tuberculosis, predominantly when they cough. Bacilli may remain suspended in air for several hours. When compared with other communicable diseases, tuberculosis is not very infectious per unit of time for which someone is exposed. However, in a context of frequent exposure and overcrowded living or working conditions, there is a high risk of case contacts becoming infected.[77] The species of mycobacteria that most commonly cause tuberculosis in humans are *Mycobacterium tuberculosis and M. bovis.* However, it has recently been recognised that a number of other species collectively known as mycobacteria other than tuberculosis (MOTT), give rise to less severe disease than *M. tuberculosis* but can be more difficult to treat. *M. kansasii,* in particular, is often found in association with mines. The diagnosis of tuberculosis is usually made using a combination of X-rays, a tuberculin test (a skin test of hypersensitivity reaction which indicates lifetime exposure) and a sputum test (in order to confirm the presence of the tubercle bacilli and to test their drug sensitivity).

The pathogenesis of tuberculosis involves the inhalation of the tubercle bacilli into the mid-zone of the lung. This is followed by the development of an area of tuberculous bronchopneumonia known as the primary lesion, in which the organisms proliferate. The primary lesion may become calcified and thereby surrounds the bacilli, in which case a patient has no symptoms but gives a positive Mantoux test on tuberculin testing and retains a latent infection unless given anti-microbial therapy. If the primary lesion is not contained, the organisms migrate to regional nodes in the hilum of the lung and then via the lymphatic system into the systemic circulation and may ultimately be distributed throughout the body.[78]

The clinical manifestations of tuberculosis range from asymptomatic patients reactive to a tuberculin test and a small, nondescript density barely visible at X-ray, to those patients who exhibit massive pneumonic and necrotic pulmonary disease. In an otherwise healthy population, about 5 to 10 per cent of infected people ultimately develop active disease. Resistance to the tubercle bacilli is partly genetic and partly the result of favourable socio-economic conditions.[79] Initial disease symptoms include tiredness and loss of appetite. As the disease progresses, chronic cough, productive sputum, weight loss and haemoptysis become evident.[80]

The earliest tuberculosis lesions appear as tiny densities so small that they sometimes do not cause a chest X-ray to appear abnormal. As the disease evolves, cavitation and tissue destruction become radiologically apparent. Successful chemotherapy will result in the clearing of the inflammation and areas of tissue destruction will gradually become fibrotic.

Tuberculosis is second only to trauma in the number of lives that it claims on South African mines. Data from the Chamber of Mines indicate that in 1993, tuberculosis notification of mortality amongst gold miners was 25 per 100 000 whereas the notification rate for active disease was 1100 per 100 000.[81] There is evidence to suggest that the notification rate of tuberculosis amongst mineworkers varies widely between mines, ranging from 1000 per 100 000 to over 2000 per 100 000 in the pre-AIDS era. In order to understand the seriousness of the industry specific notification rates, it is important to note that the 1996 tuberculosis notification rate in the general South African population was 311 per 100 000.[82] All the countries in the Southern African Development Community (SADC) have high notification rates, ranging from 172 per 100 000 for Malawi to 380 per 100 000 in Botwana.[83] Many West African countries have significantly lower notification rates (e.g. Nigeria has a rate of 12 per 100 000). For countries in Eastern Europe and the former Soviet Union, rates vary from 19 per 100 000 in the Czech Republic to 102 per 100 000 in Romania. In Western Europe, notification rates range from 5 per 100 000 in Norway to 22 per 100 000 in Spain. Clearly, notification rates often underestimate the true extent of the problem. That does not, however, alter the fact that notification rates in South Africa are amongst the highest in the world, with rates in the South African mining industry being considerably higher. It is also interesting to note that when one sorts the notification rates per country, it is found that, apart from Eritrea (which has a notification rate of 608 per 100 000), the next six highest figures are for countries in the SADC region. This region accounts for 33 per cent of all notified cases of tuberculosis in Africa. The SADC countries are all linked through migrancy and mine work.

There is evidence to suggest that the above data for the gold mining industry underestimate the current incidence; a recent autopsy study indicated that 40 per cent of those with tuberculosis had not had their infections detected when they were alive.[84] A mortality survey of 3971 white South African gold mineworkers found an increased standardised mortality ratio (SMR) (95 per cent confidence interval) for tuberculosis of 153.8 after 9 years of follow-up (41.9-394.1) and an SMR of 306.4 after 20 years follow-up (192-463.9).[85] It is likely that the risk in black South African gold mineworkers is even higher, given the higher silica exposure, higher background rate of tuberculosis and the increasingly high incidence rate of HIV infection.[86] The Commission of Inquiry into Safety and Health in the Mining Industry expressed 'grave concern over the failure to control tuberculosis in the mining industry'.

Although an association between silicosis and tuberculosis has been shown in many of the epidemiological studies discussed above, the epidemiological data pertaining to dose-response relationships between tuberculosis and cumulative silica dust exposure in the absence of silicosis, is less well described. In South Africa, where large numbers of workers are exposed to silica dust, the association between tuberculosis and silica dust exposure must be viewed as an issue of major public health importance.

Experimental studies have shown an association between changes induced by silica particles and increased susceptibility to mycobacterial infection.[87,88,89] It has been suggested that depending on the dose of silica dust, silica particles can destroy pulmonary macrophages or in lower doses, can cause changes in their metabolism and function, thereby reducing the capacity for effective antibacterial defence.[90] The presence of silica particles in the lung has also been shown to lead to an alteration of cell-mediated immunity.[91] There is, furthermore, evidence to suggest that resistance to mycobacterial infection decreases in direct proportion to total lung burden of silica dust.[92]

A study of Danish foundry workers[93] has shown that morbidity from tuberculosis in workers without silicosis increases with duration of exposure to silica dust. This investigation can be criticised for its definition of 'without silicosis' in that the presence of silicosis was established during initial examination and the incidence of tuberculosis was measured during a ten-year period. Earlier in this chapter, the potential for silicosis to progress has been discussed. This could have affected the silicosis status of the study subjects over the follow-up period.

