ASBESTOS DISEASES IN BRAZIL AND THE BUILDING OF COUNTER-POWERS: A STUDY IN HEALTH, WORK, AND GENDER

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Asbestos is a naturally-occurring mineral fiber with a silky texture whose distinctive properties - high mechanical strength, even at high temperatures; incombustibility; good insulating qualities; durability; flexibility; indestructibility; and low cost - have caused its widespread use in industry.⁴

Brazil is among the world's five greatest producers of asbestos and is also an important consumer of the mineral. There is, therefore, a great deal of attention being paid by the world scientific community to Brazilian practices now that most European countries have prohibited the use of asbestos. The largest asbestos mine in Brazil at the present time is located in the Municipality of Minaçu in the State of Goiás. The mine is managed by subsidiaries of the French multinational Saint-Gobain, whose home country has prohibited asbestos since the beginning of 1997. Asbestos is used in thousands of products in Brazil, especially in the construction industry (roof tiles and water tanks) and in other sectors and products such as brakes (linings and pads), joints, gaskets, clutch plates, cloth, and in special coatings and coverings such as paints and floor tiles, among other uses (Giannasi, 1995).

Canada (after Russia) is the world's second largest producer of asbestos and is a large exporter of the raw material, but compared to Brazil it uses relatively little asbestos. Annual asbestos consumption averages 500 grams/capita in Canada, about 1,400 grams/capita in Brazil, and only 100 grams/capita in the United States (Castleman, 1995).

This initial look shows that there is a great difference in the production and consumption of asbestos between the countries of the Northern and Southern hemisphere, especially in the case of Brazil. This contrast can be explained by the fact that asbestos is a proven carcinogen (INSERM, 1996), whose lethal qualities are widely known to the citizens of the North, who refuse to allow themselves to be exposed to this known risk and demand less dangerous alternatives. Asbestos is a good example of how some multinational companies transfer production from Northern countries

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⁴ This article is one of the results of the research project "Asbestos and Its Social and Familial Consequences: A Comparative Franco-Brazilian Study".

where facing strong opposition including prohibition laws developing countries, especially of the South hemisphere, which people are unaware of the dangerous effects of the product. This strategy has come to be called the policy of the *double-standard:* business representatives(lobbyists) of multinationals which produce products banned or restricted at home campaign assiduously for the freedom to expand production, sales, and exports of those products in developing countries.

Invisibility of Occupational Diseases

In Brazil the data regarding *diseases caused by exposure to asbestos* are scattered, rare, and almost always highly influenced by the interests of the asbestos industry. This situation must be understood within the broader context of *occupational diseases in Brazil*⁵, which are notoriously underreported. The invisibility of asbestos diseases, therefore, is on a par with the invisibility of occupational diseases in general increasing its seriousness, according to Lipietz(1997), because usually manifest themselves far from the workplaces where they were contracted and often many years later. As a result exposure/disease causal links, official notifications, and the social visibility of asbestos diseases become very difficult to establish.

Between 1992 and 1993 the number of occupational disease cases reported to the National Institute of Social Security (INSS) almost doubled from 8,299 to 15,270 - out of a total of 23 million officially registered workers (over half of construction employees in Brazil work off the books, which is equivalent to "under the table" work in the United States). This sharp increase in reported cases was due, in part, to a change in the legislation and also to a higher level of organization and consciousness on the part of the workers (INSS, 1997). While cancer was the fourth leading cause of death in Brazil in 1991 (RDHB, 1996), it is rarely associated with work-related causes in official documents.

In the specific case of asbestos-related diseases, we can point to other factors which contribute to a fragmented institutional awareness: the high turnover of workers in the labor market; the fact that Brazilian legislation began only in 1991 to mandate rigorous medical follow-up for people exposed to asbestos; and the inexistence of epidemiological projects which actively seek out cases of asbestos disease, either among workers or among those whose exposure did not come in an occupational context. We will examine other factors which reduce official awareness of asbestos disease later in this article.

