school, the school could not take the responsibility for administering his inhaler. When she protested that his asthma might become very bad before she reached the school, she was told an ambulance would be called. As his asthma was regularly bad by the end of lunchtime play, his mother visited the school daily to give her son his inhaler, yet still she had frequent requests to collect him. She worked as a hairdresser, and though her employers were supportive, the disruption to her (and potentially to her clients) was severe [HC39a].

Other parents complained that teachers did not notice when children's asthma worsened, and did not tell children too young to know themselves, when they needed their inhaler. Conversely, they were criticised for not preventing children over-using their inhalers. One woman, a classroom assistant, had stopped a child taking her blue inhaler after the number of puffs was well into double figures, and she had pointed it as often at the mouth of her friends as she had put it in her own, often without the chamber attached. The girl was, she thought, playing with her inhaler, especially as she could see no sign of her asthma. Since then she has refused to let her daughter take her own inhaler to school despite her assertion that parents never forget asthma's lethal potential [MI10].

Inhalers were most definitely the mainstay of asthma's material management, but a few children, whose asthma had persisted despite their regular inhalers, also took tablets regularly for their asthma. Others had tried them but they had made no difference. Occasionally also, inhalers were supplemented by the nebuliser that C1 used to have at home. It was the least portable of all asthma treatments, but for the few children who used it, it was the most effective treatment when their asthma was at its worst as it moistened the medicine making it less irritant to breathe in. Similarly, steam helped a few children's asthma. When asthma worsened a woman took her daughter into the bathroom, turned on all the taps and gave her a hot bath [MI2]. Another woman took her

son into the kitchen, made sure all windows and doors were shut and boiled water continuously on the stove [MI8], and steam from the hot shower accompanied the stories M1 read to her son in the bathroom.

Steam alters the environment within which asthma is experienced but its environmental management was, however, directed principally at eradicating or avoiding the agents that stimulated attacks, and was therefore preventive in intent. Mites living in house dust, especially in bedding, that parents blamed for their children's night time asthma were the main target. The most common strategy to 'manage the mite' was the purchase of protective covers for their children's pillows, duvet and mattress. The price of these ranged from a few pounds in local stores to a few hundred pounds from specialist manufacturers. Other strategies commonly employed were daily vacuuming and damp dusting of the bedroom, at least weekly changes of bedding, and banishing soft toys from the child's bed or freezing them every month if their loss was too upsetting for the child. Some parents had also replaced curtains with a blind and removed the bedroom carpet, and C14 had had a new bed and bedding. However, the constant repetition of 'on a night time' all too often bore out the experience of the woman who went

> "to a lecture at the hospital. I've forgotten his name – Professor something or another. He was supposed to be the expert on asthma and the dust mites. I came home and stripped his bedroom completely down to the floorboards and redid the whole of his bedroom – got special mattress covers and everything – and it didn't make a damn bit of difference!" [MI17].

Another woman who did all the above, and dusted with antibacterial wipes instead of a damp cloth was wondering whether to move her daughter into the bigger spare bedroom in case the central heating boiler on the other side of her bedroom wall was the culprit [MI2]. Other parents had turned off the heating in their children's bedrooms because it dried the air, thereby aggravating both dust and asthma, but children might then become too cold. A woman compromised by heating the air in her son's bedroom, and moistening it with his brother's fish tank [HR61a].

Though the asthmatic bedroom was the principal environmental focus, a few families had replaced the living room carpet with a laminate floor, while others had chosen a leather suite rather than a fabric one because it was less attractive to dust. Though dust was certainly asthma's prime suspect, other indoor agents were also included in

environmental management strategies. The mothers of the teenagers who smoked were trying to persuade them to stop and a few parents had given up cigarettes themselves when their child became asthmatic. Others smoked only outside the house, in a different room from their child, or by an open window. Aerosol perfumes and deodorants and hairsprays were banned in some households to the dismay of a few teenage girls, and a few mothers. A woman joked, but with feeling, that she had to put on her hairspray outside [HR97] while others had found polishes, air fresheners and pot pourris harder to give up. Usually, however, pets were hardest of all, to give up. One family had found another home for their cat [MI15], but several families had pets, most commonly dogs, while others had cats, rabbits and rodents. None affected their children's asthma although the family dog had been banned from the bedroom of C7 since a bad night of asthma after it had slept on his bed during the day. Only dogs that cast their coats worsened C16's asthma; nevertheless I left her home with hairs on my clothing. "We're not blaming you, are we Barney [the dog]? You're family!" [MI5] epitomized the status of pets in many asthmatic families.

4.3.3b Asthma's psychosocial management

The significance of psychosocial management strategies became increasingly apparent as research progressed. That they emerged (Glaser and Strauss, 1967), is probably a reflection of their invisibility, and of their potential costs, like their benefits, being psychosocial and hence equally invisible. Alternatively, they might have emerged because my medical gaze was focused initially on medical management.

The key psychosocial management strategy of asthma attacks was to stay calm: older children and their parents stressed its importance as being absolutely vital to their management. For this reason also, military metaphors of asthma are not adequate representations of the attacks of asthma, because although children might fight for their breath during an attack, they and their parents tried to avoid a psychological counter-attack. Asthma could only be defeated psychologically by outlasting it so that it retreated exhausted. Calmness contrasts the attack of the sword and the defence of the shield, being the inner strength of the soldier and citizen, that reflects the moral heroism of Kleinman's (1988) chronically ill.

Control was asthma's second psychosocial management strategy, for although the means of control might be material as were inhalers, the significance of the oft-repeated word went beyond the material. To control was to tame the wild and dangerous and thereby make it safe. Control moves asthma even further from the battlefield as the inhalers that were the principal agents of control, bore a greater resemblance to fashion accessories than to weapons of war, although one should not forget the few young children who experienced them as the latter. Their colour labelling imbued them with a cheerful homeliness that encouraged remarks about multi-coloured ones, favourite colours, matches or clashes with clothes and colour mistakes. "That's not right!" protested one father "orange and green don't make purple!" when told that the orange and green inhalers were now available jointly in purple [HR101]. Recognized and used by families and by health professionals alike, their colour names facilitated the transfer of their ownership from the latter who prescribed them to the former who used them. Asthmatic children might have a blue toothbrush and an orange inhaler at home, and a *Toy Story* lunchbox and an *Accuhaler* in their schoolbag, all equally in their possession – psychosocially as much as materially.

A third psychosocial strategy for managing asthma was not to let it stop – another recurrent word – children or their families. "He never stops. When he goes to his nana's the dog goes 'phew'!" said a mother of her young son [HR87]. Often though, asthma did stop children, as it stopped the young boy who ran everywhere, but stopped to cough and catch his breath along the way [MI9]. Parents might also wish that their children would let their asthma stop them. "'Listen to your breathing!'", a mother urged her daughter, when she got out of breath playing. "'I know, mam, but I'm playing!'" was the usual reply [MI2]. More often though, stop was metaphorical. Children were not stopped by their asthma when they were equal to, or ahead even, of their peers in activities affected by their asthma, and in the overall fullness of their lives. Despite her fears of being separated from her inhaler, C6 competed in swimming and cross-country running, and exercised her lungs also by playing the flute and singing in a choir. Her artistic pursuits went beyond therapies for her asthma as she enjoyed playing the piano, dramatics and painting, and she found time to attend extra classes for gifted students. C17 who was so breathless when his asthma was bad that he crawled upstairs on his hands and knees, kept going in school PE lessons until told by his teacher to stop, played the trumpet in a local orchestra and was near the top of his class despite missed

schooling. Aged three years, C9 above had learnt to swim and to ride his bicycle without stabilisers. One year older, HR119, diagnosed with severe asthma, was wearing a sweatshirt with the logo of a Montessori school. When I remarked on the logo her mother told me that as lots of people had praised her daughter's intelligence she had enrolled her the previous year and was pleased with her progress. When shopping recently her daughter had stopped suddenly and said "Look mum, money!". As her mother scoured the pavement, her daughter directed her eyes upward with "No, mum, Monet!" as she pointed to a poster in the window of an art shop. She was learning the language as well as the art.

A final psychosocial management strategy was to make asthma unimportant by incorporating it into family life, such that families were simply living, not living with asthma. Repeatedly, asthma, however severe, was part of life and they just got on with it. Younger children acted rather than articulated its unimportance. A girl, who according to her mother was very keen to talk to me ignored most of my questions about her asthma and told me instead about her friends and her school. Then she asked if she could show me her bedroom, but for reasons unrelated to her asthma. On leading me into the hall we met her father who was going to visit her grandmother, and despite her parents' protestations she abandoned me and her asthma and went with him instead [CI10].

4.3.3c Managing families with asthma

Thus I end this section on a cautionary note. Asthma in the family was my priority, but often during fieldwork I was reminded, as above, that families might give themselves priority over their asthma. When I telephoned parents to arrange interviews, often they left to hunt for diaries, and when I arrived, notice boards in kitchens or halls might be several layers thick with scraps of paper, children drawings, cards, and appointment cards. Daytime interviews were impossible when parents worked and evening interviews sometimes equally difficult to arrange because children were being transported to and from clubs, activities and friends. More often than not, interviews were interrupted by telephone calls, visitors and visits from their own children, and perhaps not solely out of curiosity – requests for food and for help with schoolwork were the most common reasons. Listening to women in the community centre talking about home and family life suggested that bath times and bed times were not always

happy times, and unhappy children might continue their protest by protesting against their inhalers. Going out, especially for single parents, frequently involved a baby sitter, often the teenage daughter of a friend. If children had not taken their inhalers before parents left, they might not be taken at all. Family mornings were not observed or overheard, but occasional references to them suggested asthma and its management are even more onerous in the morning than in the evening.

Talking, or trying to talk, to families with asthma sometimes demoted it. Money spent on 'managing the mite' could be better spent elsewhere and children and their families might prefer to be with their asthma than without the agents and places that might trigger it. Some clinic appointments and many interview requests never even took place, perhaps because the respective cards and letters were lost or incorporated into a deeper layer on the notice board, or simply because asthma was not a sufficiently big issue beyond the clinic or one researcher to merit a response. Parents might also have been deterred if their asthmatic child was well, or if not too ill, would have to wait to be fitted into a clinic, especially if the child and perhaps siblings as well, were irritable, or might become so in the waiting room. Equally, child-care demands might have deterred families from expending time and energy on an interview. Most of all, I remember the time and effort it took women at the community centre to arrange child care for a single mother of four children who wanted to accompany one child to hospital for a planned overnight stay. When an asthmatic child might be ill at night, and unpredictably and repeatedly, family management of asthma might take on the aura of necessity. Especially when there is only one adult carer the possibility of having to evacuate the entire family to hospital might have kept asthma at home. Asthma is managed within the lives of all families and if managing asthma mismanaged families, then families might come first.

4.3.4 Living with Other Asthmas

Asthma's potential to impact on the lives of Teesside's children and their families, and their responses to it, feature also in its other biographies. Children studied by Eiser and Havermans (1994:103) were forthright if non-specific: asthma "stops me doing things, stops me having fun, it's a nuisance". Other children were disappointed that they could

not have a dog or go to the zoo, and being teased by their peers, and being reluctant to take daily medicines were also reported (Colland, 1988 in ibid). Nocon and Booth (1989) and Gabe *et al* (2002) document alterations in daily activities to avoid asthma's triggers, of which some, such as pollution including tobacco smoke, and those associated with poor quality housing, tend to be concentrated in impoverished urban spaces (Harrison, 1983; Evans and Kantrowitz, 2002). Some restriction of activities were reported by adults interviewed by (Adams *et al*, 1997:192), most sensationally by a woman who

> "had difficulty even going into the garden to put out her washing ... and was genuinely concerned that she might lose her husband as it was all she could do to keep breathing during sexual intercourse let alone exhibit signs of enthusiasm or pleasure".

The potential for asthma to impact psychosocially is, however, confirmed by about half those interviewed by Nocon and Booth (1989), reporting it as a source of tension within their families.

The NAC has highlighted loss of schooling (p.2), and Nocon and Booth (1989) also found that most children missed some school, though usually only a few days each year. Children were restricted also in their participation in sport, a consequence of particular significance to some boys interviewed by Gabe *et al* (2002). In their study teachers, especially PE teachers received a mixed, though perhaps marginally better press, than in Teesside, but one asthmatic girl was sent out of an exam because the teacher said her cough was disturbing her fellow pupils. Their study confirms also the support of friends, but contrasts it with negative reactions from peers, particularly panic when witnessing an attack, and anger when asthmatic classmates are unable to keep up during team games.

In tackling asthma, teenagers' relationships with their inhalers in Williams's (2000) study both reflected and contrasted those amongst Teesside's teenagers and young adults. She reported teenage boys as being reluctant to use any inhaler in public whereas in Teesside the blue one was acceptable when asthma attacked provided no chamber was in sight. By contrast, and in contrast to teenage girls in Teesside, the teenage girls studied by Williams (ibid) were more accepting of their inhalers in public because in her opinion, they were more accepting of their asthma as part of their identity. As teenage

girls in Teesside were in general more willing to take regular inhalers than teenage boys, they too were probably more accepting of their asthma. However, their reluctance to take any inhaler in public, even when distressed by their asthma, suggests that in public their asthma is more acceptable than their inhaler, perhaps because the latter attracts more attention. Some adults interviewed by Adams *et al* (1997) and by Sweeney *et al* (2001) similarly hid to take their inhalers, and the former noted that these adults rejected their diagnosis of asthma, re-diagnosing themselves with bad chests.

Inhalers were not stigmatizing to other adults studied by Adams *et al* (1997), nor to most interviewed by Gabe *et al* (2002). The latter, however, shared many of Teesside's families' worries about the brown, and a few of their adult peers interviewed by Sweeney *et al* (2001), did not take it regularly. Significantly, many contributors to the above studies stressed their agency in their asthma management, and, as in this study, of controlling it by staying calm and by using their inhalers, but also of controlling their inhaler use, such that they and not their inhalers managed their asthma. Finally, acting normally was an important psychosocial management strategy for Gabe *et al*'s (2002) respondents and for those studied by Adams *et al* (1997) irrespective of whether or not they were accepting of their diagnosis. "Some [however] *admitted*" to Sweeney *et al* (2001:23) "not wanting to interrupt their normal planned activities" (emphasis added).

For many of the above, asthma was therefore, a significant, if usually manageable, problem. By contrast, most in Prout *et al's* (1999) study "did not generally regard asthma as a major problem, rather they saw everyday symptoms as tolerable and their impact on everyday life as limited. They made few changes to their regular activities" (ibid:138). Like many children in this study, one child's asthma was "an everyday thing" (in ibid:145), while another child had never had asthma "to the extent that 'it's really stopped him'" (ibid:146). Asthma that was everyday to their children and did not stop them could be accommodated into family life rather than *vice versa*. The adults with asthma interviewed by Drummond (2000) also reported their asthma as having relatively little impact on their lives. He makes, however, the interesting observation that quality of life or impact studies tend, especially if questionnaire-based, to apply universal standards to individual illness experiences, and that qualitative as well as quantitative studies, have tended to assume that all impact is negatively perceived. His study asked adults with asthma about their quality of life in general and what influenced

its quality, before asking them about the influence of their asthma on it. "The findings indicated that asthma was in general not considered to be important in the process of assessing or experiencing quality" (2000:235). Asthma had caused one respondent to give up golf, but he had replaced it with bowling, and his relationships – the main contributor to his quality of life – were unaffected by the impact of asthma on his golf. Asthma restricted many children's participation in sport in this study and in others (Gabe *et al*, 2002; Nocon and Booth, 1989), but some without their asthma, might have been "not sporty ... a couch potato" [MI8], and unwilling participants in school PE lessons. Notably, Eiser *et al* (1988) found that only a minority of children whose asthma restricted their sporting activities minded that it did so. Also, negative impact might be short-lived or reassessed subsequently in a more positive light. Another man interviewed by Drummond (2000) had wanted to join the armed forces, as did two teenage boys in Teesside, but by the time of interview he had no regrets about being excluded, though he had been disappointed at the time.

Prout *et al* (1999) echo Drummond's perspective in that their study focuses upon how children and their families adapt to their asthma in order to minimise its impact on their lives so that a "sense of worthwhileness is maintained" (ibid:140). Wheezing was an everyday thing for the child above and family life continued as normal for many in Teesside. Maintaining a sense of ordinariness – of being just like other children and other families – is a key adaptive strategy that is founded upon the normalization of the illness experience (James, 1993), and the aim of the psychosocial management strategies described above. Prout *et al* (1999) comment, however, that chronic illness can be studied from the opposite perspectives of impact and adaptation. In consequence illness accounts might differ because of the differing perspectives of their researchers: impact studies presenting the negative, adaptation studies the positive. My aim is to present both.

Yet it is evident from Prout *et al's* (1999) study that the illness of asthma remained, however much it was normalized and adapted to by children and their families. Most children had had an attack in the last two weeks and some were restricted socially by their asthma. The boy above, who according to his mother had never had a really bad attack, had previously been admitted to intensive care. Her assertion echoes the apparently genuine surprise of the mother of HR1 who was regularly carried home by

his friends gasping and blue, when told by the health professional that her son had severe asthma. Also, Prout *et al* (1999:146) highlight the significance of the "It's *only* (our emphasis) about three or four times a year that she has a really bad do" (ibid:146). Finally, the interplay between impact and adaptation is apparent in their citation of the girl who had replaced running with bicycling and football, but nevertheless missed her former pursuit.

An interesting case-study by Hepper *et al* (1996) of an asthmatic boy at school also presents the duality of asthma as impact and adaptation. His asthma was severe enough to average two hospital admissions a month, yet his reputation among his peers was of being good at sport and the best footballer in the class. The boy attempted to manage both his asthma and his reputation, balancing the needs of both. Thus when his asthma was bad he opted for basketball rather than football at break time as it was played more slowly, but when his asthma was good he played football till the end of break time rather than stop in time to take his inhalers. As he took them after the bell had rung, he was reprimanded frequently for being late for lessons, but being labelled disorganized by his teacher was better than being labelled sick by his inhalers. However, as he took his inhalers, being ill might have been the worst of all.

All studies on asthma reveal to varying degrees the potential for it and its management to both disorder, and to order, time and space. Nights and winters might go on forever, days are interrupted or turned into the sleep of night, and plans might have to be altered or abandoned. Home, other people's homes, school, restaurants, parks, busy roads might be altered or avoided. Moreover, when asthma disorders space it had the potential to disorder others with whom the space is shared, as when C6's asthma had frightened a waiter in a restaurant and caused another diner to offer assistance. Its management had a similar potential to disorder. Being teased or stared at when taking inhalers in public damaged relationships with peers and created them with strangers. Children taking inhalers 15 minutes before school PE lessons had to fit them into the previous lesson. Prout (1992) notes that school time is more structured and less flexible for children than home time, as Hepper *et al*'s (1996) boy knew to his cost. More generally, social time is scheduled such that social life is subjected to routines (Giddens, 1993; Zerubavel, 1981) and unforgiving of spontaneous and unpredictable entities such as asthma. Scheduling of time can also impart different values to its component parts, and it was because the

asthmatic boy studied by Hepper *et al* (1996) valued play time that he waited until work time before taking his inhaler. Finally, modern time is scarce, as Evans-Pritchard (1940:103) realised when envying the Nuer of the Sudan who never "experience the same [his] feeling of fighting against time or of having to coordinate activities with an abstract passage of time... Nuer", he concluded, "are fortunate".

Equally, however, asthma and its management have the potential to order, or to reorder, space and time. The bed and bedroom protected against mites, the steam filled bathroom or kitchen, the rooms in which smoke and sprays were forbidden, the inside of the home from which winter could be excluded, and the outside space where asthma had never been, and was not expected. The ordering of space close to home is particularly important not only because it is where most time is spent, but also because it is the space shared by family and friends – the safe private space in contrast to the threatening public space occupied by strangers (Campbell, 1964). Asthma and its management also order time, thereby acting in the same way that MacClancy (1992) describes for food, as our calendar and our clock. Inhalers before bed, will, it is hoped, ward off asthma's nocturnal presence and in the morning they are taken upon rising or before or after breakfast. Asthma times the seasons in that it may be worse in one than in the others and more inhalers might be taken in that season than in the others. The preservation or restructuring of time and space in such a way that order is maintained, or is restored from disorder are, it is suggested, key to living with asthma. Thus everyday asthma might be normal.

4.4 BEYOND ASTHMA

> 'He [the king] is ill.' (I imagined the first alarm.) 'He has told his Mother.' (Some relief.) 'He is fighting hard. (Massed prayers in churches.) 'He is worse.' (Cries of doom in the streets.) ... Certainly I took pains to give them something to be anxious about, but also I bid them be strong. 'He wishes no special arrangements made. Only bands and tanks. A parade or two. And perhaps a *three* minute silence (emphasis added).
>
> Laurie Lee[17]

Although Lee ([1959] 1992) is writing of his childhood pneumonia[18] he illustrates many of the themes in this final section that have emerged already in relation to asthma, but are discussed here in the context of their relevance to illness in general. Like asthma in Teesside's children today, Lee's pneumonia experienced in the early decades of the last century, was a relatively common, and for a few children including Lee, a recurring illness. Pneumonia today is by contrast, an acute illness that rarely visits children and even more rarely returns. Childhood pneumonia and childhood asthma have therefore diverged with respect to their illness trajectories (Strauss, 1975) or life courses. As acute illnesses are limited to one time they have no illness trajectory, unlike asthma whose chronicity imparts to it a life course. Narratives of illness are this chapter's core, but the patterning of illness in time has significant implications for its narrative construction. Chronic illness, because of its duration, generates "an extended narrative, a 'Patient's Progress' of choice and moral self-definition ... and a new social role" (Brandt, 1997:43).

This chapter has, however, stressed the variability of asthma in the present – its patterning in space – and its future is equally variable. The two children whose asthma made the greatest impression on me appeared to have very differing trajectories, and will perhaps have very different futures. C1's asthma has steadily been getting better as he grows older, but HR33 was no better at her first clinic consultation, and though better at the second, she had been better before only to become worse again. Thus illness narratives of asthma might also have to explain such variation and one's place in it, as well as managing present and future uncertainties. This additional burden was perhaps

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[17] Lee ([1959] 1992:146).

[18] As Lee's ([1959] 1992) memory as an adult of his childhood pneumonia is dominated by its fever rather than by respiratory distress, it has been excluded from 'asthma's analogous biographies'.

eased by most parents hoping that their children would grow out of – another oft repeated phrase – their asthma. In comparison to diabetes (Kelleher, 1988) and epilepsy (Scambler and Hopkins, 1988; Weinbren and Gill, 1998), the other relatively common chronic illnesses of childhood, asthma is a more optimistic illness.

The chronic obstructive pulmonary disorders that usually begin in adult life have a more pessimistic illness trajectory, hence their comparison to asthma was confined to their attacks where the immediacy of their experience over-rides temporarily their differing illness trajectories. The optimistic illness trajectory of asthma distinguishes it also from the eventually fatal cystic fibrosis (Blue Bond-Langner, 1991; Burton, 1975) and potentially fatal childhood cancers (Sourkes, 1995), for although parents of children with asthma might remember always that asthma can kill, usually it is not expected to do so. The illness trajectory of asthma has, however, characteristics that Strauss (1975) perceives as particularly distressing and disruptive, namely its uncertainty and its unpredictability. "[A]llaying the spectre of randomness" is, according to Brandt (1997:47) a core aim of all therapy, and at its most extreme, asthma is random.

A key theme of social science literature on chronic illness (Kleinmann, 1988; Radley; 1993; Hydén, 1997), and also of a few medical texts (Greenhalgh and Hurwitz, 1998), is the role played by narrative[19] in the explanation and understanding of, and adaptation to illness, and its communication to others. Although this study has included children's narratives and illness experiences, it has drawn primarily on the accounts of their parents, principally their mothers. The audience therefore, rather than the actor has taken centre stage and the chief narrative is not the experience of the illness itself, but a review of its performance. Anthropological accounts of illness have stressed also the importance of illness performance. When the Gnau of Papua New Guinea become ill, they do not report or describe their illness to anyone, rather they act out its presence, by adopting a passive and wretched demeanour, covering themselves with dirt and lying in a dark hut (Lewis, 1975). The separation of narrator from performer in this study might be significant as Wensley and Silverman (2001) found little agreement between children's assessment of their quality of life, and their parents' perception of their children's quality of life, when they were asked to put themselves in their child's

[19] As metaphor is a narrative device it has therefore, also a positive portrayal (Radley 1993; Good, 1994; Mabeck and Olesen, 1997).

position. Children perform their experience; parents witness their performance.

Further, the actors in this study were children, whereas much of the literature on chronic illness pertains to adults. Children – in modern western society at least – may have different experiences of time from adults. Christensen (1993:497) describes a child who, on seeing in Disneyland watches whose hands rushed round, enthused that "even the watches are made for children, for they [children] always find the time passes so slowly". Though time during asthma attacks might be longer for children, time between them might also be longer. Therefore, the adaptive forgetting documented by Drummond (2000) in adults, might be achieved more quickly and more easily by children, than by their parents. It might be one reason why at the time of interview, when no child had asthma that was audible or visible to the interviewer, children seemed less frightened of their asthma than were their parents of their children's asthma.

Children also, according to Christensen (1993) differ from adults in the importance they attach to immediate and direct visual experience. "Look!" (in ibid:498), she identifies as one of the "most frequent requests among children themselves and of adults ... Look when I climb up the tree" (ibid:499). The visible (and audible) manifestations of asthma may therefore be of added significance to children, both as a sign that they are deserving of the sick role, and as a stigma that brings unwanted attention. By contrast, the pain and tiredness of asthma emphasised by children in their own accounts are invisible and inaudible. Hence, their impact might also be greater because greater effort is required to make them social, and children might have become more skilled in their verbal communication for that reason. In general though, the performance of illness might play a greater part in the communication of illness by children, than by adults.

However, distinguishing children from adults evokes modern western concepts of childhood where children and adults are perceived as different social beings rather than the former being simply smaller versions of the latter. As "in mediaeval society childhood did not exist" (Aries 1962:98), childhood is a social construction rather than a natural phenomenon that in western society is perceived as a stage during which children have to be socialized into adults (James, 1998). In such a model western society perceives children as empty vessels that are dependent on adults, both for their filling and until they are full.

An alternative model of childhood that has gained strength in the social sciences views children not as passive absorbers of adults' instruction, but as "interpretive social actors" in their own right (Prout, 1992:123). He describes the complexity of children's negotiations with parents and teachers when they said they felt ill and wished to be excused school. Most of the negotiations were unsuccessful though, especially before and during exams, thus further illustrating the constraints imposed by school time and scheduled time. Negotiations might be more successful within the family, and some of the strategies adopted by 13 year olds in Wilkinson's (1988) study when they said they were pretending to be ill, are potentially pertinent to Teesside's children. They included 'not do what you normally do'; 'mope around the house'; 'have something your parents can't really tell'; 'being quiet' and 'coffing (sic) down the loo and saying I've been sick' (ibid:180). Parents' descriptions of their children being not themselves before and/or during asthma's manifestations, are reminiscent of all but the last, which brings to mind PE teachers' dismissal as fake, the asthma in their coughing, wheezing, breathless and protesting pupils. Children therefore, might not always receive the credit they deserve for the performance of Foucault's word (p.11), as well as of Wittgenstein's thing (p.2).

A final illness distinction that must be made, gives priority not to illness, but to its location in time and space. An illness that begins before memory might differ from an illness whose beginnings are remembered. Bury introduced the concept of illness, especially chronic illness, as biographical disruption: "that kind of experience where the structures of everyday life and the forms of knowledge that underpin them are disrupted" (1992:169). The emotional, cognitive and social means by which chronic illness is normalized, thereby enabling chronically ill children and their families to normalize themselves, are born out of the biographical disruption it has caused. Williams (2000) has, however, questioned the relevance of the concept to illnesses present from birth or beginning early in children's autobiographies. Asthma cannot disrupt the autobiographies of children who have never known life without asthma, therefore although its potential to cause pain, fear or stigma remain, children and their lives do not have to be put together again because neither have been interrupted. Such children are, however, potentially disruptive to the biography of their families who have lost, or have been denied, a well child (Burton, 1975). Interestingly, Wensley and Silverman (2001) found much greater similarity between parents' assessment of their

own quality of life and their perceptions of their child's quality of life, than between their perceptions of their child's quality of life and their child's own assessment of it. "Ordinary ... is what you are used to. This may not seem ordinary to you now, but after a time it will. It will become ordinary" (Atwood, 1985:43). Asthma may always have been ordinary to their children, but it may not have been always, or will ever be so, to their families.

4.5 CONCLUSION

This chapter has explored my principal research question 'What is asthma' from the perspective of asthma as an illness. It has described the experience of asthma in children with it, and as experienced by families with asthmatic children in them. A key conclusion is that asthma has both a variable personality in time and variable personalities in space. What it is, it seems it might always also be not, both in the same child, and in different children. Most children coughed, but not always, and occasionally were just not themselves; sometimes and/or in some, asthma was severe, but other times and/or in others, it was mild; many children it visited only now and then, but a few it accompanied almost all the time. Children and their families differed also in their responses to their asthma. For a few, it was a fearful enemy; others had negotiated a truce, or had become, or had always been, compatible, with it; so compatible that it might even be an ally. Consequently, its impact on the lives of children and their families was equally variable, and the extent to which it could be predicted, and thereby perhaps prevented, emerged as crucial to its impact. The asthma that attacked unpredictably was the most threatening of all.

This chapter has focused on the experience of asthma, but as those who witnessed it rather than those who experienced it were its main contributors, I end by suggesting that it is in effect the performance of asthma that was its principal subject. Families sensed – saw, heard and felt – it in their children. Thus they experienced the performance of asthma in their children and/or their children performing asthma. Its performance is significant, as in the next act it leaves the family to meet its first critic – an expert witness and professional commentator – in the free garden.

PRESENTING ASTHMAS

In one family all children had been diagnosed with asthma. Their mother's account of their asthmas is summarized below [MI4].

The family has an adopted daughter aged 20 years and three daughters aged 11, 10 and five years. When their adopted daughter 1C4 was in her first year at secondary school she had attacks of gasping for breath that happened always at school. Her GP told her they were panic attacks and advised her to breathe in and out of a paper bag. Her attacks continued at school and the paper bag brought no relief. Then the school nurse told her mother that she thought her daughter was suffering from asthma as the attacks were happening during PE classes. Her mother took her to a different GP in the practice who diagnosed asthma and prescribed inhalers. Her attacks of breathlessness disappeared, and did not return after her mother stopped her inhalers.

About two years after their eldest daughter was diagnosed with asthma, the third daughter 3C4, then four years old began to cough. Her GP diagnosed a respiratory infection, but antibiotics had no effect. Her cough worsened into coughing fits when she coughed until she vomited. Then she began to wheeze and to get out of breath on exercise. Her GP prescribed inhalers, but these had no effect. One day she was coughing so much she could not take her inhaler. Her mother telephoned her GP, who told her to wait until her cough had abated, then try again. Soon after, during a coughing fit, her breathing became laboured, she turned grey and her eyes rolled. Her mother called an ambulance and she was admitted to hospital. Initially, whooping cough was suspected, but tests proved negative, and a definite diagnosis was made of asthma when her cough responded to high dose asthma therapy. Since then her asthma has troubled her when she has a respiratory infection, but also at other times without any obvious trigger. She becomes very quiet and apathetic, then begins to cough like a dog barking.

Two years later her elder sister 2C4 then aged seven years had a cough and cold that did not clear up. Her mother took her to her GP who diagnosed asthma and a chest infection, and prescribed inhalers and antibiotics. Her symptoms disappeared within a week and never returned. Her mother stopped her inhalers after a year, and coughs and colds have been normal since.

Shortly after 2C4 was diagnosed with asthma her mother took 2C4 and 3C4 for review at the GP asthma clinic, accompanied by her youngest daughter 4C4, then aged one. The nurse diagnosed asthma in 4C4 because her breathing was noisy and prescribed inhalers. They had no effect on her breathing and her mother stopped them after a few weeks. Her daughter had been a noisy breather since birth, and was no different on the clinic day. About two years later she began to cough in her sleep. Her cough was not eased by cough medicines, antibiotics or by inhalers. It continued to worsen until it woke her from sleep, and she began to have fits of coughing and vomiting. One day when her cough was particularly severe she became quiet and sleepy. Fever and vomiting followed, then she became very upset saying her head hurt. Her mother telephoned her GP who advised home remedies to bring down her temperature. When these had no effect he admitted her to hospital with suspected meningitis, but no signs of meningitis or any other infection were found, and her symptoms disappeared with high dose asthma therapy. She remained well on treatment until about a year later, shortly after a general anaesthetic, her cough returned with a runny nose. Since then she has had fits of coughing and vomiting, wakes several times most nights coughing, has a persistent day time cough and wheeze, and gets out of breath very easily. Her asthma therapy has been increased several times and her asthma was improving, but slowly, and several weeks after her last therapeutic increase, it was troubling her still, every day and every night.

Chapter 5 ASTHMA IN THE FREE GARDEN

5.1 INTRODUCTION

This family had the greatest number of children diagnosed with asthma. In describing how they were given the word asthma by their health professionals, it has introduced the chapter's core content, namely an exploration of how asthma is known in the free garden. The free garden is symbolically the imaginary and idealized birthplace of modern medicine "where by common consent, doctor and patient met" (Foucault, 1963:52). In this chapter it is represented spatially as the medical places in which consultations between health professionals and children with asthma and their families were observed, and about which they were narrated during interviews. Thus it is the space in which people are transformed into patients (Conrad, 1990), and their illnesses might or might not be transformed into diseases (Cassell, 1976). Its space extends, however, from the material into the metaphorical as it stands also for the body of medical knowledge and practice, firstly, as it is administered by health professionals to patients, and secondly, as it is represented in the medical literature. Patients bring their illnesses to their health professionals, but patients end at the end of the medical consultation. Their unhealths remain in textbooks, journals, patient records, case histories, conference presentations, conversations and anecdotes. It is therefore predominantly as text – words, numbers and images, written and spoken, formal and informal – that unhealth is transmitted throughout medicine. Thus it is transformed from "*the totality of the visible*[1] to the *over-all structure of the expressible*" (Foucault, 1963:114).

In the free garden unhealth is subject to the medical gaze, and it is its object. The political dimensions and consequences of the gaze featured heavily in Foucault's (1963) account of its birth, but my focus is upon the intellectual, and above all, observational, properties of the gaze. In essence it is a knowing gaze as diagnosing, or knowing, asthma is its aim. According to Helman (2001:80) the unhealth of asthma that it aims to detect is the disease of asthma that forms

[1] More generally sensible in the sense of being perceived by the senses.

> "[t]he medical definition of ill health based on objectively demonstrable physical changes in the body's structure or function, which can be quantified by reference to 'normal' physiological measurements. These abnormal changes, or *diseases*, are seen as 'entities', each with their own unique 'personality' of symptoms and signs. Each disease's 'personality' is made up of a characteristic cause, clinical picture (symptoms and signs), results of hospital investigations, natural history, prognosis and appropriate treatment".

The actuality or material reality of disease is at the heart of the medical definition of ill health, but disease is nevertheless a cultural construct because "there are no ... diseases in nature" (Dingwall, 1976:82). "The snapping of a septuagenarian's femur has within the world of nature, no more significance than the snapping of an autumn leaf from its twig" (Sedgwick, 1972, in Dingwall, 1976:82). Disease is an evaluative term applied by medicine to changes in material reality resulting, or possibly resulting, in the absence of ease and inconvenience from which disease has its literary origin (p.4). The disease of asthma in children did not exist before the mid-nineteenth century (Gabbay, 1982).