A retrospective study of South African gold miners[94] found a rate ratio for tuberculosis of 2.3 among workers exposed to high dust levels, compared to those exposed to low dust levels - after adjustment for age, length of service and radiological silicosis. High dust-level workers were defined as drillers, mining team workers and stope team workers. An analysis of a sub-group of workers for whom HIV status data were available, showed that the rate of tuberculosis was unlikely to be the result of confounding due to HIV infection. Recent consideration of the risk of tuberculosis in relation to silica dust exposure and silicosis in white South African mineworkers, led to the conclusion that exposure to silica dust is a risk factor for the development of tuberculosis in the absence of silicosis even after there is no longer exposure to silica dust.[95] Results show that silica dust exposure in mineworkers who did not have silicosis at necropsy was an important risk factor for the development of tuberculosis and that the effect is dose dependent. In those without silicosis, the risk of tuberculosis was four times higher in individuals with the highest dust exposure level.

Mining lifestyle is also a risk factor for tuberculosis. In addition to silica exposure other key factors involved in reactivation of latent tuberculosis in gold mineworkers, are poor nutrition, physiological stress, concurrent diseases and a compromised immune system. In the context of this debate, it is important to recognise that no novice mineworker is employed with active tuberculosis.[96] This indicates that at the very least, mines are a site of reactivation of latent tuberculosis. This is interesting, given that only 5-10 per cent of people with latent tuberculosis in the general population ever develop active tuberculosis. The new generation of DNA finger-printing studies are beginning to shed light on whether new infection or reactivation is the cause of tuberculosis on the mines in South Africa. A study by Murray *et al.* using DNA finger-printing, revealed that up to 67 per cent of recent cases of active tuberculosis on South African gold mines were the result of current transmission rather than reactivation of latent tuberculosis.[97]

It has been argued that the high rates of tuberculosis on the gold mines are merely a reflection of high prevalence of tuberculosis in the rural areas from whence the mineworkers are recruited.[98] An autopsy study of tuberculosis prevalence among workers on asbestos, coal and gold mines, showed significant differences in prevalence of tuberculosis according to the type of mineral mined. However, the author comments that "this reflects little more than the epidemiology of tuberculosis in their areas of African labour recruitment."[99] Others argue that there are factors inherent in gold mining that are associated with the high prevalence of tuberculosis amongst gold miners.[100] Support for the conclusion that the high level of tuberculosis in gold miners is inherent in the nature of the work, is supported by the finding that notification rates for tuberculosis in gold miners are not only 3-5 times in excess of those of the general public, but also consistently and significantly higher than those of coal miners.[101]

Tuberculosis and the gold mining industry are linked by a unique set of political, social, economic and biological processes. Latent tuberculosis can be reactivated by exposure to dust, and the physiological stress that is common in the industry as well as the afore mentioned conditions, also predispose workers to new infection. Packard has said that there is a backlog of disease in South African workers and their families that is unsurpassed internationally.[102] The increasing prevalence of HIV infection in the country generally and among mineworkers in particular, is likely to further aggravate an already serious situation.

given the increased susceptibility to tuberculosis of those infected by HIV. A recent study of the effect of HIV infection on silicosis and tuberculosis incidence in black South African gold mineworkers, found that HIV increased the incidence of tuberculosis by five times and silicosis increased the incidence of tuberculosis by three times.[103] The presence of both silicosis and HIV increased the incidence of tuberculosis by fifteen times.

5.4.9 Chronic obstructive pulmonary disease

According to the American Thoracic Society standards, Chronic Obstructive Pulmonary Disease (COPD) is defined as a disorder characterised by abnormal tests of expiratory flow that do not change markedly over periods of several months of observation.[104] COPD encompasses chronic bronchitis (symptoms), emphysema (pathology) and airways obstruction (physiology). Lung function tests show reduced air flow resulting from increased resistance caused by bronchial narrowing, so that emptying of the lungs is slowed down during maximum forced expiration (FEV_1).

Chronic bronchitis is characterised by a sputum-producing cough, present for at least 3 months of the year for at least 2 years. Mucus hypersecretion caused by inflammatory processes in the central airways,[105] impaired ciliary function and reduced lung defence mechanisms, are key features of this condition.[106] Emphysema is defined as a pathological state of the lung, characterised by an increase in size of airspaces distal to the terminal bronchioles, either from dilation or from destruction of their walls. The reduced number of alveolar wall intercepts in the inflated lung, results in destruction of elastic recoil and a consequent reduction in the efficiency of expiration. Emphysema is accompanied by narrowing of lung airways and concomitant airflow obstruction and reduced FEV_1. The key clinical symptom is dyspnoea. The early stages of emphysema are not seen on an X-ray film. In more advanced disease, there is depression and flattening of the diaphragm, and areas of translucency due to loss of alveolar tissue, are apparent. The lateral view of the lung shows an increase in retro-sternal space. It is important to note that an X-ray does not give a reliable diagnosis of COPD. Therefore, COPD should always be confirmed by lung function testing.