Work-related diseases caused by asbestos include *asbestosis* (a chronic, irreversible, and progressive lung disease), *cancers of the lung, cancers of the gastrointestinal tract*, and *mesothelioma* (a rare malignant tumor which attacks the pleura and the peritoneum and which has a latency period of about 30 years). In Brazil few of these diseases have been characterized until recently as being related to asbestos exposure. Less than a hundred cases of asbestos disease are cited in the Brazilian medical literature of this century--including 56 asbestosis cases, two cancer cases, and four cases of mesothelioma. And even though the mesothelioma cases were diagnosed

⁵ The legislation relative to occupational diseases in Brazil allows for only 27 situations or agents (including asbestos) for which causality can be proven almost automatically, so long as exposure is established (see Decree 611 of July 21, 1992 which approved the Regulation of Benefits Under Social Insurance). This narrow limit to the recognition of agents which cause occupational diseases contributes to the invisibility of those diseases.

with a known and investigated causal connection, they did not receive any official recognition and were not listed in Social Security records and statistics as work-related (Costa, 1983; Menezes, 1956; Teixeira & Moreira, 1956; UNICAMP, 1980).

In our research, which we carried out to assess the impact of work-related asbestos diseases on families (Scavone; Giannasi; Thébaud-Mony; 1997), we looked for cases of mesotheliomas, because this disease is almost always associated with exposure to asbestos and which usually leads to death in under two years. The problems in finding statistics about this disease were almost endless: it was only in 1995, with the publication of the 10th edition of the International Classification of Diseases (ICD), that mesothelioma was classified for the first time with a specific code (before it had been subsumed under cancers of the pleura or cancers of the peritoneum). The second reason was the incapacity of doctors to diagnose this disease, because courses in occupational medicine in Brazil are offered only to post-graduate specialists, rather than forming part of the basic medical school curriculum. And while a requirement exists for compulsory registration of all cancer cases, there is no centralized data bank in Brazil and different data sources use non-uniform criteria, which make it nearly impossible to estimate the true incidence of the disease.

In a search we made of the registries of INCA (National Cancer Institute), we encountered 193 cases of mesothelioma between 1976 and 1985. Of this total, we were able to find more complete data on only 55 cases (28.5%). These data reveal the lack of uniformity of information regarding this disease: since during that period mesothelioma did not have an ICD code, in some registries only the general type of disease (cancer of the pleura, lung, or peritoneum) was mentioned; in others the exact form of the disease (mesothelioma) was also mentioned.⁶

In the State of São Paulo, between 1980 and 1997, we found 54 cases of mesothelioma, of which 18 were women and 36 were men. For the City of São Paulo, at PRO-AIM (Program for the Perfection of Information on Mortality), which is part of the municipal burial service, we found mesothelioma cases recorded for the first time only in 1996; a change which coincided with the aforementioned adoption of the 10th edition of the ICD. For that year, of the seven cases mentioned, four were men and three were women.

The high proportion of women caught our attention, because in principle, women were *formally prohibited, until the passage of the Constitution of 1988*, from working under unhealthy conditions, which were defined to include contact with asbestos.⁷ Of the four women who died of

⁶ The registries used to estimate cancer-related incidence and mortality published by Pro-Onco/INCA are registries based on the population of six state capitals: Belém, Fortaleza, Campinas, Porto Alegre, Goiânia, and São Paulo which comprise approximately 5% of the national total. The morbidity data come from the hospital-based registries and the mortality data are supplied to Pro-ONCO by the State Secretariats of Health by the respective states, based on death certificates (INCA/Pro-Onco, 1997).

⁷ There is also the possibility that the illnesses were contracted while working in informal, "under the table" jobs, or at jobs in which the legal prohibition in effect until the Constitution of 1988 was ignored. Research carried out at an asbestos factory in Rio de Janeiro uncovered cases of women workers with asbestosis as a result of exposure to asbestos for a period of from 12 to 22 years (D'Acri Soares, 1997), exposures which would have occurred prior to 1988. There is occurrences of cases of women with illnesses linked to asbestos exposure in other countries, such as a study of the presence of asbestosis and mesothelioma related to exposure to amphibole asbestos in Turkey, "where asbestos is used as plaster in houses (and where the plastering is done, for the most part, by women). The exposure begins as birth and lasts for an entire lifetime" (Scliar, 1998).

mesothelioma in the City of São Paulo, two were housewives and under 40 years of age, which suggests a history of childhood exposure which probably occurred in a non-occupational setting, because of the long latency period for the disease. It is probable that exposure to asbestos occurred through family members in contact with the carcinogenic agent or even as a consequence of ambient environmental exposure.