This chapter uses two distinct sources in its search for the medical personality of asthma. The first comprises children with a diagnosis of asthma and their families who were observed in the clinics and/or interviewed in their homes or in the community centre. It comprises also health professionals encountered in clinics, in illness narratives, at medical conferences and when friends, outside medical places. The second source comprises medicine as displayed in the medical literature, which has a dual, and it is acknowledged, contradictory, role. The chapter portrays it as a source of knowledge on the disease of asthma, but in keeping with the mild version of social constructivism (p.10), it interprets the knowledge as well as imparts it.

The chapter opens by returning to Hunter's (1991) imagery of health professionals as detectives: in the first section they are charged with detecting the disease of asthma in the clinic. The next section continues the search for asthma in medical discourse[2] as represented by its literature and the words of its professionals. It ends by suggesting that medical representations of asthma's personality both in the clinic and in the literature

[2] I am using the word literally and superficially as "written or spoken communication or debate" (*The New Oxford Dictionary of English,* 1998:527). I have, however, chosen it because of Foucault's discussion (usefully summarized by Fox, (1997)) of how deeper structures of, and relationships between, power and knowledge give his word its authenticity.

have implications for its status as a disease entity. They have implications also for asthma's patients who return to focus in the final section, beginning with the birth and re-births of asthma in them, and ending with its medical management whose aim is its death. Its focus therefore, is upon interactions between asthma in the family and asthma in the free garden.

5.2 DETECTING ASTHMA

> In the old days folk didn't know what illness was. They went to bed and they died. It's only nowadays that we're learning words like ... lung ... and I don't know what! ... it's true there aren't any sick people now, not as there used to be. Now everyone's sick, everyone's complaining of something. Those who were dying used to suffer a lot ... Who's ill nowadays? Who's well? Everyone complains but no-one stays in bed; they all run to the doctor. Everyone knows what's wrong with him now.
>
> An old Kabyle woman[3]

Health professionals use the clinical method (Lumley and Bouloux, 1994) prescribed by medicine to ascertain whether the disease of asthma has been committed in their patients. If they detect the disease in the illnesses that their patients bring to them they give the diagnosis. As asthma as an illness is intermittent, the clinical method is applied both to the first detection of asthma in the diagnosis of a new asthmatic, and its subsequent detection in previously diagnosed and therefore, old asthmatics. This section explores the personality of asthma in the clinic according to the characteristics of disease identified by Helman (2001). Though Helman begins his disease personality with causes, usually the clinical method begins with symptoms, the first part of his clinical picture. Thus disease enters the gaze of the health professional in the illness narrative of the patient. The patient is distinguished from the person because the health professional, in whose presence the person becomes the patient, has the potential to influence the illness narrative in two ways. The first is passive by being a medical, not lay, audience. The second is active by questioning the patient in order to construct the symptoms or happenings – the literal translation of its ancient Greek word (Nutton, 1993) – that the illness is causing the patient. Symptoms are the medical text of an illness: medicine may, or may not, rewrite them as the text of a disease. Medicine stresses the importance of the illness narrative in asthma, as being intermittent, and frequently nocturnal, it rarely presents itself to the health professional (Milner, 1993; Levy and Hilton, 1999), and it presented itself to me in only a handful of patients

[3] In Bourdieu (1977:166).

attending the clinics. Asthma's medical text may therefore, be written only from its illness narrative.

5.2.1 Symptoms

Symptoms are according to Foucault (1963) closest to the disease as they are its presentation to patients who then present their experiences to the health professional. The old Jew (p.80) was in fact, presenting himself to his doctor. Asthma's symptoms are presented here as re-presentations of the atoms of asthma.

5.2.1a Cough

> "She was walking around the house coughing all the time, just a little [cough] as though she was clearing her throat all the time {mother mimics cough}. It went on for a while. I thought perhaps she was getting a cold or something. It didn't develop and she kept on doing it. I wondered if it was asthma – I was aware of it – so I took her along to the doctors and they diagnosed it" [MI15].

Her cough had been as straightforward to diagnose as her asthma has been since (p.79). Many asthmas had been less revealing of their personality in that many children who only coughed, or mainly coughed, had had many visits to health professionals for 'coughs', 'colds' 'chest infections' or 'bronchitis' or simply because they were 'chesty'[4]. Many had been treated with antibiotics or cough medicines before their asthma was diagnosed. A mother first took her son to his GP when he was 18 months old with "a bad cold [that] went to his chest". Aged four years of age, he was diagnosed with asthma by which time his GP practice must she said, have been sick of the sight of her coughing son [MI8]. Another four year old boy began to cough on exercise. Several months and several courses of antibiotics later he was diagnosed with asthma and started on inhalers [MI3]. A five year old girl had repeated visits to her GP with coughing fits before being diagnosed with asthma and prescribed inhalers when her parents took her to a different GP in the practice [MI6]. Less commonly coughing children might be diagnosed initially as having rhinitis – seasonal (hay fever) or perennial (year round). Rhinitis, described as one health professional as "asthma up your nose" might be the cause of the coughs and colds; treating asthma up the nose often

[4] Lay diagnoses are enclosed in quotation marks.

improved asthma in the chest. The young boy (p.82) who coughed so much he developed a rash from ruptured capillaries had seen his GP seven times over several weeks in the early summer and hay fever had been diagnosed on each occasion. His hay fever became asthma when his mother took him to her local hospital [MI7].

Like their health professionals, none of these parents had suspected asthma initially despite all having asthma in the family. "If you'd given me a list of 50 things we'd never have put asthma on it" said one father [FI6]. Asthma had not been a suspect because asthma in their families wheezed whereas in their children it only coughed. None now doubted its presence in their children, but a few parents whose children only coughed still disputed their clinical diagnosis. "She can't have asthma – she's a'right. She doesn't wheeze you know" asserted the mother of a girl who coughed when outside in cold, dry weather [GP97]. By contrast cough defined asthma for the teenage friend of a patient who proclaimed loudly that "Me doctor says I've an asthmatic cough, it's in me notes!", when her illness narrative was doubted by her health professional because there were no inhalers in it [GP29].

The diagnosis of cough in old asthmatics might be equally uncertain. "I didn't know whether it was his asthma or whether it was a cough" [GP79]. "It's an ordinary cough. There's definitely a different sound to an asthma cough, and it didn't sound like an asthma cough" [MI17]. These two lay diagnosticians stand at opposite ends of a spectrum from uncertainty to certainty when cough dominates asthma. Both their children are coughing and both have asthma, but only the former might have asthma now. Medical diagnosticians have to be equally discerning. A teenage boy with a persistent dry daytime cough that was unaffected by exercise and was not associated with other respiratory symptoms did not have an asthmatic cough [GP17]. Another health professional had suggested that a girl's cough was just a habit, but the girl protested strongly when her mother relayed the putative diagnosis to me, shouting out "It's not a habit! It's not a habit! I wouldn't cough in my sleep if it was a habit!" [CI2]. Her mother said she did, and I agreed silently with her daughter.

Significantly, new cough might interact with old asthma. A girl described coughing fits productive of green phlegm, that were worst during the day and causing her embarrassment during school lessons, but troubled her also at night and on exercise. She

was diagnosed with a chest infection and prescribed antibiotics that changed her phlegm from green to white but her cough in her illness narrative remained unchanged. In the health professional's disease narrative, however, it changed from an infective into an asthmatic cough to be treated not by increasing her inhalers, but with the much stronger steroid tablets (their first prescription in nearly 20 clinics) because the girl's asthma had deteriorated suddenly several times previously. Again her cough remained unchanged, and again its name changed, this time from an asthmatic cough to an irritable, habitual or psychogenic cough to be soothed with a cough medicine from the pharmacist. Asthma therapy had therefore been exclusionary, if not therapeutic, and she was discharged with good wishes for an imminent overseas holiday [GP26,a,b/C15].

By contrast, a second coughing child began with asthma. His inhalers were increased and he was referred to the practice nurse for advice about asthma management. His cough remained unchanged but as his asthma usually improves by the sea the family went to visit relatives on the coast. His cough remained unchanged so they returned home to their GP who prescribed antibiotics for a chest infection. His cough remained unchanged again in all but name until his mother took him to the local hospital where he was diagnosed with whooping cough and some of his relatives on the coast were subsequently diagnosed with the same [MI22].

Cough can therefore be problematic. It may be absent – neither GP17 not C15 coughed in the clinic – and its illness narrative might merge fact with fiction. Chang *et al* (1998) attached cough meters to children with asthma and found both children's reporting of their cough and parents' reporting of their children's cough considerably overestimated its severity as recorded by the cough meter, especially when the cough was nocturnal. Conversely 1C4 in the opening presentation has never coughed; neither did the first asthma in the medical literature in the second century AD when according to the Cappadochian physician Aretaeus

> "[t]he symptoms of its approach are a heaviness of the chest, sluggishness to one's accustomed work and to every other exertion, difficulty in breathing on a steep road ... But if the evil gradually gets worse, a wheeze during the waking state, but the evil much worse in sleep, a desire of much and cold air ... they breathe standing as if desiring to draw all the air which they can possibly inhale and also open the mouth ... During the remissions, though they may walk erect, they bear the traces of the affection" (in Sakula, 1988:36).

Cough had come into being by the time of the first specialist text on asthma at the end of the seventeenth century, but only as its third symptom: "wheeze, straitnefs of breath, a little cough and phlegm" (Floyer, 1698:8). Early last century, West (1909:592) refers to it by its potential absence: "peculiar dyspnoea [breathlessness] ... loud wheezing ... not necessarily attended with either cough or expectoration". Three decades later, Maxwell (1938:138) notes it only to dismiss it as "considerable useless cough ... wheeze is the most characteristic feature of asthma". As the century progresses Davidson (1935), Coope (1944), Benson (1958) and Smart (1964) introduce cough towards the end of asthma attacks, though as recently as 1975 it is absent from descriptions of acute asthma attacks (Brewis, 1975). Its presence is nonetheless hidden in the reference to "cough syncope" (ibid:115) as a possible cause of loss of consciousness during an attack, an outcome one would assume had lay, if not medical, significance.

Extending the search from specialist texts to published papers revealed that cough had become asthma's newest suspect three years earlier when Glauser (1972) had successfully treated with asthma therapies five adult patients with intermittent nocturnal cough, but without wheeze, breathlessness, and in one case only, mild chest tightness. Most had, however, signs of nasal and/or sinus disease. However, cough has since then played an increasing role in asthma, firstly in adults, and subsequently in children. McFadden (1975) described adult asthmatics who had paroxysms of coughing before, after, or between episodes of asthma, and attributed their cough to another manifestation of their asthma. At the end of the decade asthma was first diagnosed in adults with chronic cough as their sole symptom (Corrao *et al*, 1979). The beginning of the following decade brought the diagnosis of asthma to children with chronic cough as a sole presenting complaint (Cloutier and Loughlin, 1981; Konig, 1981; Hannaway and Hopper, 1982), and since then cough's status as a symptom has increased, particularly in children, to become childhood asthma's prime suspect. It is the first symptom listed by Rees and Kanabar (2000) and in general practice it is the most common symptom of childhood asthma (Levy and Hilton, 1999). Cough, especially nocturnal cough, distinguished the asthma of pre-school children from all other ages in a recent study of more than 12,000 patients drawn from GP practices throughout the UK (Neville *et al*, 2001). Moreover, it might be asthma's only suspect as Spelman (1991) found persistent or recurrent childhood cough without other symptoms of asthma to be highly responsive to asthma therapy. Only two out of more than 100 children were still coughing at the

end of 16 weeks of treatment. Cough was also predictive of future asthma as by two years later about 50% of children had developed other symptoms of asthma, thus rendering it also asthma's first suspect.

Cough's increased status has the potential to increase the diagnosis of asthma in at least four ways. Firstly, epidemiological studies suggest that diagnosis of asthma on the basis of cough alone has increased. In 1991, one in eight primary schoolchildren on Merseyside who reported cough as their only symptom in a respiratory questionnaire had been diagnosed with asthma; two years later the proportion diagnosed with asthma had doubled (Kelly *et al*, 1996). Cough was sufficient for asthma according to the majority of health professionals contributing to this study. Secondly, diagnostic transfer from other respiratory diseases to asthma may have occurred. Taussig *et al* (1981) suggested that many of the 2.5 million children in the United States diagnosed with chronic bronchitis on the basis of a chronic cough, could equally be diagnosed with asthma, concluding that "for many children there appears to be few ways to distinguish asthma from CB [chronic bronchitis]" (ibid:1). One health professional stated that children should not have bronchitis, and that all children who coughed, especially at night, without any other obvious cause, were asthmatic until proven otherwise. Thirdly, asthma may be an additional diagnosis to other respiratory diseases. Asthma as a potential diagnosis of a cough that persists after a respiratory infection, is increasingly reported by health professionals and in the medical literature. Both raise also the possibility that respiratory infections might in fact be asthma. Fourthly, awareness of cough as the earliest symptom of asthma has the potential to increase medical monitoring and therefore diagnostic opportunity. Spelman's (1991) study recruited children with cough alone from several different GP practices. His successful treatment of their cough with asthma therapy might have made the children's GPs more likely to instigate trials of asthma therapy in coughing children or advise them to return if their cough persisted or recurred.

Contemporary medicine suggests that up to 50% of people with chronic cough have asthma (Gibson and Saltos, 1997). Cough has become both a core symptom of asthma and the sole symptom of a new asthma – cough-variant asthma but "whereas all that wheezes probably coughs, all that coughs certainly does not wheeze" (McKenzie, 1995:175). The medical ambivalence of cough's asthmatic status was personified by one

health professional listing as asthma's symptoms, wheeze, breathlessness and chest tightness then adding "I suppose I would have to consider nocturnal cough as well". The profession appears to share her ambivalence. ISAAC, involving 156 centres in 56 countries, has in one of its questionnaires six questions on wheeze, one on asthma and one (the last) on cough, and only at night and in the absence of a respiratory infection (ISAAC, 1998, Pearce *et al*, 1998). Cough receives little attention in Kaur *et al's* (1998) publication of an ISAAC study of more than 27,000 children throughout the UK. It is absent from the abstract, from the section on prevalence of symptoms, and though geographical variations in cough are mentioned in the results section, discussion of geographical variations is confined to wheeze and doctor diagnosed asthma. It is only from an accompanying table that one learns that 29.4% of children in the study have a cough. Cough is, however, excluded from the heading of that table, which mentions only wheeze and asthma. Moreover, Denn *et al* (1995) included statistics on the prevalence of asthma and wheezing in Teesside, but not asthma and coughing. Yet, cough was twice as commonly reported as any other symptom including wheezing with a cold or on exercise.

Secondly, when asthma is diagnosed on cough alone, it is likely to be mild (Milner, 1993). Pattermore *et al* (1999) noted in a follow up to an asthma survey that children aged seven to eight years in the original survey who coughed but did not wheeze, had better respiratory health three years later than children who had wheezed but not coughed. Similarly, more than 80% of children under six years of age with a chronic cough either coughed less, or not at all, two years later (Lewis, 1994).

Thirdly, asthma is only one of many causes of cough in children, and cough is extremely common with over 30% of seven year olds reporting cough and about 15% reporting cough without wheeze (Gibson and Saltos, 1997). An excess of childhood cough has, according to Keeley and Silverman (1999), been ascribed to asthma. As evidence they cite the following. Most children who report cough as asthma's sole symptom will report wheeze also on closer questioning, or it will be audible on medical examination; young children who cough are no more likely to develop wheeze than young children who do not cough, and children without asthma may cough for weeks after respiratory infections. In contradiction to Spelman (1991), a trial of asthma therapy brought no benefit to children with cough alone. "It may be safer practice" Keeley and Silverman

(1999:626) conclude, "to dispense with the spurious diagnosis of 'cough-variant asthma'".

Finally, Chang and Asher (2001) find it necessary to remind health professionals that cough often disappears without any therapy. A successful trial of asthma therapy does not therefore imply that the cough was asthma, and guidelines recommending therapeutic trials should they suggest, include such a reminder. Knowledge, it would seem, might be forgotten, and common sense left behind, on entering the free garden.

5.2.1b Wheeze

Wheeze was audible in Aretaeus's earliest description of asthma, and its status as its most important symptom was undisputed for most of its history. In recognition of its distinctiveness Marin Marais (1656-1728) composed the *Allemande L'Asthmatique*[5] for performance on viol (Cohen, 1996). For its present day medical supporters "[t]he classical clinical feature of asthma is wheeze" (McKenzie, 1995:175), but rarely I heard it. Often health professionals and I were told that children wheezed, rattled, breathed noisily or less often whistled, squeaked, or sounded like an old man, or a named elderly relative, or simply sounded. I did not always find it easy to match the names with their noises despite health professionals mimicking them if they detected uncertainty in their patients. Cane *et al* (2000) in a study of what parents of wheezy children understand by wheeze reported that over a quarter of parents described wheeze in their children in terms of what health professionals described as difficulty in breathing or more diffusely, generally unwell. Interestingly, more parents knew their child was wheezing because of what they felt or saw in their child rather than what they heard. Cane *et al* (2000) did not attempt to distinguish between the different sounds listed above but Østergaard's (1998) conclusion that "'rattling', the sound of sputum in the airways [is] perhaps analogous to wheezing" (ibid:155) differs from my conclusion that while rattle is the sound of phlegm in the airways, wheeze is the sound of air in narrowed, but otherwise empty, airways.

Wheezing is extremely common. Wright (2001) estimates that over 50% of children have at least one attack of wheezing before three years of age. Nearly half the British children aged 12-14 years in Kaur *et al*'s (1998) ISAAC study had wheezed at some

[5] A dance with a rhythm associated with Allemaigne (French for Germany).

time in their lives, and one third had wheezed within the last year. Figures vary however as Duran-Tauleria and Rona (1999) also in a large-scale study, reported wheezing in the previous year in only one sixth of children aged 5-11 years. As wheezing decreases with age (Wright, 2001), the differences might suggest that wheeze is becoming more common as the latter collected their data in 1990-1 while the ISAAC data was collected in 1995. Duran-Tauleria and Rona (1999:479) are though, of the opinion that "differences in methodology are likely to be responsible" rather than differences in wheezing. The prevalences of both wheeze and asthma, ever-reported or symptomatic in the past year had, however, increased in the 4-11 year old children studied by Venn *et al* (1998) between 1988 and 1995.

Moreover, Chevalier Jackson had warned medicine more than a century ago that "[a]ll that wheezes is not asthma" (in Cohen, 1996:40). Several health professionals described the happy wheezer, a young child who wheezes, often noisily and persistently, but is rarely ill or disabled by the wheeze, except perhaps during a respiratory infection. 4C4 in the opening presentation might have been a happy wheezer when she was first diagnosed with asthma but unlike her, happy wheezers usually grow out of their wheeze without growing into asthma. Conversely, Pedersen (1998:860-1) disputes the entirely benign status of the happy wheeze, describing

> "an infant with persistent wheeze who even at his or her best appears to be functioning suboptimally. If well adapted, *fat* and content, the term 'happy wheezer' is sometimes applied. This group of children normally continues with persistent symptoms later in childhood... Without any treatment lung functions grow significantly less than expected during the first six years of life" (emphasis added).

However, even if wheezing in infants and young children is defined as unhealthy, it is not always defined as asthma. It is not, according to Silverman and Wilson (2000:1899), "simply asthma in small people". The medical consensus that many, though not all, small people who wheeze, stop wheezing during early childhood has persisted (Wright, 2001), yet prevailing medical opinion has reversed over the status of the small person's wheeze. In the 1970s it was not asthma, thus excluding young children from its diagnosis, but in the 1980s it became asthma, thus admitting all young children. Now opinion differs, and perhaps the best consensus is that it might be asthma. When wheeze is not asthma and not in a happy wheezer, it might be wheezy bronchitis but this diagnosis appears to have a dual medical relationship to asthma. Firstly, it may be

confined to infants and young children who wheeze (unhappily) in association with respiratory infections (Hilton, 1994). Secondly, health professionals might diagnose wheezy bronchitis in children with mild asthma (Rees and Kanabar, 2000). In the former it diagnoses a variant of asthma, possibly the disputed variant above; in the latter it is an alternative diagnosis to asthma in general.

Might the wheeze of both deafen health professionals to the wheeze of asthma? Not I think in Teesside as only one happy (and healthy) wheezer was diagnosed and wheezy bronchitis was sought only in the past medical history. In the recent past though, an oft-cited paper by Speight (1978), suggested that GPs in both Newcastle-upon-Tyne and in London were under-diagnosing asthma in children[6] they referred to hospital outpatient clinics for specialist assessment. Of the 34 children diagnosed asthmatic by the hospital specialist, only two had a GP diagnosis of asthma, and asthma was mentioned as a possibility in only another six referral letters despite many having experienced severe symptoms prior to referral. One child, according to her GP, had had "recurrent bronchitis since babyhood with attacks every six weeks" (ibid:331), and had missed six months of school in the previous year. Nearly half the children had missed more than six weeks of school in the previous year, many were restricted in their participation in sport, most had severe nocturnal symptoms, and a few had had previous hospital admissions. Speight pursued his clinical observations in a study of 179 children in North Tyneside aged seven years who had wheezed in the previous year. Only one in eight children had been diagnosed with asthma despite over 90% having consulted their GP because of chest symptoms (Speight *et al*, 1983). A follow up study one year later showed that treatment for asthma had improved the wheeze in all these children (Lee *et al*, 1983).

These conclusions are borne out by a study commendable for its openness by Levy and Bell (1984) who in a practice audit of their diagnosed asthmatic children, reported an average of 16 to 20 consultations for respiratory problems before being diagnosed with asthma. Prior to diagnosis, 75% of the children had wheezed. Nine of the 52 children had had more than 20 consultations and one child with a previous diagnosis of wheezy bronchitis had had 48 consultations and four hospital admissions. Most children had been repeatedly prescribed antibiotics and cough medicines, though nearly a fifth had

[6] Speight does not state whether all children were wheezing but it is implied by his assertion that asthma can generally be diagnosed on the basis of episodic wheezing.

also been prescribed asthma therapy. The authors comment, however, that when no diagnosis, or a diagnosis of infection or wheezy bronchitis, was recorded in the patient records, asthma therapy was unlikely to be continued as all the above were viewed as temporary problems. Thus a reluctance to name asthma, and thereby legitimize it as a disease, translated into a reluctance to treat the child's asthmatic symptoms beyond their immediate resolution.

Further evidence for the under-diagnosis of asthma comes from studies recording both the doctor diagnosis of asthma and the self-reported symptom of wheeze. These have consistently reported higher prevalences of the latter (Burr *et al*, 1989; Strachan *et al*, 1994; Rona *et al*, 1995) though whether the self-reported wheeze had ever reached the doctor is unstated. The same studies showed also that the proportion of children with wheeze diagnosed with asthma had increased when asthma and wheeze were recorded a second time 3-15 years later, though again the respective contributions of patient consultation and doctor diagnosis cannot be assessed. Further, the disability caused by wheeze to Croydon schoolchildren diagnosed with asthma had decreased between 1978 and 1991 (Anderson *et al*, 1994), while less severe wheeze was being diagnosed as asthma in Sheffield primary schoolchildren in 1999 than in 1991 (Ng Man Kwong *et al*, 2001). Nonetheless, Kaur *et al* (1998) concluded from the recent ISAAC study in which one third of children who wheezed one or more nights per week had not been diagnosed as asthmatic, that asthma is still being significantly under-diagnosed on the basis of its cardinal symptom.

Finally, Duran-Tauleria and Rona (1999) suggest that the higher prevalence of wheeze, but not of asthma among English inner-city children as compared to their peers nationally, might indicate a socioeconomic bias to under-diagnosis of asthma in poor people. Their suggestion is interesting in the light of the absence of a consistent association between prevalence of asthma and poverty in the UK in the medical literature (Rona, 2000), although a recent survey reported asthma to be more prevalent in the lower social classes (Rona *et al*, 1999). Severity has a clearer relationship to SES. Wheezing on most days was significantly more common among English inner city children than their peers nationally (Duran-Tauleria and Rona, 1999). Hospital admission rates for acute asthma at all ages have been associated with the Townsend Index (Walters *et al*, 1995) and with lower social class and unemployment (Landon,

1996). Most of those who died of asthma investigated by Innes *et al* (1998) and Mohan *et al* (1996) were experiencing socioeconomic difficulties, and most had asthma that according to medical opinion, was poorly managed.

However, even the cardinal symptom of asthma is disputed, albeit by a medical minority. "Asthma is the diagnosis for the teenage athlete with exercise-induced wheezing ... the toddler who wheezes with every upper respiratory tract infection, and the college student who returns home and wheezes around her cats. These conditions are not the same... They only share a common symptom: wheezing" (Giannini, 1996:800). Giannini is highlighting the distinction made earlier between a symptom and a diagnosis: the more wheeze becomes asthma the greater its prevalence, and the greater the diversity of symptoms accompanying wheeze, the more variable its personality. Silverman and Wilson (1997:62) ask "Asthma – time for a change of name?" and though they conclude no, they do so because all possible name changes or divisions into multiple names would be as insensible as those currently named asthma. Undaunted, Falliers (1987:71) has a stab with "variable obstructive intrabronchial disease (VOID)".

5.2.1c Dsypnoea

Dyspnoea (difficulty with breathing) caused 3C4's hospital admission. I am glad to say I cannot contribute to it, either as a patient or as a researcher, but as a former health professional I read in Salter's (1860:2) terrifying medical narrative[7] dyspnoea as I knew it then in

> "a face expressive of the intensest anxiety, unable to move, speak or even make signs, the chest distended and fixed, the head thrown back between the elevated shoulders, the muscles of respiration rigid and tightened like cords, tugging and straining for every breath that is drawn, the surface pallid or livid, cold and sweating – such are the signs by which this dreadful suffering manifests itself".

Dyspnoea was asthma in the writings of Hippocrates (c. 460-360BC), while severity was added to symptom when Celsus in the first century AD described asthma as breathlessness that was more severe than dyspnoea (breathlessness unspecified) and less severe than orthopnoea (breathlessness on lying down) (Ellul-Micallef, 1976). Dyspnoea may not, however, translate easily into breathing difficulties, it being "difficult to know

[7] Salter was asthmatic and one of his case-studies is believed by Sakula (1985) to be himself. As his text is, however, ostensibly about asthma in his patients, his contribution was excluded from 'Asthma in the Family'.

what is meant by parental reporting of shortness of breath in a child as this is a subjective symptom" of asthma (McKenzie, 1995:179). The relationship between breathing difficulties and asthma might be even harder to ascertain when it is its only symptom as it was of 1C4's asthma, especially as Homer reminds us that Aeneas was the first to breathe asthmatically after strenuous exercise. As Aeneas was healthy his breathing difficulties were healthy then. All in the free garden – health professionals, families with asthma, and the researcher – acknowledged that breathing difficulties could be healthy now, or if not, because we are less accustomed than Aeneas to strenuous exercise.

5.2.1d Colour changes

Cyanosis (blueness) is a medical hallmark of severe asthma, but it is indicative of insufficient oxygen in the blood and it is not specific to asthma (Lumley and Bouloux, 1994). Also, as it is all too literally asthma's last gasp, health professionals would prefer it not to contribute to their diagnosis of asthma. Of asthma's other colour changes, being pale or pasty (whiteness) might be a totally non-specific sign of being ill, while a high colour (redness) might be produced also by a cough that is non-specific, and by fever that signifies a precipitating infection, though in 4C4 it signified her asthma. The final colour change of shadowing under the eyes (baggy-eyed) is a better clue to asthma as its medical equivalent – allergic shiners (Schramm, 1997) – is evidence of allergy or atopy[8]. They are, however, insensitive of asthma as few children had them.

5.2.1e Chest tightness

Being insensible to medicine, it was listened to in illness narratives (p.82).

5.2.1f Rest of asthma

Unlike their patients (p.83-5), health professionals, according to Beer *et al* (1987), only rarely read the rest of asthma, though when they do they read it in abundance. At a conference a paediatrician produced a list of non-respiratory symptoms of which itchy chin that M21 (p.84) has recognized already was the most specific to asthma. Combining Levy and Hilton (1999) and Pederson (1998) generates palpitations, sweating, dizziness, dry mouth, thirst, tiredness, sleepiness, depression, anxiety,

[8] Atopy is a form of allergy associated with raised levels of Immunoglobulin E (IgE) and a tendency to develop hypersensitivity reactions.

irritation, muscular aches, increased urinary frequency, fever, itching, skin rashes, loss of appetite and abdominal pain. Notably, such non-respiratory symptoms made a much greater contribution to asthma's historical medical narrative. Floyer (1698) described a fullness about the pit of the stomach accompanied by wind and flatulence, headache, sleepiness, retching and yawning and the voiding of large quantities of pale urine before the emergence of respiratory symptoms. In fact, so symptomatic was the stomach that Gabbay (1982) suggests that the abdomen rather than the chest was the main locus of asthma until the eighteenth century.

Contemporary medicine usually confines asthma's symptoms to the chest, but it does not as the above has shown, confine them to asthma. Certainly, the more symptoms or personality traits of asthma, the more likely it is that the unhealth is asthma. Thus asthma has symptomatically a core personality, but many illness narratives leave its surfaces ill-defined. Illness narratives might, however, give health professionals other clues to the disease in their patients as they speak also of the cause of the disease that is Helman's (2001) first contributor to its personality. The previous chapter wrote asthma's causes as agents; this chapter rewrites them as stimuli.

5.2.2 Stimuli

Lists of agents and stimuli were similar, thereby providing medical reinforcement of the potential interactions of asthma with SES (p.104). By contrast, differences in their classifications have the potential to effect a separation between asthma's illness and disease personalities. Rees and Kanabar (2000) separate crying and laughing from other emotional stimulants or agents because it is dry air not the accompanying emotion that triggers asthma. Crying or laughing increases the quantity of air inhaled, especially through the mouth, thus bypassing the humidifying, and also warming of air that occurs during nose breathing. Thus it is the performance of emotion rather than the feeling of it that stimulates asthma, and laughing, crying, exercise and cold weather form a family group founded upon the stimulus of dry air. A second classification incorporates successively inducers, enhancers and triggers into a three stage vertical hierarchy (Platts-Mills *et al*, 1997). Inducers, also called allergens, include house dust mite, moulds, pollen and animal dander, all of which stimulate asthma. Enhancers assist inducers in the stimulation of asthma, but are incapable of acting alone and are not classified as

allergic in nature. Respiratory viruses and air pollutants – industrial emissions, vehicle fumes and tobacco smoke – are asthma's most common enhancers. Both inducers and enhancers stimulate asthma by creating airway inflammation, thereby thickening its wall and narrowing its lumen. Triggers, particularly cold air and exercise, are the final stimulants of asthma. Like enhancers they cannot act on their own, but unlike them they stimulate asthma by causing contraction of the muscle encircling the airway wall, thereby narrowing it to the point of symptoms.

Platts-Mills *et al*'s (1997) classification of asthma's stimulants has controversial implications for its disease personality. It implies all asthma is allergic as inducers are allergens, and without their involvement enhancers and triggers cannot stimulate asthma. Allergy's universal contribution to asthma's personality is, however, disputed by Silverman (1995:1), who claims that

> "[t]he term asthma ... has been all but usurped by allergists and clinical immunologists to imply variable or reversible airway obstruction on a basis of allergic (Ig-E mediated) inflammation ...There have been attempts to squeeze all of asthma[9] (or physician-diagnosed asthma, a *vague and confusing* term) ... into this Ig-E mold ... It ignores population-based data which suggests that in the community there is a huge and *dimly recognized* group of people with perhaps only occasional wheezing with colds... [They are] the remnants of the 'Big Bang' – that enormous explosion of non-atopic airway disease of infancy and childhood" (emphases added).

As Silverman and Wilson (2000) later query the asthmatic status of wheezing in infants and young children, the wheezing remnants might not have asthma. In general, perhaps it is safe only to conclude that asthma is more likely, and more likely to be severe, when stimuli are multiple, and some at least, are allergic.

The involvement of atopy in asthma creates relationships between it and other atopic diseases such as rhinitis, eczema and food allergy. It is also of great significance to the development of its personality, for as atopy has a genetic[10] component the family might have a history of asthma.

[9] Asthma from middle childhood onwards.

[10] The genetics of asthma are excluded as they are far removed from the clinics and beyond the scope of the dissertation and its author.

5.2.3 Family History

The medical literature supports an asthma diagnosis of respiratory symptoms if there is a family history of asthma or other atopic diseases, though Christie *et al* (1998) suggest that another reason for asthma's increasing prevalence is its increasing diagnosis in children without family histories of asthma or atopy. Nevertheless, one health professional cited family history before symptoms when asked what would make her suspect asthma in a patient, and in the opening presentation 2C4 and 4C4 were diagnosed with asthma at their first presentation of respiratory symptoms to the health professional: 4C4 was not even the patient. Their sister 3C4 had already been diagnosed with asthma but she had not been diagnosed at her first presentation despite having symptoms that were more severe, perhaps because her asthmatic sister 1C4 was adopted. The medical significance of family history is borne out also from the community study by a family whose son, his father and more distant relatives had all been diagnosed with asthma. The family, however, disputed the diagnosis of asthma in their son, attributing it to the diagnosis of asthma some years before in his father whose diagnosis they disputed also, as his symptoms had not returned after he had finished his asthma therapy. His diagnosis they attributed in turn to the diagnosis of asthma in the more distant relatives, whose diagnoses they did not dispute. A paediatrician to whom they had been referred at their insistence had reinforced their scepticism by attributing their son's symptoms to enlarged tonsils and adenoids and he was awaiting their removal. Hence, their son's asthma was to this family historical, rather than medical, in that it had been constructed out of a positive family history.

5.2.4 Signs

Thus far, asthma has been spoken; now it is observed as the health professional seeks its signs in the body in the clinic. Hunter (1991:12) metaphorizes "the patient as text and the physician as a well educated, attentive close reader of that text". The signs that the physician reads originated as "what can be perceived by sight, touch, hearing, smell, taste" (abridgement of a text by the Greek physician Galen quoted by Nutton, 1993:10). Medicine observes with all its five senses, but signs and gaze speak of seeing, justifiably so, as sight was the dominant sense of classical medicine (Nutton, 1993) and remains so

in modern medicine (Foucault, 1963). Signs are medically significant because they signal the entry of the doctor into the diagnostic process as an entity independent of the patient's story – the detective becomes the scene of crime officer. Medical eyes see for the first time, and medicine sees its eye as objective as "[t]he observing gaze [that] refrains from intervening: it is silent and gestureless. Observation leaves things as they are" (Foucault, 1963:107).

It is pathognomonic of some social scientific literature on medicine that history has become dominated by observation, and in consequence the patient has become dominated by the profession (Armstrong, 1983; Foucault, 1963). The observing role of medicine has definitely increased. William Cullen, the most celebrated physician of late eighteenth century England diagnosed by post as well as in the presence of the patient (Porter, 1993), and physical examination of the patient became accepted practice only in the nineteenth century. In 1881 Arthur Conan Doyle the medical creator of Sherlock Holmes, berated "a frightful horror" of a patient. "She won't let me examine her chest. 'Young doctors take, such liberties, you know my dear'" (in Porter, 1997:676). Domination of observing over listening is however, challenged by Hunter (1991:60) who suggests that "something so subjective and potentially unreliable as the patient's account of illness is so powerful [that it] can be, for the good physician a perpetual source of uneasiness". Although "the physician's high regard for history coexists with a strong skepticism", the good health professional recognizes the impossibility of going behind the history to "bare uninterpreted 'facts'" (ibid:60). Further, her assertion that "[p]hysicians do not really know – and *know* they don't know with any reliability – until the patient's history is confirmed" (ibid:60), echoes Foucault's (1963) assertion that symptoms are closer to the disease than signs.