Hnizdo and Murray correlated clinical and autopsy COPD findings and were able to show a strong exponential relationship between FEV_1 and the degree of emphysema found at autopsy.[107] Even a small degree of emphysema identified at autopsy had caused a measurable lung function impairment during life. Tobacco smoking is the primary risk factor associated with the development of chronic bronchitis and emphysema although other environmental and occupational pollutants, especially high-level dust exposures have proved to be secondary risk factors. In this context, it is important to note that exposure to silica dust and tobacco smoke are associated with a significant increase in the prevalence of simple chronic bronchitis and that the combined effect is synergistic. Tobacco smoke has been shown to inhibit the ciliary action, reduce the antibacterial action of macrophages and release elastase from leukocytes.[108] Hnizdo found that the average loss of FEV_1 due to the effects of 25 years of gold mining, was 236 ml (95 per cent CI 136-337).[109] In comparison, the average loss because of smoking of one packet of cigarettes per day over 30 years, was 552 ml (95 per cent CI 461-644). Thus, the additive effect of silica dust and smoking can be as high as 981ml.Whether or not a workplace exposure constitutes a hazard for the development of COPD, has been shown to depend on the type and level of exposure.[110, 111]Epidemiological studies of American coal workers have shown a dose-response relationship between lung function impairment and increasing coal mining dust exposure.[112]

5.5 Conclusion

This chapter has shown that there is a high silica content in the reef formation of the Witwatersrand gold fields and that there are high prevalences and incidences of occupational lung diseases which result from the inhalation of silica dust. This chapter makes it clear that while South Africa has had a gold mining industry for over a century and whereas legislated dust management mechanisms and regulations have been in place for most of that time, the prevalence of silicosis, tuberculosis and COPD presented above, indicate that neither past nor present practices are safe.

While existing TLVs are supported by studies of in-service workers, they may over-estimate safe levels, considering the evidence that pneumoconiosis may progress after the cessation of silica exposure. The suitability of the existing TLVs in a South African context are further called into question when one considers that the present international silica safety recommendations reflect the results of research conducted in countries with a low prevalence of tuberculosis. As has been discussed, there are higher prevalences of occupational diseases in South African mineworkers as compared with miners of other nationalities whose estimated cumulative silica exposure has apparently been similar. There is a need for more information in order to establish the true nature of exposure-response relationships and to assess the role of the latency period so as to determine whether existing dust level standards are adequate.

Previous legislation has been criticised for its artificial separation of occupational hygiene surveillance from the surveillance of occupational disease. This has lead to a culture within the South African mining industry whicch has concentrated on monitoring dust levels rather than monitoring disease prevalence and finding engineering solutions to reduce dust levels. The enactment of the MHSA introduced an innovative approach to the prevention of occupational disease and injury including the right to leave a dangerous workplace. However, it is perhaps somewhat unrealistic in respect of the onerous duties it places on all stakeholders to give effect to its intention. The MHSA has been said to represent a new constitution for the mining industry which will effect changes that mirror the broader transformation of South African society. The challenge of the MHSA is to ensure that knowledge of dust monitoring and disease prevalence are adequately communicated to and understood by rank-and-file mineworkers and members of labour sending communities, so as to allow for informed judgements to be made as to what constitutes a dangerous workplace.

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CHAPTER 6

An Economic and Demographic Profile of Libode

"The work involved in this survey was difficult and time consuming out of all proportion to what might appear possible to anyone unacquainted with the special circumstances surrounding this undertaking, such as the great distances to be traversed by motor car, often along primitive roads, many of which become almost impassable for this kind of transport in the rainy season ... tracing the native repatriates was frequently troublesome, because they often change their names when going to work and in many instances it was found necessary to seek the assistance of a local trader or official in order to identify the individual ... Despite these inherent difficulties, the work has provided a great deal of useful and interesting information regarding tuberculosis in the Transkei and Ciskei."

South African Institute for Medical Research (SAIMR). Tuberculosis in South African natives with special reference to the disease amongst the mine labourers of the Witwatersrand.1932.

6.1 Introduction

This chapter describes the economic, political, demographic, ecological and climatic conditions of the field site. Chapter one considered the economic environment of the Eastern Cape Province and found it to be underdeveloped, with an eroded subsistence economy and heavily dependent on mine wage remittances. In this chapter, the provincial picture will not be re-examined but attention will be focused on the study district of Libode. Provincial data will only be used where none are available at a magisterial district level. Subsequent chapters will examine the economic burden of occupational disease experienced by study subjects and their households. The economic impact of occupational disease on state health services in Libode will also be evaluated in later chapters.

The research environment in Libode in 1996 was in many ways very similar to that experienced by the SAIMR investigators in the early twentieth century.[1] Research discussed in previous chapters has shown that the characteristics of mine labour sending areas are the primary dependence on mine wage remittances, the very limited subsistence income from agriculture, and absence of the potentially most productive members of the community, who are involved in wage labour elsewhere.[2,3] These characteristics are conspicuously present in Libode. In 1995 the magisterial district of Libode had a population of 119 202 people, of whom 1.2 per cent lived in an urban area.[4] The village of Libode lies 20 kilometres south-east of Umtata by road, on the route to the town of Port St Johns. The village serves as an administrative and commercial centre for the surrounding rural settlements of the district. Umtata is the major business centre for the eastern part of the Eastern Cape (known as the Transkei) and was the capital of the former 'independent state'. Libode falls into the Pondoland sub-region of the Transkei.

Libode district, which has 1.9 per cent of the population of the Eastern Cape, contributes less than 0.6 per cent to the provincial economy. Such economic activity as there is, is based in subsistence agriculture and the government services. In 1995, the provincial unemployment rate was 41 per cent of the potentially economically active people over 15 years old. It has been estimated that in Libode district one wage was supporting ten people.[5] Examination of the sex-ratio in the Libode district reveals that between the ages of 20 and 44 years, the male population of Libode district is 30 per cent less than the female population, indicating a significant degree of male migrancy. While it is important to note that we do not know the gender and age-specific mortality rates for this community, this ratio can be taken to represent a lower limit for the prevalence of male migrancy.

