9 | Demystifying occupational and environmental health: experiences from India

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Introduction

In India's industrialized zones, health problems linked to occupational hazards and workplace conditions affect many workers, while others are at risk from industrial accidents and their environmental effects. Workers themselves have accumulated much experiential expertise of such occupational and environmental health issues, interpreted within their own life-worlds. Yet having these perspectives and experiences recognized, and occupational diseases identified and acted upon by government agencies and corporations, has proved a much greater struggle. This chapter documents such struggles, which can be seen as central to the citizenship practices of factory workers. Not only have these struggles brought workers' own knowledge and experiences of occupational risks into the public policy domain, but this has been linked to a variety of rights claims: whether rights to material compensation, to medical treatment or to improved working conditions. These citizenship practices have, moreover, been forged in a context where workers' very survival is at stake, and their motivation for struggle is low.

Workers have not waged these struggles alone. Indeed, the chapter focuses on the key roles played by a set of intermediary actors in brokering and bridging the worlds of affected workers, and of scientific and policy institutions. It is based on ten years' experience of the Occupational Health and Safety Centre (OHSC) and the Environmental and Occupational Health Section of the Society for Participatory Research in Asia (PRIA). The OHSC was formed by unions, workers and activists, medical professionals, safety experts and lawyers in 1988, and has worked consistently since then to help identify and spread information about occupational diseases, and to fight for compensation. Central to this brokering has been interpreting and reframing workers' experiences to fit the concepts and standards of legitimacy of dominant scientific culture, while educating workers to participate in diagnosis and monitoring (Murlidhar et al. 1995). The science of occupational diseases has thus been 'demystified' for workers. In this, the worlds of workers and scientists have been bridged largely in terms of science, rather than those of workers' own ways of being, and a particular

model of the scientifically literate citizen has thus been promoted. Yet as the chapter suggests, given the scientific uncertainty and even ignorance surrounding many issues of occupational and environmental health, this has been a process of demystification for scientists too, as through the work of OHSC, and the workers' citizen science that it has supported, new knowledge of and diagnostic precision in occupational and environmental health have emerged.

The chapter begins by outlining the origins and early work of the OHSC in a context of high scientific uncertainty about occupational diseases, official reluctance to acknowledge them and extreme marginalization of factory workers. It then addresses the case of occupational lung diseases, and the process through which the OHSC supported workers' citizenship practices around this issue. The chapter goes on to address, more briefly, a range of further occupational and environmental health issues, where similar brokerage has been undertaken, including occupational noise-induced hearing loss (NIHL), disability assessment more generally, and chemical accidents and pollution, drawing out common themes in the emergent relationships between workers as citizens, scientific institutions and governance.

The origins and early work of the Occupational Health and Safety Centre

The OHSC was formed against the backdrop of several serious setbacks to workers' organizations in the 1980s. An unsuccessful strike by textile workers in Mumbai was followed by the rapid closure of many industries there, with the onslaught of the new economic policy pushed by right-wing governments, and amid forces of economic globalization. Nearly 60 per cent of industries in the Agra Road and the Thane–Belapur Road, one of the largest industrial belts in Asia, were shut down. The poor economic conditions, vulnerability and low morale of workers that ensued provided the context in which the OHSC began its work in diagnosing and monitoring occupational and environmental diseases.

When OHSC started its work, there were many obstacles to recognition of workers' experiences of occupational disease, and to translating such recognition into realized rights to treatment or compensation. Many occupational and environmental health problems are surrounded by uncertainty, making diagnosis difficult. Some of these uncertainties are socio-political, others scientific, and some combine both these aspects. There is frequently uncertainty about the causes and precise sources of a health problem, and about the nature and speed of disease processes – despite the perception that medicine is an exact science. This uncertainty is compounded by the

lack of a clear regulatory framework and the lack of understanding among concerned parties about the limited legal regulations.