On the other hand, as observation begins as soon as the patient enters the gaze of the health professional (or researcher), signs may precede symptoms. Rarely did they do so in my presence as I cannot remember a child entering a clinic wheezing or breathless, and although some coughed while in the clinic, so occasionally did their families, the health professional and the researcher. More often I observed noisy breathing, and breathing through the mouth rather than nose that is a sign of rhinitis. Never did I observe the dyspnoea and cyanosis seen by a health professional in her waiting room.

Ideally "[f]or your diagnosis and the indications you observe, you should always choose things that are extremely powerful and easy to recognise" (Galen in Nutton, 1993). How ideal are asthma's signs? Not ideal in the sense that cough and wheeze are predominantly auditory not visual. Asthma's cough has, however, according to Gibson and Saltos (1997:1457), a characteristic sound that enables it to be distinguished from "the barking cough" of viral laryngotracheobronchitis (croup) and "the goose-like honk" of a psychogenic cough. Asthma's wheeze can also be heard, and is characteristically worse on expiration (breathing out), but the resultant air trapping in the lungs that expands them, thereby depressing the diaphragm is invisible. Since Laennec invented the stethoscope[11] nearly two centuries ago the expiratory wheeze can be listened to inside the chest and renamed rhonchi. One health professional hears rhonchi twice as often as she hears wheeze. Characteristically, rhonchi in asthma are distributed throughout the lungs rather than located in one place, and, according to Barnes and Godfrey (2000), may be accompanied by crackles or crepitations especially in young children. For Milner (1993), crackles alone distinguish children who are chesty from children who are asthmatic.

Dyspnoea, interruption of speech and cyanosis signify severe asthma. Dyspnoea can be described quantitatively as respiratory rate and qualitatively by naming the extra muscles recruited to the work of breathing; interruption of speech can be measured as a sentence, a phrase or a word between breaths, while cyanosis can be converted into, and quantified as, arterial blood oxygen saturation. None of these signs are, however, specific to asthma, and as asthma is typically intermittent, there may be no signs of asthma during the medical consultation. The most specific and permanent sign of childhood asthma is a characteristic chest deformity called metaphorically a pigeon chest, but it develops only in the most severe and persistent of asthmas (Rees and Kanabar, 2000), and is therefore insensitive to its presence. In the absence of direct evidence of asthma the patient might have to be searched for clues, and the medical detective is encouraged by Schramm (1997:1424) to seek circumstantial evidence of

[11] Despite the protestations of Conan Doyle's patient, the stethoscope had several decades earlier assisted diagnostic parity for women as it enabled the male doctor to listen into the female chest without applying his ear to it.

> "mouth breathing with dry or chapped lips; conjunctival injection [inflammation]; puffiness or bluish discolouration of the lower eyelids (allergic-shiners), additional furrows of the lower lid ... a transverse crease over its [the nose] lower external portion, caused by frequent pushing up on the tip of the nose to relieve nasal irritation the 'allergic salute'" (sic).

It is of note that Schramm's medical detective relies on his naked eye. By contrast Laennec's stethoscope signalled the entry of technology that transports the health professional into disease's hidden domain. The role of technology becomes increasingly significant, however, in the next stage of the clinical method in which the observing gaze intervenes, and thereby transforms its observations into investigations.

5.2.5 Investigations

Investigative tests aid the observing gaze by recreating for medicine that which is invisible, or more generally insensible in the patient, as images, graphs, numbers and pathological specimens. Technology deepens observation but its increased penetrance was brought about by ideological as well as instrumental means. The clinical gaze deepened in the dead with the legitimization of post-mortems (Foucault, 1963); technology permits medicine gaze into the living. Technology is ideologically significant also because it separates the unhealth, or a representation of it, from the patient, thus giving it to medicine for posterity. Though medicine could record asthma's wheeze or rhonchi as a contemporary to Marin's *Allemande L'Asthmatique*, its records of asthma are predominantly visual. Radiographs image asthma as airway thickening and air trapping though their reading is subjective: when reading the report, one health professional always reads also the name of the reporting radiologist as in her opinion, one sees more asthma in radiographs than his colleagues. Phlegm coughed up from the airway may be visualized under the microscope. The bronchoscope invented more than one hundred years ago by the same Chevalier Jackson[12] who warned that all wheeze is not asthma, permits the health professional to see inside the airway and biopsy it for microscopic inspection, or to wash out the contents of its lumen. Thus the bronchoscope achieves visually what the stethoscope achieves audibly.

[12] http://jeffline.tju.edu/SML/archives/exhibits/notable_alumni/chevalier_jackson.html.

Biopsies like radiographs separate the unhealth from the patient but this separation is of greater significance because what has been appropriated by medicine is not a representation of the disease, but part of the disease itself. Microscopy and bronchoscopy are, however, usually research rather than diagnostic tools that belong to the laboratory rather than to the clinic. Moreover, asthma's investigations are more commonly exclusive of, rather than diagnostic of, asthma in that they identify other pathologies, usually infective.

5.2.6 Pathology

What pathology would the medical eye see in the lungs, the airways, most specifically the terminal bronchioles, and what does medicine say? Inflammation, according to a recent introductory text.

> "The inflammation in the airway wall involves oedema [swelling], infiltration with a variety of cells [belonging to the immune system] ... particularly neutrophils and eosinophils, but also lymphocytes and a few mast cells ... disruption and detachment of the epithelial [surface] layer, and mucus gland hypertrophy [enlargement]. Changes occur in the subepithelial layer with the laying down of ... collagen [a fibrous substance] and ... proteins ... This remodelling of the airway wall in response to persistent inflammation can resolve but may result in permanent fibrotic damage [scarring] thought to be related to the irreversible airflow obstruction that may develop in poorly controlled asthma ... In severe asthma, there is mucus plugging within the lumen and loss of parts of the surface epithelium" (Rees and Kanabar, 2000:2-3)

Airway inflammation in asthma is according to Woolcock and Barnes (1997), better known to medicine than all other aspects of the disease of asthma. Inflammation thickens the airway wall and irritates its muscle causing it to contract. Its relationship to asthma in the patient is, however, less well known as "there may well be other ways in which the symptoms of asthma can be produced" (Woolcock and Barnes, 1997:3) and "[w]e do not understand how inflammation leads to the symptoms of asthma" (ibid:4). Thus seeing and saying are no longer one. Also, and especially before the 1990s, medicine speaks of thickened contracted muscle encircling and constricting the airway, but inflammation although spoken about in asthma since the early twentieth century (Brocklehurst, 1976), now dominates the airway muscle and the medical eye (Woolcock and Barnes, 1997).

In contemporary medicine the gaze goes ever deeper in its search for the inflammatory entities of asthma such as " IL-4, IL-5 and GM-CSF" (Kay, 1997:60). Its increasing penetration is highly significant to its patients, and even to its practitioners. While interleukin (IL) might be familiar to most health professionals and to a few of their patients, as granulocyte macrophage-colony stimulating factor (GM-CSF) belongs to a deeper gaze, it might be invisible, even to the medical majority. As the gaze goes deeper, the saying of what is seen requires the construction of a new language to express the till then unknown and therefore unnamed. Medicine, according to Falliers (1988:317),

> "now know[s] about immunoglobulins and their fractions and subfractions, about lymphocytes, eosinophils, and mast cells and their functions and malfunctions, about arachidonic acid, prostaglandins, leukotrienes, PAFs, and...gaffes".

The increasing depth of its gaze has consequences also for its patients, as the medical language of disease becomes increasingly divorced from the lay language of illness. Returning to Hunter's (1991) metaphor of the patient as text, medicine is increasingly engaged in the creation of a foreign language in which to rewrite the patient's illness. The deepening of the clinical gaze in both its technological and linguistic dimensions magnifies the role of investigation in what is observed and how it is narrated. The part played by the symptoms and signs in creating Foucault's (1963) totality of the visible and over-all structure of the expressible is correspondingly reduced. Thus Marinker (1975:2) following Foucault (1963:14) has termed the original storyteller "the accident of the disease" in order to emphasise the significance of the patient's pathology to medicine. The deeper medicine seeks its pathology, the more accidental its patients.

Occasionally, however, asthma might appear accidental in comparison with other pathology. Frequent and severe respiratory infections were the principal cause of the disease in a few children because of deficiencies in their immune system, or because they had been born prematurely and suffered permanent damage to their respiratory system, or most often for reasons that were unknown. They were being treated also with asthma therapy but whether or not they had asthma was less certain. Asthma might be contributing to their symptoms or it might be that their infective pathology was triggering the processes that characterize asthma.

Asthma's peculiarities were even more blurred when its symptoms were attributed primarily to a pathology beyond the respiratory system altogether. A boy had bronchiolitis (a viral respiratory infection) as a baby and wheezed intermittently thereafter. He was diagnosed with asthma at 18 months, but as his wheeze had disappeared by the time he was three years old, therapy was stopped. About five years later his wheeze returned this time accompanied by chest tightness and by coughing fits culminating in vomiting, and he was re-diagnosed with asthma. However, increasing dosages of asthma therapy brought no relief. Eventually his mother insisted upon a hospital referral because "my GP couldn't see beyond asthma". At the hospital clinic his chest tightness was translated back into chest pain and refined into the burning pain of reflux of gastric acid into the oesophagus. His symptoms were attributed to gastric acid reaching and irritating his airways, a diagnosis of gastro-oesophageal reflux was made and he was commenced on antacids. His diagnosis of asthma was, however, retained and his inhalers continued in case the gastric acid had caused his asthmatic symptoms [HR26]. Whether or not children such as him have asthma depends on the extent to which asthma is perceived as an entity in itself. If they have asthma, then it is more as a symptomatic process in that they are being treated for asthma because their airways are, or might be, behaving as asthmatic airways behave.

5.2.7 Pathophysiology

Abnormalities in the behaviour of asthmatic airways – their pathophysiology – is investigated by lung function tests (LFTs). The simplest records the peak expiratory flow rate (PEFR) – the maximum speed of airflow when the patient breathes out as rapidly as possible. Its recording device can be used at home where it was used most often to detect asthma's nocturnal presence when PEFRs are typically lower in the morning than in the evening. A few mothers attributed the reduction on weekdays to lack of effort by their sleepy children, rushing or being rushed, to get ready for school.

More detailed LFTs, called spirometry, requiring more specialist equipment, are usually available only in hospitals or laboratories. The key spirometric investigation in asthma records the forced expiratory volume in one second (FEV_1) – the volume of air that the patient breathes out in the first second of a maximum breath out. The maximum breath

out, the forced vital capacity (FVC) can also be visualized graphically, and in asthma its slope is characteristically concave, especially in its mid portion. 'Ski-slope' – more accurately ski jump slope – was how it was depicted by one health professional. If asthma is absent during spirometry, it may be provoked in the presence of resuscitation equipment, by running patients on a treadmill if they complain of symptoms on exercise. Alternatively substances (formerly histamine, now methacholine, but increasingly 5-adenosine monophosphate) that are irritant to the asthmatic airway might be inhaled (Godfrey, 2000). Reductions in LFTs are interpreted as revealing the presence of airway hyperresponsiveness (AHR) – a narrowing in response to stimuli that would not cause normal airways to narrow, and that can be reversed by asthma therapy.

AHR is promoted by the medical majority as a key contributor to asthma's personality but its status is limited by the following. Most children under about six years of age have insufficient co-ordination or comprehension to perform LFTs, but 80-90% of childhood asthma is according to Weiss (2001), diagnosed by six years of age. Further, as technique might improve with experience as well as with age, AHR might appear to decline with asthma therapy. Secondly, AHR might be short lived and detectable only when the child has symptoms, thus it might exclude asthma in the presence of asthmatic symptoms, but not in their absence (Cockcroft, 1997). Thirdly, AHR is reversed by therapy that reverses the muscle contraction of asthma not the inflammation that is perceived by medicine as the core contributor to its pathological personality. Fourthly, according to Platts-Mills *et al*'s (1997) classification, such therapy should be less effective when asthma is stimulated by inducers or enhancers that cause airway inflammation but not muscle contraction. Hence asthma's pathology as emphasised by medicine and its pathophysiology as demonstrated by medicine are different facets of its personality. Fifthly, the general consensus in the literature appears to be that AHR is not present in all children with the clinical picture of asthma. Moreover, it occurs in other respiratory diseases and in people without any respiratory disease. Its medical advocates attribute this limitation to medicine: "[g]iven that we define asthma as an unusual degree of reversible airways obstruction, then asthmatics must have, by definition, bronchial hyperreactivity [AHR] " (Godfrey, 2000:387). Godfrey (ibid) cites a lack of sensitivity of the precipitating substances as being responsible for the false negatives, and claims that 5-adenosine monophosphate will prove to have a higher specificity for asthma than its predecessors; thus chemical refinements will refine the detection of

asthma. By contrast Cockcroft (1997) suggests that chemicals are usurping clinicians in the attribution of asthma in that what was a clinical diagnosis is becoming increasingly a laboratory investigation.

Finally a hyper-responsive airway must be distinguished from a normally responsive airway. Normal enters into disease definitions (Marinker, 1975; Helman, 2001), and in AHR normal and abnormal are constructed out of numbers, "[b]ecause the distribution of airway responsiveness in a random population is continuous" (Cockcroft, 1997:1254). Medicine though, does not appear to agree on where "normal physiological measurements" (Helman, 2001:80) end and the "deviation from a biological norm" (Marinker, 1975:82) begins. Levy and Hilton (1999) and Godfrey and Barnes (1997) give slightly different procedures, equations and normal values for PEFRs, while according to one health professional, computerized programmes may offer a choice of several different methods for assessing spirometric measurements, all giving slightly different results. When asked how she had chosen her programme and method she replied that she had consulted a colleague. Godfrey (2000) blames medicine for making arbitrary distinctions between normal and abnormal rather than applying statistical techniques, but for Cockcroft (ibid:1254) "unfortunately the definition of what is normal or abnormal is arbitrary". Moreover, numbers have in themselves an ambivalent status in the diagnosis of disease because "no measurable mechanics of the body can, in its physical or mathematical particularities, account for a pathological phenomenon" (Foucault, 1963:13). The distinction between health and disease becomes a matter of degree – of quantity – rather than of kind – of quality – imparting to numbers the power to threaten the discreteness of disease and to blur its boundaries. Also, they represent disease rather than reveal it: a percentage reduction in a measurement is somehow less real than a narrowed airway or inflammatory cell. Perhaps it is this illusory quality of numbers that led Gross (1980:203) to his conclusion that "however much variable airways resistance as a start satisfies some of us, there are a large number and variety of phenomena which others feel should be the *peculiarity* 'asthma' should signify" (emphasis added).

5.2.8 Asthma in Clinical Context

What is the peculiarity (Gross, 1980) or personality (Helman, 2001) of asthma? Or simply, "[w]hat is asthma?" (Woolcock and Barnes, 1997:3) – my research question. I do not think the clinical method has answered these questions beyond reasonable doubt. It has given you clues in symptoms, stimuli, family histories, signs, investigations, pathologies and pathophysiologies, but no diagnostic test or pathognomonic personality. The words of the authoritative sounding collaboration between the British Thoracic Society and The Scottish Intercollegiate Guidelines Network (BTS/SIGN) in their diagnostic flow chart for childhood asthma summarize perfectly its clinical uncertainties. Medical history and physical examination permit a diagnosis of: 'probably asthma' or 'possibly asthma' but not definitely asthma. Further investigation and a trial of asthma therapy convert 'possibly asthma' into either 'asthma likely' or 'asthma unlikely'. Moreover, a poor response to asthma therapy returns 'probable asthma' or 'asthma likely' to 'Is it asthma?'. If stuck, the diagnostician (detective) is directed to a table of "Clues to alternative diagnoses in wheezy children" (2003:S7), but not coughing children.

In summary, asthma in the clinic has core personality traits, but as a disease entity its personality as evidenced by the clinical method is diffuse and/or multiple, and its edges are blurred. It "represents one end of a continuous spectrum rather than a specific defect" (Milner, 1993:1) and/or is not "a single disorder in children, but a number of 'asthmas'" (Silverman, 1995:1). At worst the pursuit of asthma in the clinic epitomizes the chase after Eisenberg's (1977:21) "'will o' the wisp'" of disease that reminded him of "a remark attributed to Gertrude Stein. Commenting on a nondescript American town, she said, 'When you get there, you discover there's no there there!'". Some asthma is therefore difficult to know in patients in the clinic. The next section asks whether its disease is any easier to know when the free garden is relocated from the clinic to medical discourse.

5.3 DISCOURSES ON ASTHMA

Asthma in this section is read not from the patient as text, but from medicine as text, and specifically from its representations in conventional forms of disease discourse, beginning with its definitions.

5.3.1 Definitions

Medicine has been defining asthma since the late 1950s (Burney, 1997) with the aim being to devise clear measures by which to determine whether or not a patient has asthma (Scadding, 1963). Asthma's representations in medicine[13] begin therefore with an interpretation of selected definitions in medical texts on the assumption that their words are most likely to state the essence of the disease. The first, widely quoted as the international gold standard, defines asthma as

> "a chronic inflammatory disorder of the airway in which many cells play a role, in particular mast cells, eosinophils, and T-lymphocytes. In susceptible individuals this inflammation causes recurrent episodes of wheezing, breathlessness, chest tightness and cough particularly at night and or early in the morning. These symptoms are usually associated with widespread but variable airflow limitation that is at least partially reversible either spontaneously or with treatment. The inflammation also causes an associated increase in airway responsiveness to a variety of stimuli" (*International Consensus Report on the Diagnosis and Management of Asthma*, in Rees and Kanabar, 2000:1).

The definition opens with the pathology of asthma, but pathology that is invisible to the health professional in the clinic. Its second part links pathology to symptoms, but only susceptible individuals become ill. The third part is notable for its imprecision – usually, variable, at least partially. Airway responsiveness appears only in the last part of the definition, and the stimuli that trigger it are left unspecified. It portrays asthma as a composite of different parts – pathology, symptoms, pathophysiology and stimuli – that may or may not be present in individual asthmatics, and if present, may interact differently. It is also, according to Woolcock (1997a:27), "especially cumbersome".

[13] Representations are of asthma in general rather than of childhood asthma in particular, but the principles are applicable to asthma in general.

A second definition from an international paediatric asthma consensus group, describes asthma as "a condition in which episodic wheeze and/or cough occurred in a clinical setting where asthma was likely and other, rarer conditions had been excluded" (Warner, 1992:240). This definition, perhaps because it is child orientated, includes only symptoms, suggesting that children are less accidental to the disease than adults. The symptoms have to fit the clinical picture of asthma, but as none are specific for asthma, other diseases that they might also fit, have to be excluded. Importantly, as likely is a relative rather than absolute term, the implication is that medicine is unable to definitively diagnose asthma or definitely, and equally importantly, to exclude it.

Thirdly, Milner (1993:1) decides "[f]or the *purposes of this book* the diagnosis of asthma will be used for all children ... who have symptoms secondary to bronchoconstriction [airway narrowing], which either in the short term or the long term, respond to anti-asthma therapy" (emphasis added). The diagnostic role of therapy has been alluded to several times already, and it renders medicine's diagnosis both retrospective – asthma is not definitely there until it is less there than it was – and tautological – asthma is that which is treated by therapies devised to treat asthma.

Finally, Woolcock (1997a) distinguishes between formal, practical and satisfactory definitons of asthma. The "fundamental abnormalities in asthma remain unknown so no formal definition is possible" (1997a:27). Her practical definition is based on asthma's clinical picture of wheeze, chest tightness and breathlessness (but not cough), while her "satisfactory definition is a 'state of the airways that causes them to narrow excessively in response to provoking stimuli that normally have no such effect" (ibid:31). By her last minimalist definition, asthma is hyperactive but otherwise devoid of personality.

Definitions should, according to McConnell and Holgate (2000), be useful. The usefulness of the above would appear to be limited by precisely the same limitations of asthma that emerged from its search via the clinical method. That which it diagnoses as asthma in the patient and it incorporates into asthma in the literature appears too variable to be united under one definition. Medicine, Howell (2000) suggests, has a choice between two definitional routes for the disease of asthma: nominalist and

essentialist[14]. In the former, disease is "the name that we have chosen to give to that collection of features which we identify as being common to a number of individuals and which warrants being encompassed by a name" (ibid:3). By contrast the essentialist approach believes that "if asthma is studied to the limits of full understanding it will be shown to be the results of ... the essences of asthma ... that are its essential nature" (ibid:3). Either medicine tells asthma what it is, or asthma tells medicine what it is.

McConnell and Holgate (2000:2) also adopt the essentialist approach though they reduce the essences to "the defining characteristic ... the common characteristic that exists in all individuals with a disease". Asthma must have this defining characteristic, but in the individual it has also "the other abnormalities that may be present" (ibid:2). They echo Foucault (1963) who distinguishes between the symptoms that are consequent upon the disease, and those that reflect the constitution of the body in which it resides. Medicine must abstract the pathology from the patient such that "in relation to what he is suffering from, the patient is only an external fact; the medical reading must take him into account only to put him in parenthesis" (Foucault, 1963:14). Thus patients and populations might differ in their expression of their asthma. Further, asthma is likely to change because "[a]s our level of understanding of the disease process deepens ... patients that fell within the definition at any one time may, advertently or inadvertently, fall outside it in due course" (McConnell & Holgate, 2000:2). Thus accidental patients and their peers in equally accidental populations, might fall in and out of asthma, especially as a medical conclusion to 'what is asthma?' is that "[i]n spite of the immense amount of material presented here [2182 pages of text], we do not know the answer to this question" (Woolcock and Barnes, 1997:3). The practical consequences of such difficulties were illustrated during a conference discussion between two specialist respiratory physicians. One expressed concern that many children with severe asthma were not being referred to him. The other expressed frustration that as many children with severe asthma referred to him did not have asthma at all, he spent much of his time "undiagnosing their [GPs] asthma".

However, although asthma lacks a definitive medical personality, it has many medical classifications that might be revealing of definitive personality types.

[14] Essentialism is a metaphysical theory (Loux, 1999) and Howell's usage of it shows greater affinity to scientific realism (Trout, 1999).

5.3.2 Classifications

"To classify is human" assert Bowker and Star (1999:1), and according to Lévi-Strauss [1962] (1966), the construction of classificatory systems imparts a fundamental ordering of relationships between humans and their world. Previously I classified the illness of asthma as a cast of characters (p.96); here the disease of asthma is classified by several of its medical authors. Superficially, the simplest classification is Milner's (1993) division into intermittent asthma associated with viral respiratory infections – possibly Silverman's (1995) huge and dimly recognized group – and chronic asthma associated with everything else. His classification is though, derived from an earlier description of four groups of asthmatic children distinguished according to the severity and frequency of attacks, and the frequency and duration of intervening symptoms. The criteria do not, however, include their stimuli despite one stimulus – viral infections – being the sole determinant of his binary division. Milner's classification breaks Bowker and Star's (1999:10) first rule that there are "*consistent, unique classificatory principles in operation*".

A more complex approach adopted by Phelan *et al* (1995) classifies separately on the basis of acute attacks and chronic long-term patterning. Symptoms and signs distinguish between mild, moderate and severe acute episodes. Frequency and duration of acute episodes, and the absence or presence of symptoms between acute episodes (other than induced by exercise) classify asthma according to its long term pattern into infrequent episodic asthma, frequent episodic asthma and persistent asthma. However, brittle asthma, characterized by sudden life-threatening attacks that may require ventilation is acutely severe, but its long term pattern is usually infrequent episodic. Hence its status differs according to its classificatory criteria. In order to satisfy a second rule of classification that the "*system is complete*" (Bowker and Starr, 1999:10) Phelan *et al* (1995:311) complete their classification with three "unusual pattern[s] of asthma", none of which are classifiable according to either their acute or chronic criteria. Cough-variant asthma and wheeze in the first year of life without respiratory difficulties apart from during respiratory infections (possibly happy wheezers and/or infant wheezers) are

probably not asthma at all, while hypersecretory asthma is another variant affecting mainly young children in which airways produce large amounts of mucus.

A third scheme uses both intensity of acute episodes and persistence of asthmatic symptoms to combine asthma into mild intermittent, moderate perennial and severe perennial (Godfrey and Barnes, 1997). Their classification views the acute and chronic dimensions of asthma as increasing in parallel, but "[i]n addition to the three groups described above, there are three special subgroups of asthma" (ibid:20): seasonal asthma, exercise-induced asthma and sudden life-threatening asthma. The last is the brittle asthma of Phelan *et al* (1995) and is distinguished by its symptom pattern. The other two groups are distinguished by their stimuli. Seasonal asthma includes asthma associated with respiratory infections, but also that associated with changes in weather conditions, though seasonal appearance of pollen is not mentioned. Exercise-induced asthma is confined to those patients whose asthma is largely confined to exercise, although almost all asthmatics will develop symptoms of asthma if they exercise hard enough, thus jeopardizing Bowker and Star's third rule that the "*categories are mutually exclusive*" (1999:11).

An even more complex classification devised for the management of childhood asthma in general practice appears even further removed from these golden rules that "[i]n an abstract, ideal sense" should guide classification (ibid:10) . It describes persistent cough, wheezy bronchitis, mild episodic asthma, continuous asthma, continuous symptoms and frequent exacerbations, chronic severe asthma and acute severe asthma (Hilton, 1994). This scheme distinguishes the cough-variant asthma discussed above, while the wheezy bronchitis is of the type accompanying respiratory infections in young children. The continuous symptoms and frequent exacerbations are also confined to young children, who generally improve, presumably into either mild episodic asthma or continuous asthma. Mild episodic asthma is principally associated with exposure to allergens such as pollen, but frequently it has non-allergic stimuli as well, especially respiratory infections and emotions. Continuous asthma has symptoms that are more frequent and persistent than episodic, and though severe enough to limit activities, are not sufficiently severe to be classed as chronic severe asthma. Chronic severe asthma is described only in its need for specialist medical care, while acute severe asthma is more frequent "in more severely affected children, but may occur at any time in any child" (ibid:51).

The most useful (McConnell and Holgate, 2000) classification I encountered was that proposed by Woolcock (1997a). She distinguishes six categories: obstructed asthma, persistent asthma, episodic asthma, asthma in remission, potential asthma and trivial wheeze. AHR – the sole criterion of her satisfactory definition of asthma (ibid:31) – is raised in both obstructed asthma and persistent asthma. The former is the most severe in that LFTs are irreversibly reduced below 80% predicted value, whereas in persistent asthma, though they may be reduced, they are always above 80% predicted value. Episodic asthma has less frequent symptoms than persistent asthma, and LFTs and AHR are always normal between episodes. Asthma in remission has not been present for more than 12 months while those with potential asthma have never had symptoms, but because they have increased AHR they are at increased risk of developing asthma in the future. Hence, they are not normal. They are perhaps less normal, or potentially so, than episodic asthmatics with their normal AHR apart from when asthmatic, and the even more normal trivial wheezers who have a normal AHR, and symptoms that are always mild and never require medication. The latter might be happy wheezers though as Woolcock's classification does not appear to confine them to infants, they might also be Silverman's dimly recognized group.

Classifications aim to order, but with the possible exception of Woolcock, the above disorder asthma. They classify it so differently that speaking metaphorically they risk siting medicine's classification of asthma within the Tower of Babel at best, and at worst, on a battle ground worthy of that from which Aeneas emerged. Why might classifications of the disease of asthma counter attack their practitioners? Perhaps because according to Bowker and Star (1999), who cite the work of the experimental psychologist Rosch (1978), our classificatory systems are not founded upon their golden rules. Rather, we have a rough and ready-made prototype in our minds of what some thing is. When we ascertain whether any given thing is indeed that thing, we call to mind our best example of it, and try to travel directly or metaphorically from the thing that is, to the thing we are classifying. Moreover, during our journey we might deviate further from the golden classificatory rules by furnishing our original idea by metaphor and analogy. Such embellishments might alter both our prototype and its relationship to that which we are attempting to classify. Bowker and Star continue by citing Taylor's (1995) distinction between a prototype classification (founded upon Rosch's prototype)

and an Aristotelian classification that is based upon the ideal of binary characteristics that are either present or absent. If the ideal is absent then Everitt (1993) suggests that we should adopt the equivalent of a nominalist approach to classification, in which its success is based not on whether its principles are true, but on whether its results are useful. Yet the prototype of the thing in the mind is the equivalent of the essence of the thing in the body sought by the essentialist approach to defining disease. Perhaps the classificatory disorder of asthma is the outcome of the conflict between the Aristotelian principles of medicine and the prototypes of its practitioners.

However, before labelling asthma the classificatory equivalent of a personality disorder, the potential for severity – a classificatory criterion in all the schemes above – to restore/create order will be explored.

5.3.3 Severity

According to Woolcock (1997b:1499),

> "it is not yet possible to know what determines the severity of the disease or how to measure it. ... [S]everity can apply to the symptoms of asthma, to an exacerbation of asthma, and to the disease or diseases of the airways ... The word severity appears frequently in articles about asthma ... Most authors assume that the symptom score or the variability peak expiratory flow (PEF) measurements indicate severity and, obviously, editors of journals agree with them since the term appears with such regularity in the titles of articles".

Woolcock (ibid) has, however, ignored the distinction between acute and chronic severity in most of the classifications above.

5.3.3a Acute severity

Apart from brittle asthma (a diagnosis in itself), current national guidelines begin by classifying severe asthma in terms of use of therapy and of medical services by its patients, and according to their past experiences of asthma (BTS/SIGN, 2003:32). The previous guidelines cite percentage of best respiratory function as "a realistic gold standard" (BTS:1997:S7), but state also that peak expiratory flow measurements should include "other features of severity [unspecified]", current treatment and previous medical history, especially hospital admissions (ibid:S5). Moreover, they cite two

different values of their gold standard of PEFR as requiring hospital admission: one based upon "published evidence", the other being "arbitrary but widely accepted and supported empirically in the BTS audit" (BTS, 1997:S4). Both sets of guidelines then proceed to provide detailed and specific clinical criteria according to which severity is to be assessed.

However, patients "almost always recover from acute attacks" (Woolcock, 1997b:1501) and deaths from asthma are rare, especially in children. In 1996 only 20 children died of asthma in England and Wales (Levy and Hilton, 1999). Milner (1993:7), without specifying his source, cites 50 deaths per year in children under 15 years, of which only 4-7 deaths per year occurred in children under five years of age, giving an annual mortality rate of 1-2 per 100,000 "wheezing preschool children". Though risk of dying increased with age in Australian children studied during 1986-1990, the rise was from only 1 per 100,000 asthmatics per year under 5 years to 1 per 13,000 asthmatics per year aged 15-19 years (Robertson *et al*, 1995). While annual mortality rates for asthmatics 5-34 years increased in many countries throughout the 1970s and early 1980s (Beasley *et al*, 1997), for countries in European Community, the increase was confined to the 15-34 age group (Burney, 1997). Moreover, mortality rates for the 5-34 year age group have since declined in both England and Wales and Australia (Beasley *et al*, 1997), and deaths from asthma in the UK are currently at their lowest recorded (Hartley, 2002).

However, death is not so improbable for a few asthmatics if medicine classifies asthma as multiple personalities: brittle asthmatics may experience the snapping of the autumn leaf from Sedgwick's (1972 in Dingwall, 1976) twig with little warning. Nonetheless, death is so rare it seems statistically insignificant, though it is substantively significant to MI10 (p.87). It might also be substantively significant to the GP called to a dyspnoeic and cyanotic boy in her waiting room as her specialist interest in asthma began with that encounter. Thus the significance individual health professionals attach to disease might be influenced by direct experience of their actual occurrences. Asthma's potential to kill permeates also the medical literature in chapters in specialist texts, population studies of its mortality and in the above guidelines recognizing and managing life-threatening asthma. This suggests that the significance medicine attaches to disease is influenced by its severity alone, irrespective of the probability of its occurrence. Acute asthma might be only an occasional visitor, but if the visitor is unacceptable enough to be an intruder

then medicine might act to try to prevent its return by present and future control measures. Experience by patients of one severe attack might increase the subsequent management of their asthma by their health professional, while the witnessing by health professionals of an unexpectedly severe attack might increase their subsequent management of all their asthmatic patients. Finally, health professionals' exposure to the medical literature on severe attacks has the potential to increase the management of the entire asthmatic patient population.

5.3.3b Chronic severity

Nonetheless, in the specialist asthmatic literature "it is the severity of the underlying disease and its management that is more important" (Woolcock, 1997b:1501) because persistent inflammation may cause irreversible airway narrowing with permanent reduction in lung function. Medicine's intellectual treatment of asthma is therefore focusing increasing attention on chronic severity – on the frequency and duration of symptoms – rather than upon acute severity – their intensity. Perhaps because the evidence base for acute attacks is more likely to be derived from clinical observations, there is according to Woolcock (ibid) a greater medical consensus regarding assessment of acute attacks than for the underlying disease that is chronic asthma. To assess asthma's chronic severity she proposes a combination of three criteria based on frequency of symptoms, frequency of inhaler use to relieve symptoms and percentage reduction in morning PEFRs over the previous three months.

Godfrey and Barnes (1997:18-19) extend the time frame to a year and the criteria to include those "which reflect the amount of disturbance to the everyday life of the patient or his family". Their list is long and its criteria are diverse. It comprises daytime attacks (frequency, duration and severity); nocturnal waking with symptoms (frequency only); symptom-free intervals without therapy (frequency and duration); exercise tolerance in comparison to peers; amount of school/work absence; regular medication (type and number); frequency of additional medication use to relieve symptoms; frequency of Accident and Emergency attendance; hospital admissions and transfers to intensive care (but not GP visits or call-outs). Some of these criteria are included in Kaur *et al*'s (1998) ISAAC study. Using ever having had a diagnosis of asthma as the diagnostic criterion, in the previous 12 months, 70% of children had had four or more attacks of wheeze, 66% were disturbed by wheezing more than one night per week and 51% had wheezed

on exercise. Their protocol, however, introduces new severity criteria of wheeze severe enough to limit speech and wheeze severe enough to disrupt daily activities that had affected respectively 62% and 76% of children.

A variety of questionnaires have been designed to assess chronic severity (Jones *et al*, 1992; Quirk and Jones, 1990; Rosier *et al*, 1994; Ungar *et al*, 2002) by correlating patients' assessments of their symptoms to medical assessment by means of LFTs. A different approach assesses chronic severity in terms of its impact on health-related quality of life (French *et al*, 1994; Juniper, 1997). Juniper (1997:1491) draws an important etic-emic distinction between questionnaires that "focus exclusively on symptoms and physical activity limitations that clinicians consider important... [and those that] ...incorporate all the functional impairments ... that patients with asthma have identified as important". Strong correlations between quality of life and symptoms, but not between quality of life and LFTs or medication requirements, were reported by Guyatt *et al* (1997) in asthmatic Canadian children. As symptoms, LFTs and medication requirements are themselves commonly used criteria for severity, from the patient perspective they would appear to be assessing asthma differently.

5.3.3c Assessing severity

Several consequences follow the differing approaches to assessing the severity of asthma. Firstly, as there are different dimensions to severity that are assessed by different methods and assessed differently by different practitioners, severity does not order medicine's asthma. Nonetheless the approaches outlined above expand our gaze on how medicine perceives disease and contain further clues as to why its asthma might be difficult to know.