The climate of the district is temperate, with rain in the summer. The average rainfall is 700 mm per annum with the maximum occurring between October and March. The vegetation of the area is classified as Eastern Province Thornveld, consisting of dense, sourish mixed grasses. The most common land tenure system in operation is one in which every family head has the right to graze cattle and cultivate a piece of land. The traditional leadership confers this right and retention of the right of access to land requires maintaining a household in the area, which thus forms one pole of the oscillating migrant labour system in the rural areas. People practice stock farming all year round and maize cultivation between September and April. Yields are largely dependent on the efficacy of ox-drawn ploughing and the availability of a high labour input at peak periods in the crop cycle. Labour at peak periods is often in short supply because of the high level of male migrancy, so that maize yields are often low.[6]

There are no available data on the overall literacy rate in Libode but a recent survey of the number of years of schooling received by female heads of households in Libode revealed that 27 per cent had no schooling and a further 50 per cent had less than five years of schooling.[7] It has been estimated that 60 per cent of male migrant workers from the Eastern Cape are illiterate. The pupil-teacher ratio for the Eastern Cape Province for 1991 was 39 pupils per teacher as compared to a national average of 32.

The majority of Libode residents live in scattered settlements in houses predominantly made of wattle and daub, thatched with grass. A corrugated iron roof is regarded as a status symbol. Only 45 per cent of Libode households report having access to clean drinking water, 25 per cent report having access to flush or pit toilets and only 6 per cent of households have electricity.[8]

No health data are available for the Libode district. Provincial level data for 1991 indicate that life expectancy in the Eastern Cape Province is 59 years, as compared to a national average of 63 years, while the infant mortality rate is 58.2 per 1000 live births, as compared to a national average of 41.8. The number of hospital beds per 1000 population is 4.6 and the number of medical officials per 1000 population is 0.3, as compared to a national average of 5.1 and 0.6, respectively.[9] The Libode district has no hospital and makes use of the St Barnabas Hospital in the neighbouring Ngqeleni district. The hospital in Ngqeleni is very far from the homes of the majority of Libode residents and transport facilities are poor, infrequent and expensive. St Barnabas Hospital has 320 beds, of which 100 are set aside for acute care, and 63 for chronic infectious conditions. The hospital has 130 professional nurses and 5 doctors. There are fifteen satellite clinics in the Libode district, which are visited once a month by a doctor from St Barnabas hospital. A recent survey found that the average household in Libode lives a distance of 1.24 hours in walking time from their nearest clinic.[10] Material constraints often affect promotive, preventive and curative health care - only two of the clinics have electricity, four have telephones and none have running water in addition to which there are inadequate access routes and transport services for patients and staff and many essential items of equipment are lacking.[11]

The Libode Rural Transitional Local Council was democratically elected in 1995. The traditional authorities are served by three chiefs and 29 headmen. The traditional leadership plays a legal role, through the administration of tribal courts, and a developmental role, via their participation in the construction of infrastructure and land allocations in the areas in which they continue to have considerable authority. Civic structures are represented in Libode by the South African National Civics Organisation (SANCO). This social division can be seen as a clash of political cultures between an hereditary leadership, which was employed by colonial and more recent apartheid governments to administer rural Africans, and a modern political culture ostensibly based on representation, delegation and recall, represented by

SANCO. Both traditional leaders and SANCO are represented on the Libode Development Forum.

6.2 Vulnerability to enviromental hazards

Recent environmental research carried out in the United States of America has found that some populations within the nation are more vulnerable than others to health risks from environmental threats.[12] In the USA, exposure to toxicants and the resultant health problems have been found to be disproportionately high in urban ghettos, rural 'poverty pockets' and impoverished Native American reservations.[13,14] Such communities are disproportionately affected by unhealthy air, dangerous chemicals, toxic wastes, etc.[15] A key area in which low-income communities have been shown to to be exposed to elevated environmental hazards, is at work.[16] There is an increasing body of environmental research results which suggest that environmental inequities are the result of decision-making which is shaped by the values and ethics of state and employer bodies. While the migrant labour system may blur the concepts provided by American researchers, I would argue that the Libode community (and indeed other mine labour sending communities) constitutes a low-income community at high risk of exposure to environmental hazards in the workplace.

6.3 Conclusion

This chapter has set out the high level of poverty in the study area. Libode has been shown to have a primary dependence on the mine wage remittances of migrant workers, a very limited subsistence agriculture base, high levels of illiteracy and limited access to health care. It has been argued that the socio-economic conditions in Libode make study subjects very vulnerable to occupational health threats and that, in a context of poverty, the significance of the costs of disease for household viability is high.

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[10] Corplan, 1997 op. cit.

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CHAPTER 7

A Methodological Outline of the Study

"People were helpful once they knew what we wanted ... one child said that a blue car would be outside the home of the patient we were looking for. How could she be sure, I wondered? We could see the blue car from a long way off; it will be there for years, for it has neither wheels nor engine".

Strang JIG. Tracing patients in rural Africa. Lancet 1996.

7.1 Introduction

This study may be distinguished from other surveys involving of migrant workers and also from other research on mineworkers in the method it employed to define and trace the study subjects. This investigation is one of the few surveys which has been community-based in its design. The Libode community was involved in the planning and implementation of this study. Active community participation in the research design resulted in the creation of a new sampling methodology, which involved the development of a reliable sampling frame from which to draw a random sample.