There were also other major hurdles that obstructed the process of recognizing and claiming for occupational health issues. Doctors were poorly trained in recognizing and diagnosing occupational diseases. The attitudes of both doctors and other relevant professionals to doing so was influenced by a bias among the professional class against blue-collar workers in general. At times, this led to professionals deliberately misguiding workers who came to them with occupational and environmental health problems. When studies were carried out on workers, these were not made available to anyone except the select few conducting the study, and so were not open to public scrutiny. Should an occupational disease be identified, workers faced further problems in gaining medical or disability certification. Neither was given readily, while disability certification, which is required for compensation, was frequently not understood by doctors and hence not given to workers. Lawyers, even those whose general stance was pro-worker, tended to have a poor knowledge of progressive laws related to occupational health. Poor training, as well as undermanning and general apathy, also characterized the staff of the Employees' State Insurance (ESI) scheme – a contributory health insurance scheme with large financial reserves. This led to apathy in using these financial reserves for workers, and in particular for occupational health problems. Finally, all these problems were compounded by information issues, including difficult access to the Internet owing to a shortage of resources, and all information being in English (with some Latin and Greek), creating serious difficulties for workers in understanding scientific, legal or insurance issues. These factors, as well as Kafkaesque 'red tape-ism' (procedural delays), daunted even the bravest of workers armed with medical certification forms seeking justice.

In beginning to demystify the process of problem identification and routes to rights-claiming, OHSC's first major work addressed the occupational diseases of workers in the underground sewer department of Mumbai, acting together with the municipal workers' union. Later, work in diagnosing occupational diseases, educating activists and fighting for compensation was carried out with many unions and collective groups, such as the All India Trade Union Congress, the oldest workers' union in India, and the major textile workers' union, the Trade Union Solidarity Committee, Mumbai (Murlidhar et al. 1995). OHSC also worked together with citizens' groups, for instance in chemical belts such as Parivarthan in Maharashtra.

I now go on to discuss in detail OHSC's role in the struggle to have occupational lung diseases recognized and compensated.

OHSC fought the issue of occupational lung disease as part of a larger campaign in India, the National Campaign on Dust-related Lung Diseases, which involved many collectives and unions.

In 1992/93 when the OHSC first thought of working on the occupational diseases of textile workers, the diagnosis of occupational lung diseases was clouded with difficulties. These included a lack of means through which workers' own experiences could be expressed in scientific terms, and problems in identifying and differentiating between different diseases. Byssinosis is a lung disease caused by cotton dust and is widely studied. Yet even the source and mode of the changes in the lungs associated with it are not precisely known, while there are difficulties in differentiating byssinosis from chronic obstructive lung disease. Both diagnosis and cause can be complicated by the effects of smoking. There were also pervasive confusions in interpreting lung function tests and the computerized output of the results, based on prediction equations pre-installed within the machine. OHSC worked to demystify each of these issues, until the first case of byssinosis in Mumbai was diagnosed and compensated in 1994, and the results presented in peer-reviewed literature in 1995 (ibid.; Nemery 1995).

A path-breaking study of this disease of textile workers had been carried out in the city of Mumbai in 1977. The study was presented in international forums, and as a result the Indian government accepted byssinosis as a prevalent occupational disease in India and appropriate legislation was brought into effect. Strangely, however, not a single worker participant was informed about the disease, not even the affected workers who were experiencing byssinosis symptoms, albeit interpreting them in other ways. OHSC began its work on byssinosis in Mumbai in 1994, seventeen years after the above study was published and ten years after byssinosis entered the official list of compensatable diseases. The first draft of our booklet in Marathi was circulated among worker activists for comments before printing. One of the activists said, 'I have seen many workers with similar symptoms and we had suspected occupational causes. But we did not know the legal position. Let us plan a medical check-up in my textile mill.' During the check-up, the workers learnt how to perform lung function tests and how to administer them to others. The participating medical and non-medical professionals did likewise. The report was given to each affected worker and the consolidated report was given to the management and the worker activists.