The approaches demonstrate an increasing separation between that which is being assessed and the health professional assessing it: the acute asthma of medical guidelines was assessed directly by the health professional; asthma in health related quality of life questionnaires is assessed by the patient. Severity criteria move increasingly from the disease to the illness: the former assessed its severity according to clinical signs and investigative tests; the latter according to its impact on quality of life. Extension of criteria beyond those observable to the health professional, or observing of the disease of asthma, introduce a multiplicity of factors pertaining to the patient and to the

patient's environment that have the potential to intervene between the disease and its medical assessment. As Guyatt *et al* (1997) imply above, patients vary in their perception of the severity of their symptoms when these are compared with the severity of airway narrowing as measured by LFTs (Woolcock, 1997b). A teenage boy in this study felt well despite his LFTs being only 48% of predicted, presumably because he had grown accustomed to life at what medical guidelines define as indicative of severe acute asthma [HR105/C18]. By contrast a girl felt ill despite her PEFR being within the normal predicted because her normal was markedly above the population normal [CI6]. Patients vary also in the degree to which they tolerate symptoms that medicine perceives as severe (Godfrey and Barnes, 1997). C15 who was prescribed oral steroids by the health professional because of previous sudden and severe attacks had, according to her and her mother, never had acute severe asthma. In fact I selected her mother's description of her illness experiences (p.79) as representative of mild asthma in the family.

Significantly though, severity in the past of the individual patient does not always predict its future. Robertson *et al* (1995) in their reporting of childhood deaths from asthma, emphasise that only one third of children were known medically as having severe asthma. The boy in the GP's waiting room, dyspnoeic and cyanotic had been diagnosed a couple of years previously as probably having wheezy bronchitis in association with respiratory infections. He had been untreated and his wheezy bronchitis had remained unchanged till his life-threatening asthma attack that had begun that morning without any sign of a respiratory infection. After that attack he returned to his symptoms in association with respiratory infections, though now his GP practice call it, and manage it, as asthma.

Asthma's acute and chronic severity are, moreover, extremely significant to its status in the long term – to its natural history, its clinical course or its prognosis that forms a further part of its disease personality. The medical outlook on childhood asthma is optimistic, though perhaps more cautious than parents of children with asthma (p.121). Childhood asthma that is mild, both acutely and chronically, is more likely to improve or remit than severe asthma. On the basis of wheeze alone, Rees and Kanabar (2000) suggest that over half the children who wheeze infrequently will be symptom-free by the time they reach adulthood, whereas only 20% of those with more troublesome wheeze

will be symptom-free at the same age, though another 20% will have improved. In a minority (15%), asthma will worsen with age. Thus its disease trajectory varies. Whether asthma in remission (Woolcock, 1997a) ever becomes asthma in the past, is, however, uncertain. According to Rees and Kanabar (2000), one third of children whose asthma is in remission for more than one year will have their asthma return, possibly many years later. Once an asthmatic, always an asthmatic because even if one is not symptomatically so, somewhere pathologically asthma remains. The asthma that the child had grown out of might one day, catch up the grown-up and constrict once more. Importantly though, what is probabilistic in the asthmatic population will be present or absent in the asthmatic patient. Thus its projected natural history in the individual patient is being derived from the experience of the asthmatic population. But the individual wants to know what will happen to *me* (Rosenberg, 1997; Misselbrook and Armstrong, 2002). One health professional never assumes that children have grown out of their asthma. She tells them that their asthma might return at any time, and advises them always to keep medication at home and to keep a check on its expiry date. Further, if self-cure cannot be assumed, treatment may be continued, even in its absence, because medicine has a forward gaze on asthma that might see it, even in its absence.

Medicine's forward gaze on asthma further interacts with its therapies to increase asthma's significance as an illness. Though medicine can treat asthma with drugs it cannot cure it. At best it can silence it with regular therapy but in so doing from the patient perspective it converts asthma that might only have visited the child occasionally into asthma that is a permanent resident. In consequence, the child changes from being well most of the time to potentially ill all of the time. Interestingly, a minority of adults studied by Adams *et al* (1997) did not dispute their diagnosis of asthma, but they disputed that they had it all the time: it was an occasional visitor not a permanent lodger. In this study a few teenage boys and young men, attempted to evict their medical lodger by rejecting regular therapy because their symptoms were not too troublesome, and were relieved by their blue inhaler (p.108). The difference in perspective between these asthmatics and their health professionals is another illustration of the difference in lay and medical gazes upon asthma. The asthmatics' gaze, as noted also by Sweeney *et al* (2001), was on their own asthma and backwards; by contrast their health professionals' gaze was on all asthma and forwards. Their concepts of space – individual or population – and time – past or future – were opposite.

From the medical perspective, however, its management of the chronic dimensions of severity has the opposite aim of preventing the occasional visitor becoming a permanent resident. Regular preventive therapy for asthma aims to prevent the inflammation and muscle contraction of acute attacks, but also the persistent inflammation of chronic asthma scarring and permanently narrowing the airways. Preventive therapy further orients medicine's intellectual treatment of asthma towards the future. Moreover, medicine's interventions in the individual patient to prevent acute asthma and to prevent the irreversibility of chronic asthma have different evidence bases. Death apart, acute asthma is always reversible, hence acute asthma has the potential to exist in the past of the individual patient. Chronic asthma might exist in the patient's present or past, but until or unless it becomes irreversible, its irreversibility exists only in that patient's future. Before then irreversible asthma exists only in the asthmatic population, in the medical literature, and in the intellect of the health professional. Thus acute asthma can be managed according to its own past in the patient but as with its natural history, the past of others plays a much greater role in the management of chronic asthma. The past of others becomes the patient's potential future. The clinical gaze has to look backwards to the asthma in these multiple others, before it can look forward to the asthma in its individual patients.

Medicine can nevertheless silence asthma even if it cannot destroy it, thus Frank *et al* (2001:117) highlight the importance of the early identification of patients with *likely* asthma" (emphasis added). Medicine should they suggest, screen for asthma in the not asthmatically diagnosed population. Their screening of 1563 children aged 5-15 years by means of a postal questionnaire of symptoms, whose questions were stratified to distinguish between mild and more severe asthma, found 22.5% of children had "possible" (ibid:119) mild asthma and 15.5% possible more severe asthma. Of these possible asthmatics, 7.9% of the milder category and 3.9% of the more severe category had neither been diagnosed with asthma by their GP, nor treated in the past year with asthma therapies. This study indicates the potential for screening to increase the amount of asthma in the population managed, and diagnosed, by medicine, and the amount of mild asthma in particular. It suggests also, that the harder medicine looks for asthma, the milder the asthma it will find, hence the overall severity of asthma in the asthmatic population will decline.

Medicine's forward gaze on asthma is most potent in Woolcock's (1997a) construct, potential asthma, in her classification. Potential asthma is another product of screening, but unlike the likely or possible asthma above, this asthma has no symptoms. Its asthmatic status is derived from medical intervention that demonstrates a raised AHR, and exhibits it as evidence of a silent pathology. While asthma is potential, its stimuli may gradually be stimulating its pathology until eventually asthma becomes actual. Symptomatically, it is a new arrival, but pathophysiologically, it was always a permanent resident. As asthma's earliest stimuli may act prenatally, potential asthma originates pre-conception, and its medical management would have to begin with potential parents.

Potential asthma has no symptoms. Trivial wheeze – the final character of Woolcock's (1997a) classification of asthma – has symptoms but they are never severe enough to require treatment. Her inclusion of them as asthma indicates that her asthma can be so mild as not to impair function unacceptably. Thus trivial wheeze takes asthma to the boundaries of disease. It might, however, take it even further, if Woolcock's trivial wheezer is the happy wheezer identified by some health professionals. If the happy wheezer is not diseased at all, or only so marginally that it takes another disease, a respiratory infection, to unacceptably impair function, then asthma has the potential to cross the boundary constructed by medicine between a disease and a change (or not) in material reality.

5.3.4 Asthma in Medical Context

Although these debates may be about the peripheries of asthma, they have an ideological significance that strikes at the essence of the medical definition of ill health founded upon disease entities identified by their personalities: "asthma-like illness" (Maier *et al*, 1998) and "asthma symptoms" (Kaur *et al*, 1998) – two extracts from titles of papers – reinforce its medical indeterminacy. The debates have also a practical significance as many asthmatics (or non-asthmatics) present with such asthmas or are presented with them. "The hardest thing to know sometimes", as one health professional said to me, "is if it's *really* asthma". Other times, it might be harder to know if it is really *not* asthma.

Such debates about the personality or personalities of asthma, and its boundaries with other unhealths, or with health, are conducted principally in the research literature and in the most specialist texts. In some general and practice orientated texts, debate is settled or lost, and in consequence the asthma that emerges tends to be more definite, but it may be markedly different from its neighbour. Thus, in two general paediatric texts, "[p]ersistent cough, even without wheeze will often be asthma" (Modell *et al*, 1996) and "[i]f the child does not wheeze or the wheezing is not intermittent, consider other diagnoses" (Hull and Johnson, 1999). Textual asthma might also reflect medical relationships: "it is difficult to diagnose asthma without either wheeze or the objective evidence of reversible respiratory disease" writes McKenzie (1995:175) in an text edited by the cough-variant sceptic Silverman. Thus the asthma residing in the intellect of individual health professionals might have the potential to influence the asthma that is transmitted through medicine.

The extremely influential movement of evidence based medicine attempts to reduce the medical significance of such personal opinion. It aims to bridge the gap between research and practice in medicine, by integrating individual clinical expertise and judgement with best available population evidence (Geyman *et al*, 2000; Sackett *et al*, 1996; Trinder and Reynolds, 2000). The gap between research and practice in asthma might, if Falliers (1988:317) is to be believed, be particularly wide. He asks, rhetorically, if the increasing depth of medicine's gaze into asthma has led it down a "dead-end scientific path ... with no immediate applicability to the problems of asthma". Or, and equally rhetorically, whether the increasing diversity of its gazes has generated a "multiplicity of relatively irrelevant data creat[ing] a veritable biomedical Tower of Babel".

Evidence itself, however, requires judgement, and is therefore distinct from facts: an assessor must judge facts as relevant before they can become evidence. "The concept of evidence is therefore parasitic upon the concept of judgement" (Downie and Macnaughton, 2000:10). The word consensus in the title of the sources of the first two definitions of asthma indicates that they have been based upon the negotiated agreements of expert opinions. The role and significance of such negotiations are evident in Grassi *et al*'s (2001:20-21) description of asthma's clinical diagnosis that was

to form the gold standard against which to compare its epidemiological diagnosis by a community questionnaire.

> "[S]ubjects were classified [as asthmatic or not asthmatic] according to the diagnosis formulated (independently) by three experienced clinicians ... Diagnosis was immediately formulated if there was agreement among the clinicians ... in the case of a disagreement, the diagnosis was formulated when the experts reached major agreement, after discussing all the data".

Epidemiological studies have therefore, to add clinical uncertainties to their own difficulties in defining and classifying asthma in the population. Weissman (2002:6) describes the doctor's dilemma: clinical diagnosis "underdetects subclinical mild asthma", but the AHR which might detect such asthma, might in his opinon, detect also asthma in many people without asthma. Remes *et al*'s (2002) conclusion that measures of AHR did not increase significantly the concordance between clinical diagnosis of asthma and a self-reported symptom history, suggests that other clinicians agree with him; thus the patient's history is a major contributor to medicine's evidence base for it.

Uncertainties in the medical evidence for asthma have implications also for its medical management, which is becoming increasingly formalized by the publication of official guidelines such as those of the BTS (1993, 1997); BTS/SIGN (2003). Guidelines aim to introduce systematic rigour to health professionals' management of unhealth, but in practice their implications might be limited by their being unknown, as a conference discussion admits.

HP1 "Can you remind me what the [BTS] guidelines are?"

HP2 "Not without prior warning."

{laughter}

HP3 "Isn't it just a bit of *ventolin*?"

The second health professional had been a member of the committee responsible for the 1997 BTS guidelines. Secondly, guidelines might be lengthy. Pearson (1993:197) comments that "[t]he 1990 British version [adult asthma only] was unusual in that it was the most succinct (seven pages long)". BTS (1993) had grown to 24 pages; another 24 were added to BTS (1997) and BTS/SIGN (2003) has nearly doubled again to 94 pages. Thirdly, as there is, according to Woolcock and Barnes (1997:6) "a mania in the production of management guidelines", health professionals might be following an

alternative, perhaps the paediatric version (Warner and Narpitz, 1998) or the 72 page long international version (cited in Pearson, 1993). The threshold for regular therapy is lower in the international guidelines than in BTS (1997).

Alternatively, the guidelines might be ignored because the asthma they manage is in the population, not in the patient. "Individual patients," as Neville *et al* (1997:156) accept "have individual management needs" and the right of the individual health professional to assess these and act accordingly is enshrined in the ethos of evidence based medicine. Health professionals' management might be equally individual. Senior *et al* (in press) suggest that Welsh GPs might have been influenced by the prescribing practices of hospital consultants to whom they referred their asthmatic patients, and noted in general, that older GPs prescribed fewer preventive therapies for asthma than their younger colleagues. In New Zealand, health professionals, according to their national guidelines, over-prescribe antibiotics in asthma care (Kljakovic and Mahadevan, 1998). Patients were prescribed antibiotics because they asked for them, because health professionals wanted to terminate the consultation, or because they lacked the confidence not to. They also prescribed antibiotics for reasons more in keeping with their Hippocratic Oath. Some thought the guidelines were wrong in principle – many asthmatics needed antibiotics – or in practice – the few who might need them later could not be monitored adequately once they had left the clinic. Others had bad memories of individual cases that coloured their prescribing practice for all their patients.

These return us to the interplay between the asthma in the body of the individual and in the body that is the population. They illustrate also the tension that remains between the bodies of medical knowledge enshrined in the guidelines of the medical profession, and in the intellects of individual health professionals. The intellect was the sixth observing sense of the health professional in classical medicine (Nutton, 1993), and as Hunter (1991:46) has observed aptly and poetically, "[m]edicine is practiced somewhere between the forest of textbooks and a thicket of algorithmal[15] trees". That somewhere is in the health professional in the clinic whose role it is to "individualize the generalized

[15] An algorithm is according to Sackett *et al* (1991:6) the "*multiple-branching or arborization* strategy of diagnosis: *the progression of the diagnostic process down but one of a number of potential, preset paths by a method in which the response to each diagnostic inquiry automatically determines the next inquiry to be carried out and, ultimately, the correct diagnosis*".

evidence" (Downie and Macnaughton, 2000:42), and who, according to Brandt (1997:47), is "notoriously slow to think in terms of probability".

Asthma can therefore, be perceived symbolically as residing in the body of the health professional, perhaps as the prototype referred to earlier. If, as Lakoff and Johnston (1999:3) suggest, "the mind is inherently embodied", not independent of it as it has been since it was separated from it by Descartes, the prototype has a reality to its possessor. Reason and the intellect arise out of, and are inseparable from, our physical selves and our experiences, and "reason ... is based on various kinds of prototypes, framings and metaphors" (ibid:5)[16]. Health professionals have their individual prototypes such that at opposite ends of the health professionals' spectrum we may have 'asthmaphiles' and 'asthmaphobes'. The contribution of asthma's sceptics to medicine is evident in its literature and at its meetings but these are unlikely to be asthmaphobes as they are sufficiently interested in asthma to contribute to its debates. They might even join asthma's experts whose role in creating the disease of asthma in medicine promotes its existence as a consensual prototype rather than as an ideal Aristotelian entity. However, the more varied the individual prototypes creating the consensus, the more abstract and vague it might appear to individual health professionals in comparison to their own prototype. Further, if clinical asthma is the model for epidemiological asthma the abstraction imparts qualitative and quantitative variation to asthmatic populations, according to their asthmatic criteria and asthmatic prevalences, respectively (Magnus and Jaakkola, 1997; Kaur *et al* (1998), Duran-Tauleria and Rona, 1999; Samet *et al*, 2001)[17].

This chapter began with the disease of asthma in the body of the patient but has developed asthma in other bodies – the health professional, medicine and the population. Asthma has thus been portrayed as residing in four bodies, and relationships between their asthmas are complex, and influenced by relationships between the

[16] Further exploration of relationships between prototypes and evidence-based medicine is beyond the scope of this dissertation, but interesting starting points would be diagnostic "'rules of thumb'" (André *et al*, 2002:617), the "art of uncertainty" in case presentations (Lingard *et al*, 2003:603), and whether "[i]ntuition and evidence [are] uneasy bedfellows" (Greenhalgh, 2002:395).

[17] Comparing similar dates and ages, the prevalence of doctor diagnosed asthma among 8-10 year old Australian children in 1992 was 37.7% (Peat *et al* 1994) and among 9-11 year old West German children in 1989-90 it was 9.3% (Von Mutius *et al*, 1994).

material and the metaphysical, and the single and the multiple. The chapter has, however, ignored thus far the principal 'bodies' of asthma in this study, namely patients as persons. They play a greater role in much of this final section in which their asthma is restoried[18] into the being they present in the clinic. In the process it encounters the restorying of their asthma to them by health professionals.

[18] After Hunter (1991:141), in the sense of being restored to, and narrated as, the asthma that patients/persons presented to me.

5.4 RESTORYING ASTHMA

Asthma is born in the clinic when it is named in its patients.

5.4.1 Naming asthma

Asthma was named in a two year old girl who had "a bit of a cold". Over a few hours she began to wheeze and became breathless. She was admitted to hospital and discharged after three days with a diagnosis of asthma [MI10]. But it was not always christened so easily. A three year old boy had "a drippy nose". Over a few hours he began to wheeze and became breathless. He was admitted to hospital and discharged after three days with a diagnosis of a chest infection. About a month later a drippy nose again led to wheeze, breathlessness and a hospital admission, but this time he was discharged with a diagnosis of asthma triggered by a chest infection. About six weeks later a third drippy nose led to a third rapid onset of wheeze and breathlessness and a third hospital admission, and this time he was discharged with a diagnosis of an asthma attack triggered by the common cold [MI19]. Thus his asthma increased in severity while its triggers decreased in severity. A second boy was treated by his GP for chest infections, then diagnosed with asthma by the nurse-practitioner[19] and referred back to his original GP, who referred him to the nurse-run asthma clinic symptomatically unchanged, with "a touch of asthma". Thus he was diagnosed differently by different health professionals, and the same symptoms were diagnosed differently on different occasions by the same health professional [MI12].

Health professionals were, however, most likely to disagree when faced with asthmatic symptoms in Silverman and Wilson's (2000) small people. As BTS/SIGN (2003:S45) acknowledge, assessment of asthma in children under two years of age "can be difficult. Intermittent wheezing attacks are usually due to viral infection and the response to asthma medication is inconsistent". Its "guidelines are intended for those who are thought to have asthma causing acute wheeze". Cough is conspicuous by its absence.

[19] A practice nurse who has undergone specialist training.

It is therefore of note that 4C4 in the opening presentation was diagnosed with asthma when she was a year old. Other health professionals were, however, resistant to naming asthma in other children before their second birthday. A boy, now 18 months old, has been "chesty" since birth. He has had several hospital admissions for "bronchitis" and whooping cough had been suspected on one occasion, but excluded. One week he had three emergency hospital visits and was admitted overnight on two of them. Each time he was treated with antibiotics and asthma therapy but was discharged on antibiotics only. He became ill during a family holiday and attended a different hospital where the health professionals told his parents that he might have asthma, but he was too young for them to be sure. They advised him to contact their GP immediately on their return, and he was discharged without asthma therapy. He was ill again by the time they returned home and was treated as before in their local hospital. This time the father asked the health professionals if it could be asthma, but was told his son was too young. He felt he was being "fobbed off" and got very angry, but his son was discharged without asthma. When the family told their GP that asthma had been suggested by the other hospital they left the consultation without asthma but with a prescription for asthma therapy and a specialist referral. At the hospital clinic they were told that the child was too young for asthma to be certain, but because he has asthmatic symptoms and responded to its therapy, he should be treated as though he has asthma [HR74].

A second boy had frequent GP and hospital visits for attacks of wheezing that began before he was a year old, and responded to asthma therapy, but unlike HR74, he was rarely treated with antibiotics. He too though, was not given asthma, nor any treatment for home use until he was two years of age [HR87]. A third boy was treated with inhalers from a few months old, and diagnosed first with a touch of asthma, then with asthma after his second birthday. His brother[20] developed similar symptoms at the same age, but they were more severe and more rapid in onset. Despite his brother's asthma his GP "fobbed [her] off with he's only a baby and only chesty" so she took him to the local hospital. The doctor there told her "'it could be asthma'" and treated him as though it was asthma. His symptoms disappeared and she was told "'it is asthma'" and he was sent home on asthma therapy [MI1]. Once again asthma therapy had found the unhealth to be asthma.

[20] The subject of the previous chapter's asthma presentation.

Diagnostic delays that translated into therapeutic delays could be stressful to children. C6 (p.85) retained the emotional legacy of nocturnal coughing fits that were diagnosed and treated as asthma only after she consulted a different GP in her practice. After diagnosis and therapy the boy whose diagnostic delay had been narrated before hers underwent a metamorphosis that was both physical and psychological: his mother "really couldn't believe the change in him" [MI3]. Uncertainties over diagnosis and therapy were stressful also to parents. As with HR74 and M1 above, parents spoke repeatedly of being 'fobbed off' by their health professionals, and M4 had found the time to diagnosis of asthma in 3C4, and second time around, in 4C4 very stressful. Sutherland's (1987) account of her daughter's asthma stresses also the distress when this uncertain time is prolonged. Her daughter's first attack occurred during an overseas holiday and though she was treated in hospital she was given no diagnosis, and on her return home her GP attributed it to a one-off infection. Her persistent nocturnal cough was attributed subsequently to attention seeking behaviour, their daughter being jealous of her parents sharing the marital bed. After several GP night visits she was diagnosed as having "childish wheezing...[or]...wheezy bronchitis" (ibid:35). Eventually her parents persuaded their GP to refer their daughter to a specialist, who diagnosed pneumonia and told them she might be "an allergic child" (ibid:35). At the second consultation, asthma was mentioned for the first time.

Burton (1975) in her study of children with cystic fibrosis emphasises also the stress to families caused during the time to diagnosis. For one mother, "'That was the worst time of the lot, knowing something was wrong, and not knowing what'" (ibid:22). By the time of diagnosis more than a quarter of families had lost faith in the medical profession and some subsequently changed their GP or sought legal advice. Their hostility was most severe when like the parents in Teesside, they felt their concerns were dismissed as nonsense, imaginary or a fuss about nothing. They were less resentful when the wrong diagnosis was made, or when doctors were open about not knowing what the diagnosis was, because in each case the uncertainty of the medical profession did not challenge the certainty of the parents that their child was ill. Nonetheless, in this study naming emerged as significant in itself, as not knowing what was being treated added to the stress. While her eldest son was being treated in diagnostic silence M1 felt "like grabbing hold of the doctor and saying 'Tell me what it is!'". Similarly, another woman has felt much more in control of her son's asthma since its naming, despite his worst

attack occurring since his diagnosis [HR87]. Cornford *et al* (1993:195) comment that a few local women who consulted their GP because their child was coughing feared the "child might develop an asthma attack and die, although not all of these children appeared definitely to have asthma". Perhaps uncertainties over whether the child had, or might develop, asthma contributed to their fear.

However, the time after naming was equally stressful for a few families in this study because asthma therapy took time to prevent asthma's symptoms, and even to relieve them. It failed initially for 3C4 and 4C4. It was therefore, not unusual for children and their families to have to endure a time when asthma had been diagnosed but when its therapy was ineffective. That time prolonged the children's distress and might be particularly stressful for parents as the apparent failure of therapy led them to fear their child had something worse. Their differential diagnosis usually included a 'weakness' of the chest or a 'vulnerability' to chest infections but occasionally cystic fibrosis emerged as an alternative diagnosis – one shared by the hospital clinic where children were frequently tested for it. However, and mindful again of Burton (p.79), often diagnosis had gone smoothly: most tellingly of all several parents interviewed could remember little about it. Their faded memories are suggestive of an uneventful and easily forgettable time.

But being intermittent, asthma's diagnosis does not end with its initial diagnosis. It must be re-named every time it makes itself manifest, and as asthma may persist, and be persistent, children, their families, and their health professionals have the opportunity to become experts in their knowledge of their asthma.

5.4.2 Knowing Asthma

Certain parents interviewed, especially parents of children who have been asthmatic for a long time 'know' – an oft repeated word – their child's asthma, but its illness personality was not always its disease personality. The cough like a dog barking was asthma in 3C4 however much medicine attributes a barking cough to croup, while MI22 knew the cough her GP had diagnosed as asthma in her son was not his asthmatic cough. Two years later her worst memory of that time was not her son's whooping

cough and its transmission to his relatives, but her referral by her GP to the nurse-run asthma clinic because she had let her son's asthma get out of control. He was she felt, casting her as a bad mother and her relations with her GP had taken longer to recover than her family's health. In a case presentation, a medical student paid more, if sceptical, attention to the parents who "'*claim[ed]* it didn't appear as a typical asthma cough, cause normally, when she starts getting asthmatic, she also gets a runny nose'" (Lingard *et al*, 2003:613, emphasis added).

Similarly 'not being themselves' was not something health professionals in Teesside should ignore because there was no sign of asthma. Parents in Østergaard's (1998:155) Danish study felt the same. They "came to recognize that they could read the child better than the doctor and ... recognize their child's specific asthma pattern ... [They] noted the doctors' inability to listen to, understand and correlate these individual non-specific patterns". Health professionals listened too much with the stethoscope and too little to them. "'I know my asthma better than anybody'", concluded an adult asthmatic interviewed by Sweeney *et al* (2001:23).

Another of parents' most frequent complaints was that health professionals underestimated the severity of their children's asthma. When M4 took 4C4 to her GP because her chest was so sore from coughing, he told her that as she had "slight asthma", it was only to be expected. Thus, health professionals did not always take the child's asthma 'seriously' – another recurring word. 'Seriously' shared the conceptual world of 'knowing': it was not just asthma that health professionals were criticised for not taking seriously, it was the parents and the child patients themselves.

Lagerløv *et al* (1998) and Wahlström *et al* (2001) suggest that doctors who focus upon asthma as a disease tended to be authoritarian while those whose focus included more of the illness perspective were more likely to be democratic. The former identified four management styles among GPs: authoritarian (I will manage it); teaching (I will teach you to manage it); empowering (we will manage it together) and passive (I do not know how, or even whether, to manage it) (Lagerløv *et al*, 1998:88). They liken the first three styles to the relationships between an adult and child, adult and adolescent and adult and adult respectively, while the fourth was confined to recently qualified and uncertain GPs. Also, as they draw parallels between management styles in asthma and doctor-

patient relationships in general, they suggest that it is the doctor rather than the asthma that determines the management style. Authoritarian managers are least likely to take patient or parent knowledge seriously or to treat it with respect. As the child patients and their parents are asthma's managers beyond the clinic, the more authoritarian the medical management, the greater the likelihood that they will reject its authority to manage their asthma in the family. Erikson (1964:52), who shares Hunter's (1991) conception of medicine as an interpretive activity shared by its practitioners and its patients, suggests that "a 'good' doctor ... [makes] the 'patient himself' an associate observer and assistant doctor".

In this study parents' relationships with their health professionals appeared much stronger when they felt that their knowledge was respected. It did not have to be right, but it had to be listened to, and treated as though it might be right. Yet clinic observations and my own clinical experiences make clear health professionals' relationships with their patients are strongest when they feel that their re-storying of the patient is listened to, and treated as if it might be right. Often this happened because as pointed out perceptively by Hunter (1991:7), however "[c]hillingly unrecognizable and "scientific" as the resulting case may sound ...it is just what he [the patient] has come for: to have his story retold as a medical story as part of the effort to determine the meaning of the events he reports". Nevertheless, in a minority of cases the story and re-story "may travel back and forth ... to be modified in turn on the medical and on the lived-experience side, in a sort of shuttle diplomacy that might make achieving peace in the Middle East look simple by comparison" (Brody, 1998:xiv). Moreover, as asthma might last a lifetime, so might the shuttle diplomacy, and as asthma can be difficult to pacify, so might it be difficult to keep the peace permanent between its patient and professional managers.

The mother who introduced the previous chapter summarized her relations with her GP as "it's a hell of a fight" [MI1]. M20 had all but given up the fight. If I speak medically, by her own description of her son's symptoms and her responses to them, she did not know asthma, but she felt she knew her son's asthma. However, several encounters with health professionals had left her feeling accused either of over-reacting and being hysterical, or under-reacting and being callous, and of being "stupid" either way. She was losing faith in herself and in health professionals and had on several occasions

delayed seeking, or avoided altogether, medical help when her son's asthma had deteriorated. By my own assessment (p.43) on at least two occasions her son's asthma was life-threatening. Further, her loss of confidence was worsening the emotional impact of her son's asthma on her, and possibly on her son as well. Most often though, it was the complexity of the relationships between asthma and the emotions – asthma attacks and the panic attacks with which 1C4 was diagnosed initially – that transported the free garden to the Middle East.

Parents' confidence in their knowledge of their children's asthma, and their children's confidence in their parents' knowledge of it in them, emerged in this study as a core of successful (from their perspective) life with asthma. Moreover, if we assume that asthma is managed according to how it is known, knowing has significant practical implications for living with asthma. 'Living with Asthma' has described already how asthma is managed, but as most of its management is medically prescribed, it is revisited below.

5.4.3 Managing Asthma

Returning to the external-internal dichotomy of the previous chapter, asthma can be managed either by engaging with it inside the patient, or by trying to avoid engagements between it and its stimuli outside the patient.

5.4.3a Managing asthma from the inside

Of the medicines which play a major management role in asthma, only those most commonly used by the patients in this study are described here, and detailed schedules are not included as these are given in many of the specialist texts and guidelines cited above.

5.4.3a(i) *Drugs*

All had blue inhalers and were permitted up to 10 doses when asthma was bad. Blue inhalers contained β2 agonists either salbutamol (*Ventolin*)[21] or terbutaline (*Bricanyl*). β2 agonists attach themselves to β2 receptors on nerves that when stimulated cause relaxation of the airway muscle. Hence they are known also as bronchodilators as their action reverses within a few minutes the bronchiole narrowing caused by muscle contraction. Only blue inhalers could relieve acute asthma outside the clinic, thus health professionals advised children and their parents not to become separated from them unlike the teenager (p.106) who had left his blue inhaler at home the day an asthma attack left him partially sighted. Blue inhalers prevent muscle contraction as well as relieving it. Thus they might also be taken before exercise, and on a regular basis during a respiratory infection (if a stimulant), or if asthma is generally worse. However, as they last only for several hours, they need to be taken at least four times a day if their effect is to be sustained. Usually two puffs were taken when used in a preventive role.

Finally, as mentioned several times already, blue inhalers have a diagnostic role. Their diagnostic role is explicit in trials of asthma therapy when health professionals are uncertain as to whether to give the word asthma to their patient, and especially when children are too young for LFTs. If the blue inhaler relieved their symptoms then their health professional might make their symptoms into asthma, but families might conduct their own trials after the health professional had diagnosed asthma. One woman had doubted her daughter's asthma because she was only coughing at night unlike her asthmatic son who wheezed on exercise. Her daughter's cough stopped after she started inhalers but her mother did not renew them in case her cough had got better of its own accord. It returned after a few weeks and again responded to inhalers. As "the proof of the pudding is in the eating" [GP34], inhalers, not health professionals, diagnosed her daughter's asthma. By contrast women in the community study had found asthma not guilty in their therapeutic trials. One woman had stopped her child's inhaler after a couple of weeks because it had no effect on her child's cough, which got better after a few weeks of its own accord. Another woman stopped treatment after a few days because her child's cough had got better. At the time she did not know whether it was

[21] The first name refers to the generic drug, the second to its proprietary brand.

the inhaler that had made it better, but as it had not returned since, it had she assumed, simply got better. Both women said their child had been diagnosed with asthma but it is possible that their inhalers had been prescribed diagnostically rather than therapeutically, and reified by them into a prescriptive diagnosis. Such reification increases the prevalence of asthma as a word and lowers its status as a disease.

The lowest status asthmas might be treated with blue inhalers only, but most children used also the brown or orange steroid inhalers that prevent asthma. So pervasive was continuous therapy that its absence was highlighted in my notes. The weaker inhaled steroids – beclomethasone dipropionate (*Becotide*) and budesonide (*Pulmicort*) – were brown; the stronger one – fluticasone propionate (*Flixotide*) – orange (BTS, 1997). Dosage was one to four puffs twice daily, though it might be increased if the child's asthma worsened or a respiratory infection developed. Over a period of several weeks inhaled steroids reduce, and ultimately prevent, the inflammation of asthma, thereby preventing also the permanent damage to the airway that irreversibly impairs lung function. Health professionals were concerned that inhaled steroids might cause oral candidiasis (thrush), hence they advised children to have a non-sugary drink after their medication. They rarely, however, shared the concern of older children and parents that inhaled steroids would inhibit growth, because being inhaled direct to the airways they could be given at much lower doses than when given orally. Growth was monitored, and a few children were found to be small, but health professionals did not necessarily attribute their smallness to their steroid.

Blue plus brown or orange were asthma's most common therapy, but if these failed to control asthma the green inhaler called salmeterol (*Serevent*) might be added, or the colour combination might be reduced by replacing the orange and green inhalers with the purple one (*Seretide*) that combined their contents. The green inhaler, like the blue ones, acted principally on the airway muscle, but it lasted longer – up to 12 hours – and unlike the blue inhalers it took about an hour to work.

The therapeutic significance of the colour codes had to be explained to patients. In general health professionals presented inhalers in two explanatory frameworks – action and aim. Blue and green inhalers acted on airway muscle; brown and orange on airway inflammation. Blue inhalers aimed to relieve asthma; all the others aimed to prevent it,

hence blue inhalers were often called relievers and the other inhalers preventers. However, a few children used their green inhaler as well as, or instead of, their blue inhaler as a reliever as they had been told by health professionals that it was like the blue but stronger because it lasted longer. It was like the blue in its site of action, in that both acted on airway muscle, but not in its therapeutic aim as blue inhalers aimed to relieve the muscle contraction of an asthma attack, while green inhalers aimed to prevent the muscle contraction that caused an asthma attack.

The above colour confusion highlights a more general potential for the reliever-preventer distinction to confuse. One woman could not understand why her son's blue reliever should prevent his asthma worsening during a respiratory infection [MI12]. Another woman gave her daughter her blue inhaler four times a day when she had a respiratory infection, but not in between times as she thought it could not act as a reliever when it was being taken as a preventer [HR109]. Some parents appeared to equate therapeutic aim with mode and site of action: relievers relaxed constricted airway muscle, preventers stopped the development of airway inflammation. By contrast, the medical equation is between therapeutic aim and rate of response. All inhalers can relieve as well as prevent, but only relievers can relieve rapidly. Hence relievers are rapid actors, preventers slow actors. The relationship between speed of action and its mode and site has, nonetheless, great therapeutic significance because there are no rapid actors on inflammation, only on muscle. Medicine's preventive ethos was personified by a health professional's warning that "One day your blue inhaler won't work and you'll end up again in hospital very poorly, and your preventer will prevent that". Her prediction finds support in a recent national study which found that inhaled steroids decreased the risk of dying from asthma, while the relative risk of dying was increased 50 times if patients were prescribed one or more blue inhaler each month (Lanes *et al*, 2002). The absolute risk of dying was though, extremely uncommon: 43 deaths in more than 96,000 asthmatics between 1994 and 1998, a statistic those rejecting of their preventer might qualitatively be aware of.