While most epidemiological studies have failed to examine rural labour sending communities, there are some notable exceptions, in particular, the work of Strang, Felix, Arkles, Steen *et al.* and Davies.[1,2,3,4,5] The work of Strang involved tracing tuberculosis patients who had been discharged from hospital and who had returned to rural homes. Strang's study shows the importance of persistent detective work and good community relations. Felix undertook a study of pleural plaques as a marker for environmental asbestos contamination in the village of Mafefe in the Northern Province. The methodology for her study required a census of the community to be undertaken, from which a random sample could be drawn. Likewise, Steen *et al.* conducted a house-to-house survey in the village of Thamaga, Botswana, in order to identify former mineworkers. They subsequently drew a random sample from this data. Arkles, when refused access to the records of Rand Mutual Hospital, devised a method of sampling via networking techniques. Davies, in his study carried out in the Northern Province of South Africa has undertaken what amounts to an examination of an extended case series, so large in size that despite not being a random sample, it provides a clear picture of the scale and magnitude of the burden of occupational lung disease in that area. The study in Libode is unique in the extent to which community organisations (political movements, unions, civic bodies, and traditional leaders) and public authorities (health-related departments within local, regional, provincial and national structures) participated in planning, implementation and the service provision which was based on the study findings.

This chapter provides a summary of the methodology employed in the selection and examination of the study subjects. In the discussion that follows, the key features of this method and its effectiveness for meeting the study objectives are critically examined.

7.2 Study methodology

7.2.1 Objectives

A cross-sectional investigation was conducted in order to determine the prevalence of occupational lung diseases in a random sample of ex-mineworkers in the Libode district. The hypothesis on which this study was based, was that there was a significant amount of undiagnosed, uncompensated occupational lung disease in the area. The objectives were as follows. First, to establish a cross-sectional prevalence study of occupational lung disease in a random sample of black former gold mineworkers resident in a rural labour sending area. Secondly, to conduct univariate and multivariate analysis in which radiological evidence of pneumoconiosis, tuberculosis and emphysema is tested for association with age, total length of service, type of service, smoking history and age. Thirdly, to examine two key measures of lung function: FEV_1 and FVC, each in relation to smoking status, radiological tuberculosis, pneumoconiosis and emphysema, age, weight, height, length of service and type of service. Fourthly, to quantify the economic burden occupational disease to study subjects and to extrapolate that to the population of ex-gold mineworkers. Fifthly, to quantify the compensation liability and to assess the impact of raising the dust levy on the economic viability of the mining industry. Sixthly, to explore the reasons for radiological inter-reader variation within the ILO Classification for Pneumoconioses. Seventhly, to find out if any of the mineworkers in the study group might be eligible for compensation and to help them claim such compensation. Finally, to document processing of compensation claims and thereby assess the empirical evidence of the functioning of the compensation system.

7.2.2 Preparation

The preparation for the medical fieldwork was begun in May of 1995, and the actual fieldwork was undertaken in March 1996. The prevalence of occupational lung disease was determined by means of the medical examinations performed between March 11 and March 24, 1996. After consultation with employees of both TEBA and the NUM, Libode was chosen as the study area because it was felt that it was typical of the mine labour sending communities of the Eastern Cape Province. Mine recruitment data confirm that the recruitment pattern for the area reflects the numbers and types of employment in the former Transkei generally.[6] TEBA Recruitment records for this district are still available. This was

fortuitous, as these records are usually destroyed after five years.

7.2.3 Sampling frame

The study population consisted of all mineworkers recruited by TEBA between 1969 and 1980. There were 11 706 records for the Libode magisterial district for this period. The time frame was considered appropriate in that it provided sufficient opportunity for diseases with a long latent period to manifest. During the period 1969-1980 it was illegal for black mineworkers to contract with gold mines outside of TEBA. Thus for the study period this is a complete record. Subsiquent recruitment practice has made it possible for workers to contract for mine employment without using TEBA.

7.2.4 Sampling method

A sample of the men was chosen by numbering the available records and generating random numbers using the statistical package S-Plus to select the sample.

7.2.5 Sample size

A sample size of 400 was calculated, using Epi Info, on the assumption that we needed to be able to detect a prevalence of 10 per cent with 95 per cent confidence limits equal to ± 3 per cent. In order to allow for the possibility that some mineworkers might be dead, missing or still working, a further 400 names were drawn and submitted to the community for tracing purposes. The total number in the random sample was, therefore, 800.

7.2.6 Volunteers

In addition to the random sample, members of the Libode community who had worked in the mining industry were invited to take part in the study as volunteers. Inclusion criteria for volunteers were a work history of at least ten years in a high-dust job, defined as drilling, lashing or winch driving. Proof of service was required in order to obtain entry to the volunteer arm of the study. Volunteers who met the selection criteria were taken on a 'first come, first served basis.' Two hundred and sixty-four men were selected on this basis. The volunteer arm of the survey was included in response to a request for such a component from community structures. The selection criteria were designed in consultation with them and this illustrates the need to work with the study community in this kind of fieldwork. The TEBA office in Libode was used as a screening point for volunteers wishing to take part in the study. Volunteers were screened by a member of the Libode Development Forum, working with a member of the research team. Because the inclusion criteria for the volunteer section of the study were such that they could bias the study in the direction of long service and high-dust exposure, this arm of the survey was not included in the statistical analysis.