The hurdles faced in using the findings of this participatory study were stupendous. They included top professionals misleading OHSC researchers into searching the weekly British Medical Journal (BMJ) from 1980 for a particular article, when it was actually in the Journal of the American Medical

Association (JAMA) (these were the days before the Internet revolution). The social security system for workers, the Employees' State Insurance Scheme (ESIS), also created many hurdles that could be tackled only by collective effort. As a result of this study, the first case of byssinosis was compensated by the ESIS in 1995.

Following this success, OHSC directed its efforts towards reaching out to more affected workers in the city, and at the same time sensitizing the medical and legal fraternity, whose participation and cooperation would ensure a smoother claim process for workers.

In Mumbai, an ESIS support group has taken shape. Three times a week, affected workers (those who suspect that they are suffering from work-related illnesses) converge at the office of the Girni Kamgar Union – affiliated to the oldest union in India, the All India Trade Union Congress (AITUC) – where activists take a detailed history of the affected worker, study the case, perform a lung function test or audiometry (hearing test) as appropriate, and analyse the results. After filtering out those workers who do not show compensatable disease, those who appear deserving are issued with medical certificates. Activists and co-workers help the worker through each and every bureaucratic step until he clears the medical board. Many of the workers helped by the support groups have subsequently joined the support group and continue to help others.

Through such processes, many workers have understood the process of diagnosis and how to seek justice for this crippling occupational disease. In this, they have come to engage as scientifically and legally literate citizens. Through their union, they have set up ESI groups in many parts of India, teaching their co-workers the difficult process of diagnosing occupational lung diseases. They have learned how to handle the lung function test machine, and how to take a good occupational history. They have also learned to guide fellow workers through the process of getting compensation. These worker activists spread the message about the support centre by word of mouth and also by poster campaign. After byssinosis, the first case of occupational asthma was diagnosed and compensated in Mumbai. A number of workers who gained compensation for either of these diseases contributed some of their benefits to the purchase of medical equipment for the future diagnosis of others. Otherwise, their work has been supported by voluntary help from sympathetic doctors and also by non-governmental organizations (NGOs) involved in occupational and environmental health, such as PRIA, New Delhi. Indeed, PRIA held similar diagnostic camps in other textile cities such as Aurangabad, Amritsar and Rajnandgaon, where similar independent support groups have also formed and compensation claims have been settled.

OHSC found that the medical fraternity was equally mystified about byssinosis. This is partly because occupational diseases are given very little emphasis within formal medical training. OHSC therefore made efforts to reach doctors and present to them the medical aspects of diagnosis and interpretation, including how to compare a worker's lung function with appropriate predicted lung function. This is a tricky matter, since lung function machines are produced in developed countries and the predicted values are calibrated according to the expected lung function of Western people. Doctors and professionals needed assistance to substitute an appropriate, ethnically corrected reference point for Indian workers, and OHSC provided the necessary equations for this. Many doctors were also under a faulty impression about the medico-legal aspects of byssinosis, considering that they had to be experts and specialists in order to issue medical certificates for occupational diseases. In fact, there is not a single medical college in India offering a postgraduate course in occupational and environmental medicine.

In 1996, the findings of our byssinosis study were published in a peer-reviewed journal. This is not a necessary condition for compensation, but fulfilling it helped to counter scepticism among medical professionals. Subsequently, teaching faculty and resident doctors from medical colleges, doctors from ESI hospitals, private practitioners and doctors sympathetic to unions were trained in Ahmedabad, Vadodara, Mumbai, Vellore, Amritsar, Gwalior and some parts of interior Maharashtra. In the training sessions of doctors, workers and activists were present and contributed to the programme. Some of the worker activists came to train doctors in medical colleges, where they were addressed as doctors by medical students.