Yet, more often than not, at clinics therapy was increased rather than reduced, usually on the evidence of symptoms as peak flow charts were rarely produced and spirometry was often normal. Only a few children whose asthma was very seasonal had their inhalers reduced or stopped when their good season had arrived and they had been

without their asthma for some weeks. However, while children and their parents stressed the acuteness of symptoms, it was their chronicity – their frequency and duration more than their intensity – that usually appeared to stimulate health professionals to increase therapy. Such everyday symptoms were those that children and their families were most used to (p.119), hence health professionals in their prescribing of inhalers might appear to their patients both to overreact to everyday asthma and to underreact to asthma attacks.

Interesting relationships between asthma and its inhalers are drawn by Willems (1998). His social constructivist claim that "different treatment practices involve the making of different *diseases* – different asthmas and – and different *lungs* as the locus of the disease" (ibid:107) ignores the different pathology and pathophysiology that made one health professional distinguish "the swelling part... [and] ...the squeezing part" of asthma. However, the attention he draws to the role of inhalers in changing the personality of asthma, and of the lungs themselves, is important. Medicine's increasing focus on regular inhaled steroids is causing, metaphorically, the lungs to change their character from the constricting dry tubes of a poorly lubricated engine to the inflammatory wet surfaces of a soggy sponge. Hence, to echo the health professional above, increasingly asthma is being transformed from a character that squeezes to a character that swells. Inhalers may not create asthma, but they may be character building, despite their therapeutic aim being to destroy asthma.

If they fail to destroy it oral therapies might be added. Monteleucast (*Singulair*) aims to prevent asthma by inhibiting the release of specific chemicals called leukotrienes that form part of the inflammatory response. As leukotrienes cause muscle contraction as well as inflammation of the airway, monteleucast may prevent muscular as well as inflammatory components of asthma. Health professionals were adamant that monteleucast either worked or not: children were told that either they would be much better or no different. It changed C17's life (p.82), though sadly HR33's life (p.99) had remained unchanged.

If asthma persisted still or worsened, oral steroids, usually on alternate days, might be added as a regular therapy of last resort. More usually courses of oral steroids of 3-5 days, but occasionally up to 10 days, were taken to relieve the inflammation underlying

a severe acute attack or a more gradual worsening of symptoms. Health professionals were much more concerned about the adverse effects of oral steroids than of their inhaled counterparts. Repeated use might cause growth stunting, bone mineral loss, diabetes and facial swelling giving rise to a characteristic moon face. They were rarely discussed at clinic consultations, and were prescribed only three times to children.

5.4.3a(ii) *Delivery*

Two properties of inhalers influenced the efficacy of delivery of the medication: whether drug release from the device had to be co-ordinated with the patient's breathing, and the force with which the patient had to inhale the released drug in order for it to reach its destination.

The most commonly used inhalers were metered dose inhalers that require considerable co-ordination in breathing. It was for this reason that all health professionals at clinics encouraged children to inhale the drug through the plastic chamber that was unpopular with many of their older child patients (p.107). Inhalers and chambers have to fit, and they only fit together when manufactured by the same pharmaceutical corporation. On several occasions patients were prescribed a change of inhaler without a change of chamber. One family discovered the mismatch during an overseas holiday [HR53].

The discrete and fashionable breath actuated inhalers called *Accuhalers* or *Turbohalers* (p.107) that were used without the chamber, do not require co-ordination of breathing with firing, as breathing triggers or actuates the firing of the drug. Their drawback is that they require much greater inspiratory effort than the metered dose inhaler used through a chamber (approximately three times for *Turbohalers* and six times for *Accuhalers*). Thus blue breath actuated inhalers might fail to relieve asthma that is already severe enough to cause airway obstruction, as the children who had returned to their chamber when troubled by their asthma had discovered for themselves (p.107). One boy lost faith in both his blue and brown *Accuhalers* because he saw no reason why the brown one should work when the blue one did not [HR49].

Nebulisers were used in hospital or in GP surgeries, but increasingly health professionals at the study hospital were treating acute asthma with metered dose inhalers plus chambers. Their therapeutic action, supported by the NAC (2000), had, however,

the potential side-effect of reducing the status of hospital therapy. One woman complained that she had made several night time trips with her son to the hospital only to be treated there as she had been treating him at home[22]. Moreover her son had a nebuliser at home that he found better than his metered dose inhaler plus chamber when his asthma was at its worst [MI20]. Her belief that the nebuliser, by moistening the medicine, made it less irritant to breathe in, was relegated to the comfort of the placebo by some health professionals.

The diversity of the drug management of asthma in terms of its pharmacology and its mode of delivery increases the scope for therapeutic choice but also for therapeutic error. Health professionals frequently recommended changes to therapies or their doses, and parents or their children occasionally responded that the change had been tried already, and had failed. Inhaler technique when inspected, was often found to be wrong. Masks were held over faces for 10 seconds rather than 30 seconds; 10 deep breaths were taken instead of five, and two or five but not 10, doses of blue inhaler were the maximum taken at any one time. Inhalers were not shaken before attaching to the chamber, or were not detached and shaken and reattached between doses; breaths were not deep enough or too deep; chamber valves did not click and chambers were not tilted. "I've been doing it all wrong. Even after four years it's so confusing" [GP24]. Prout and Christensen (1996) relate the complexity of inhaler use to medical surveillance of their users: identification of faulty technique necessitates "reprogramm[ing] the users through the techniques of training and monitoring" (ibid:207). A further attempt at reprogramming [GP24] was made at the clinic, but whether her confidence could be reprogrammed is less certain. The frequency of what might be termed unintentional non-compliance and its destructive potential for family confidence makes its sensitive management by health professionals a core challenge in their role in the management of asthma from the inside.

5.4.3b Managing asthma from the outside

At clinics and in the literature medical advice focused upon three areas: tobacco smoke and other indoor pollutants, exercise and allergens, again especially indoor. Avoidance of smoking – both active (smoking by the asthmatic) and passive (inhalation of the

[22] I explained to her the importance of the hospital's other rapid interventions, but she remained unconvinced.

smoke of others) was universally stressed: "families should be encouraged to stop smoking, or smoke in areas away from children and outside the house" (Rees and Kanabar, 2000:48). Health professionals usually asked teenagers if they smoked. A girl said no initially[23], but admitted she did so after her friend told the health professional [GP29]. Her friend laughed as she said it and nudged playfully at her companion, but her tone of voice and the intensity with which she looked at the health professional spoke of a deeper concern, as was her assertion, still laughing, that her friend should stop. The mother of another teenage boy said in clinic that she thought he had started smoking again after promising to stop – her son remained silent [HR105/C18].

Those that spoke about their smoking in clinic said only that they smoked because their friends did[24]. All were urged to stop and all promised to try to, but in my assessment, with varying degrees of sincerity. The role of smoking in their lives is evidenced by two of the boys' acknowledgement that their asthma had worsened since they started smoking. M18 told me that her son's younger sister had first alerted her to his smoking, and when she asked him, he had offered her a cigarette, she being a smoker as well. She, as well as his health professional, had urged him to stop, not only because his own asthma had worsened, but also because a sibling had died during an asthma attack. He had promised he would stop, but his mother believed that if he had, he had started again as a relative, who being a non-smoker was sensitive to the smell of tobacco smoke, had smelt it on his clothes. "He won't listen" his mother kept repeating, his "problem is he thinks he doesn't have asthma. He won't accept it. He tries to be just like all the other kids". Her son had originally consented to interview, but changed his mind.

Health professionals advocated also against aerosol perfumes, deodorants and hairsprays to the dismay of some of their patients and their parents (p.111). By contrast, exercise was strongly encouraged in order to maintain and even improve lung function. In particular, Barnes and Godfrey (2000) recommend swimming in the hot humid environment provided by indoor pools as that reduces the risk of inhalation of cold dry

[23] This was the only consultation to reveal a lie. Fainzang (2002) attributes patients' lies to feelings of inequality in power relationships inside the clinic, while Lee (1993) notes in general, that respondents are more likely to lie when the topic is sensitive. Smoking in relation to asthma epitomized both these conditions, and my observations of verbal and non-verbal communications pertaining to it, suggested that in several consultations, it generated considerable unease in either or both the patient and the health professional.

[24] The consultation did not reveal whether the girl's friend smoked [GP29].

air triggering asthma. Team games – the contemporary sporting equivalents of Aeneas's battles (p.3) – were also recommended perhaps for social as well as physical reasons though in school PE classes, battles might be contemporary (p.102).

The third medical focus was upon the strategies to remove or reduce indoor allergens. The mite living in house dust, especially in bedding that stimulates children's nocturnal asthma was its first target. The strategies for managing the mite (p.110) require "committed families" (BTS/SIGN, 2003:S12); so onerous are they, they are repeated here. They included protective covers for pillows and mattresses, replacement of curtains with a blind, removal of the bedroom carpet, removal of soft toys from beds, daily vacuuming and damp dusting, frequent changes of bedding and monthly freezing of remaining soft toys. A detailed 12 point list given by Tovey (1997) included also removal of upholstered and foam-filled furnishings. Recognizing the economic costs of his recommendations, Tovey (1997) provides a budget version that emphasised the attention to bedding, and regular chemical treatment, vacuuming and washing of carpets. In recognition perhaps of the social costs to women, Rees and Kanabar (2000:48) illustrate similar advice with a photograph of a man doing the vacuuming. The principal social cost to women, however, is perhaps in the washing: Tovey (1997) recommends a hot water wash of all sheets, blankets, duvets and soft toys on the bed every two to four weeks, but Hakonarson and Grunstein (1997) prefer weekly. Worse, as the milder the asthma the greater the benefit, the potential reward is less when asthma is less severe, and, as discovered by M17 (p.110), is less likely when it is severe (ibid). Finally, when health professionals are faced with asthmatic stimuli like Barney (p.111), the "difficulty for physicians ... [is] ... that pets may develop an important social position in the family and patients may rather change a physician ... than remove a pet" (Tovey, 1997:1894).

5.5 CONCLUSION

In conclusion, there is a core personality to the disease of childhood asthma. Cough and wheeze (or wheeze and cough), breathlessness and chest tightness are its core symptoms; expiratory rhonchi its most pathognomic sign; a pathology visible as inflammation and muscle constriction in terminal bronchioles; and a pathophysiology that demonstrates itself as AHR. The resulting reversible airway obstruction is typically induced by certain stimuli, and other atopic diseases may be present in the child or in the family. Severe asthma is likely to be severe in both its acute and chronic dimensions; to have multiple identified stimuli of which at least some are atopic in nature; to persist with age, and even if it improves, to worsen again in adult life. Mild asthma is likely to be mild in both its acute and chronic dimensions; to have few identified and mostly non-atopic stimuli, especially respiratory infections and exercise; and to improve with age, and possibly to disappear altogether. But in happy wheezers and wheezy bronchitics it may not be asthma. Asthma is uncertain at its edges, and what, and where, its edges are, are equally uncertain. Thus as with its illness, asthma as a disease might both be, and be not, especially as having no diagnostic test it might be difficult to know, and equally difficult not to.

The chapter has constructed a family of relationships between various asthmas. Firstly, relationships between asthma in the patient and asthma in the health professional; secondly, relationships between asthma in the individual patient and asthma in the population; thirdly, relationships between asthma in the population and asthma in medicine; and lastly, relationships between asthma in health professionals and asthma in medicine. Thus asthma it has represented as residing in four bodies – the patient, the population, the health professional and medicine. Two are lay – the body that is the asthmatic population and the body of the asthmatic patient. The other two are medical – the body of medical knowledge and the body that is the intellect and experience of the health professional. Two are individual – the patient and the health professional; the other two are multiple – the population and medicine. Relationships between them are complex, and again asthma might be in one, what it might not be in another.

This chapter and the previous chapter have therefore, highlighted the variability of, and variation in, asthma, and the uncertainty of, and uncertainties about, it. Both have suggested also, the existence of asthma in other than the ill/diseased body of the child/patient, namely the family in the previous chapter, and the population, the health professional and medicine in this chapter. The next chapter travels even further with asthma beyond the family and the free garden into its pleasant land.

She went to check her son. His asthma had been bad that day and he was coughing a lot. He was dead and his brother C18, was asleep beside him.

C7's uncle was sitting on a garden wall when his neighbour spotted him. He had locked himself out of his house and his blue inhaler was inside. She drove him to a friend nearby who had oxygen at home. The emergency services arrived a few minutes later but he was unconscious by then. He was on a ventilator for two days, in a wheelchair for several months and is now partially sighted.

GP36, who has had asthma since a child, was rushed to hospital after her husband cut the grass. Sometimes he carries her into her GP practice saying she cannot breathe, and that her inhalers and home nebuliser are not helping. She gets better with the same treatment in the practice nebuliser.

HR51 often feels breathless at school. His blue inhaler helps but being excused lessons and resting in the sickroom helps more.

1C4 had no more trouble with her breathing during PE lessons after she stopped her inhalers.

If C5 forgets his inhaler he does not want to do PE. He remembers a bad attack when riding his bike. It happened a few hours after his GP had advised him to reduce his inhalers, but before he had done so. His worst attack came on in an overseas airport during a family row. His blue inhaler did not help, but he got better after he got away from everybody, and sat under an air conditioning duct.

Sticking her head out of the window helped C23's asthma during an attack on an overseas school trip. It started just before a reprimand for bad behaviour. This was the first time fresh air had helped, but telephoning her mother helped even more.

Since her early teens GP39 has had attacks of breathlessness, chest tightness and coughing. These had been particularly troublesome since a recent illness during which

she felt she had damaged her throat from constant coughing. Her cough left her so breathless that she was panting as soon as she left the house. She had tried a blue inhaler but felt she had been unable to breathe deeply enough to get it into her lungs. It did though, relieve a ball in her throat that she tried constantly to swallow. The ball was worse after coughing, in bed at night and when she was feeling stressed or tired. At its worst she felt as though her throat was closing and she had to arch her head back to keep it open.

The previous week, when the sister of GP17 had been very angry and tearful, her chest tightened and she had difficulty breathing. Since then her chest had felt tight when she exercised, and she had begun to cough in her sleep. When awake often she had a feeling in her throat that made her want to cough, so she tried, and when the cough came, the feeling went away for a little while. Her older asthmatic brother interrupted her to complain bitterly that her constant coughing noises were driving him mad and that she was doing it to annoy him. She laughed and gave him a mischievous glance.

C2 coughs in her sleep. She coughs more if reprimanded. Her mother leaves her to cry and to cough until both start to quieten. Then she gives her, her inhaler.

GP77 coughed mainly when he woke up. A few weeks of a blue inhaler stopped his cough, but by then his younger brother had started coughing as well. The boys share a bedroom, and according to their mother had coughing competitions first thing in the morning.

The friend of GP29 has never had a blue inhaler, but she says she has an asthmatic cough in her medical notes.

Chapter 6 ASTHMA IN THE PLEASANT LAND

6.1 INTRODUCTION

This chapter is about asthma in the other, and the role of others in asthma. In the re-presentations with which it opened, I was the other, but as I concealed myself in the realist style of writing (Van Maanen, 1988) you, the reader, replace me. Do you detect asthma in all these others? And how certain are you? I have introduced you to asthma as a sickness, and you as an other, play the critical role in this "external and public mode of unhealth. Sickness is a social role, a status, a negotiated position in the world, a bargain struck between the person ... [and] society" (Marinker, 1975:83)[1]. As he has made clear already, sickness is most certain when it is founded upon the possession of that "much treasured gift, the disease. Sickness based on illness[2] alone is a most uncertain status" (ibid:83). This chapter is about the sickness of asthma. It presents its personality as a sickness, and to emphasise its focus upon the role of the other in sickness, it presents my etic constructs of asthma, created out of others' stories of asthma. As some are not of asthmas witnessed, but of asthmas transmitted by people's words, images and ideas – as "atom[s] of the mind" (Gunn, 1956:7) – some are those of the double other – my respondent and myself.

Yet it might seem as though the other has played the major role in asthma throughout this dissertation. Mothers were the main contributors to asthma in the family, and in the free garden, medicine was the other in relation to the families' asthma. Mothers and all family members were exempted from the status of other as Helman's (2001) illness definition (p.76) includes those around the ill person, while medicine's contribution was restricted to its professional and intellectual spaces. Here, both become others, not in the family or the free garden, but in Teesside. Further, as I have democratized asthma (p.4), their diagnostic expertise derived from their status as parents or physicians of asthmatics

[1] There are two versions of sickness in the anthropological literature. The first, advocated among others by Eisenberg (1977) and Kleinman *et al* (1978), view it to be the sum of disease and illness; the second, whose supporters include Frankenberg (1980) and Young (1982), hold that it is more than the sum of the above – sickness can exist in the absence of both. I subscribe to the latter version.

[2] How certain are you that all have the illness asthma?

is not assumed. To put it colloquially and metaphorically, we begin on a level playing field on which all asthma's detectives conduct their investigation into asthma.

The sickness of asthma is analysed in several ways. Firstly, cultural and historical comparisons are drawn between it and other sicknesses especially infections. The contribution of language to their relationships is discussed, and the role of metaphors is revisited. Secondly, the analysis is extended from how asthma is perceived in others, to how people with asthma are perceived by others. It suggests that the sickness personality of asthma imparts a personality to the person who is sick with asthma. The chapter constructs various cultural personalities of asthma and reduces the personalities of asthmatics to these constructs. Thirdly, its analysis of the cultural personality of asthma and people with asthma incorporates the role of environment in shaping the personality in a way that is analogous to its influences upon the physical body. The social landscape inhabited by asthma and by people with it is, it will be argued, inseparable from both, in that certain places as well as certain people characterize the sickness of asthma.

The chapter develops the theme of uncertainty of the previous chapters into its formative principle. Its first section 'Appearances of Asthma' opens with certain asthma, which has the gift of disease. The section continues by contrasting certain asthma with uncertain asthma. Uncertain asthma is not, however, Marinker's (1975) uncertain sickness based solely on illness because it might still be based upon disease, and conversely it might not even be based upon illness. That is the uncertainty of uncertain asthma – which mode or mode(s) of unhealth, if any, is it? For that reason the labels uncertain and certain are used rather than false and true or unreal and real. It is always someone's word, but whether it is more than a word is for the other to decide. The second part of the chapter explores the 'Origins of Asthma'. Its origins shape culturally its personality in the same way that genes influence biologically the body it inhabits. Thus cause is fundamental to its cultural pathology. The final section 'Asthmatic Times in Asthmatic Spaces' brings together the influences of asthma, people and places on how I as the first other in this dissertation now know asthma in Teesside's children.

6.2 THE APPEARANCE OF ASTHMA

> Psychics and physics sound oddly companionable terms for warriors. Indeed their friendship has long been known to philosophers as Duality.
>
> Neil Gunn[3]

The appearances of certain and uncertain asthma are constructed out of the accounts of various others: local people – asthmatic families and other Teessiders – the media and the free gardeners[4]. Certain asthma is refined into ultimate asthma and uncertain asthma into the two contrasting uncertainties of hysterical asthma and benefit asthma. Ultimate, hysterical and benefit asthmas incorporate respectively the physical, mental and social dimensions of the WHO definition of health as a state of total wellbeing (1946, in Seedhouse, 2000).

6.2.1 Certain Asthma

6.2.1a According to local people

An emergent theme from home interviews was the differing attitudes held by some women to their children's asthma and the asthma of other children. Several were afraid of other children's asthma. M3 became a different woman when talking about her nephew being a page at her wedding and nearly stopping breathing while she was on her honeymoon. The cheerful matter of factness with which she had been speaking about the asthma in her sons left her as she leaned forward in her chair and spoke into the distance. When her eldest son was diagnosed her reaction was "Oh no! Here we go in and out of hospital". M2 who left her daughter to cry and cough if a reprimand from her triggered her asthma, always slept badly if her niece stayed the night even if she was perfectly well before going to bed. Her niece was HR33 who I suggested, lived under the siege of her asthma (p.99). Teachers, according to M7 had been afraid of her brother's asthma, as often she had been summoned when he had an attack, and the two women who had witnessed him stop breathing during his worst attack might have been left afraid of all asthma. The audience was bigger when C6 choked and gasped for

[3] Gunn (1956:7).
[4] The free gardeners comprise all the medical contributors to the previous chapter.

breath in a restaurant and terrified the waiter, and perhaps also other diners (p.86). Certain asthma was well known also in the community study where some women who did not have asthmatic children knew of such asthma in others, and Cornford (1999:124) identified local concerns about asthma among women whose young children consulted their GP with a cough. According to one mother, "[t]here's a lot of asthma around here and it worries me, I don't think Sophie's got asthma... [b]ut ... there's about three different children in this road with asthma".

The above descriptions have spanned over 30 years. Time has relevance because a second emergent theme was differences between past and present asthma. Most local adults stressed the relative uniformity and severity of asthma in the past – an elderly lady had fainted with the shock when her son was diagnosed over 30 years ago – and addition of past to present might have increased the contemporary significance of asthma as a sickness. Most stressed also the rarity of asthma in the past. Some had few memories of any respiratory illness, but a minority described symptoms in others that reminded them of the asthma in their children, but these children had never said they had asthma. Often a school friend of GM7 had coughed so much she had had to be excused from class. In this respect, earlier studies of British illnesses are revealing in that they include children who wheezed and had persistent coughs but asthma is never mentioned, neither by their parents nor by their doctors (Locker, 1981; Blaxter and Paterson, 1982).

Others remembered certain children as being 'chesty'[5] or having 'a bad chest' or 'just colds', suggesting that a certain level of respiratory unhealth was perceived as normal in Teesside. In support of this conclusion the elderly person who described the worst respiratory health locally during his childhood had moved into the area from the Scottish countryside when he was 10 years old. He was so struck by the coughing of his urban peers that he used to joke that in the town the birds coughed rather that sang – a joke that persists in Teesside today (Bush *et al*, 2001). The same man suggested also that fears about pulmonary tuberculosis dominated respiratory health concerns when he was a boy. Nevertheless the assertion by F6 that there cannot have been much asthma like his daughter's before she was treated, or else there would have been a lot of dead children, illustrates the prevailing view, shared with some respondents in Cornford's

[5] In this chapter all lay and professional terms or colloquialisms are enclosed in quotation marks.

(1999) study, that certain asthma had become more common. Addition of quantity to quality might also increase its significance as a sickness.

6.2.1b According to the local media

Certain asthma was easy to construct out of its reporting by the local media. In the early 1990s the Middlesbrough public library began to collate entries on asthma in one of the most widely read local newspapers, *The Evening Gazette*. As only matters of public concern are catalogued for posterity, the inclusion of asthma testifies to its local significance. The role of the media in generating public concerns rather than merely reacting to them is, however, often debated. Renn *et al* (1992) suggest that public concern about an issue is strongly influenced by its media coverage but Heyman (1998) promotes the opposite view that the media reflects rather than creates public opinion, as it is itself part of public culture. Perhaps a compromise stance is that media reporting might exacerbate local asthma, but it is unlikely to cause it in the first place.

The Evening Gazette's reporting of local asthma unites the worst of its present and past worlds. It is common and it is severe. Moreover, it is becoming ever more common, and the addition of rapid growth to quantity and quality further increases its significance. The newspaper'*s* most striking contribution to the certainty of local asthma is its headline "ASTHMA EPIDEMIC" (*The Evening Gazette*, August 16, 1996, p.3) because epidemic is a word that is powerfully imbued with meaning, both scientific and social. Last (2001:60) defines epidemic as the "occurrence in a community or region of cases of an illness ... clearly in excess of normal expectancy". It entered scientific usage at a time when disease was predominantly infectious, but its usage has since broadened scientifically as well as popularly, to non-infectious diseases (Hennekens and Buring, 1987). However its social significance is derived from its origins in infectious disease, and according to Sontag (1991), to plagues in particular, to which *The Times* was perhaps alluding in its claim that "Britain [is] the most asthma-ridden society in Europe" (July 19, 2000, p.5). The data cited by Camus (1947) (p.30) was collected during a cholera epidemic in an Algerian town whose disruption is documented by his fictitious doctor. Giesecke (1994:15-16), an epidemiologist, makes tacit reference to the social characteristics of epidemics when acknowledging that "[s]ome people ... would like to include [in their definition] something about 'sudden rise in incidence' or 'very large number of cases'". His awareness of their social significance is apparent in his

suggestion that "others might want to relate it to the public's perception of the health problem" (ibid:16). As the "word 'epidemic' has an ominous ring to it" (ibid:16), the social significance of epidemics is profoundly negative.

Epidemics are, according to Frankenberg (1992:73) created when "disease escapes the individual body into the body social and its presence is relatively unbounded in both time and space". They are experienced by societies rather than by individuals, and they are experiences beyond the control of society. Frankenberg (1992) distinguishes also between the social experience of epidemics and the personal experience of the illnesses that create them. Epidemics are created when the illness of individuals is externally narrated, and thereby transformed into a sickness that is both a social product and a social experience. Sickness is socially significant because it threatens culture's control of nature, and by extension the social order that both generates culture and is preserved by it. "Epidemics are *social* social sicknesses in which the whole social relationship between nature and culture is put in question for many individuals at the same time" (ibid:80). Thus the local paper's elevation of local asthma to an epidemic represents its ultimate socialization.

Epidemics are also, according to Frankenberg (1992:74) "supermetaphors" because metaphors and language in general, are the means by which illness is translated into sickness. It was concluded earlier that metaphors of attack in asthma are not entirely appropriate to its experience as an illness. They are, however, more appropriate to its conception as a sickness as the essence of an attack is a hostile action by a social other. Popular tracing of the source of epidemics past and present leads repeatedly to the social other – groups perceived as different and usually inferior – such as Jews, who were Erikson's victims of all nations (p.80), as the source of mediaeval plague (Frankenberg, 1992) and Africans of AIDS (Sontag, 1991). In this respect, attack serves as a supermetaphor of its sickness status, but Frankenberg (1992) is of the opinion that the epidemic source is never totally external to the social body. Epidemics can be caused by revolts from within as much as by invasions from without.

Teesside is the national capital of childhood asthma. "Child asthma on Teesside is reaching epidemic proportions and now tops a UK league, alarming figures revealed yesterday" (*The Evening Gazette*, August 16, 1996, p.3). The alarm implicit in the word

epidemic is projected onto the figures and further enhanced by Teesside's status at the top of the national league. The introduction of the national asthma league takes asthma into the metaphorical sporting arena and extends the asthma epidemic from Teesside to the nation. Its local significance is reinforced by it being sufficiently important nationally to merit official recording and compilation of its statistics. Notably though the article omits any of the previously cited local asthma statistics (p.65), while national statistics might dispute the league position of Teesside's asthma[6]. As what is not said is left to the imagination of the reader, the significance of certain asthma might be increased by what is unknown about it, as well as what is known.

Epidemics have the greatest cultural resonance when the sickness is new. Another article on asthma reinforces the newness of Teesside's asthma epidemic (*The Evening Gazette*, October 8, 1997, p.14) by advising the public on how to treat asthma. Subliminally it boosts the status of certain asthma as it conveys the dual implication that the public does not know because the epidemic is new, but that it should know because it is an epidemic. An asthma attack may arrive without warning and to paraphrase a public health education campaign promoting resuscitation skills, there is unlikely to be a doctor in the bus queue. In consequence the asthma epidemic is no longer the sole property of asthmatics, their families and their health professionals – the central characters of the dissertation thus far. It has become important enough to be everybody's business: asthma has escaped from the family home and the free garden onto the streets.

The Evening Gazette's reporting of professional reactions to asthma bolsters its status on the streets. Local health professionals are quoted as expressing concern that asthma is increasing in Teesside, particularly among children (June 7, 1995, p.7) and that it "IS a serious problem for children in Teesside" (September 13, 1996, p.14). Cleveland Education Authority, who had by early 1995 distributed written guidelines on the management of asthma in the classroom, is described as a national leader in the formulation of an asthma policy for schools (September 13, 1996, p.14). Finally, its reporting of asthma's economic costs has added significance as Teesside's poverty frequently hits its headlines[7]. Asthma's costs to the region increased from £3.6 million –

[6] The Northeast and Yorkshire came sixth out of the eight regions in Kaur *et al*'s (1998) national study reporting prevalences of 12-14 year old children who had ever had asthma.

[7] A qualitative assessment gleaned from billboards in the streets, front page of local newspapers in newsagents and reading other people's newspapers on public transport.

an average of £6.43 per head of population – in 1992 to £4.7 million or £8.37 per head in 1994. In keeping with local media's positioning of it at the top of the national league, the increased spending of over 30% far exceeded the national average figure of around 20% (June 7, 1995, p.7). The economic costs of asthma are borne by society and are transmitted from asthmatics to non-asthmatics: asthma is not contagious, but its costs are. It can, according to Rose and Manderson (2000:347) be "represented as public health risks – where the cost to 'the public' is defined as financial, not infectious".

Moving finally and briefly from the local newspaper to local television, a short item on the local news highlighted both the qualitative and quantitative significance of local asthma. A seven year old girl from Sunderland had just died of asthma and a recent study by researchers at Sunderland University[8] had found that nearly a quarter of local children had asthma (*Look North*, BBC1, 24 January, 2002, 2225-2230hrs). What I remember though, without recourse to my notes, was its image of children skipping and talking in the school playground. "All these children have something in common. They have asthma" said the voice in the background. Do they, I wondered, and if so, had the scene been created for the cameras, or were children with asthma now being segregated from their peers in all physical activity, not just school sports (p.102)? Irrespective of its authenticity it portrayed asthma as a hidden threat to all our children. Local television's portrayal of certain asthma was also powerfully, if indirectly, evoked by its reaction to a study of the health impact of industrial pollution from a coking works. The study generated considerable public interest, but when the results were made public

> "local television, who had covered the story from the beginning, did not broadcast the findings, and instead showed a piece on a new study into childhood asthma and industrial air pollution" (Moffatt *et al*, 1995:891).

6.2.1c According to the free gardeners

Health professionals promote asthma in a variety of ways that emphasise the certainty of its existence. Their advice to children and their parents about how to recognize and respond to severe asthma introduces it to them when it might otherwise have remained unknown. For reasons that are personal, professional or a mix of both, some health

[8] The study following the ISAAC protocol (p.137) recorded asthma in 22.3%, and wheeze in 31.3%, of 13-14 year old children in the north east of England (Shamssain and Shamsian, 2001).

professionals may promote certain asthma more fervently than others. Some had asthma themselves or in their families, or a particular interest in asthma. One GP's interest in asthma (p.147) had like mine (p.6), arisen out of a memorable encounter with a patient. Health professionals also promote asthma indirectly via patient literature. Leaflets may be given to patients at clinics or scattered in waiting rooms or other community spaces, while a range of comics, puzzles, colouring books, stickers and badges has been designed for children. Though educational in intent and generally reassuring in delivery, they nonetheless promote asthma as worthy of the patient's attention in the same way that the media reports asthma as worthy of society's attention. Several parents commented that both medicine and the media publicize asthma and its publicity had according to one man "made asthma important" [FRI3].

A recurrent theme of the children's material is that certain asthma is active asthma. Their asthmatics – children and cartoon characters such as Desmond Dragon and Monty Martian[9] – lead active and often sporting lives. By overcoming their unhealth, such characters bolster the image of both asthma and people with asthma. In Australia health promoters have used famous asthmatic athletes to front asthma campaigns in the national media (Rose and Manderson, 2000). There would have been plenty to choose from if Australian athletes mirror their American counterparts who took part in the 1996 Olympic Games at Atlanta. The prevalence of asthma was higher in the American athletes than in the general population, especially in sports where healthy lungs are a premium. Nearly half the cyclists and mountain bikers had "active asthma" (Weiler *et al,* 1998:722). One participant's experience of New Zealand in the 1970s epitomized active asthma in healthy asthmatics. Health professionals promoted exercise to his asthmatic son and the family was surrounded with exercising asthmatics. Many asthmatics jogged to and from their workplace and the rugby team in which he played had eight asthmatics. All took their blue inhaler before the match and left them on a table specially provided in the changing room so that further preventive puffs could be taken at half-time [GM7]. A striking contrast was, however, painted by a local health professional. Asthma is common in Teesside as in New Zealand: so common in fact that she had begun to think of it as being almost normal, but it is unhealthy. She thought that local people, even young people had very low expectations of their own and others'

[9] Desmond Dragon requires healthy lungs to breathe fire; Monty Martian, by contrast, is named after the drug monteleucast.

health. It was, she said, normal to be unhealthy in Teesside, and asthma was a particularly common local manifestation of unhealth in children.

A particularly dramatic negative portrayal of asthma by its free gardeners used it in a public health campaign that took it from the free garden into the streets, most visibly on a poster displayed in bus shelters (North East Against Tobacco; Health Action Tyne & Wear). Its asthma was unhealthy and miserable and belonged to children as both artist and subject. It featured a child's drawing of a girl whose bright blue and oversized face and hands symbolize asthma's severity. Her down-turned mouth symbolizes its misery though its redness sacrifices biological authenticity for artistic effect. The face is according to Sontag (1991) both privileged by and separated from the body in western culture. In consequence "however lethal, illnesses ... that do not damage or deform the face never arouse the deepest dread" (ibid:126). The face is the principal identifier and signifier of the person and has a vital role in communication and sensation. In all these attributes hands come second to the face, so perhaps the significance of the transformative power of illness can be extended to them. Sontag (1991) identifies the transformative power of illness as central to its stigmatizing potential. Transformations that are permanent and especially those that are progressive are the most stigmatizing. Blueness in life is usually reversible, so perhaps rather than stigmatizing it as an illness, its irreversibility on the leaflets and posters advertizes it as a sickness.

Asthma is also irreversibly blue in the otherwise black caption, in childish writing, that reads, "This is how my *asthma* makes me feel. Your smoke gives me *asthma*". The health promotion message – distinguished by its capitals and typewritten script – at the bottom of the picture "STUB IT OUT IF THERE'S A KID ABOUT" confirms that this asthma belongs to an anti-smoking campaign. However, the role of the child, the colour of asthma, the size of feel, and the underlining of both asthma and feel, gives its immediate impact to that child's asthma experience. Preventing asthma in children is worth not smoking for. The child status of the asthmatic portrait is extremely significant because the "image of sick child is a potent one" (James, 1998:97). "[O]ur most protective and ethically sensitive relationship [is] towards children ... To deny a sick child the sick role is a particularly inhumane act" (Siegler and Osmond, 1979:151). To make the child ill in the first place is more inhumane still.

The poster colours asthma with the blueness of acute attacks which frightened children's families, but medicine's focus is increasingly on chronic asthma that rarely causes cyanosis. While it might be no more than a gimmick to catch the public's eye and to shock its psyche, there are signs of a continuing counter culture of blue asthma in medicine. Asthma was a focus of medical media attention in the 1960s when mortality rates rose sharply in several countries, the UK included, and again in the following decade, though the second mortality epidemic was confined to New Zealand (Robertson *et al*, 1995; Beasley *et al*, 1997). Though iatrogenesis was the main cause – the adverse cardiac effects of certain potent β2 agonist inhalers – and elderly people with cardiac problems the main victims, the cultural shorthand is that asthma can kill. Moreover, the asthma that can kill is simply the asthmatic state – the literal translation of *status asthmaticus* whose medical usage denotes life-threatening asthma. Thus the language of medicine renders all asthma potentially fatal.