7.2.7 Study awareness and tracing techniques

In order to initiate the study, the key organisational stakeholders (Department of Health, National Union of Mineworkers, Chamber of Mines, The Employment Bureau of Africa (TEBA), Libode traditional leaders and civic structures, Libode Development Forum and Libode health workers) were approached and a series of meetings were called to communicate the aims of the investigation and to discuss the methodological issues. Full co-operation was secured at these meetings. They were held because it was felt that it was important to consult with representatives of all the major stakeholders who might be affected by recommendations emanating from the research project. Such stakeholder meetings also conferred legitimacy on the project. A field worker was employed from January 1996 to communicate the aims, objectives and limitations of the study. The fieldworker was an ex-mineworker, resident in the Libode district. He helped to overcome the practical logistic problems involved in tracing subjects living far from the hospital where examinations were to take place. Subsequent to the organisational stakeholder meetings, a general meeting was convened at district level, to which all ex-mineworkers in the district were invited. The aims and objectives of the study were communicated through a series of community meetings held in each of the settlements that took part in the study. Between 50 and 100 men came to each settlement meeting.

depending on the size of the settlement. At these gatherings, the aims of the study and the potential benefits to individuals and the broader community were discussed in isiXhosa. The meetings provided a forum in which to anticipate and deal with the expectations that could potentially have been raised by such a study. The differences between a study and a service were discussed in detail. The selection and timing of the volunteer arm of the study was also discussed. A series of information messages were also broadcast on Radio Transkei.

The community leadership structures (both traditional leaders and South African National Civics Organisation leaders) were enlisted to assist with the community meetings and the tracing of men in the random sample. The Community Health Matron of the local hospital assisted them in this task. Identifying information from TEBA contracts was supplied to a representative of both of the above organisations for each settlement within the Libode district. TEBA contracts list the individual's name, settlement, headman and chief.[i] Tracing was facilitated by a widespread awareness of and enthusiasm for the aims of the study. Pilot tracing was carried out in February of 1996.

7.2.8 Informed consent

Written informed consent was obtained from all study subjects and volunteers. The text of the consent form was read to each study subject in isiXhosa and a signature or mark was obtained prior to commencement of the medical assessments. A copy of the consent form is attached as appendix 1.

7.2.9 Data collection

7.2.9.1 Medical examinations

The medical examinations took place at St Barnabas (Ntlaza) Hospital. All the men in the random sample were transported to the hospital by TEBA, who did this under contract. The volunteers were reimbursed for their transport costs to and from the hospital. The study subjects all underwent spirometry, radiography and a general medical examination to determine whether or not the subject had an occupational lung disease. A mining occupational history was taken for each individual by a trained fieldworker, who was himself an ex-

i This information acts as a rural address and is sufficient to trace a study subject.

mineworker resident in Libode. The information supplied in the work history was later corroborated from TEBA records.

Each person had a full size posteroanterior 125 kV chest radiograph taken, which was carried out by the radiographer from St Barnabas Hospital in accordance with ILO specifications.[7] The chest radiographs of the random sample were read into the ILO classification of the pneumoconioses by three readers; one an experienced registered pulmonologist and occupational medicine practitioner, one an experienced occupational health practitioner and authorised B reader, and the other an experienced, registered radiologist. X-rays were read in a blinded, independent fashion. A fourth reading was undertaken by the radiologist attached to the Medical Bureau for Occupational Diseases (MBOD) according to a shortened version of the ILO International Classification of Radiographs of Pneumoconiosis criteria. This fourth reading was not designed as part of the study and the researcher had no control over the conditions under which it was executed. Consequently, it is used only for comparative purposes in the discussion of the radiological results that follows. Spirometric tests which included FVC and FEV_1[ii] were performed while the subjects were seated and wearing a nose clip. Bacterial/viral filter mouthpieces were used. All tests were undertaken by a trained technologist using a Vitalograph compact spirometer (Buckinghamshire, UK) which was calibrated according to American Thoracic Society criteria. Respiratory function tests were carried out according to American Thoracic Society guidelines.[8] Full, detailed instructions were given in isiXhosa, the home language of the participants. Subjects were required to perform three acceptable curves, the best of which was selected. In only 8.3 per cent did the two best curves differ by more than 5 per cent and these cases were excluded from further analysis. Given the exclusion of this group, the results are likely to be conservative in relation to the extent of disease.[9] The height, weight and blood pressure of each study subject was recorded.

Medical benefit forms for the purpose of applying for workers' compensation were completed

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ii Lung function tests can be used to obtain several measures of lung function, including the forced vital capacity (FVC) and the forced expiratory volume in one second (FEV1). Lung function abnormalities can be either obstructive, restrictive or both. Conditions which limit airflow cause a reduction of FEV1 relative to the FVC. Such a reduction is an indicator of an obstructive disease pattern. In the case of a person with emphysema, the Total Lung Capacity (TLC) is well preserved but FEV1 is decreased because of a loss of elasticity in the lungs. The FVC is better preserved. Conditions in which there is a shrinkage of the lungs (i.e. a reduction in TLC) cause a reduction in the FEV1 and the FVC in equal proportions (as is the case with silicosis). This is indicative of a restrictive disease pattern.

for all study subjects and, together with the chest radiographs and spirometry results, these were forwarded to the compensation authorities.

A medical history questionnaire was administered, in isiXhosa, to every study subject by a trained field worker. The questionnaire was translated into isiXhosa and then translated back into English by an isiXhosa first-language epidemiologist. This translation and back translation were undertaken in order to ensure that there were no ambiguities in the final version. The medical history questionnaire included detailed information relating to previous compensation and hospitalisation history, and current respiratory disease symptoms. The respiratory disease symptom questions were adapted from those recommended by the American Thoracic Society (ATS).[10] The aim of the questionnaire was to evaluate the respiratory symptoms profile of the study group and to assess the factors that contributed to this symptoms profile. Respiratory symptoms evaluated in the questionnaire included cough, phlegm production, haemoptysis, dyspnoea and wheezing. Information relating to smoking habits, previous compensation received for occupational lung disease and hospitalisation, was also recorded. The full questionnaire is included as appendix 2. A questionnaire dealing with the impact of occupational lung disease on the study subjects and their households was administered to those found to be suffering from such diseases. This questionnaire is the input into a compensation liability model and an occupational disease burden model that were developed in this thesis that are elaborated upon in chapters 11 and 12.