It is important to call attention to the fact that only recently have large asbestos-using firms in Brazil begun to use industrial laundries to limit the risks of indirect or quasi-occupational conditions (GIA, 1988; GIA, 1993). The goal is to prevent workers exposed to asbestos dust from carrying the dust home on their contaminated clothes and exposing other family members. Not surprisingly, it is the women of the house who, given the classical sexual division of labor, wash and take care of the men's work clothes. Costa (1983), in a study carried out in the city of Leme, noticed this fact and called attention to the risk of asbestos exposure which employees took home with them on their work clothes.

Family Impacts of the Illness

Based on this general picture, we decided to carry out qualitative research regarding the four cases of mesothelioma mentioned above in which we had information about a causal connection. Our goal was to carry out an in-depth analysis of the course of the knowledge and/or official recognition (or not) of the disease and of the consequences for their families. Our choice of these families for study was based on the unequivocal fact that in these records the diagnosis of the disease was linked with asbestos - which, as we have already pointed out, is still rare in Brazil, despite the fact that mesothelioma is caused by this agent in the majority of cases cited in the relevant medical literature (Pezerat, 1995).

Of the four cases under consideration, we were able to find the families of three male workers with mesothelioma; two families agreed to participate in the study.

We did exploratory research utilizing the technique of in-depth interviews; our principle informants were the wives of workers who had recently died when we entered into contact with them. For secondary informants we used some of the most closely related family members. With the evidence we had gathered we created time-lines of family life, work history, and health of the afflicted workers as well as the life-histories of their wives. This methodology made it possible for us to visualize the inter-relation of the three areas under study - work, health, and family - and avoid a pre-determined outcome of the research project. In the two cases which had occupational exposure, one had worked directly in an asbestos-cement factory and the other had been an employee of a contractor for a large multinational firm in the asbestos-cement industry. The families live in Leme, a city in the interior of the State of São Paulo where two medium-sized asbestos-cement factories are located, along with a few smaller asbestos firms. In fact this region is where most of the major factories of the sector are located.

Our first case involved a family with a modest standard of living composed of Regina and João, a married couple with four children: sons aged 24 and 16 and daughters of 21 and 13 years of age. Regina grew up in a family of rural workers, attended school through the third grade, and worked

⁸ In Brazil, 90% of the asbestos which is produced for the internal market is consumed by this sector.

temporarily in the harvest of cotton, oranges, and coffee. João had four years of primary education and worked, over the years, as an agricultural laborer, industrial worker, bank messenger, truck driver at a large farm, and as a laborer for the city. He also worked for one year, from 1967 to 1968, in an asbestos-cement factory in Leme. At this time he was living with his mother and took his work clothes home to wash.

At first João attributed his illness to a fall from a truck when he worked in a cardboard factory, because after this he began to feel back pains and breathlessness. The relation between his illness and asbestos exposure was first suggested by physicians who diagnosed a *tumor*. The family also began to suspect that his illness had something to do with the time he had worked in the asbestoscement factory. In Leme, the word among workers is that cancer is somehow related to working in the asbestoscement industry, which probably raised the suspicions of the family.

The fact of having a brother-in-law who died of cancer and who had worked for 17 years in the same asbestos-cement factory forced the family to compare the two men and relate the illness to exposure at work. Nevertheless, they were never formally informed of the possible tie between asbestos exposure and João's cancer, and in any case they didn't have the energy or will to verify their suspicions and demand compensation⁹: "People thought it would be difficult, (...)so I didn't pursue the matter" (Regina). The onset of the disease upset the financial and emotional equilibrium of the family, overloading the wife (and also the eldest daughter) both physically and emotionally, though Regina never admitted as much. The family spent three years dealing with treatment and a succession of diagnoses, a period during which the illness took over the lives of the worker and his family, three years in which the threat of death was a constant presence.