6.2.1d Ultimate asthma

Deaths from asthma are its greatest advertisement as a sickness because they signify the asthma that is the most certain of them all. GP88 whose asthma began when she was a child did not have "the asthma you can die from". That asthma had killed the brother of C18, and childhood friends of F6 and M13. Charlotte Coleman, the actress best known for her role in the film *Four Weddings and a Funeral* died of a "massive asthma attack" (BBC1 News, 17 November 2001, 2200-2220 hours). *The Evening Gazette* personalized its asthma epidemic with the "schoolboy tragedy" (August 16, 1996, p.3) of a teenager dying in a friend's flat. Another local death several years ago was more public. A young man walked into a bank. At the counter he pulled out an inhaler. As he walked towards the door of the bank he collapsed and died. These sicknesses were of the highest status: "[b]est is an acute physical disease in a young man[10] quickly determined by recovery or death – either will do, both are equally regarded" (Marinker, 1975:83). As his death from asthma is still talked about locally, it is continuing to contribute culturally to the local asthma epidemic via its transmission through the community as an idea. "[I]deas may" according to Audy and Dunn (1974 in Trostle and Sommerfeld, 1996:264) "be likened to infectious particles, transmitted among people who may be susceptible or who may also develop resistance (immunity)". Susceptible people become afraid "of the

[10] Or a celebrity.

word asthma because you hear of people dying of attacks – coming on sudden, like" [MI8].

Though asthma rarely kills, if its potential to kill is transmitted to susceptible people – asthmatics and non-asthmatics alike – all asthma becomes potentially fatal and all people with asthma in danger of dying.

This section has described the asthma to which people are most likely to remain susceptible; it turns now to the uncertain asthma to which resistance is most likely to develop.

6.2.2 Uncertain Asthma

6.2.2a According to local people

The woman whose fear of her nephew's asthma opened the previous section, had in fact, had two reactions to her son's diagnosis. Her other reaction was "Not another one on the bandwagon!" [MI3]. The bandwagon represents a doubting of asthma in others that recurred during fieldwork irrespective of whether or not the respondent had asthma or had asthma in the family. As the other usually said they had a medical diagnosis of asthma, doubting extended from asthma to health professionals.

Virtually all contributors believed health professionals had made asthma more common, but many were less certain that they had made it more severe as well. Some suggested doctors had failed to diagnose asthma in the past. GM7's school friend who had coughed so much that she disturbed lessons has since been diagnosed with asthma. Her daughter added that in the past asthma may not even have reached the doctor because "people just died then" [MI7]. The majority, however, were of the opinion that health professionals had lowered their threshold for diagnosing asthma, to the extent that some were criticised for 'fobbing off' parents with a diagnosis of asthma and a prescription for an inhaler. In so doing they contributed to "the culture of asthma ... by see[ing] it [asthma] as the easy answer to children having coughs and chests ... it's a cop-out for the medical profession" [FI14]. The prevalence of asthmaphilic (p.173) or "'asthma happy'" doctors reported by local residents in a previous study did not appear to have decreased (Hudson *et al*, 1998:23). Local people's questioning of its medical diagnosis

of asthma is doubly significant. Firstly, they are challenging the authority of a more powerful group that claims expert status (Moffatt *et al*, 1995). Secondly, their challenge separates the two elements of Cassell's (1976) definition of disease (p.4), namely its origins in organs and its diagnosis by doctors. Locals dispute the disease status of uncertain asthma, thus they uncouple the diagnosis of asthma from the disease of asthma, and thereby extend the sickness of asthma beyond its representation as a disease and/or illness to a diagnosis – a word.

Many of asthma's lay diagnosticians commented also that the medical threshold for giving significance to unhealth in general had fallen – a view that is supported by the following interview extract from Locker's (1981:90) study of how mothers categorize illnesses in their children.

> "(Mrs P) 'And I told them about the bronchitis and the doctor said, 'Tell me someone who hasn't had bronchitis...'
>
> (Int) 'So you don't think Lindsay's abnormal in that respect?'
>
> (Mrs P) 'I guess not by what the doctor said'"

Though Mrs P appears less certain than her doctor of her daughter's normality, many in this study extended the temporal lowering of the threshold for the significance of unhealth from health professionals to the general public. More was accepted in the past as being normal. There were two elements to this acceptance: recognition and tolerance. Normal symptoms were not recognized as originating out of illness or if they were ascribed to illness, the illness was unworthy of medical attention, especially before the advent of the NHS that is free at the point of delivery. In Teesside's past " you just put up with things, now you get a leaflet from *Boots*" [FRI3] or you "take them to the doctor for the least little thing" [MI14] because "people just want a name for everything" [FI25].

Some, especially women and younger respondents, felt that too much had been put up with in the past. Their views embrace the WHO's positive conception of health as multidimensional well-beings, or what Thomas (1979:45) summarizes succinctly as a "seeking [of] more exuberance in living". These contrasted with the dominant perceptions of health in Blaxter and Patterson's (1982) study of women in a Scottish

city as being not ill and well enough to carry on normally. Interestingly, healthy children avoided chest complaints in particular. Their respondents were working class and Blaxter and Patterson (ibid) suggested that lower social classes tend to perceive health as an absence of unhealth, with the latter being defined as above in functional terms, while higher social classes hold more idealistic conceptions of health. The difficulties described earlier in recruiting poorer families may have contributed to the present findings but women attending the community centre in a deprived location in Teesside spoke similarly. As confirmation, at a health fair at the community centre, the stalls advertising alternative, complimentary or holistic therapies were far busier than those advising on how to improve heating efficiency inside the home, treat and prevent back pain, better the family diet and stop smoking. Teesside's women and younger people would therefore, appear to have more in common with those participating in a later and much larger survey by Blaxter (1995) which did not reveal any class differences in perceptions of health as being not unhealthy.

Conversely, others felt that too little was put up with in the present, sharing the view, forthrightly expressed by F25 that "[w]e've become a nation of bloody hypochondriacs instead of just getting on with it". Such sentiments are expanded upon by Thomas (1979:45-47) who chastises us because

> "we have become obsessed with Health ...We do not seem to be seeking more exuberance in living as much as staving off failure... We have lost all confidence in the human body. The new consensus is that we are badly designed, intrinsically fallible, vulnerable to a host of hostile influences inside and around us... The new danger to our well-being is in becoming a nation of healthy hypochondriacs, living gingerly, worrying ourselves half to death".

We are, according to Brandt (1997), more likely to focus on our health when change and chaos characterize our social world; we turn inwards in search of order in ourselves, and of control over our bodies[11]. Risk, uncertainty and unpredictability disorder us, and Beck (1992) relates our hesitations and fears to the breakdown in traditional ways of coping with stresses and uncertainties that are moreover, being cast increasingly as falling within the domain of individual, as opposed to social, responsibility (Brandt, 1997). Subscribers to Beck's (ibid) risk society are further burdened by the criticisms levied at the most positive conceptions of health including those of the WHO (1946),

[11] I am confining my discussion to contemporary western society as our perceptions of and responses to stress are influenced by cultural and historical processes (Helman, 2001; Porter, 2002).

that they are unattainable (Seedhouse, 2000). Hence society is put at risk of suffering the ill effects of a shattered idealism.

Asthma was doubted in Thomas's healthy hypochondriacs when it did not behave as befitted the doubters' prototypes of certain asthma. It might as C15 observed, get better without any treatment. Her scepticism regarding a classmate's asthma emerged clearly when I[12] asked her

> "(Your school, people in your class at school. Have you seen any of them have an asthma attack?)
>
> No. I can remember a while back when [child's name], I don't know whether he was having an asthma attack, but one of the class came up to the teacher and said I think [child's name] is having an asthma attack, 'cos he was sitting on the floor, doing that {mimes gasping for breath}. We don't know if he did.
>
> (Do you know what the teacher did?)
>
> I think she just went over".

Thus she doubted his asthma because it got better without a blue inhaler – their teacher's attention was sufficient.

Asthma was therefore, uncertain if it did not conform to expectations of asthma derived from personal experience or from witnessing it in known asthmatics, or from others' accounts of it in themselves, or in others. However, before asthma could be doubted it had to be known through relationships with others – families, neighbours, friends – through which it was sensed or was discussed. When I asked M16 if she knew of any other children with asthma she drew a detailed comparison of the asthma in her daughter, her neighbour's son and her neighbour's son's friend. Her neighbour's son's asthma was much less severe than her daughter's asthma and his friend's asthma was much less severe than his. Her neighbour had told her that her son's friend never needed his inhalers despite playing outside in all seasons while her son needed his inhalers to keep up with him. C16 though, would have been incapable of such play even with her inhalers. However, her certainty about asthma in children she knew, evaporated when we moved onto asthma in Teesside. She became extremely reluctant to give her own

[12] My contributions are in parentheses throughout the chapter.

opinion saying only, "Well, there's more kids with it, but whether that's because they are calling it asthma". Her use of the word they evoked a contrast between 'I' and 'they'

that emerged in several interviews. 'I' autographed accounts of known asthmatics. 'They' appeared to be the impersonal 'they' of strangers that went beyond the 'they' of local health professionals, and 'they' were presented with a mixture of uncertainty and distrust. 'I' re-emerged in this woman's conclusion, "I don't really know what is going on. I only know what I see". What 'they' saw she could not see or more generally sense, thus asthma was more likely to be uncertain when it was the insensible asthma of the impersonal 'they' of statistics and professionals.

Distrust of unknown asthma appeared also to be rooted in the evidence on which it was based, and the frequency with which it occurred.

> "*Every other* mother you speak to, they *say* their child has asthma"
> [MI16, emphasis added]

> "*[E]verything* is asthma.
>
> (You feel that round here?)
>
> *Everybody says*, or you know I am sick of *people saying* my so and so's got asthma, so and so's got asthma, so and so's got asthma"
> [MI14, emphasis added]

> "(Do you think asthma is getting more common?)
>
> "Well, that's what the *statistics say*"
> [MI17, emphasis added]

Too much asthma is said and too little asthma is sensed.

Continuing M17's interview revealed another common theme about local perceptions of local asthma, namely that even if it appeared certain initially, it became uncertain on deeper exploration.

> "(Is there a lot of asthma in these schools?)
>
> Yes, I think it's the area actually... There certainly seems to be more around this area. I mean I would say that more than 50% of the children down at [local school] have got asthma.
>
> (Really? That many?)
>
> Yeah, or they say they have.
>
> (They say they have?)

> Well, you know, I don't know. They talk about attendance not good you know. They'll say I was bad with my asthma, and I would say it's about half of them" [MI17]

Inhalers emerged as symbolic of uncertain asthma. M10 talked about her daughter "with asthma" but when asked about other children 'with asthma' she converted them into children "with inhalers". When asked why, she replied that she wondered if all really had asthma. As a classroom assistant she had never recognized asthma at work, but she had seen many children use their inhalers because they said their asthma was troubling them. Her separation between the certain asthma of her daughter and the inhalers used by the children in her class suggests that for her, children "with inhalers" are pathognomonic of children with uncertain asthma. Her scepticism contrasts, however, the schools attended by two contributors to Gabe *et al*'s (2002) study, where possession of an inhaler validated the claim to asthma. It challenges also, the medical diagnostic role of inhalers in asthma (p.182).

A final theme to emerge from local people's doubting of asthma dismisses uncertain asthma as having more style than substance. When M3's eldest son began nursery school she told his teacher that he was asthmatic. "'Oh, don't worry!'" his teacher replied, "'You're the odd one out if you don't have it these days ... Just add yours to the pile'". She produced a large box full of inhalers but reassured his mother that her son would probably never need his. Inhalers might be fashion accessories (p.107), but this woman has gone much further in attributing asthma to fashion.

According to the local media

Uncertain asthma was not detected as Marinker's (1975:83) "treasured gift of disease" was always in its possession.

According to the free gardeners

There was a consensus among local health professionals that asthma was "very popular around here", as one remarked with a wry smile. The majority including those distant from Teesside, shared the public's view that they personally, and their profession in general, were diagnosing more asthma than their predecessors. Most attributed their diagnostic increase to a combination of an increase in – their prototype (p.161) – of asthma, and to past under-diagnosis.

Cultural reasons were, however, also suggested. One health professional cited treatment advances as encouraging the diagnosis of asthma, in particular the introduction of selective β2 agonists in the late 1960s and inhaled steroids in the early 1970s (Christie, 1994) that offered the first effective preventive therapy for asthma. Therapeutic improvements make diagnoses more acceptable to patients, and perhaps also to health professionals, as the word can be better treated. Silverman and Wilson (2000) suggest a change in wording from wheezy bronchitis to asthma in consequence. Secondly, the increasing ethos of preventive care steered health professionals towards continuous inhaler therapy that required a diagnosis of asthma in order to justify it to patients. A third possibility related to changes in approved medical practice. As the profession is concerned that antibiotics are being over-prescribed especially for respiratory ailments, inhalers might be prescribed instead for symptoms that would previously have been diagnosed as infective, but that were now being diagnosed as asthma. All three possibilities promote uncertain asthma, as they are most likely to apply to the sorts of non-specific symptoms and signs that Shorter (1992:305) describes adeptly as being in search of a diagnosis.

A final possibility applies solely to Teesside. It was suggested by a local professional, not himself in the health professions, when he recalled a meeting with a local community paediatrician. In the early 1990s the county of Cleveland of which Teesside is a part, was the venue for a major and very public inquiry into the medical diagnosis of child abuse which had resulted in many children being taken into local authority care. Certain local health professionals feared that the inquiry's findings, which were largely in favour of the families, would result in a severe loss of public confidence in them. They suggested that one way of rebuilding public trust would be to develop community initiatives targeting the major health concerns of the local people. Asthma was one of the targets and became incorporated thus into a public relations exercise, creating the companionable "Duality" between Gunn's (1956:7) physics and psychics. His physics was the science to which the physical atom belonged, my physics are health professionals[13]. Psychics are all with atoms of asthma in their minds.

[13] Both originate literally from *physica* "things related to nature" (*The New Oxford Dictionary of English*, 1998:1400).

Why might asthma exist in the mind irrespective of whether it exists in the body? To address this question a distinction is drawn between two types of uncertain asthma. They are presented in their extreme forms in which rather than being uncertain asthma, they are 'certainly not asthma'. However, the accounts of the asthma out of which they have been constructed usually, and as will be shown later, importantly, preserved the possibility, though not the probability, of certain asthma.

6.2.2d Hysterical asthma

Hysterical asthma is asthma is caused or exacerbated by fear of certain asthma, not asthma triggered by emotion. Several parents of asthmatic children who either worked in schools or were involved with local youth groups, described children getting out of puff on exercise and saying it was their asthma. In their opinion it was physical unfitness, not asthma. They did not doubt that the children believed they had asthma that had been triggered by exercise; neither did they doubt that their symptoms and signs had been triggered by exercise, but they attributed the children's pathologizing of them to asthma to their fear of asthma. F25 was again forthright in his assertion that "in the past when you got out of breath running, you just got out of breath, now you get asthma". Hysterical asthma might arise also by proxy when parents' fear of certain asthma caused them to "go over the top. Everything going wrong with their child is put down to asthma. They play on it, panic" [MI1]. In this instance, the children have the symptoms and the signs, and their parents diagnose them as asthma. In both cases a hysterical reaction to the sickness of certain asthma causes the symptoms and signs in the self or the child to be transformed into hysterical asthma.

Hysterical asthma has a dual status: as an illness it is certain asthma, but as a sickness its status is uncertain. As the latter it has similarities to the hysterical epidemics identified by Showalter (1997), such as gulf war syndrome, chronic fatigue syndrome and multiple personality syndrome. These, she believes are

> "epidemics of hysterical disorders, imaginary illnesses... Infectious epidemics of hysteria spread by stories circulated through self-help books, articles in newspapers and magazines, TV talk shows and series, films, the Internet, and even literary criticism. The cultural narratives of hysteria, which I call *hystories*, multiply rapidly and uncontrollably in the era of mass media, telecommunications and email" (ibid:5).

Showalter's focus is upon sicknesses that she perceives as having no organic basis. The actuality of asthma is fundamental to my analysis, hence asthma is not a hysterical epidemic, but hysteria[14] surrounding certain asthma might nevertheless contribute to its epidemic status. In this respect the response to asthma resembles public responses to epidemics of infectious disease where fear of catching the disease dominates perception and action. However, as health professionals can with greater certainty prove the absence of infection than the absence of asthma (p.150), asthma can be transmitted culturally in ways that infections cannot. Hysterical reactions might accompany infectious disease epidemics, but the infection itself cannot be transmitted by hysteria.

The term hysteria as Showalter (1997:8) notes, "has insulting connotations... [and] ...for centuries it has been used to ridicule and trivialize women's medical and political complaints". Hysteria is insulting because organic sickness has a greater social status than psychogenic sickness in modern western culture (Kirmayer, 1988; Marinker, 1975). The distinction between certain asthma and uncertain asthma is founded upon respondents' attribution or otherwise, of an organic basis or material reality to the asthma in question, hence the label hysterical asthma is implicitly derogatory. It is used despite its negative connotations for both descriptive and analytic reasons. '[H]ysterical', 'over-reacting' and 'over the top' recurred during fieldwork, while Showalter's own usage of the term has resonance with uncertain asthma. Her attribution of hysterical epidemics to a "cultural symptom of anxiety or stress" (ibid:9) that "is part of everyday life" (ibid:13) blurs the boundaries between unhealth and health, and abnormality and normality, that were equally blurred in uncertain asthma. Also, her description of hysteria as "a mimetic disorder; it mimics culturally permissible expressions of distress" (ibid:15) has, as will be suggested later, parallels with the asthma – certain as well as uncertain – that afflicts Teessiders. Finally, her reference to Shorter's (1992) symptom pool described by Shorter as templates provided by culture that represent its "collective memory of how to behave when ill" (ibid:2), echo asthma as an acceptable, even fashionable, sickness.

Furthering the analysis of Shorter's (1992) symptom pool converts it into a useful tool for expressing the uncertainty that was usually inherent in hysterical asthma. A sickness

[14] Returning to Fernandez's (1986) performative metaphor (p.94), in hysterical asthma the word asthma rather than the illness of asthma (p.96) is responsible for the performance.

that is truly psychosomatic has according to Shorter (ibid:305) as a "pre-condition ... a pool of nonspecific symptoms in search of a diagnosis". When they find their diagnosis they become its template and the sickness that it diagnoses spreads by "broadcasting this template to individuals with often quite different symptoms, who then embrace the template as an explanation of their problems" (ibid:305). As applied to hysterical asthma, the template is, however, founded upon a material reality, and the uncertainty that characterises it is whether or not the template has a material reality in the individual claiming any, or all, of its symptom pool. Moreover, temporal changes in its symptoms, such as the ascension of cough to a core and even its sole template, might legitimize the embracing of cough because coughing individuals claiming asthma might no longer have different symptoms from the diagnosis of asthma. However, asthma's symptom pool has a hierarchical structure and cough's social status in its hierarchy is disputed. Consequently, its recent rise to prominence in the symptom pool of asthma has the potential to increase the uncertainty of asthma in the present as compared to asthma in the past.

Hysterical asthma is therefore to a greater or lesser extent psychological in origin, but Kirmayer (1988:71) makes an interesting

> "split between two types of psychological causation: rational and irrational, reasoning and emotion, motivated and capricious, conscious and unconscious. When wilful or conscious action gives rise to symptoms, the person tends to be viewed as responsible ... He is mentally strong but morally weak. In contrast, unconscious or inadvertent action gives rise to symptoms for which the person is not responsible. He is not bad, but may well be perceived as mentally weak".

Hysterical asthma conforms to Kirkmayer's (ibid) second type of psychological causation.

6.2.2e Benefit asthma

Benefit asthma displays the attributes of Kirmayer's (ibid) first type of psychological causation. It is asthma caused or exacerbated by a rational calculating assessment of the potential benefits of having asthma, or having a child with asthma. Hence it is an illegitimate occupation of the sick role, or an illegitimate casting of others in it. The label 'benefit asthma', also encountered by Hudson *et al* (1998), was cast locally upon asthma used to gain social security benefits, but it is extended below to all asthma that was perceived as being used with conscious intent for secondary gain.

Many working in schools believed children made use of their inhalers and/or their asthma. Children who had no signs of asthma, but who said their asthma was bad, or asked for their inhalers during PE lessons, or when playing outside in bad weather were described as trying a "'skive' – they'll say 'I need my inhaler'. You can't say no even if they are spoofing" [MI17]. Older children were accused of using their asthma to avoid PE or as M17 intimated earlier, school altogether. Finally, a teenage boy presented a case of childhood benefit asthma that will hopefully remain hypothetical. He joked that if ever he were mugged he would pull out his inhaler and try to frighten away his attacker by telling him he might die of an asthma attack [CI5]. Hypothesising a stage further he might fake an attack of benefit asthma if his assailant were undeterred by his threat, or alternatively he might be attacked by hysterical asthma. Fraud and hysteria were differential diagnoses in nineteenth century America (Smith-Rosenberg, 1984), but should I add to my differential diagnosis the actuality of his asthma, that might be triggered by emotion or by exercise if he resisted or tried to run away?

More often, parents were again cast as principal beneficiaries. One woman was in no doubt as to asthma's economic potential,

> "Quite a few people were saying that the children had asthma, and they couldn't do this and they couldn't do that, and they were claiming money and they got money and they got washing machines and they got ten phones put in and they got the full works and they were getting money because the kids had asthma. The kids were running round the streets, they were riding bikes, they were doing things that a child who had severe asthma couldn't do. You know, even on a night they were out like nine o'clock and half past nine on a night" [MI14].

M14 was by far the most explicit about the economics of asthma but the theme of its material benefit occurred in several interviews with the parents of asthmatic children. Another woman had heard "you could get money for asthma" [MI8]. Women in the community centre also mentioned it spontaneously. One, who had an asthmatic child spoke of a neighbour who got "lots of money because her children have asthma" while a second knew one family who had got a car, and another who had got a washing machine because their child had asthma.

The money and the goods were reported as coming from two sources – government and charity. Less was known about the latter though someone knew of an application from a

family who had an annual overseas holiday and whose asthmatic child was well enough to compete regularly in sporting events. As it was a charity, those who were perceived as its undeserving recipients on the grounds of their asthma or their wealth were perhaps viewed more negatively than the undeserving recipients of government benefits. Government benefits were both material and financial. One family who lived in council housing had had central heating installed by the local council [I18]. The boy's asthma was extremely severe according to medical criteria, but the award of central heating shows that asthma could indeed be a home improver. Disability Living Allowance (DLA), a social security payment to carers of ill relatives was, however, the most commonly awarded state benefit for asthma. DLA applications require the completion of three forms by the parent, a confidential report by a professional nominated by the parent, and a statement included in one of the forms from someone who knows the child well.

DLA was not held in high regard. Most who had applied for it, or knew others who had applied, dismissed it as a lottery, irrespective of their own success or failure. M4 felt she was in an authoritative position to know. She applied successfully for DLA for her third daughter but her application failed for her fourth daughter whose asthma was much more severe. When 3C4's DLA came up for renewal she expected it to be stopped as her asthma had much improved, but it was continued. She felt she no longer deserved 3C4's DLA, but had reapplied because she deserved it for 4C4. The other woman whose application for DLA had been successful was the woman who compared the asthma of her daughter, her neighbour's son and his friend. It had been a struggle, and probably the source of her comparative analysis that was so detailed it gave the impression of having been prepared previously.

> "(What did you have to do to apply for it?)
>
> Fill books and books and books ...it's three leaflets I think they call them but they're books you know ... with repetitive questions... I was actually refused three or four times and what made me do it was because my neighbour next door, her son has asthma and she applied and got it straight away and he's really not as bad as [daughter's name], anywhere near, and I thought well I'm going to have another go at this.
>
> (How did she get it?)
>
> I don't know. I think they sit in a room and go that one can have it, that one can't" [MI16].

Others, however, suggested successful routes for avoiding the lottery. One woman in suggested that before applications were made or renewed, children with benefit asthma were taken repeatedly to their GP with exaggerated or fabricated accounts of their symptoms. Several health professionals suggested that a nebuliser for home use had until recently been symbolic of severe asthma and described by one as a "passport" to DLA. Parents' reluctance to give up home nebulisers was therefore attributed to economic as well as emotional dependence.

The above routes to success pertained solely to benefit asthma, hence those who were successful were by definition, undeserving recipients of the benefit. Whether any mother was deserving of DLA was, however, questioned by several, including the woman who struggled so hard for it.

> "[W]hen I got it I felt really guilty because it's my job anyway to look after her, not getting extra money to do it ... I only really did it out of madness because my neighbour got it. I thought 'If she can have it, I'm having it!'" [MI16]

DLA blurs the boundaries between the world of the family and the world of business, and between emotions and economics. Jobs in the latter are paid for, in the former care should be freely given. Taken to extremes a mother asking for payment for looking after her child is open to the accusation, including self-accusation, that she sees her child as an economic cost rather than as an emotional benefit.

When DLA was awarded for benefit asthma, recipients were not only undeserving, but also bad parents who put their own pleasures before the needs of their children.

> "It's dirty and rotten inside their houses ... children living in squalor ... like they can't afford decent clothes or something ... you see children that's dirty when you know that the socks haven't been washed ... you see them [their parents] walking around with cigarettes in their hands ... and I don't see call for that" [MI14].

Finally, benefit asthma gained in immoral potency when certain asthma was suspected as well. When the child of a woman in the community study was diagnosed with asthma she told me that her neighbour who has three children with asthma told her to fill out DLA forms and get them signed by her doctor. She refused to fill them in because "I would never wish asthma on my children. It's not right trying to make money out of them being ill". Why she appeared to perceive the act of applying for DLA as akin to

making asthma in her children by witchcraft, only became apparent when our conversation turned to the asthma in her neighbour's children. Her rejection of DLA seemed to be inseparable from her conception of her neighbour as a bad mother whose house was "smelly and scruffy" and who smoked in front of her children. As her neighbour's children had been in hospital with their asthma, their asthma was in her opinion certain. Its certainty added moral weight to her belief that her neighbour "deliberately made their asthma worse" before medical assessments for DLA or other benefits. When I asked how *could* she do this (with a deliberate dual meaning of practical and moral) she replied that she smoked more in front of them. As she deliberately made their suffering worse, she was guilty of child abuse. Worse still, she abused them for her own personal gain, and was personified thereby as an immoral mother who did not love her children. Thus the blurring of the boundaries between benefit asthma and certain asthma is of profound moral significance.

By contrast when families were not charged with trying to increase the contribution of certain asthma to benefit asthma, some revealed a grudging respect for those who benefited. Benefit asthma did not challenge the moral foundations of family relationships; in fact if the benefits were distributed to the entire family, and to the children especially, they enhanced them. Secondly, the benefit lottery could be mastered by those who have "a degree in benefits" [FI14]. Though said in a derogatory tone it nevertheless attributed a resourcefulness to those who overcame its unpredictability. More positively, in a poor community where educational qualifications were low and struggles with benefits were commonplace, success could be a source of community pride. It showed that "[p]eople around here aren't stupid, you know!".

Benefit asthma crosses the boundary between illness and deviance – a "deviation from social rules or norms which carries disrepute, stigma and disapproval" (Rock, 1983). While illness is a personal ascription, deviance is a social ascription. It is defined by the reaction the act engenders: "deviant behaviour is behaviour that people so label" (Becker, 1963:9). Deviance is inherent in the sick role as illness threatens the healthy functioning of society (Parsons, 1951). The sick role permits ill people to deviate temporarily from their prescribed social function without jeopardizing the social order. Its occupation is, however, socially legitimate only if illness is perceived as an undesirable state and if its occupants want to get well. Benefit asthma is illegitimate in

relation to both as it has the hallmarks of Doyal's[15] (1979:15) "form of deviance which individuals can 'choose' if they do not wish to fulfil ... their appropriate role obligations", as they might choose to exaggerate, or even to fabricate, their illness. Benefit asthma is moreover, doubly deviant because benefit asthmatics and their families steal from the public purse as well as deceiving their fellow human beings. In both respects, it is an attack upon society. However, as deviance is defined by the other, the grudging respect for benefit asthma permits its reconstruction as resistance by those with empty purses against the poverty makers, thereby transforming it into a socially legitimate effort to narrow the immoral gap between rich and poor.

Publicity, payments, public relations and public attitudes may therefore, have contributed to the causation and/or exacerbation of uncertain asthma. This section ends by reinforcing that it is the uncertainty of uncertain asthma that gives it significance beyond the psychosocial. Might hysterical or benefit asthma one day become ultimate asthma? Thus, uncertain asthma derives its significance from certain asthma: it begins as a word, but it might end as a social reality. Further, the material reality that is gifted by society to certain asthma thereby giving it its social reality is a core contributor to the potency of certain asthma, and by extension, to its uncertain counterpart. The other core contributor to the potency of both is the thus far neglected causation of certain asthma. The next section 'Origins of Asthma' speculates on this and its significance for the personalities of the sicknesses of asthma, of children with asthma and of places with asthma in them.

[15] Doyal's (1979) provides a useful but critical summary of Parson's sick role as it conflicts with her critical or political economic approach to unhealth.

6.3 ORIGINS OF ASTHMA

> 'Why me?' 'Why now?' These questions ... demand an interpretation that goes beyond the individual body and the medical diagnosis. The answer that is given transcends the search for causes and becomes a quest for meaning.
>
> Claudine Herzlich[16]

At the origin of asthma lies its cause or causes that were unknown in its original illness derivation (p.4). Causation has, however, two possible meanings in relation to an intermittent and recurrent unhealth such as asthma: the cause(s) of its first appearance and the cause(s) of its subsequent appearances. Only the first category of causation is considered in this chapter, the second category describing the agents or stimuli that trigger asthma having been discussed in the previous two chapters. The two categories of causation are discussed separately for three reasons.

Firstly, their consequences for the person are significantly different. Asthma's first appearance creates the asthmatic; its subsequent appearances merely confirm the asthmatic status. Secondly, asthma's triggers were everyday, but its origins delved deeper. Conrad (1990:1261) distinguishes between "everyday meaning [that] people create and attribute in the course of their everyday lives", and "the more 'ultimate' meaning people give the events in the context of their lives, including the more 'metaphysical' understandings ... of life, death and the unknown". Further, some of the original and subsequent causes differed, as did the certainty attributed to them. Though not all could identify the triggers of asthma in their own children, the concept of triggers appeared to be certain. By contrast, even though initially some appeared equally certain of the cause of asthma in their own child and in others, underlying ambiguities, contradictions and uncertainties gradually emerged. One contributor to the differing certainties might be that the search for the cause(s) of asthma's first appearance is dependent upon memory – upon a retrospective recall that might seem as subjective and incomplete to parents as it does to epidemiologists (Hennekens and Buring, 1987). As asthma's triggers occur repeatedly, they are more open to repeated retrospective, and also to prospective, analyses by the children and/or the parents. Thirdly, original or first cause is of great importance to the social sciences and to medicine. According to a

[16] Herzlich (1987:100).

recent medical text on asthma "[a]s the level of knowledge increases, so we move closer to causation as the defining characteristic of a disease" (McConnell and Holgate, 2000:2), while the significance of illness causation to the former is evident in Herzlich (1987).

As the primary academic focus of my research is anthropological, this section introduces three anthropological approaches to causation and discusses their relevance to medicine, which forms its second academic focus. The first anthropological approach distinguishes personal causes from natural causes (Foster and Anderson, 1978). The former invokes human agency or its spiritual representation, the latter the influence of natural forces or elements. Medicine makes a similar analytic distinction between causes that can be influenced, and those that are beyond intervention by itself or by its patients. Helman (2001) retains natural causes but divides personal causes into individual, social and spiritual. Individual causes are self-inflicted, while others are implicated in social and spiritual causes. Social others are human and alive, spiritual others divine or dead. A similar distinction between the individual and the social is drawn by medicine in its attribution of cause to individual lifestyle or to social environment.

The second approach distinguishes according to levels of causation rather than their types. Evans-Pritchard [1937] (1976), in his account of the causation of misfortune, of which illness is but one manifestation, among the Azande of the Sudan, distinguished witchcraft as its ultimate social cause from its proximate natural and individual causes. A man died while sleeping under a granary in the shade of the afternoon sun because termites had eaten away its posts causing it to fall on top of him. Termites, the granary, the heat of the sun, the man's choice of sleeping place, and perhaps his laziness were the immediate causes of his death but only witchcraft could explain why the fatal constellation of proximate causes had caused that particular man's death at that particular time in that particular place. Why him, why then, and why there?

Levels of causation are recognized by medicine, and by epidemiology in particular, which is giving increasing attention to poverty and culture as diseases' ultimate causes. Thus it links together causes such as termites' dietary preferences and witchcraft into webs of causation (Krieger, 1994), but it conceptualizes them differently. Poverty is distinguished from the lifestyle of the poor and their poor environment. "It is important

to consider whether we are dealing with structural poverty – that is characteristics that are essential to being poor – or characteristics that are associated with the poorest groups" (Rona, 2000:239). The latter are reduced to discrete elements and represented as proximate causes of disease, such as smoking or pollution, that confound poverty's relationship to disease. The concept of confounding factors is central to epidemiology but it is a consequence of its theoretical perspective "not a property of the real world" (Ludermir and Harpham, 1998:230). Wing (1993 in ibid:230) summarizes perfectly social scientists' difficulties with the concept as epidemiology's

> "belief in confounding depends on both the assumption that 'independent' variables are indeed separate things, rather than different aspects of the same things, and the assumption that even if they are different things, they can be separated from one another, i.e., taken out of context, without any obligation to put them back together again".

Thus epidemiologists separate and isolate into risk factors what social scientists wish to merge and combine (Phillimore, 1998:210), and what is confounding to epidemiologists is compounding to social scientists (Moffatt *et al*, 1995:890). From the perspective of the latter, the parts are being removed from the whole that is moreover, greater than the sum of all its parts – the essence of anthropology's holism. Cause looses its emic significance if being poor is not about living a poor life in a poor place. Moreover, levels of causation represent different orders of things – witchcraft is irreducible and termites are not witches. While culture or poverty might have nodes in epidemiologists webs, the former is Geertz's (1973) webs of significance (p.16) and the latter the web of mystification of his critic Keesing (1987) (p.17). However, Krieger's (1994) criticism that epidemiologists conceal their role as the spiders that made their webs has equal relevance to anthropologists (p.47). Finally, but importantly, I agree with Brandt (1997) that epidemiological models might satisfy my intellect, but they do not fulfil my quest for meaning, as it is substantive, not statistical significance (p.17) that I am most interested in.

The third approach, and the one adopted primarily in the following analysis, distinguishes external causes that "refer to *illness as attacking human beings from the outside"*, from internal causes that "see *illness as residing within the individual and*

connected with that person" (Herzlich, 1987:118)[17]. A classification according to space was chosen because interactions between people and their worlds recurred in respondents' accounts of causation and because space distinguishes medically between genetic and environmental causes of disease. As respondents distinguished between past and present when discussing the causes of asthma, the approach continues also the recurrent themes of the significance of space and time to asthma.

Beliefs and thoughts of local people, particularly the families with asthma, are the primary contributors to asthma's origins, but not those of children with asthma as like Gabe *et al*, (2002), I found that few shared my interest in the cause(s) of their asthma. I begin by presenting asthma's internal causes describing first those that my analysis suggests that respondents perceived as having the most direct causal and spatial relationship to asthma. The analysis continues with more indirect relationships or associations between asthma and aspects of the child's physical and psychological make-up. These provide a link to external causes that are analysed in the reverse direction beginning with those that affect the entire child rather than just the lungs. The analysis ends with asthma's most proximate external cause, but argues that it is in fact symbolic of its ultimate causes.