7.2.9.2 Data capture and analysis

All data were coded using Microsoft Excel for subsequent statistical analysis using EPI Info and STATISTICA. Data were cross-checked in order to detect and correct coding errors. The high level of illiteracy and innumeracy (60 per cent of the random sample could not sign their names on the consent form) precluded any community involvement in the analysis of these data.

7.2.9.3 Results report back

The Libode community was kept informed as to the results through community meetings. All papers written from this study were made available to all stakeholders and copies were deposited with the traditional leaders, the SANCO leaders, the Libode magistrate, the TEBA staff and the health workers for the district. All medical results were kept confidential and only released to the mineworker concerned (or where necessary, his widow) by a trained, Libode-based field worker employed for this purpose. Five post-fieldwork community meetings were held in order to inform the broader community of the epidemiological findings.

7.3 Discussion

7.3.1 Methodological premise

In undertaking this prevalence study of a random sample study of ex-mineworkers, the initial methodological problems revolved around how to trace study subjects. The study design was based on the assumption that the details contained in a TEBA mine recruiting record were sufficient to enable a person to be found, once he had left the mining industry. Recruiting records have been used by the mining industry to call back into service workers who have particular skills that are in demand. These records also enable the mining industry to contact the relatives of a deceased person and to know where to deliver the body. It seemed reasonable to assume that ex-mineworkers could be traced for epidemiological purposes, given that this was a small step from what the mining industry was already doing. In his report on tracing tuberculosis pericarditis patients who had been discharged from hospital and had returned home to rural communities in the Eastern Cape, Strang argues that in order to follow up patients in rural areas:

> "you have to be trusted and you need to be persistent and to work like a detective. Good relations with the community are important and a good doctor-patient relationship is fundamental. The African bush telegraph will carry your messages further than you may think and the response will depend on how you treated your patients, not just medically, but as people"."

Furthermore, the involvement of the Libode community allowed for the use of an existing, effective communication system that members of labour sending communities use to communicate with members who are migrant workers. The expression 'bush telegraph' is used to describe the phenomenon of rapid communication in rural situations in the absence of a technological communications infrastructure. These communication systems allow individuals to maintain extensive and up-to-date contact with home areas while either in employment or while searching for employment far from home. Strang writes that:

> "rural Africa has retained something far more precious than a telephone, fax machine or a rapid postal service, you have to talk to people and it pays to know them, since your life and welfare

may depend on it. If you do not know your neighbour, you cannot love him."[12]

Much epidemiology fails to examine the knowledge that local people possess regarding their own health and community resources.[13] This theme will be returned to later in this chapter.

7.3.1.1 Political obstacles and how they altered the study methodology

Initially, the tracing method for this study was designed around employing TEBA staff to perform the tracing as this agency had both the expertise and the logistical ability to find ex-mineworkers and bring them to a point for examination. However, this proved to be impossible, for political reasons. Despite the submission by the Chamber of Mines to the Leon Commission calling for research into the health of ex-mineworkers in rural areas and despite the Chief Medical Advisor to the Chamber of Mines being part of the Epidemiology Research Unit (ERU) management committee which unanimously approved the project, a senior mining house medical advisor surreptitiously withdrew support for the study and applied pressure on TEBA not to cooperate. TEBA were consequently unable to contract to supply tracing services for the study. This situation mirrors the experience of Arkles, who in her research conerning disabled ex-mineworkers, initially envisaged that the personal injury records of the Rand Mutual Assurance Company could be used to provide a sampling frame from which the names for a random sample of disabled mineworkers could be drawn. Arkles was refused access to these records.[iii]

Denied the use of an agency to perform tracing on behalf of the study, it became necessary to carry out the tracing of study subjects directly, using a method which depended for its success on the active assistance of the people in the Libode district. What started as a serious threat to the study, serendipitously helped to transform the study methodology and allowed for a high degree of community participation. This produced both better science and facilitated the development of a health intervention of benefit to the study area. The implementation of the study required extensive co-operation with the people resident in Libode and consequently their views were carried back to modify the study methodology. The ex-mineworkers and community leaders involved in the survey became research collaborators rather than passive objects of study. This community participation resulted in the development of a highly effective tracing methodology. As will be shown in later chapters, the response rate to the

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iii Personal communication: prof JCA Davies.

medical survey was such that the results can be considered epidemiologically representative of the Libode adult male population as well as extrapolatable to similar mine labour sending communities.

7.3.2 Alternative research paradigms

In recent years a number of research approaches have evolved in response to a common frustration with the perceived inability of traditional positivistic social science methods to inform questions of practice or social action. There has been a growing rejection of the separation of researcher from the subject of research, the researcher as the only expert, and the possibility for a research question to be value neutral. Positivistic social science research has been criticised for being too dogmatic in its adherence to the demands of 'scientific distance' which can result in research becoming an excuse to avoid social action and activism. Reason and Rowan argue that one needs to avoid the danger of ending up with 'research results which are statistically significant but humanly insignificant.'[14]

7.3.2.1 Participatory research

In response to these criticisms, research strategies which emphasise community participation are gaining greater respectability within health research.[15] There is a growing sense that involving local people as participants in research and planning can increase effectiveness and, in the long term, save time and money, although the cost and time savings may not be apparent in the short term.[16,17] There are a range of research methodologies which make use of community participation to a greater or lesser extent. Cornwall and Jewkes argue that in some sense, all health research requires participants who are called upon to participate in different ways and that all researchers from 'participant observer' anthropologists to epidemiologists and medical doctors are also participants.[18] They argue that for research to be defined as truly participatory, local knowledge must not only be acknowledged but must form the basis of the research and planning. The choice of research topic must reflect local priorities and must have been identified by local people. They argue that data collection, interpretation and analysis must be undertaken by local people in line with local concepts and frameworks and that subsequent action must be undertaken by local people. Gaventamaintains that participatory research:

"attempts to break down the distinction between the researchers and the researched, the subjects and the objects of knowledge production by the participation of the people themselves in the process of gaining and creating knowledge. In the process, research is seen not only as a process of creating knowledge but simultaneously as education and development of consciousness and of mobilisation of action." [19]

The ideal in this type of research paradigm is for all the participants to gain greater control over their lives through the acquisition of skills and knowledge.