At times, sympathetic lawyers have also been guided by OHSC activists through misconceptions regarding the diagnosis of occupational diseases, the establishment of cause–effect relationships and judging the appropriateness of a claim for compensation. Most lawyers, doctors and even trade unionists believe that for every occupational disease the connection between work and disease has to be proved beyond doubt, as in criminal law. Even the mere existence of the possibility of another cause for the worker's problem disproves that the problem is an occupational disease, they believe. In reality, the law has listed certain diseases to which certain types of worker are vulnerable, and it is clearly stated that unless any other cause is proven, the connection between work and that particular occupational disease is presumed by law. In one case concerning another problem, acid injury causing death, the defence lawyers were sure of victory when they managed to get an OHSC witness to say that 'the injury may have been caused by agents other than acid'. But the court finally ruled in

favour of the worker's family, since the contrary had to be proved beyond doubt by the defence. For the worker, it was enough to show possible causal association between acid exposure and his illness.

Finally, PRIA, New Delhi, played a facilitatory role in opening up a dialogue with the higher echelons of the ESI board, and influencing some of them to view the on-the-ground reality of occupational diseases more sympathetically. This, too, was an important component of the demystifying process.

OHSC has also engaged with workers, and helped translate their experiences into terms that are deemed legitimate by scientific and policy institutions, on a number of other issues. Here, I outline briefly how this unfolded for NIHL, for disability assessments more broadly, and for chemical accidents and related environmental pollution.

Noise-induced hearing loss

In the mid-1990s, workers in a chemical factory in Mumbai complained about hearing loss. They suspected that this loss was related to high noise levels near the boilers where they worked. Many sources of mystification surrounded the identification of occupational NIHL at this time, however. These included a prevalent belief among doctors that a person cannot have hearing loss if they understand spoken words, and problems in conducting audiometry. For example, many doctors mistakenly thought that a soundproof room was necessary for conducting audiometry, and so without such resources did not undertake it. When mass audiometries were conducted by doctors, this was frequently without the all-important bone conduction. Indeed, these Mumbai chemical workers were being checked regularly by a firm specializing in legally necessary medical check-ups of factory workers, yet this firm had never recorded the bone conduction of sound, thus omitting the test that could actually reveal irreversible effects on the nerves responsible for hearing. Diagnosis of NIHL was also clouded by biased assumptions among doctors and lawyers that workers were merely malingering, and indeed by problems of true malingering. By painstakingly working on these and other such problems, OHSC was able to assist in bringing the first Indian case of NIHL to full diagnosis and compensation in 1998 (Murlidhar and Kanhere 1998).

OHSC's approach, again, was to seek to translate workers' experiences into scientific terms, and to educate both worker activists and medical professionals in the specificities of diagnosis and rights claiming. As for lung diseases, workers acquired new scientific skills and became active participants in diagnosis and monitoring, expressing their citizenship in such particular, scientized terms. OHSC began by arranging for a medical

check-up of the workers in a public hospital. The doctors involved were informed about the relevant literature regarding the diagnosis of NIHL. A group of worker activists learned, in the hospital lecture room, about the interpretation of audiometry readings. They also learned methods for assessing the resultant disability. We had noticed in our orientation courses that most doctors were ignorant of procedures for assessment of disabilities due to hearing loss. Thus workers themselves took over the role: the group of trained workers actually assessed the disabilities of the affected workers and the 'experts', who were authorized to prepare medical certificates, agreed with their assessment figures.

The ESI support group also does considerable work in this field. The audiometries are carried out by worker activists, the results presented in graphs and the disabilities calculated. Any doubtful case is referred to a teaching hospital for review. If the ESI support group is fully convinced, it then requests a sympathetic doctor to issue a medical certificate. Many cases come to the centre that turn out to be non-occupational diseases, such as middle ear deafness. Such cases are referred for treatment, and although the workers are disappointed at their inability to claim compensation, they are at least listened to patiently, and have the opportunity to discuss the nature of their problem. Nearly 60 per cent of the certified cases from the ESI support group do end up receiving compensation, however, while those who are felt to have a legitimate claim but are rejected by the medical board for compensation are encouraged to fight using persuasive dialogues and legal methods.