[17] Herzlich's (1987) spatial division bears similarities to Young's (1986) internalising and externalising medical belief systems. The former emphasize explanations originating inside the body and characterize complex or modern societies. The latter emphasize explanations originating outside the body and characterize simple or traditional societies.

6.3.1 Internal Causes

6.3.1a The family

Asthma according to most local people ran in families – many had 'asthma in the family' before asthma originated in their child. Parents referred to asthma being in the genes or being inherited – a concept of causation shared by medicine (Rees and Kanabar, 2000). However, the allergic state to which medicine ascribes such significance in the causation of asthma had a much lower profile. Some mentioned hayfever, eczema and food or skin allergies as also being 'in the family' and as being related to asthma, but others shared one man's certainty that "asthma's not an allergy ... It's something you're born with" [FI6]. Allergy if implicated, appeared to be perceived as an irritation which gave one child "twitchy airways" [MI17], rendering asthma an "irritable illness" [FI6]. More often beliefs about asthma's inheritance invoked concepts of weakness. "[I]f someone has a weakness in the lungs, then they're susceptible ... It's the weak part of the body. Poor chests are on both sides of the family ... It's just your make-up" [MI8].

6.3.1b The child

Weakness or irritation might extend from the chest to the child. Though parents did not make explicit causal connections between asthma and the physical or psychological characteristics of children, possible associations emerged in their descriptions of their own children. C8 was, his mother emphasised repeatedly, neither sporty nor good at games, but his physical incapacity was described more as part of his 'make-up' than as a consequence of his asthma. Davison *et al* (1991) introduced the concept of the 'candidate' – the person perceived by others as being the typical person to get a particular illness. Thus the candidate personifies the high risk group of epidemiology. Their study in a South Wales mining community of coronary candidates identified physical appearance as an important route to, or risk factor for, becoming a candidate. One woman in describing her surprise at her son's diagnosis disclosed her asthma 'candidate': "he wasn't your typical asthmatic as I knew then – thin, weedy, undernourished" [GMI7]. Her son had been diagnosed nearly 30 years ago but images of weakness remained in a mother's repeated usage of 'not strong' to describe her son who was "not a strong swimmer ... not strong at football" [GP35,a]. Her ascription of his weakness extended from the physical to the psychological as her son was easily upset

and was emotionally dependent on his blue inhaler. The boy remained silent. Adults with asthma interviewed by Adams *et al* (1997) and by Sweeney *at al* (2001), similarly described asthmatics as wimps and weaklings, and as "sort of decrepit" (Adams *et al*, 1997:195).

The most striking image of weakness was the invalid portrait by a mother of her 11 year old son. The boy was obese in keeping with contemporary images of physical unfitness. Asthma was only one of many health complaints, and his health had deteriorated to the extent that he rarely attended school, played sport or even ventured outside. Most of his time was spent in bed. From a medical perspective his asthma was of questionable severity and all his other health complaints were medically minor. His mother appeared to perceive his asthma as severe, but in relation to his other complaints my impression was that she believed her son to be too weak physically to fight them off or to overcome them. She never referred to his psychological state but my impression of him during two long consultations was of profound emotional withdrawal. Mostly he sat silently staring at his feet and direct questions from the health professional were met usually with monosyllabic answers, also directed at his feet [HR80,a]. Images of weakness were inherent in the boy's family as his mother was physically disabled by an unhealth that medicine perceives as having a significant psychological causation. She had also "excitable asthma" that she described as a type of asthma triggered by any heightened state of emotion.

Association of asthma with weakness is stigmatizing to asthmatics, especially to boys, who were in Williams's (2000) study more likely to try to conceal their asthma in public. A literary image[18] of asthmatics in the poem *Runt* by Rhea Tregebov (1991:24) about her asthma and her asthmatic son personifies its emasculating weakness. "Well", she writes, "Will you look at that. Runt", and later, "my runt, my single litter, small masculine self I will never be, self-sufficient".

Asthma's irritability also has the potential to extend to the entire person. From clinic observations a very tentative association is drawn between asthma and what might

[18] Portrayals of fictional asthmatics are rich sources on the appearances and personalities of asthmatics that unfortunately are beyond the scope of this dissertation. Fictional British asthmatics include Piggy in William Golding's *Lord of the Flies*, Billy Prior in Pat Barker's 'Regeneration' trilogy, Marcus in AS Byatt's *The Virgin in the Garden* and Catherine in Susan Sontag's *The Volcano Lover*.

colloquially be termed an irritable personality. ADHD gradually entered my consciousness because of surprise at the number of children described by their parents as having 'ADHD' or of being 'hyperactive', the latter being spoken with an authority that gave the adjective a diagnostic label. Whether or not parents made any causal connection between asthma and ADHD is unknown, but their association extends the irritation of the airways to an irritation of the personality. A tenuous link can, however, be made to a very small twig in the tree of medicine's discourse on asthma which implicates disturbances in the regulatory cycles of the body, resulting in an "amplified dysrhythmia", in the causation of asthma (Falliers, 1987:71). A second asthmatic personality that emerged principally from interviews was that of a caring sensitive child. One mother called her daughter a "proper mother hen" after describing how on a winter's day in the school playground she had given her gloves to a classmate who had none. Yet if friends did not want to play with her, she became extremely upset and showed it in a manner befitting the child she was or even younger [MI10]. A third asthmatic personality that emerged in both clinic consultations and home interviews was the asthmatic achiever – the children who never let their asthma stop them (p.112).

Associations between asthma and personality feature also in the medical literature. "Superior intelligence, creative genius, extraordinary personality and/or social prominence have been associated with asthma often enough to raise the question of a non-random occurrence" (Falliers, 1986:157). His sketch of the asthmatic achiever was given substance in a long running series 'Asthma among the Famous' which biographies both the asthma and the fame of the one hundred included in the 'Who's Who' of asthma (Cohen, 2002). However, while intelligence features in the majority of medical accounts of the asthmatic personality, until recently, medical texts were more critical of its remainder. Their influence on public perceptions of asthma is suggested by the lay stigma attached to 'excitable asthma' or 'nervous asthma'. Two women in the community study who attached these labels to their own childhood asthma, had been told by their parents not to mention it outside the family, and to try to conceal their symptoms in public. Writing in the decade before these women were asthmatic girls, Boland (1963:478) suggests that

> "[t]here is some evidence that a high proportion of asthmatics are to be found amongst the more intellectual section of the community; but sufferers from asthma are often more aggressive, more self-assertive and emotionally less stable than their non-asthmatic associates".

The asthmatic child "was anxious always to be at the centre of attention" (Davidson, 1954:172) – perhaps sceptics would suggest, the psychological precursor of uncertain ADHD or a benefit asthmatic. Or "persons of nervous disposition, highly strung and displaying evidence of general nervous instability" (Davidson, 1935:148), whom the same sceptics might suggest were at highest risk of hysterical asthma. Many health professionals of the time identified a type of asthma whose origins were predominately emotional and responded to 'psychological' treatment.

> "[M]edication was sternly denied to him, and his mother advised to forget that he had ever exhibited any asthmatic symptoms ... [He] suffered one attack of asthma in the succeeding four years. One threatened spasm was instantly aborted by his father's stern interjection 'Stop that' as soon as the boy began to wheeze at the dinner table" (ibid:172).

Thus medicine in earlier decades also distinguished between certain asthma and hysterical/benefit asthma and imputed to the latter negative personality traits reminiscent of the medical characterization of the female hysteric in nineteenth century America (Smith-Rosenberg, 1984)[19].

6.3.2 External Causes

Relationships between asthma and the personality and constitution of children with asthma, bridge internal and external causation as certain external causes were perceived as affecting the whole child, not merely the child's lungs. They influenced the child's physical and psychological make-up in such a way that they predisposed the child to other causes – both external and internal – of asthma. These are described as five constructs of living.

6.3.2a Stressful living

Stressful living also invokes the psychological in asthma's causation but responsibility lies with the social environment rather than the individual personality. A few parents implicated the stress of 'modern life' in the causation of asthma in children today. Only

[19] Asthma was classified in the 1950s as a psychosomatic disorder – one of the original "'holy seven' diseases" (Kimball, 1970:310) and continues to be ascribed as such in an off-shoot of the medical literature.

one specific stressor of children was identified: school aptitude tests (SATs). More commonly, stress was described in terms that were generally vague and diffuse, giving modern life the characteristics of an overarching or ultimate cause. The stressful modern life that parents referred to is conceptualized academically as the "fragmented and disorganised social relations ... 'multiple realities' and ... 'decentred' selves" that characterize "'postmodern society'" (Bury, 1997:12), and promote Beck's (1992) 'risk society'. Nostalgia for the "unifying categories of culture, social roles, self and identity" (Bury, 1997:12) of their parents' childhood may have contributed to parents' ascription of stress to their children's lives. Thomas (1979:71) enshrines the past poetically into a time when "[p]rimitive man, rose-garlanded, slept well".

Parents' inclusion of stress as a cause of asthma has earlier roots in medical writings, but in these the stressors are typically the parents themselves, the mother especially. The "over-anxious, often neurotic, mother" (Ellman, 1952:61) is a recurrent character in asthmatic families, who "must be given correct insight into the psychological aspects of asthma, such as over-protection (e.g. over-clothing at all times of the year), and abnormal anxiety" (ibid:61). Wheezy bronchitis (p.139) was, according to Rees and Kanabar (2000:1), preferred by health professionals to asthma because of a medical "belief that this would protect the parents from the label of asthma". Asthma therefore was potentially stigmatizing to parents as well as their children, but implicit also, is a medical belief that the diagnosis of wheezy bronchitis might protect the child from the parents.

De Salvo (1997:146-7) also invokes stress as a cause of asthma. Her psychological intensity is evident in her belief that asthma "is caused by abuse and that it is probably a manifestation of post-traumatic stress ... a (perhaps abusive) crisis or crises – emotional, physical, sexual, environmental – during which the infant's or child's natural ability to breathe freely has been severely compromised". The stressors proposed by De Salvo and by the medical profession were notably more concrete than those of the parents in this study, and the dysfunctional family rather than postmodern society their principal source. Both however, strongly implicate psychosocial causes of asthma, and in so doing project the physical constriction of the asthmatic airway into the psychosocial constriction of the asthmatic child.

In Teesside only mild asthma was attributed to stress, but mild asthma might become more severe either through the continued action of stress or via its synergistic interaction with other causes. How stress caused asthma or lowered resistance to its other causes, was unclear to me, but parents bridged the psychosocial and the physical when they suggested that stress might weaken the immune system – a suggestion not discounted by medicine (Martin, 1997). Thus, stressed asthmatic children were at greater risk of infections as well as of exacerbations of their asthma. The weakened immune system did not, however, appear to increase the child's risk of asthma, perhaps because of the relatively low profile of allergy which parents also associated with the immune system.

The involvement of the immune system in asthma is culturally significant as it forges another bond between asthma and infection that transports asthma into other metaphorical worlds. Firstly, Martin (1990:410) suggests that both lay and medical descriptions of the immune system conceptualize "the body as nation state at war over its external borders". The immune system distinguishes the self (nation state) from the non-self (foreign states). "Besieged by a vast array of invisible enemies, the human body enlists a remarkable complex corps of internal bodyguards to battle the invaders [Jaret, 1986:702]" (in Martin, 1990:411). The external world is therefore, foreign, hostile and threatening in a way that in its complexity and invisibility is characteristically postmodern. Nonetheless its pathogens and allergens echo the invisible arrows of witchcraft flying through the air that caused unhealth and other misfortunes among the Azande (Evans-Pritchard, [1937] 1976). The externality of the enemy – the pathogen in infections and the allergen in asthma – is also significant as it casts the unhealth of both as a "visitation" (Brandt, 1997:59) from outside. Brandt (1997) and Helman (1995) have suggested that unhealths caused by such external agents have less of a "moral valence" (Brandt, 1997:56) than those arising from within the body. They are depersonalized and thereby de-moralized, consequently sparing or absolving the unhealthy person from blame of "sin, moral turpitude and idleness" (ibid:56)[20].

However, lay descriptions of the immune system included also the concept of building up one's immune system that led to some immune responses and the bodies that housed them as being judged stronger than others (Martin, 1992). Asthma's indirect linkage to the immune system via the aegis of stress and infection associates it culturally with a

[20] Brandt (1997) excludes sexually transmitted infections from his analysis.

weakness that is both physical – an unfit immune system – and psychosocial – an inability to cope with stressful living. As well as labelling some immune systems and their owners weaker than others, these images introduce sport as a second source of metaphor that conjures up images of the idle unfit asthmatic who is too lazy and/or lacks the willpower to get into shape. They return us also to an internal cause for asthma, and to the potential 're-moralization' of asthma and 'demoralization' of the person with it.

6.3.2b Sedentary living

Physical unfitness, had however, a more direct role to play in asthma causation. Several parents described lungs lacking in strength because of lack of exercise, such that either they became asthmatic, or they increased the child's risk of developing asthma if exposed to its other causes. Like stressful living, sedentary living weakened more than the child's lungs – general physical constitution, and even moral fibre, might be adversely affected as well. Modern children lacked fresh air, spending too much time inside in front of computers, satellite television and all things technological. Their parents spoke approvingly of a time when as children they had played outside in the wind and rain and gone for long bicycle rides into the country. Then one might presume, they had come home to metaphorically, "turn off the engines and climb down into the countryside" (Thomas, 1979:71), and sleep undisturbed by asthma like his rose-garlanded primitive man. Nostalgia and beliefs about what constitutes a healthy upbringing may have influenced parents' ascription of sedentary living to asthma causation, but their belief is shared by health professionals and may have been derived from them. Moreover, Godfrey and Barnes's (1997) recommendation of team games because intermittent exercise is less likely to induce asthma could be interpreted as an antidote to the technology that facilitates the solitary existence of the asthmatic child. Sedentary living provides also a medical link between asthma and the 'diseases of civilization' such as heart disease, cerebrovascular disease, cancers and non-insulin dependent diabetes mellitus. Unlike asthma these diseases generally develop during adulthood[21], but like physical unfitness in asthma, they are associated with the 'lifestyle factors' of epidemiology, including sedentary living.

Indoor allergens, such as house dust mite, are, however, most symbolic of medicine's focus on sedentary living. Children have more opportunity to become sensitized to

[21] Non-insulin dependent diabetes mellitus is emerging in children.

indoor allergens and hence to develop asthma (Platts-Mills *et al*, 1997). The dangers of indoor living "'pathologize' the home because they invest ordinary behaviours and objects with the capacity to cause ... deadly illnesses" (Tomes, 1999:47). Tomes was writing about the "gospel of home hygiene" (ibid:54) that proselytized the United States in the late nineteenth century after the medical development of the germ theory of infectious disease. If household germs as the cause of infections are metamorphosed into allergens as the cause of asthma, the history of what were then called 'house diseases' repeats itself. Both germs and indoor allergens, such as house dust mite (specifically their faeces), moulds, animal fur and in the United States in particular, cockroaches, signify the dusty, dirty and unkempt breeding grounds of the "potentially mortal 'filth' diseases" (ibid:66). The dirt of indoor allergens also separates them culturally from the relative cleanliness of outdoor allergens, principally pollen that belongs to the healthy world of fresh air and summer sunshine that in the late nineteenth century were natural disinfectants against germs (Tomes, 1999). It separates them also from the wind and rain of their parents' childhood in Teesside.

Medicine's focus upon indoor allergens in asthma causation thus links asthma culturally and historically with infectious disease. Dirt has significance for both infections and asthma as a route by which they might acquire Brandt's (1997) "moral valence". Then as now, as Tomes (1999:64) notes "the work of cleanliness, both in symbolic and practical terms, landed squarely in women's cultural domain". Childhood asthma that is potentially stigmatizing of boys in particular, thus becomes potentially stigmatizing also of mothers and housewives. According to Tomes (1999) hygiene manuals for late nineteenth century American housewives attempted to inspire guilt and anxiety.

> "'External vigilance is the price of everything worth the having or the keeping.'. The careless woman, she warned, only came to comprehend the importance of hygiene 'when, too late, she stands beside the still form of some precious one, slain by some one of those preventible diseases that, in the coming sanitary millennium, will be reckoned akin to murders'" (Plunkett, 1885 in Tomes, 1999:64).

Douglas (1966) allies dirt with disorder and suggests that the importance attached to hygiene is governed less by fear of unhealth than by a desire to positively order or re-order the environment. In late nineteenth century America the role of order in banishing dirt extols the moral value of self-control and self-denial. "To propitiate the goddess of health we can well afford to sacrifice on her alter the superfluous draperies, carpets and

ornaments of our living and sleeping rooms" (Talbot and Richards, 1883 in Tomes, 1999:60). Today mothers of asthmatic children are encouraged similarly, to worship inside their homes (p189).

Indoor living was cited also by parents as a cause of asthma, but their concerns centred upon central heating, air conditioning and double glazing rendering air stuffy, stale and artificial. Nonetheless, their concerns about air freshness further link asthma to infection as ventilation was another concern of late nineteenth century public health. Poor ventilation reduced air quality, making it both more dirty and less fresh. "T.J. MacLagan [1880] put the premise simply in the *Popular Science Monthly*: 'Keep the windows shut, and you keep the germs [or allergens] in; open them, and they pass out with the changing air'" (Tomes, 1999:58), though other parents in Teesside today took the opposite view. Indoor living should make asthma less common because home air in modern houses without coal fires or damp and mould was cleaner.

6.3.2c Clean living

Cleanliness appeared, however, to have a dual status in relation to the origins of asthma because it was also a cause of modern asthma via a mechanism that deepened still further the relationship between asthma and infection. "There's not so many bugs as used to be. When there were lots of bugs we built up resistance. Now we don't build up resistance to anything, and asthma's one of the consequences" [FI6]. His concept of resistance links clean living to both stressful living and sedentary living. Stressful living weakens the immune system; clean living prevents the training necessary to build it up in the first place. Like sedentary living therefore, clean living prevents the body becoming strong, though it is specifically the immune system that suffers from lack of exercise. Parents' conceptions of clean living weakening the immune system are most probably derived from the 'hygiene hypothesis', first proposed in 1989. It suggests that

> "allergic diseases ... [are] prevented by infection in early childhood, transmitted by unhygienic contact with older siblings, or acquired prenatally ... Over the past century declining family size, improved household amenities and higher standards of personal cleanliness have reduced opportunities for cross-infection in young families. This may have resulted in more widespread expression of atopic disease" (Strachan, 2000:52)[22].

[22] Asthma is more prevalent in the developed world but it is emerging as an important cause of unhealth in developing countries (ISAAC, 1998). Prevalences were extremely variable, e.g. 2.8% in Addis Ababa, Ethiopia as compared with 18.4% in Ibadan, Nigeria.

The hygiene hypothesis has several cultural implications. Firstly, substitution of the pathogen for the allergen changes the nature of the enemy. The former invades from foreign lands and is the enemy of all; the latter originates within society and attacks the allergic minority only. Allergens are not weapons for most of us. Hence they are the same, not the other (Frankenberg, 1992), belonging to the familiar safe world of pets, countryside and comfortable beds that is far removed from the strange alien world of invisible enemies. The cultural consequences for asthmatics are considerable. If allergens are not enemies, their immune system becomes the aggressor that 'picks a fight', rather than the internal bodyguard that protects. Continuing the metaphor of strength, the friendly nature of the target converts the bodyguard into the bully, but it was suggested earlier that the association of the immune system with allergy conveys images of irritability rather than of weakness. The immune system has reacted to lack of exercise and loss of status – the respective biological and cultural consequences of the historical decline in the importance of infectious disease – by becoming hyperactive, or by seeking attention. Then the national soldier, now the child with ADHD.

Yet, such images of conflict and inequality are founded upon the hostile metaphors of the relationships between the immune system and micro-organisms. Martin (1990) cites the work of Fleck, a Polish biologist who in the 1930s challenged immunology's "'primitive images of war'" (ibid:420). Immunology, according to Fleck, ignored the many harmonious and healthy relationships between humans and micro organisms, citing the now familiar relationship between the human intestine and bacteria that aid digestion. It is but a small cultural step from intestinal bacteria to the intestinal worms or helminths that have been implicated in the hygiene hypothesis as the main infectious stimulants of the production by the immune system of the immunoglobulin IgE – the immunological signifier of atopic disease including asthma. Medicine's negative attitude towards worms contrasts with the positive attitude of Guatemalan and Malian villagers towards them (p.77). Their attitudes do not alter the pathological effects of their worms, but the postulated protective role of worms in asthma challenges their medical status as the ubiquitous and universal enemy.

The biological link between killing worms and causing asthma is indirect and dependent on the intermediary IgE attacking worms, hence worms do not protect against asthma. Nevertheless during a medical symposium on asthma Holt (1997:53, emphasis added)

described a deworming programme in Caracas, Venezuela that "*created* a new disease, which was inhalant allergy to HDM [house dust mite] allergens". At a higher level of cultural abstraction asthma can perhaps be portrayed as the retribution on humanity of the misunderstood and pathologically labelled microbiological world, and even of the entire natural world, of which it is a harmonious part. Hence asthma has cultural parallels with the plagues with which the spiritual world punished the social world, with an added irony that loss of the agents that punished with plagues is being implicated in epidemics of asthma and other allergies.

Returning to earth in Teesside, some women added a further cultural connotation to cleanliness by using words evocative of medical defences against the agents of infectious disease. Clean living was achieved by the processes of sterilization and disinfection that brought the practices of the hospital into the home by "all of the *Dettol* and things that people are going crazy about you know, spraying work tops with *Domestos*. It makes you wonder if we are weakening ourselves with all of this stuff" [MI15]. Irritating, rather than weakening, one physician of asthma might answer. Falliers (1987; 1988) attributes the epidemic of asthma to excessive consumption of the drugs used to treat allergies and asthma itself. Thus he metaphorizes asthma as the plague wrought upon Thebes consequent upon the sins committed unknowingly by Oedipus[23]. For the women in Teesside, however, perhaps association of cleanliness with the external world of the ill added to feelings of ambivalence over its benefits as boundaries between health and illness were no longer as secure. Clean living also brought the products of industry into the home via brand name cleaners or simply 'chemicals'. The impersonality of the latter threatened boundaries between the familiar and the alien: if pathogens were aliens, cleaning chemicals might have the potential to alienate.

[23] Falliers's idiosyncratic perspective (p.23) is made more interesting by his association with, and citation of, mainstream names in the medical literature, e.g. Barnes, Godfrey, Holgate and Naspitz. It could not be more entertaining, and as he leaves the dissertation here, I leave you with his literary "relationship between asthma ... and rhythms ... [that] encompasses more than the consonants they share, THM. (These, incidentally, sound euphonic in Greek (θM) but often seem hard to pronounce in English)" (1987:71).

6.3.2d Convenience living

Clean living was further alienated by linkage of the chemicals by which it was achieved to other industrial chemicals that eased modern life, but respondents worried, at the price of damaging health. Chemical additives to convenience foods that eased mothers' workloads and were enjoyed by their children were singled out for their potential harm. In the process women reflected the moral pressures on them as mothers and housewives. Though additives were implicated in food allergies and in hyperactivity, in a more general sense they were poisons. Poisons included also pesticides that contaminated the most 'natural' of foods – fruit and vegetables – and chemicals – hormones and antibiotics – that were fed to animals and made them unnatural. Convenience chemicals were not explicitly linked to asthma by any causal mechanisms, but they emerged as further means by which the body might become vulnerable to asthma.

The role given by parents to the modern diet in asthma causation is shared by medicine, but the latter has entirely different suspects in the dietary niches of its epidemiological web of causation. The epidemiologist's diet of formula feeds, high salt intake, lack of vitamin C and of fish oils builds a second bridge across the years between childhood asthma and the adult 'diseases of civilization' (Jarvis and Burney, 2000). Thus far medical evidence implicating diet in the causation of asthma has been inconclusive and it is of note that the candidates cited above largely comprise medicine's usual suspects[24]. Might epidemiologists be biased towards the selection for investigation of their causal role in asthma, of agents or behaviours that have been identified as either predisposing towards, or protecting against, other 'diseases of civilization'?

Although parents and medicine implicated different dietary constituents as potential causes of asthma, they shared the idea of asthma as a cost of convenience living, in the sense of it being the price of the time and labour saved in food purchase and preparation. As with clean living, such ideas potentially implicate the mother as again being most responsible for her child's asthma. Further, parental emphasis on chemicals and poisons implicated asthma as a cost of interfering with the natural order of things. M15's concerns about *Dettol* and *Domestos* extended to "all kinds of things we interfere with our ecosystem all the time ... even the foods the kids are eating. You just don't

[24] With the recent exception of breastfeeding that according to Sears *et al* (2002), might increase the child's risk of developing asthma.

know how their resistance is developing". At the heart of their uncertainties and insecurities is perhaps a feeling that in a postmodern society "[t]he only solid scientific truth about which [we] can feel totally confident is that we are profoundly ignorant about nature" (Thomas, 1979:73).

6.3.2e Polluted living

Via its association with chemicals, asthma became linked to other sicknesses such as cancer or genetic/birth defects. "[T]he so called 'Teesside Mist has long been suspected of causing ailments from asthma to birth deformities" (BBC1 *Look North*, 6 December, 1995 cited in Moffatt *et al*, 2000a:7) thus forging a link between asthma and sicknesses that both transforms the physical body and represents loss of personal and social control over it. The Teesside mist creates a relationship also between polluted living and clean living, as its chemicals are believed to pollute Teesside's air. Polluted living is, however, given its own sub-section because pollution was most people's first cause of local asthma, and in contrast to the more general effects of the other chemicals, usually pollutants specifically irritated the lungs. Hence they were asthma's most proximate cause. Further, those that mentioned both pollution and chemicals tended to describe the former as being much more certain and material, as in "I think it's the muck in the air, me" [MI5]. Its certainty and material nature emanated in part at least, from it being very local in contrast to the global harm caused by chemicals. The wider pollution picture entered Teesside only when one woman asked "Is it Chernobyl?" with a laugh and a serious expression. "I don't know" she answered herself [MI9]. Her uncertainty bore a greater resemblance to the concerns of M15 about the pollution of modern life than those of M5 about the pollution of Teesside.

Notably among Teessiders, pollution was almost exclusively outdoor pollution. Most of the fieldwork was conducted after the poster campaign but cigarette smoke was never mentioned as a pollutant or as a cause of asthma. Passive smoking – inhalation of the smoke of others – and prenatal exposure via women smoking during pregnancy has been the focus of considerable medical attention though "[e]pidemiological studies have been *unable* to show that maternal smoking in pregnancy causes wheezing illness in early childhood" (Jarvis and Burney, 2000:23, emphasis added). The low profile given to smoking echoes Cornford's conclusion that "although they [local people] recognised

that smoking might be partially the cause of the problem [chest diseases] too much was made of it and pollution was the main cause" (1999:197).

Outdoor pollution was of two types: emissions from vehicles and from industry. When telling me about walking her child to school along a busy road, one woman interrupted herself with "I think it's pollution – I really do! It just horrifies me, the thought of the little babies breathing it in" [MI24]. Overall though, traffic pollution appeared to be perceived as playing the much smaller role in asthma causation, perhaps because the majority of those who spoke of pollution were car owners themselves. Even direct questioning generated little data from the majority. The only respondent to talk at any length about traffic worried that it might run over her children rather than give them asthma [MI11]. This relative lack of local concern over traffic pollution contrasts the greater significance given to it in Cornford's (1999) study and also the national prominence given to its role in asthma's causation. *The Independent on Sunday* (24 February, 2002, pp.19-22) devoted a major feature to an "asthma campaign" that it had launched after "ground-breaking new evidence against cars" (p.19)[25]. The evidence was that children living close to a main road were more at risk of wheezing (Venn *et al,* 2001). The quantity of epidemiological studies of asthma generated by traffic pollution bears testament to its continuing medical relevance, the majority of which have, according to Anderson (1997), reported negative or inconclusive findings. Medical discourse might, however, be beginning to re-write itself, as a recent and authoritative assessment suggests that a "high diesel particulate environment increases the incidence of asthma" (BTS/SIGN, 2003:S13). The introduction of traffic pollution into asthma's causation is nevertheless of great significance as it propels it into green politics. Before my research began I remember on the television news one evening a *Friends of the Earth* spokesperson criticising the government for building new roads when one in seven children in Britain have asthma.

[25] Tracking down this study was revealing of relationships between academic research and the media (p.50). *The Independent on Sunday* cited it as being conducted in conjunction with the NAC, but on enquiry I was told by the NAC only that they thought it had been published, and advised me to contact the journalist responsible. When I contacted the newspaper via its public information helpline the respondent was unable to provide me with the reference and advised me to contact the NAC. My second query to it received no reply. As the newspaper cited the journal in which it was published and I referenced it from a *Reuters Health* report. (www.aerias.org/news_article.asp?article=567)

By contrast, industrial pollution was the principal, and most proximate, cause of local asthma in Teesside. "[I]t's the pollution from the works – you can see it" [MI3]. The conviction of this woman's belief and those of a few other families contrasted with the "uncertainty, expressible in the idiom of 'what if' and 'maybe'" that characterized local statements about pollution in Phillimore and Moffatt's (1999:139) study where its consequences could "often only tentatively be linked back to causes". Possibly the link was more certain here because their children's asthma had focused their minds onto pollution. One woman borrowed the language of epidemiology when she spoke of how it was only since her son's diagnosis that she had realised she was living "in a high [asthma] risk area" [MI1]. Also, when asthma begins in the early years of life, multiple causation, confounding and delays between cause and consequence that are especially relevant to epidemiological studies of the effect of pollution on health (Phillimore, 1998), are minimized.

Causation is most certain when it is believed to be seen. M24 believed traffic pollution was asthma's main cause because she saw babies in push chairs breathing in the exhausts from car fumes as they, and the cars, waited together at a busy crossroads. Her conviction is based nonetheless upon a conceptual leap between cause and effect for which conclusive scientific evidence is lacking. Worry about the ill-effects of pollution might though, according to Moffatt *et al* (2000b), be more significant than living close to industry as it had the strongest statistical association with self-reported illness among Teesside residents. Similarly Pless-Mulloli *et al* (2001) concluded that there was little evidence of an association between residential proximity to opencast mining sites in the north east of England and self-reported asthma or wheeze. An earlier study by Dunn *et al* (1995) had found asthma to be more prevalent in residents close to a factory in County Durham, but only amongst middle-aged and elderly people. Moreover, BTS/SIGN (2003) implicate a reduction in coal burning in asthma's increase.

The title of Dunn and Kingham's (1996:831) paper, "Establishing links between air quality and health: searching for the impossible?" raises, however, the possibility that methodological difficulties make such evidence hard to find. The lack of conclusive scientific evidence with which to charge pollution with causing asthma was to some locals, including two health professionals, simply beyond belief – a reaction paralleling the ridicule reported by Phillimore and Moffatt (1999). At its most fervent, belief in

industrial pollution as the cause of asthma echoed the old religious meaning of belief (p.10). At the heart of the faith is the seeing of the pollution – seeing is quite literally believing – and in this respect Teesside's pollution, as noted by Phillimore (1998), differs from the invisible nature of most contemporary environmental risks (Beck, 1992). Teesside's pollution has the sensory nature of an old enemy about whose existence there can be no uncertainty, and it may be that the certainty of its existence provided the foundation upon which certainty as to its cause-effect relationship with asthma was superimposed[26].

The visibility of pollution emanated from many accounts as in "You can see it in the air ... great big black clouds come over, and on a night they burn it off, don't they?" [MI5] The conviction with which she delivered the question rendered it rhetorical. Local pollution could be smelled as well as seen. Several contrasted the smell of their air with the smell of air elsewhere, usually in the pastoral landscapes of the countryside and the coast. Similar negative public perceptions of local pollution have been documented earlier by Cornford (1999), Hudson *et al* (1998) and Bush *et al* (2001), showing that public attitudes have not changed in recent years. They highlighted similarly the sensory nature of local pollution. It was a "glittery chemical thing" (Cornford, 1999:196) or "whacking great black clouds" and "Sahara sand" (Hudson *et al*, 1998:25) with "a smell ... like rotten eggs" and "clouds of black ash [that] litter your dressing table and your window sills" (Bush *et al*, 2001:52).

Remarks about seeing and smelling pollution acted as self-prompts for stories with a recurring theme of home and away. "When I'm on holiday" one girl joked, "I can't wait to get back to all that pollution and all the cloudiness and rain" [CI15]. A favourite walk of some parents was to the top of a hill outside the town from where they could look down on their home or on the pollution that was hiding it. Similarly, on trips along the coast people looked back to see a polluted line that both hid and identified their home, and on the journey home, home began where they could see or smell the pollution. For

[26] Durham respondents stressed also the contribution of pollution but with much less emphasis on its visibility, though M24 who saw babies breathing in car fumes, thereby reinforcing its visual significance, was a Durham respondent.

C15's mother pollution did more than identify home, it was home. "[W]hen the plane door opens you can smell it. It means home to me".

Pollution was therefore intimately associated with home. Most families interviewed spoke positively of their home – their house and its immediate neighbourhood. Thus pollution entered into a relationship, if an uneasy one, with the positive, and may have been portrayed less negatively in consequence. While the majority expressed concerns about pollution only a minority spoke with any great emotion, hence it had perhaps been subjected to a similar process of normalization that was described in relation to asthma in the family. The interview bias towards middle class families living at least one step away from industry may have enabled them to distance themselves from the pollution. Both Cornford (1998) and Bush *et al* (2001) noted that local pollution was perceived as having a very local effect: people living further afield portraying those on industry's doorstep as being worse affected than they were. On a psychological level though, pollution has to be pacified if home is to remain 'home sweet home', perhaps even with the coal fire burning (BTS/SIGN, 2003). Inside the comfortable homes of the families with asthma, I sensed pollution as 'the devil you know', but with the emphasis upon the 'know'.

On the other hand, home and pollution might be inseparable for those living closest to industry. In the mid 1990s more than 70 local families began legal action against a local industry for causing their children's asthma. Three years later legal aid was withdrawn because of lack of supporting scientific evidence for their claim. A local councillor thought differently.

> "People are utterly convinced that toxic pollution which has caused these health problems has originated on Teesside and Middlesbrough council agrees that this is the case. Someone is not coming clean" (*The Evening Gazette*, May 20, 1994, p.7).

The reported council support is in marked contrast to the official reaction encountered by The TEES Group (1995). Their single positive association between ill health – lung cancer in women – and proximity of residence to industry, was reduced by both local government and health agencies to such small print that the result was rewritten as evidence for the harmful health effects of poverty in general, and of smoking in particular. (Phillimore 1998; Phillimore and Moffatt, 2000). The difference may reflect

no more than the biased attitude of a renegade councillor, but it is evidence nonetheless of a counter-culture that does more than blame pollution. It morally pollutes the perceived polluters and their co-conspirators.

Reporting of local pollution by the local media in newspapers and on television also brings it into the home, thereby mounting a verbal psychosocial challenge to the words of officialdom that as there is little pollution outside the home, it can do no physical harm inside it. Moreover, its specific linking to asthma, either literally or metaphorically as in the following extracts from *The Evening Gazette*, further challenges the official discourse of reassurance encountered by Phillimore (1998) and Phillimore and Moffatt (1999).

> "The gas [ozone] can corrode buildings, damage crops and aggravate allergies like hayfever and breathing problems like asthma" (May 4, 1995, p.7).
>
> "Life is anything but a breath of fresh air for thousands of children in Cleveland" (January 8, 1996, p.5).
>
> "[P]oor air quality makes life a misery for those who struggle to catch their breath, like asthmatics" (August 22, 1997, p.12).