The family situation was transformed as the illness took over and upset the daily routines of life and the victim's wife tried to adjust to the new situation of frequent hospitalizations for her husband. The new routine came to include daily or weekly trips to the hospital in Campinas for *chemotherapy* as the seriousness of the situation became more obvious. Increasing family *disorder* triggered by the illness was intensified by frightening changes in the sick man's behavior, from a happy and loving person to a sad, mistrustful person irritated with the children and complaining constantly of sharp, persistent pains. The development of the *tumor* caused a physical deformation which was very hard for him to accept, factors which began to exclude him from ordinary social intercourse and gave birth to an inferiority complex mixed with feelings of insecurity and shame which expressed themselves in a mistrust of those who still inhabited the *world of the healthy*. João's social life outside the family began to revolve around his illness, becoming more and more limited to his treatment locales, to the *world of the sick*.

When a worker who is the main breadwinner of a family falls ill - which happened in João's case -- the inability to work becomes a particularly severe form of unemployment, a kind of *social death*, because when work stops the sick person is excluded from an important part of social interaction. The illness is experienced as a kind of defeat which makes it impossible to return to an active life. In dealing with a mortal disease like mesothelioma, there is no hope, but only a rapid process of deterioration, causing an imbalance in affective relationships in the family whose consequences

⁹ Only after our research began did the family resolve to sue the company, requesting compensation for physical and moral damages, roughly equivalent in the United States to monetary compensation for wage replacement, medical costs, and pain and suffering.

continue to snowball, overburdening the women, especially, who do most of the work in taking care of the sick person and in making sure there is enough income for family needs. Regina received a sickness/death disability pension worth US\$135/month because of her husband's illness, an amount so meager that she was forced to continue working. She finally quit her job when his illness worsened, when she began to receive some help from relatives. Thus there was a loss of family buying power compared to when João was working. After his death the family financial situation improved a little, because expenses for medicines declined. João died in 1994, at 56 years of age, of mesothelioma of the pleura associated with asbestos exposure (De Capitanai *et. al*, 1997). The death certificate, which listed the cause of death as *mortis caquexia* - the generalized organ failure-was signed by a well-known physician in the city of Leme who, aside from being active in public affairs, was an advisor to the two principal local asbestos-cement companies.

Our second case was a couple without children with a stable middle-class life-style. Marta, a retired teacher, had finished three different graduations at the university. Marcos, who had finished primary school, was the owner of a tire shop which had a long-term business relationship with a large asbestos-cement company, which assured him a certain degree of economic stability. When he became ill he had already quit the tire business. The appearance of the illness lead to a number of different diagnoses, and when the tumor was found, he underwent surgery. The operation confirmed the rarity of the case, and, as the illness progressed, he went into surgery a second time. Marcos suspected that the disease was linked to his work, that is, to the rubber dust from the tires; but he never suspected asbestos might be a cause. His physicians, however, thought it might be a factor and ended up confirming their suspicions. While the illness did not threaten the economic situation of the family (though the couple did have to sell some of their possessions), it transformed the life of Marta into a constant search for special care and treatments for her husband. Although the medical treatment in this second case was more sophisticated and included surgery, Marta ended up questioning the necessity of the surgery. (No one in the first family we studied had questioned the medical treatment, which occurred at the same time and hospital). In the end the illness progressed along the same lines and ended with the death of Marcos at the age of 56 from mesothelioma of the pleura associated with asbestos exposure. The death certificate listed the cause of death as "respiratory insufficiency and pulmonary neoplasm."

While in both cases under study the doctors had made a diagnosis of mesothelioma of the pleura related to asbestos exposure, this diagnosis was not communicated to the families until the time of our research. A medical-scientific study of these cases was recently published under the title *Mesotelioma Maligno de Pleura com Associação Etiológica ao asbesto a Propósito de Três Casos Clinicos* [Malignant Mesothelioma of the Pleura Caused by Asbestos Exposure: An Account of Three Clinical Cases] (De Capitani *et. al.* 1997). Finding out about the diagnosis made it possible for both families to secure compensation through judicial action.