Disability assessment

As we saw in the cases of both lung disease and NIHL, in occupational and environmental health (OEH) disability assessment and certification are required by law for compensation purposes. This points to broader issues concerning disability assessment which the OHSC has attempted to tackle, as a cross-cutting issue (Murlidhar et al. 1996).

To seek compensation, the legal requirement is for a worker to have a precise disability certification by the treating doctor. Lacking such certification, thousands of occupationally affected and injured victims suffer. Disability assessment is relatively straightforward in cases of amputations and total deafness and blindness. In the case of lung diseases, hearing loss and complicated injuries without amputations, doctors are asked to evaluate disabilities. Yet legal guidelines to assist this are absent.

From 1992, PRIA supported a five-year participatory process to develop guidelines for disability assessment. This involved doctors from all over India, who together worked to produce what is now the accepted book on

the assessment of disability, overcoming many of the lacunae in the only other comprehensive source on the subject, the JAMA guides (Cocchiarella 2001). In the years since the completion of the guide, many injured workers suffering from a variety of disabilities, ranging from impotence to abdominal organ damage, have benefited. Of key importance to the use of the guide, especially in legal claims, is its aura of scientific legitimacy. Despite the reality that there is very little scientific basis for the assessment criteria, popular perception is the exact opposite. To maintain the guide's scientific legitimacy, there is a continuous need to engage the certifying doctors in debate over disability assessment criteria and methods.

While working with doctors to enhance the scientific precision and standardization of disability assessment, OHSC and PRIA have also encountered instances of deliberate mystification driven by political economy. Thus doctors specializing in disability assessments sometimes avoid giving reasons or sources for their judgements. Equally, the Special Medical Boards of the ESIS generally do not provide any reasons. It became clear that assessments by the medical board are made more with a view to reducing the compensation that would have to be paid to affected workers than according to scientific criteria. OHSC has faced such issues directly: the expert doctor sending OHSC in the wrong direction to find criteria for assessment in medical literature I mentioned earlier is one example. Alongside providing a set of 'objective' guidelines against which cases can be assessed, then, it is important for workers, activists, researchers and doctors to work together to expose and challenge these instances of overt mystification.

Chemical accidents and pollution

Industrial accidents in India are a frequent source of health problems both for workers and affected local residents. Accidents in the chemical zone occur very frequently, and some of these are major, such as the Indian Petrochemicals Limited (IPCL) blast in 1990, when sixty people died of burns.

In one of the biggest chemical coastal zones in India, the Konkan, OHSC found that workers and doctors had a variety of assumptions concerning how to treat the victims of chemical accidents. Yet these were frequently not informed by the best available medical science, while many views among both doctors and workers appeared to OHSC as misconceptions: for instance, that milk ought to be given in cases of ammonia exposure, or that there are specific antidotes to almost every chemical.

OHSC therefore decided to bring out a book on chemical accidents, first aid and antidotal treatments for Indian industrial settings, adapted from the standard World Health Organization guidelines (Murlidhar 2002).

OHSC also started to educate doctors and activists in the chemical industrial belts, with the eventual aim of networking all the trained people in the coastal chemical zone. Many local activist groups in the Konkan industrial belt have shown keen interest in this acquisition of medical expertise and scientific citizenship.