Further, its reporting of "Middlesbrough – one of the national leaders in air quality monitoring" (December 13, 1993, p.3) purchasing new equipment to further increase its monitoring, portrays the local air as being sufficiently dangerous, or potentially so, to require expert and detailed attention and monitoring. The newspaper broadcasts its own surveillance by reporting air pollution in excess of guidelines, along with advice to those with breathing problems to stay indoors and take it easy (May 4, 1995, p.7; August 22, 1997, p.12), despite these occurring on average only two or three days a year. Finally, its reporting of one expert environmental opinion that "Middlesbrough has higher levels of ozone pollution than most towns because it does not have higher levels of other pollutants to cancel it out" (May 6, 1995, p.10) is to this lay reader, non-science verging upon nonsense[27].

The guilty verdict against local industrial pollution delivered unanimously by the local media was, however, only a majority verdict of those interviewed in the study. Moreover, the doubts of the dissenters were reasoned in a manner that suggested they

[27] It might, however, be substantiated by BTS/SIGN (2003)'s implication of reduction in sulphur dioxide and rise in diesel emissions as contributing to the increased incidence of asthma.

went beyond the emotional incompatibility of a happy home and a polluted place. Reasoning conformed to the principles of space and time. Two men working in local industry were adamant that it had not caused asthma in their children or in anyone else's. "How can you relate asthma to this industry when the people who actually work in the plants themselves don't suffer from it?" F14 asked. F6 exonerated his employer on similar grounds but worried that "the dust glistening in the sunlight" would damage his chest eventually, though it would not give him asthma. In relation to his own lungs the latter exhibited the "resigned acquiescence [that] is misconstrued if taken to mean that pollution risks are simply accepted" (Phillimore and Moffatt, 1999:149) by local communities, though in his case "being inured to pollution, seeing it as a necessary evil to be endured for the sake of the work associated with its production" (ibid:149) had the added personal relevance of it being his livelihood. His concerns about pollution's effects on his own health added weight, however, to his assertion that it had not caused his daughter's asthma.

Contrasts were drawn also between past and present. F6 returned to his own childhood when he "lived on the doorstep of the works... [and] ... pollution was ten times worse... [but] ...no-one had asthma then". The polluted past was vividly described. When it rained a middle-aged woman remembered her mother rushing outside to bring in the washing not to stop it getting wet, but to stop it becoming covered with soot [MI15]. Her mother's generation reminisced about battles against soot and sulphur – the black and the red. According to one elderly woman "when the red was about" washing was kept inside and windows, the front door, and doorstep were cleaned daily. According to another, "[w]e always used to say 'the nearer the works, the cleaner the step'". The mother of a 96 year old man had extended her scrubbing to the pavement outside their home, yet these were the people who had contrasted their childhood lived in the fresh air with contemporary childhood dominated by stale and artificial air. Hence the outdoor living that they looked back on nostalgically, was actually a polluted living. The fresh air was symbolic rather than actual, but though polluted in reality, it had not given them asthma. One elderly man was certain that modern air was less polluted. His reasoning was sensory. He could still see and smell pollution, though not as strongly, but he could no longer taste it. This widespread view that pollution had improved, contrasts with the view held by many interviewed by Cornford (1998) that it had worsened. As his study showed no difference in perception between those with and without cough or other

respiratory health problems, the difference cannot be attributed to their own health influencing their beliefs.

However, while most agreed that pollution was quantitatively greater in the past, its causation of asthma in the present was upheld by three families on the basis of quality rather than quantity. Space and time were again central to the reasoning of two of them as they linked the local increase in asthma to the arrival of a new industry, also identified by Cornford's (1998) respondents, that polluted their air with new chemicals. The third – the family who invoked pollution most strongly as the cause of asthma – attributed asthma's increase to new emissions from existing factories that were unknown, outside the industry at least [I7]. These last 'new' emissions were new culturally irrespective of whether or not they existed chemically. Unlike the pollution that linked past and present, they could not be seen, smelled or tasted. Some of Cornford's (1998) respondents also worried that although the air might be cleaner, in that it was less dusty, it might contain other hidden chemicals that were as, or more, dangerous. These represent the invisible risks of modern environmental dangers, the uncertainties and insecurities of modern life, and M9's Chernobyl that combine to alienate Teesside into "'something from Mad Max – [a] post apocalyptic place'" (in Bush *et al*, 2001:51).

However, might responsibility lie not with industrial pollution, but with the industrial decline that has wrought a social and cultural transformation of Teesside? Elderly respondents described a childhood dominated by 'the works'. "You couldn't escape it ... you were wrapped up in it" said one retired industrial employee after listing the factories where almost all local people worked, and which overshadowed their homes. He thought most people knew their working and living environments were harmful to their health and their lungs in particular, but it had not been spoken about among themselves and certainly not with their employers. He and others attributed their tacit acceptance of respiratory damage to a past culture in which people did not talk openly about health matters and in which doctors were both more highly respected and less accessible. Yet their main reason for silence was fear of losing their job if they complained, and of being unable to get another. 'Troublemakers' were not welcome in any 'works'.

A current industrial employee continued the story locating it in his own workplace.

> "[I]t was a big employer and there was a lot of people coming out of school and going there and training as apprentices, and it was a *conveyer belt*. If your father worked there, you tended to work there ... But about 10 years ago [company name] stopped taking on apprentices so the *conveyer belt* started to slow down ... I think that's when people's attitudes began to change towards [company name]" [FI14] (emphasis added).

Industrial decline has contributed to high levels of local unemployment – parents have been laid off and sons and daughters not taken on. Further, those who remain in employment tend to be more highly skilled and consequently can afford to live some distance from their workplace. Unemployment was associated with childhood asthma in Teesside (Denn *et al*, 1995), and now closest to 'the works' are "[p]eople who had never worked in there. There were no families in there who had no sons, daughters, aunties, uncles in there, so they weren't bothered if the place shut down or not" [MI14]. Thus family ties no longer temper local resentment against their former employers. It was families such as these that had, according to this couple, sued local industry for causing their children's asthma. Strikingly, at one point the man leaned forward and spoke directly into the tape recorder on the table. Seemingly oblivious of myself, or of his family sitting round the table, he addressed these families instead telling them "you're just after money ... it's not the illness, you're making {pause}, you're making a mockery of asthma". In local pubs he had overheard conversations blaming their asthma on his employers and had found it hard to contain his anger. His continuing anger surfaced several years later as he voiced his fears that local industry would leave the region because of the bad publicity and thereby cost him his livelihood – fears shared by local government (Hudson *et al*, 1998) in the present as well as in the past (p.63). He accused the local politicians and the local media of being irresponsible as well as wrong, in their attribution of asthma to air pollution, and particularly so in their support for, and publicity of, the families' campaign. Though much of local asthma was clearly benefit asthma to him, it was he acknowledged, certain asthma to many locally because it bought votes and sold newspapers. His anger, however, revealed a resentment that extended beyond Teessiders. Bad publicity might have provided the excuse the "big fat cats" were looking for "to move away, saying we can get this produced cheaper elsewhere". Although unlike the local councillor he never suggested that his employer might not be 'coming clean', his sympathies clearly lay not with his employers, but with

employees like himself, who would be impoverished if asthma's cultural pathology ended his livelihood.

Teesside's industrial decline might therefore, have generated widespread resentment against, and distrust of, local industry and local government, and an ill feeling that extends to national and global industrial corporations anthropomorphized as the big fat cats. The region's economic reliance on heavy industry might also have given the ill feeling a specifically local dimension because although heavy industry has contracted nationally, the north of England is one of its traditional heartlands. The suffering of Teessiders may have fuelled feelings of being ignored and being marginalized by national government. A worker about to be laid off from a heavy machinery plant in a nearby town hammers it home.

> "Well, they [the government] can speak as many big words as they like, and talk as much crap as they want to, but they want to wake up and smell the roses, 'cos as far as I'm concerned there ain't no roses up this end... They're just opening their mouths and letting the wind waffle their tongues as far as I'm concerned" (*Panorama*, BBC1, 30 November, 1998, 2130-2210 hrs).

In marginalized, poor, polluted and unhealthy Teesside, might 'the waffling wind' answer 'asthma'?

6.4 ASTHMATIC TIMES IN ASTHMATIC SPACES

"I don't know my way about"

Ludwig Wittgenstein[28]

Do I know my way about asthma in Teesside's children? Have I mapped Midgley's city of organized thought (p.14) worthy of Good's London (p.14), or the chaotic urban landscape of Descartes (p.54) and the original Teesside (p.54). I have created the verbal and visual reality of certain asthma, and ultimately of ultimate asthma, whose very existence is totally dependent upon Wittgenstein's thing with which I began my dissertation. It begets certain asthma, and gives it life because it has the power to take away your life. I know you might not have certain asthma but you might one day, and although I know that even if you do, it is unlikely to kill you, anyone who has my prototype (p.161) of certain asthma (p.6) is at risk of dying. Note though, that by raising asthma in you, I am presenting myself as the other who has created your sickness.

The status of the other in relation to certain asthma is simple: the other is a believer. If, however, the belief is modern (p.10), we begin to introduce an uncertainty into certain asthma. My distinction between certain and uncertain asthma is therefore, relative rather than absolute, and the sickness of asthma becomes a continuum. Uncertain asthma derives its existence from the interaction of asthma as Foucault's word (p.11) – when we disbelieve what they say to us is asthma – and our representation of Wittgenstein's thing (p.2) as asthma – what we say is asthma. The more their asthma differs from our prototype of asthma, the greater its affinity with our uncertain asthma, whose status declines as the emotion of hysteria renders it inferior, and the economics of benefits, render it immoral. By contrast, the greater the uncertainty in uncertain asthma, the greater its potency. The diagnostician might be proven wrong and be guilty of denying the asthmatic his or her rightful occupation of the sick role. Worst of all, the asthmatic might no longer be there to occupy the sick role. Asthma's diagnosticians can be proven wrong in their diagnosis of uncertain asthma, but they can never be proven right. As even the most certain of its hysterical and benefit personalities might conceal an ultimate asthmatic core, it is risky for you to assume that any word asthma is impotent, in case asthma tells you otherwise.

[28] In Midgley (1989:27).

There is, moreover, a close relationship between the personality of asthma and of the person named with asthma. Certain asthma is a trait of admirable people. Only certain asthma is found in the sporting elite – the physical contemporaries of Homer's Aeneas. Their intellectual peers – geniuses – also possess only certain asthma, unless their achievements are confined to a degree in benefits. The relationship between asthma and aesthetes is more complex as achievements that require a greater emotional contribution bring asthma into closer proximity to the emotions and eventually to hysteria. Socially, it is much simpler: only those deserving of the sick role suffer from certain asthma. These positive personalities contrast with negative personalities when asthma becomes uncertain. Physically the sporting asthmatic becomes the weedy asthmatic, weak and irritable; mentally the genius asthmatic becomes the neurotic asthmatic, and socially the deserving asthmatic becomes the deviant asthmatic. Further, asthma becomes increasingly uncertain as it moves from the physical to the mental to the social. At worst, weedy asthmatics have an excessive belief in their own asthma, neurotic asthmatics have a false belief, but deviant asthmatics beggar belief.

Their origins distinguish them further. The more certain the asthma, the more its imputed cause is physical, while the more uncertain its status, the greater the contribution of psychosocial influences. Secondly, though natural forces such as weather, pollen and pathogens were cited in its causation, emphasis was primarily upon human agency as proximate cause in itself, or the ultimate cause via its role in altering the former. The role of human agency differed, however, with respect to certain and uncertain asthma. Children were rarely implicated in the causation of their own certain asthma. Certain asthma is therefore the sickness of Erikson's Jew (p.80) – the archetypal victim who speaks for the victims of all nations, including poor defenceless children in Teesside, whose asthma might be "a culturally permissible expression of distress" (Showalter, 1997:15) as well as an actuality.

Victims need villains to cause their distress, and be repositories for blame. In certain asthma the villain is the other who has several guises. 'Modern life' with its stresses, insecurities and uncertainties is the most abstract, and I suggest, ultimate other, but concrete others emerge that are increasingly proximate as they are ever closer to home. Firstly there are overpowering corporate 'big fat cats', secondly local industrial

employers and thirdly car owning fellow residents. Finally and closest to home, there is family and mother especially, with convenience foods, chemical cleaners, house dust mites and perhaps even Barney (p.111). By contrast, in their relationships to uncertain asthma, these causes become words cited by those who are the ultimate causes of their asthma, because their belief in, or use of, certain asthma has created asthma in them that is uncertain to the other. Yet the family might be both victim and villain in relation to certain asthma, and it might be a cause of both certain and uncertain asthma. These multiple, overlapping and ultimately conflicting family roles illustrate Frankenberg's (1992) concept of the other as being increasingly the same, and its ultimate significance in relation to asthma is that neither you nor I are immune from blame.

In another plane, however, the different asthmas are united by their respective perceived causations, and the contrast that emerges is temporal between past and present, rather than spatial between the asthmas. The respective relationships between certain asthma and pollution, and uncertain asthma and benefits, link all contemporary asthma to poverty and to urban poverty in particular, thus transforming asthma culturally into the contemporary urban plague. Most health professionals believed on the basis of their own experiences that asthma was more prevalent among poor children, and its cultural portrayal in the medical literature suggests that its status is declining. "In the 1940s-1960s the 'asthmatic' child is portrayed as the victim of over-protective mothers in upper income families, changing to the asthmatic as 'Other', as a child from impoverished and disorganized families in the 1970s-1990s" (Kozyrskyj and O'Neil, 1999:17). Medicine's contrast between the 'precious little asthmatic' and the 'poor little wheezer' is gradually being broken down and being replaced by the 'poor little asthmatic'. Asthma's growing relationship with poverty increases poverty's claim to the status of an ultimate cause, but for poor people only. Thus poverty serves to maintain the distinction between the self and the other in the causation of asthma, both in itself, and perhaps also by compounding the influence of modern life on poor people that has been suggested as asthma's ultimate and universal cause.

Pollution was Teessiders' proximate cause of certain asthma, but it is likely to be a material manifestation of urban poverty as poor people are more likely to breathe polluted air (Evans and Kantrowitz, 2002). It has an added socioeconomic significance in that air – the commodity most vital to, and symbolic of, life – is the one commodity

that is freely available to all. Air cannot be bought or sold, but it can be polluted, and the polluters of Teesside's air are not perceived as paying either to pollute it as in an international market in carbon credits, or paying fines or compensation for polluting it. Instead poor people perceive themselves as paying for the polluters with their health. They are less healthy than their wealthier neighbours (p.62), and they may blame pollution, especially when their poor health is respiratory in nature. More generally feelings of marginalization might manifest themselves as feeling ill or worrying about becoming so. If their other – their marginalizers and their poverty makers – include their polluters, then pollution might become symbolic of their modern lives, and the ultimate as well as proximate cause of asthma in urban poor people.

Finally, pollution, poverty, poor health and marginalization might characterize place as well as people. Bush *et al* (2001) apply the concept of stigma of place – an extension of Goffman's (1968) stigma of the person – to Teesside. Initially stigmatized places were those in close proximity to industry labelled undesirable by the public. "The industrial landscape of northern England. A vision of hell on earth", was how *Alien Empire* (BBC2, 5 June 2000, 2100-2150) slated my well-travelled rail route from Darlington to Middlesbrough, while a small cartoon in *Viz* (1999:4) strikes even closer to home. "Come to Middlesbrough and smell our fumes" below which an old man in a wheel chair gasping for breath against a backdrop of factory chimneys belching smoke reinforces its appeal. To further entice holiday makers "A Fortnight in Cleveland's Petrochemical Wonderland costs from as little as £4", and a tear-off slip for a brochure is provided in case "[f]or some reason I am interested in a holiday in Middlesbrough".

> "However, by defining 'geographic stigma' exclusively in relation to labelling which arises from the location of a stigmatized technology or from an episode of toxic contamination, there is no acknowledgement of the complex web of other factors such as those relating to the social, economic and historical context more broadly, which may also produce a spoiled place identity" (Bush *et al*, 2001:48).

Four stigmas – marginalization, poverty, pollution and poor health – interact, they suggest, to give Teesside its spoiled place identity. They are its contemporary four horsemen of the apocalypse with pollution replacing, but also causing pestilence. On the other hand, their extension of stigma beyond the spoiled place may account for the dominant but paradoxical temporal relationship between declining pollution and rising asthma in Teesside's children. William Blake's anarchic *Jerusalem* contains two

contrasting images of England: its dark satanic mills and its green and pleasant land. Teesside's industrial decline has destroyed many of the former, and its land has become greener, but its asthma might suggest that it is no more pleasant. If so, should I have named this chapter 'Asthma in the Unpleasant Land'?

Part 3 – Casts

Chapter 7 CONCLUDING ASTHMA

> It's like love – we all know what it is, but who would trust anyone else's definition.
>
> Sol Permutt[1]

It's the asthma I began with but I end with the asthma I began without. I have kept its secret till now as it had no actuality then. I have hazy memories of coughing at night, cold nights especially. More vivid is the dish of water on my bedroom heater, with the lime scale building up each winter on the white enamel beneath its blue rim. Equally vivid is the winter's cross-country run that stopped me, and more inconvenient, if less dramatic, were the coughs after colds. One day I took my cough and its story to my GP because it was joining me for summer walks in London. She diagnosed asthma, attributed it to my recent entry into polluted living, and prescribed a blue inhaler. It remained a word as her asthma was not mine. My cough disappeared, but her asthma might remain a statistic in Hackney. Since then a few bad colds have awakened her statistic and one night a GP friend with whom I was staying. She thought asthma was unlikely, but advised me to have it medically excluded, especially as a couple of days before my chest had felt tight while climbing the stairs to my office. I remembered her advice when I was coughing too much to attend a conference on health risk.

So can my research tell me if I have asthma? Casting it first as an illness as it was in the family, I recognize it now in the cough that visited occasionally some of Teesside's children, especially as unlike Aeneas (p.3), I was unfit the only time my chest was tight. Thankfully, I am unacquainted personally with the most powerful atoms of its illness personality. I have never been imprisoned in asthmatic chains, nor fought for breath, or fought off suffocation, or been besieged by exhaustion or ambushed by fear, and I trust I did not turn blue in the presence of my GP friend and witness. Colds are the main agents that trigger it in me, and perhaps also cold air, dry air, polluted air, exercise and pollen – quite a list, but rarely have I to live with my illness. Now, I would know it as asthma if the blue inhaler that I rejected relieved me. Asthma began in my dissertation as what anyone says it is. Its ending as an illness is that which asthma therapies please. A literary definition has become a therapeutic definition. It might not be your definition,

[1] In Gross (1980:203).

and my illness narrative might not have satisfied you, but *my* illness is *mine*, and by my definition I cannot know yet, if I have asthma.

Yet the illness of asthma in Teesside's children was witnessed more than it was experienced, and in the interests of reflexivity, I introduce myself also as a witness. This I have kept till here as it was the last thing I decided to make public (p.8). I stopped for a while because of the unhealth of a favourite person. It was not asthma, but she experienced the atoms of asthma that were its most significant, quantitatively (p.80) and qualitatively (p.81), and they embodied the origins of illness in evil (p.4). Her illness and death accompanied me thereafter, strengthening my focus on the experience-near accounts of asthma in those with it and of its closest witnesses. As a witness to *illr* in a friend[2] I know that 'Asthma in the Family' has been "very feebly described, and with too much detail to make a telling picture ... To be fairly imagined it should be witnessed – to be fully appreciated it should be experienced" (Salter, 1860:464).

Gazing into myself, I cast my asthma as a disease, and I reject still the evidence base upon which it was founded the only occasion it entered the free garden. Medical history was limited to my presenting cough; other causes of cough were not excluded; signs were absent and investigations not performed. I protested, but my GP did not permit me the psychological equivalent of the elbow room from whose lack disease originated (p.4). Standing back now, I answer yes to ISAAC's one question on cough (p.137), but epidemiological studies derive their criteria from the evidence-base of clinical asthma (171). As a clinical case, I can rely on history only, but many health professionals do the same, and BTS/SIGN might not exclude asthma from its list of suspects (p.155). I would seek evidence for its conviction in the sign of diffuse expiratory rhonchi, but only if asthma was their most likely suspect (p.157), and to restrict my disease thus, would render uncertain much of what medicine diagnoses as asthma. Moreover, as AHR on investigation (p.153) would add to my certainty, I would have to deny myself asthma until after the age it is diagnosed in most patients (p.153).

But if disease belongs to medicine (p.4), from a nominalist perspective (p.157), it can decide what asthma is, and how it wishes to construct it. Will its words, and if so which

[2] I make this public with the consent of her husband, her closest witness.

– ISAAC or BTS/SIGN – come to define asthma and will anyone trust their definitions? Not if EBM is defeated by CRAP[3], and according to the evidence presented here, it might. Might this suggest that health professionals are essentialists at heart, believing in, and seeking the asthma that is like love? The asthma that one said to me, is *really* asthma.

Casting myself as any other casts my asthma as a sickness/diagnosis – having democratized asthma, the latter is either a sub category of, or the same as, the former, depending on whether or not one distinguishes asthma's lay and medical diagnosticians. I have the medical diagnosis of asthma, but the free gardeners' casting of it as a disease makes it increasingly difficult *not* to diagnose (p.157). I can diagnose it only as uncertain asthma, and perhaps I have succumbed to the anthropological risk of going native and caught hysterical asthma, though ethically I have had to investigate benefit asthma, as it has facilitated the writing of this concluding chapter. Though uncertain, it is potent, because it might become certain in me one day. Worse, as the potency of certain asthma is derived from the actuality of asthma, should I advise myself to seek medical advice next time I detect uncertain asthma in myself? Here I stop my analysis of *my* asthma to avoid subjecting it, and me, to the construct of ultimate asthma. Instead I end my asthma with its ultimate relevance: as it has graduated from what was certainly not asthma to uncertain asthma, my threshold for knowing the actuality of asthma in another has lowered. Thus I have influenced my research, but as I have researched reflexively, I am untroubled by my fictional counterpart's (p.72) conclusion that "I is troublesome at the best of times" (Gunn, 1956:25).

So as my research ends, and my asthma begins or not, how do I know asthma in Teesside's children? I know it as, but not only as, a material reality that conceptualizes "the relations between the biological, psychological, social and cultural factors in human life" (Geertz, 1973:37). Yet these cannot be represented by what he criticizes as their "stratigraphic conception" (ibid:37). Speaking metaphorically, it constructs unhealth as a Russian doll. Unscrew the cultural doll to reveal the social doll inside, and the psychological doll inside that, until the biological doll in the middle is exposed. This is not asthma, because to add culture to Engel's (1977) model (p.16), it is biopsychosociocultural from the inside out and from the outside in. Or, as order is important (p.78), it could be culturasociopsychobiological, and an asthma could be

[3] Clinicians for the Restoration of Autonomous Practice (CRAP) Writing Group (2002).

more one than the other, or any other version thereof but STOP!! I am speaking the nonsense that Xingjian (p.50) attributed to others before me, and Wilkinson (p.6) reminds us that models are only ways of constructing reality. My model of asthma must, however, admit the biological, for without it there is no thing, only a word.

But is its word in Teesside's children "related obviously to the year 2000" [FI14]? If it is, then SATs, stress, additives, pollutants, poverty, uncertainty, insecurity, loss of meaning, marginalization, cultural sadness and 'dis-ease' number among the millennial causes of its asthma. If my dissertation is now on Bowker and Star's fantasy shelf (p.50) because my list rivals that probably mythical Chinese classification of animals (p.72), then Marinker (1998:104) invokes the same encyclopaedist when listing the causes of unhealth in a patient. His list ends with her "belief that society does not care about the little man". My list goes further if the plague of asthma in Teesside's children cannot escape the sickness that in the mid-nineteenth century pursued another (p.4), and at the time caused Engels (1848) to accuse the richer of murdering the poorer.

As his accusation is still too close for comfort I turn to my travelling companions, but anthropology and medicine have been equally uncomfortable at times. Barthes's new object (p.14) is so difficult to make or make up (p.47) as my disciplines see things differently and use words differently. Janus (p.25) ends as my closest academic companion, and perhaps even my academic self, but is he only an interdisciplinary product? Might, I wonder, his/my two heads be the issue of a deeper relationship between the "City of Organized Thought [(p.14)] and its Town-Planners"[4] and "the rest of human thought, even ... human life" (Midgley, 1989:74)? That I leave as a question as it *is* too close for comfort.

Returning finally to the human life in this town plan, words alone have represented it, but they have presented it as my images of Teesside, its children and their asthma. These I have cast as gifts and crimes, sounds and silences, residents and visitors, plagues and fashions, and personalities and personality disorders. Yet more real to me are the elephants and wet dish cloths, old men and screeching cats, children stopped but never stopping, and a child blue and grunting. Words and the images they create in us are the primary communicants of unhealth as "narrative makes possible the

[4] Title of chapter 3.

communication of one human being's experience to another and underlines its status as mediated fact: it is often the best we have to go on" (Hunter, 1991:155). I feared Foucault (1963) had doomed my research by exposing this dissertation as a construction of discourses about discourses (p.11), but perhaps Hunter's (1991) words have the power to save it as mediated fact. Certainly, they are the best I have to go on, and I leave to others to decide whether they create the "original contribution to knowledge" (Phillips and Pugh, 2000:63) required of this academic *rite de passage*. As "I have realised that nothing about asthma is straightforward" [MI10], I return to Wittgenstein's things (p.2) that they "are what is mystical" (in Midgley, 1989:222) and conclude by citing Howell's (2000:3) invocation of *The Secret Sits* as how I know asthma in Teesside's children.

> "'We dance round in a ring and suppose
> but the secret sits in the middle and knows'
>
> (Robert Frost)
>
> But if we should reach the middle how would we know?"

I don't know.

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APPENDIX

ASTHMA CLINICS

GP clinic

Numbers of patients

	Male	Female	**Total**
0-4 years	6	5	**11**
5-12 years	25	27	**52**
13-19 years	9	16	**25**
20+ years	9	11	**20**
Total	**48**	**47**	**98**

Numbers of consultations per patient

	Male	Female	**Total**
One consultation	41	40	**81**
Two consultations	4	8	**12**
Three consultations	2	1	**3**
Four consultations	2	0	**2**
Total	**49**	**49**	**98**

Hospital clinic

Numbers of patients

	Male	Female	**Total**
0-4 years	18	14	**32**
5-12 years	48	29	**77**
13-16 years	9	1	**10**
Total	**75**	**44**	**119**

Number of consultations per patient

	Male	Female	**Total**
One consultation	69	35	**104**
Two consultations	4	7	**9**
Three consultations	2	2	**6**
Total	**75**	**44**	**119**

INFORMATION LEAFLET & CONSENT FORM FOR CLINICS

Dear Patient and Parent

My name is Alison Todd and I am visiting the asthma clinic today. I trained as a doctor and am now a research student at Durham University. I am interested in children with chest problems and what can be done to improve their care. I am writing to ask if you would like to take part in my study.

Today I would like to

- Sit in on your visit with the asthma nurse
- Make notes on how your care is going
- Look at your medical records

Later, I would like to visit a few patients in their homes. I will write to you first to tell you more about my visit. If you don't want me to visit, do nothing when my letter arrives. I will only visit you if you reply to my letter. Signing the form below doesn't mean that I have to visit you at home.

At the end of my study I will write a report for the asthma clinic and for my university. All information about you will be confidential. Your personal details won't be passed on to any other person.

If you would like to take part in my study, please fill in the consent form and give it to the receptionist. Please don't take part if you don't want to. It will, of course, make no difference to your medical care.

Thank you

ALISON TODD

CONSENT FORM

I (child's name) and _____

I (parent/guardian's name) _____

would like to take part in Alison Todd's study.

Signature of child (if possible) _____ Date _____

Signature of parent/guardian _____ Date _____

INTERVIEWS

Family interviews

Composition of interviews with asthmatic children

Asthmatic child alone	3
Asthmatic child and mother	9
Asthmatic children and mother	1
Asthmatic child, mother and sibling	1
Asthmatic child, parents and sibling	1
Total	15

Composition of interviews with adults

Mother alone	18
Mother and father	3
Mother and grandmother	1
Mother and other children	2
Mother and friend	1
Total	25

Of the interviews with adults 16 were conducted in settings in which privacy from the asthmatic child and other siblings was assured.

Community interviews

Women attending the local community centre

These cannot be counted as they were usually informal and intermittent conversations conducted within groups of shifting composition.

Clients at the day care centre for elderly people

Interviews were conducted with six women and two men, and other informal conversations took place with the elderly people and centre staff.

CODES AND CATEGORIZATIONS

Community respondents were not coded as much data was gathered during informal conversation.

Asthma Clinics

GP General practice clinic
HR Hospital referral clinic

- Consultations are numbered consecutively.

- Subsequent consultations by the same patient/family are indicated by letter suffixes **[GP26a]** refers to the second consultation of patient/family GP26.

- Where more than one consultation by the same patient/family is referred to, commas are used to distinguish between the consultations
  [GP26,a,b] refers to the first, second and third consultations
  [GP26a,b] refers to the second and third only.

Home Interviews

C Child
F Father
FR Friend
GF Grandfather
GM Grandmother
I Interview
M Mother

- Data pertaining to a clinic consultation about a child/family who were also interviewed, is indicated by the child's code followed by the clinic coding, e.g. **[GP26a/C15]** refers to data pertaining to C15 at her second GP consultation.

Age categorizations

The following terminology is used to indicate the age of the subject.

0-4 years	young child
5-12 years	child
13-16 years	teenager
17+ years	adult

Interview 1

This interview aims to collect information about the family background and the home and local environment in which the children have asthma.

Topic schedule

- Family composition
- Schooling and employment
- Recreational activities
- State benefits
- Housing quality and ownership
- Own and public transport
- Local amenities
- Future plans/ambitions

Interview 2

This interview aims to collect information specific to the children's asthma and its impact on themselves and their families.

Children's topic schedule

- Asthma symptoms and how it makes them feel, physically and emotionally.
- What their asthma is like when it is at its worst.
- What causes their asthma and what makes it worse.
- Self/family management of their asthma.
- Description of their medical management.
- Impact of their asthma on their daily lives with particular attention to school activities.
- What, if anything could be done to lessen its impact?
- Thoughts about their future with/without asthma.

Mother's topic schedule

- Asthma and related (allergic or respiratory) conditions in the family.
- Onset and diagnosis of their child's asthma.
- *What their child's asthma is like when it is at its worst, and its effect on the mother.
- *Causes/triggers of their child's asthma, including relationship with stress.
- *Satisfaction with medical management and with school management of their child's asthma.
- *Impact of their child's asthma on family life, with particular attention to economic and emotional consequences for the parents.
- What, if anything could be done to lessen its impact?
- *Thoughts about their child's future with/without asthma.

The asterisks indicate topics which will be discussed with the mothers without the children being present as they have the potential to alarm or otherwise distress the children, or undermine their confidence in their asthma carers - mothers and health professionals.

Interview 3

This interview aims to collect information on beliefs about asthma in general, and its relationship to other respiratory conditions, industry and air pollution on Teesside.

Topic schedule

- What causes asthma?
- Is asthma increasing, and if so, why?
- Relationship of asthma to other respiratory conditions in the past and in the present.
- Relationship of asthma in particular, and of respiratory conditions in general, to air pollution and industry.
- Relationship of professionals and campaigning organizations to asthma, respiratory conditions and industry.
- What can/should be done to reduce the burden of asthma on society?

Questionnaire

[The children (and their mothers) will be asked to complete monthly the following questionnaire (modified from Jones *et al* (1992). Separate questionnaires will be provided for children and mothers.]

Please circle the appropriate answer to the following question(s).

Q1 Have you (has your child) had any symptoms of asthma over the last month?

Yes/No

If the answer to Q1 is yes, complete Q2 and Q3. If the answer to Q1 is no, stop.

Q2 Has your asthma (your child's asthma) stopped you (you or anyone in your family) from doing anything over the last month?

Yes/No

Q3 Has your asthma (your child's asthma) disturbed your sleep (your sleep or anyone else's sleep) over the last month?

Yes/No

If the answers to any of these questions is yes please write an account of what happened in your asthma diary. [Children and mothers will be given loose-leaf folders for this purpose]. Please remember to put the month at the top of your account so that I can relate it to the questionnaire [which will be pre-labelled according to the month].

[Towards the end of each month families will be sent postal reminders about the asthma questionnaire and diary.]

PROTOCOL FOR REVISED STUDY

Children's interview

- Asthma symptoms and how it makes them feel, physically and emotionally.
- What their asthma is like when it is at its worst.
- What causes their asthma and what makes it worse.
- Self/family management of their asthma.
- Description of their medical management.
- Impact of their asthma on their daily lives with particular attention to school activities.
- What, if anything could be done to lessen its impact?
- Thoughts about their future with/without asthma.

Mother's interview

- Asthma and related (allergic or respiratory) conditions in the family.
- Onset and diagnosis of their child's asthma.
- *What their child's asthma is like when it is at its worst, and its effect on the mother.
- *Causes/triggers of their child's asthma, including relationship with stress.
- *Satisfaction with medical management and with school management of their child's asthma.
- *Impact of their child's asthma on family life, with particular attention to economic and emotional consequences for the parents.
- What, if anything could be done to lessen its impact?
- *Thoughts about their child's future with/without asthma.

The asterisks indicate topics which will be discussed with the mothers without the children being present as they have the potential to alarm or otherwise distress the children, or undermine their confidence in their asthma carers - mothers and health professionals.

More general questions on asthma are also included.

- What causes asthma?
- Is asthma increasing, and if so, why?
- Relationship of asthma to other respiratory conditions in the past and in the present.
- Relationship of asthma in particular, and of respiratory conditions in general, to air pollution and industry.
- Relationship of professionals and campaigning organizations to asthma, respiratory conditions and industry.

EXAMPLE OF INTERVIEW REQUEST LETTER

Dear

I met you when you visited [nurse's name's] asthma clinic last Monday. I am the doctor who is now a research student at Durham University. My research is about children with asthma and what can be done to improve their care. I am writing to you to ask if I could visit you at home to talk more about [child's name's] recent problems with his chest. I expect my visit would last about an hour or a little over.

I am particularly keen to talk to a few mothers whose children are undergoing assessment for asthma, and that is why I'm writing to you. Many of the mothers I talk to can't remember a lot about that time as their children have often had asthma for several years. It is therefore, difficult to investigate the early symptoms that might be asthma, and I would be interested to hear whether [child's name's] inhaler is helping him.

I would like to make notes during our conversation as that will save me having to try to remember everything. Please tell me if you do not want me to write things down. I will stop writing at any time.

At the end of my study I will write a report for the asthma clinic and for my university. All information about you will be confidential. Your personal details won't be passed on to any other person.

If you would like to take part, please fill in the consent form below and send it to me in the stamped addressed envelope. If you return the consent form I will get in touch to arrange a visit. If you would like to know more before deciding, please phone me on.....

If I haven't received your consent form within two weeks I will write to you again (and ask [health professional's name] to address it) in case you have lost or forgotten about my letter. Please ignore my second letter if you do not want to take part. I will not write to you again.

Please don't take part if you don't want to. Your decision will, of course, make no difference to your medical care.

Thank you

ALISON TODD

CONSENT FORM (CHILD'S NAME)

I (child's name) _____

I (parent/guardian's name) _____

would like to take part in Alison Todd's study

Signature of child _____ Date _____
(sign only if [child's name] is willing to speak to me as well as [parent/guardian])

Signature of parent/guardian _____ Date _____
(sign if [parent/guardian's name] is willing to speak to me)

Telephone number _____

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Each page entry refers to a different point pertaining to the interview or clinic consultation.

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