The analysis of the cases of these two families indicates to us a complex situation in which health, work, and gender relations are all intertwined. These cases point to the same logic of sex/gender, health, and work observed in other research: occupational disease

causes important changes in the family which are mostly dealt with by women. 10 The daily drama

¹⁰ In the cases mentioned we did not encounter women affected by the disease; therefore it is impossible

of the illness is experienced and managed mostly by the family, which is obliged to adjust to the new situation, leaving little time or incentive to reflect on the ultimate causes that produced the illness. This family role, on the other hand, allows employers to escape their responsibility for causing the occupational disease, which remains socially invisible. For the family the relation of the illness with work becomes minimized when they are overwhelmed with the urgency of securing treatment. In the case of asbestos, this invisibility contributes to the continuing use of this mineral in Brazilian industry despite all the damages which it causes to the health of the workers.

Counter-Powers: A Space for Active Citizenship

The cases we have investigated have been maintained in an invisible state by the silence of physicians and the victims' families, and by the connivance and complicity of governmental institutions. But throughout our research we have run into other, very different *victims* of asbestos who have organized themselves into ABREA - the Brazilian Association of Workers Exposed to Asbestos--a group of citizens who have struggled: 1) to learn about the real state of their health, and 2) to fight for their rights to compensation from employers, who neglected for years to tell them about the risks of asbestos, which produced irreversible and progressive disease. ABREA has also carried out a campaign of even broader social significance: the organization proposes to ban the commercial use of asbestos by building a kind of "citizenship of protest", as Souza (1994) has termed it. The truth is that those exposed to asbestos do not feel that their interests have been represented by labor unions or other social institutions of civil society. Through their organization and their actions the members of this citizens group are expressing themselves against the lack of recognition and in defense of their interests in the public sphere.

Paoli (1991) calls attention to a number of characteristics of these social movements: they create themselves around a self-defined identity which emerges in the heat of action and conflict, a collective "we" which they counterpoise to "the others". They clearly distinguish themselves from associations which function according to a "logic of assistance" based on mutual aid with the aim of solving the common problems which brought them together (Thébaud-Mony, 1990). Counterpowers, on the other hand, constantly raise questions about the causes of the problem with the goal of changing the functioning of existing institutions which created the problems from which they suffer.

These alternative movements of asbestos victims have organized themselves into true *counter-powers*. Because of their common experiences, those exposed to asbestos are trying to discuss and rethink the meaning of work, life, and the fact of getting sick; and to deconstruct prevailing paradigms such as the identification of progress with industrial growth.¹¹ They also question the

to state how this situation would be experienced by their husbands or male companions. It has already been observed in home care research that men, when they have to take care of a sick person, easily find support from other women from their own family or from the neighborhood (Favrot, G. 1988). The management of the family situation by women, in regard to work and health of the husband, has been shown in several research projects by Annie Thébaud-Mony: among subcontractors in the nuclear industry; in an arsenic factory in Salsigne; and also among workers exposed to asbestos (1996, 1991). More details of this work are available in Scavone (1997).

The work of Barry Commoner in the United States and Giovanni Berlinguer in Italy has been very important in questioning the identification of "progress" with "industrial growth"; see articles by them and Virginia

prevailing idea that politics is something which is done through and inside of the state apparatus through hierarchical organizations whose goal is to accumulate power and exercise it in the name of ordinary people at the grassroots levels, without the active participation of those people.

Counter-powers are *social movements* organized around a specific cause, and organized in protest against the established system of domination. Counter-powers are not structured like classical systems of collective representation (such as parties and unions). In the case of asbestos they have constituted themselves into an organization of those people formerly exposed to asbestos who have illnesses related to their exposure to this agent; in fact they "unite around the risks" of work exposure to asbestos (Lipietz, 1997) and its unfortunate consequences. Their identity is self-defined by the illness they acquired at work, through a process of struggle whose goals go beyond support of those who are ill to encompass the total ban of asbestos from Brazilian industry. This struggle greatly increases the visibility of the damage caused by the use of asbestos in Brazilian society at large.