Chemical and other industrial accidents also affect local environments and the health of their residents. Members of the local communities that experience such effects directly have both the need and experiential perspectives to identify such problems. In some cases, activist groups in India have worked with communities to assist such identification and to publicize the results. Yet in many cases, their efforts – and ability to gain the attention of scientists and policy-makers – have been limited by inexperience in conducting community health surveys. In some cases, they have asked to conduct such surveys, yet have floundered. This was the case for local activists in a toxic hot spot in Kerala, who were overwhelmed by the methodology of conducting a large community health survey. Although the methodology had been planned by well-meaning academics from India and abroad, it appeared to the activists as unattainable, shrouded in mystique in terms of sampling techniques and statistics, the large number of variables involved and the need to avoid bias. Working with Greenpeace India, the OHSC was able to demystify these issues; for instance, by demonstrating some simple statistical techniques, and discussing how questions of bias and choice of variables need to be dealt with in context and in relation to the specific survey aims. The activists' spirits lifted, and they came to feel in greater control of their work. In this, OHSC and the activists together came to reflect critically on the gap that often exists between scientists and academics – however sympathetic – and grass-roots activists who are linked with local social realities. Instead of setting unreachable standards of 'scientific rigour' that totally derail a programme, OHSC worked with activists to establish a middle-ground approach, which could garner scientific legitimacy while remaining achievable and attuned to its community setting.

Conclusion

The challenges faced by the OHSC and PRIA teams have been great, but as illustrated by the examples in this chapter, they have succeeded in overcoming many of these in order to help workers gain justice in many cities in India. This justice has partly been cognitive, in the sense of establishing the legitimacy of workers' own experiences of occupational health problems among 'expert' scientific institutions. This has involved a process of bridging or translation of workers' own perspectives into the terms of mainstream science. As workers have become adept at using and

expressing these scientized perspectives and tools, so this has shaped their citizenship practices. In turn, these achievements of cognitive justice have been linked to material claims and to other forms of citizenship right: to compensation, treatment and justice through the law. In some cases, these were long overdue. In the case of byssinosis, justice delayed by seventeen years must have meant justice denied to scores of deserving textile workers who would have withered away from lung disease and poverty after having been the engine of Mumbai's economy during their youth.

The process of demystification that OHSC and PRIA helped to spearhead involved challenges to established practices and interests among many scientific and policy institutions. In medical research, for instance, it involved challenging experts' practices of keeping findings from affected workers: such experts strongly believe that knowledge ought to be within the reach of only a few, and make special efforts to keep the field of experts narrow. Such mystification restricts access to knowledge even among doctors themselves. It serves vested interests and is a hindrance in the development of citizenship. As long as the affected workers and associated researchers and doctors remain inactive, the situation will be shrouded in mystery.

In post-colonial India, furthermore, language has become one of the mystifying factors. Even for a literate worker, to confirm a suspicion of occupational disease would be an insurmountable task for the simple reason that hardly any information is available in the local language. Language difficulties compound other anxieties in inhibiting workers from expressing their knowledge and experience. We have come across many workers who, out of ignorance or fear of losing their jobs, do not admit to the existence of illness in themselves or do not link it to their work environment. Those who do make the connection frequently merely attempt to treat the symptoms. Their frequent visits to their local doctor (who appears uninformed about the occupational source of the symptoms and the associated legal provisions) may result in some injection and a clutch of colourful tablets, which act at best as a palliative for the symptoms or a placebo, and at worst affect the worker with harmful chemicals. Thus at the micro level there seems to be a cycle of mystification about occupational disease fed mainly by ignorance and fear.

OHSC's efforts in engaging workers in new forms of scientific citizenship in terms of occupational disease have met with reasonable success in Mumbai and other places in India. The ESI support groups, in particular, have achieved remarkable success in the past four years. The ESI has had to deposit nearly 20 million rupees in the bank to provide monthly lifelong compensation to the affected workers in Mumbai, owing solely to the efforts of the support group of worker activists and doctors.

Demystification is most effective when it is a collective process, and if this process also proves productive in realizing rights, this gives impetus to the collective activity. While individuals may make important contributions to the process of demystifying medical and legal knowledge, OHSC found it more fruitful when people from various fields of activity came together to begin a collective process. In other words, positive changes involved the practised engagement of social solidarities linking different groups of citizen workers, doctors, safety experts, lawyers and trade unionists. Lessons having been learned from the considerable successes in demystifying occupational and environmental health in the short span of time since 1992, there is now a need for expansion into further new areas, and for involvement of more sections of society on a larger scale.