Critics of participatory research argue that it, too, fails to acknowledge the extent to which the existing power relationships continue to impact on the study process, both in terms of the relationship of the outside researcher to the community and also in terms of internal relationships of power and/ or stratification within the community. They also argue that there is often a gap between theory and actual practice.[20]

In terms of the definition provided by Cornwall and Jewkes, this study is not truly participatory, although there was considerable participation from the Libode community, especially with regard to subject recruitment and subsequent action. While the research topic was met with enthusiasm by the people of Libode, their lack of knowledge as to their legal rights under the ODMWA meant that there was limited awareness of occupational health as a priority prior to the arrival of the outside researcher. If one examines the definition of participatory research provided by Gaventa, one sees that the distinction between the researchers and the researched had become considerably blurred by the end of the execution of the research project in Libode. However, it should be borne in mind that adherence to any particular definition of participatory research was not in itself an original aim. While the project created knowledge and simultaneously acted to educate and mobilise the community for action, these were pleasant, somewhat unexpected by-products rather than the objective of the study.

7.3.2.2 Action research

Action research is concerned with producing research which can address practical concerns. It works from the premise that while the professional research worker brings to the research process theoretical knowledge, experience, and skills for conducting research, the participant collaborators bring practical knowledge and experience regarding the situation being studied.[21] The researcher and the community collaborators are viewed as having complementary expertise and knowledge critical to the research process. This study falls broadly into the area of action research.

7.3.2.3 Criticisms of action and participatory research

Both action and participatory research can be criticised for putting forward a romantic notion of 'the community' which assumes that all those with common problems are united by said problems and are without internal tensions and divisions. A community is seldom a homogeneous, well-bounded unit. Most such groupings should be seen as heterogeneous, with multiple interrelated axes of difference including those of gender, age, wealth and power.[22] In relation to this study, the term community refers to the residents of the Libode magisterial district. The success of the tracing methods illustrates the existence of bonds that knit the residents of the district into a community. This does not mean that the Libode community is completely homogeneous. A particularly important social cleavage relevant to this study is the affiliation to one of the two competing leadership structures of SANCO and the traditional leaders.[iv] These two groupings were competing with each other for power in a context where there are limited means of dispensing patronage. The study and the compensation that might flow from it could well have become a political struggle had the study design not so rigorously adhered to the policy of equal participation by both groups. This highlights the need for researchers to be aware of the potential for individual parties to try and use the researcher to further their own political agendas. It is also important to recognise that certain groups may feel that research processes in which there is community collaboration are subversive, as they can allow for the empowerment of others which can, in turn, undermine their own power.[23]

7.3.2.4 Insights gained from the theory pertaining to participatory and action research

Proponents of participatory research argue that scholars must examine their motives for conducting research, think critically about the biases inherent in the model that guides their research, and consider the potential political implications of findings. In this context, it is interesting to ask why the mining industry last undertook a study of occupational lung disease

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iv This social division can be seen as a clash of political cultures between an hereditary leadership, which was employed by colonial and more recent apartheid governments to administer rural Africans and a modern political culture ostensibly based on representation, delegation and recall represented by SANCO.

in former migrant mineworkers in a labour sending community in 1924.[24] In the light of the extensive body of epidemiological research on white miners (both in-service and in retirement) and to a lesser extent on in-service black mineworkers, there is a need to find a plausible explanation for why out-of-service black mineworkers have not been examined. This failure to follow up ex-mineworkers is consistent with the view that migrants are regarded by the industry as temporary workers and that the sole interest of the employer is the purchasing of their labour power. Where health status does not impact on the short-term ability to work, it is not regarded as relevant to the industry.

That South African epidemiologists have not pursued this large study population among whom there was good reason to believe that there was a significant burden of disease (given what was known from studies of in-service workers and white retired mineworkers), or have not provided epidemiological data to challenge this assumption, is a sad reflection on the profession. However, this failure to fully evaluate the epidemiological consequences of migrancy is perhaps inherent in occupational health studies internationally. Occupational health is a field of study that tends to be urban based and there is a tendency throughout the world to study workers while in service or those who live in urban areas and a failure to follow migrant workers back to their rural communities. The contexts in which one might expect to find such a follow up would include 'guest workers' in West Germany returning to Turkey or farm labourers in California returning to Mexico, but a literature search and a questioning of occupational health professionals in Germany, Turkey, Mexico and the United States of America, has failed to identify any such studies. Furthermore, epidemiologists internationally have also tended to avoid research that include 'fuzzy' confounding social factors such as race or class. There has been a tendency to work on research questions that produce clean data from which significant *p* values can be obtained, with social issues often being ignored to the extent that while the data may be clean it is not useful. As a result of this tendency, there is very little in the way of research findings to explain the magnitude of some occupational health problems in certain communities. A classic example of this is the lack of data on occupational lung disease in black South African former mineworkers.

7.3.3 Limitations in the study design

There are a range of limitations associated with this study design. These limitations will be discussed in greater depth in chapter seven and will only be briefly mentioned here, therefore. The cross-sectional design only gives the disease status of living people who are not still in-