Criticized by some of the established labor unions and associations of retired people as supposedly *apolitical and atheoretical* because they focus *on a single problem*¹³ and because they refuse to coordinate their protests with organizations that deal with the process of production, the fact is that groups like ABREA have been inventing a new form of doing politics in Brazil. In general these kind of counter-powers are constituted by people who have been excluded from the dominant system: women, workers, young people, old people, the unemployed and retired, those who are *unfit by and for the work*, ethnic, cultural, or sexual minorities, the dispossessed...in sum, all those who are mobilizing against the social destructiveness of capitalism.

Evers (1981) states that all these kinds of groups are in some way outsiders in regard to some more or less specific aspect of the dominant social organization: "it is these dominant ideas regarding politics and how to do politics which are being broken down and then reconstituted by these alternative movements according to some new conception." Evers argues that the short-term perspective of these new social movements -- their "immediatism" - could be their major greatest virtue as well as their greatest limitation. Evers fears that many of the elements in these movements will merely repeat the historical errors of the past.

Vogel (1997) is also concerned about the question of the short-term perspective of a struggle which builds "the identity of the group based on suffering, an identity based on something which is perceived as negative", and he reminds that if on one hand they bring visibility to the problems of health at work, they will nonetheless have a difficult time over the long term in maintaining themselves as a social force to be reckoned with. This final concern of this social scientist reflects a critique of the "logic of immediatism" which implies that as soon their immediate problems are

Brodine, Anthony Mazzocchi, and Ralph Nader in "Science and Social Action: The Contributions of Barry Commoner," in NEW SOLUTIONS, vol. 8, No. 1, first quarter, 1998.

¹² This vision of the organization differs from the traditional concepts used by labor union structures (such as Shop Floor Committees) because they defend their right to "organize according to their specific interests, rather than by the number of members."

¹³ Here we must remember that it is through this single problem that these movements begin to question the logic of the establishment which created the problems.

resolved, these citizens will stop organizing. Yet we believe that even if this happens, movements such as ABREA can already take credit for successfully making the problems of work-related asbestos disease and the risks of this agent visible to workers and to the population as a whole.

The majority of the nearly 1,000 members of ABREA are suffering from advanced stages of asbestos-related disease, which make them totally unfit for any work-related activities, particularly those which require intense physical activity. They spend a good part of their time explaining the risks of asbestos to the general population, advising consumers about the use of alternative, asbestos-free products and visiting former co-workers as well as the families of deceased co-workers, educating them about their rights and inviting them to participate in the association and to share in a sense of solidarity among equals. These old ties of solidarity, which were felt during the time that they were *fellow workers at the factory* reappear during this period of anguish and uncertainty.

The sense of active citizenship which these new social actors are patiently building has become the only real alternative possible to give public visibility to the very grave conditions of exposure to asbestos in Brazil, since in large part the Brazilian labor movement has acted in defense of industry, despite the epidemic character the diseases caused by this carcinogenic fiber, which are progressive and irreversible; and despite the fact that a worldwide movement exists to replace asbestos with less harmful alternatives.

An example of the kind of obstacles they face is the Permanent National Commission on Asbestos (CNPA), a "tripartite and equal" body created by the President of Brazil by Decree No. 2350/97, made up of representatives of management, labor, and the government only, with the stated purpose of overseeing the law on the mining, manufacture, sale, and transport of asbestos. This Commission faithfully reflects the theory of inherent risk of work, the management of this risk, and the maintenance, at any price of the present levels of employment, which, according to estimates, are on the order of 10,000 jobs directly related to the mining and manufacture of asbestos, and approximately 200,000, when the sectors of distribution, sale, construction and repair (etc.) are included (ABRA, 1996).

All these data reveal the invisibility of knowledge about the true problems related to the use of asbestos in Brazil: the health risks to workers and to the population at large which is indirectly or environmentally exposed, and the diseases - occupational, bystander, and general environmental - which are related to asbestos exposure. One of the principle causes of this invisibility is the lack of knowledge on the part of exposed people and Brazilian society as a whole about the carcinogenic properties of this product. As a result this mineral continues to be widely consumed in Brazil, while in many other countries its use has already been prohibited. Therefore we believe that it is imperative that the debate around asbestos occur throughout the country as one of the conscious duties of a concerned and activist citizenship in Brazil.

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