

Chapter 21

What is stopping the recognition of occupational cancers?

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There is a wide gap between the fewer-than 2,000 cancer cases recognized as occupational diseases each year in France and the official estimates of 14,000 to 30,000 annual cases of cancers linked to working conditions and work processes (Cancer Plan 2014-2019). This is nothing new: the compensation system has been described as failing in administrative reports going back more than 30 years. So what are the barriers to gaining recognition and compensation for occupational cancers? The survey being carried out since 2002 in the Paris region by Giscop93 (a scientific interest group on occupational cancers in the Seine-Saint-Denis region) offers interesting insights into the reasons for (not) reporting and (non) recognition.

The first, most obvious thing is that occupational cancer sufferers have to know that they may be entitled to compensation. The patent lack of public information on this right, however, is not enough to explain the large-scale failure to claim it: in the first 5 years of the Giscop93 survey, for instance, even when respondents were told of their possible entitlement and had the medical certificate required to put in a claim, 50% of them failed to try and access their right. The introduction of long-term support¹ for these individuals with cancer² has promoted the development of knowledge they could not get any other way.

The context of the disease was quickly seen to be one of the biggest obstacles to claiming the entitlement. To be told that they have cancer is a real “body blow” that knocks the persons concerned sideways, as is extensively reported in the literature. On top of the fatigue caused by treatments and the medication, lives are upheaved and priorities redefined, with more energy put into fighting the disease and making the most of the time remaining than embarking on trying to access a right with a very uncertain outcome.

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1. This National Cancer Institute-funded (INCA) intervention research conducted in 2011-2014 aimed to identify factors of social inequality in reporting, recognition and compensation, and ways of reducing them. It was done in collaboration with the Giscop93 team, especially Cécile Durand, Nathalie Ferré and Annie Thébaud-Mony, in partnership with hospital services, the Seine-Saint-Denis primary health insurance fund (CPAM) and a law firm specializing in claims for victims of occupational diseases.
 2. The study focused on primary lung cancer sufferers, mostly male (20% female) in manual and clerical job categories (80% of the survey population).

1. The cancer-work link is hard to take on board

But those concerned also seem to have great difficulty in seeing how they can be entitled to compensation for an occupational disease because they cannot take on board the link between cancer and work. There are many reasons for this. Firstly, the characteristics of the disease do not make it easy to see how work might be responsible: being multifactorial, cancer generally carries no specific signature and occurs after a latency period of anything up to several decades, usually around retirement age. Then, too, most of these people were unaware that they might have been exposed to carcinogens during their work activities: these toxicants are almost invariably odourless, invisible and with delayed effects, meaning that they neither saw nor knew about them. Even the most highly-publicized carcinogen – asbestos - is no exception: while (past) workers now know of its hazards, they knew nothing at the time; but they may also simply not have known they were in contact with these mineral fibres which are ingredients of many mixtures like sealants, adhesives, coatings, paints, etc. Even today, there is no centralized, comprehensive inventory on where asbestos is to be found, and workplace health and safety agencies themselves confess that they are unable to trace the risk of cancer. So how could these (former) employees suspect that their present health could be due to their work when the information on the risks they were exposed to was not given to them?

Then, too, those concerned do not always relate well to the prospect of getting compensation for damage done unless the collective aspects of the compensation system are explained to them. Far from it, the prospective personal “benefit” may actually clash with the value systems that underpin their lives. Some, for instance, are unwilling to “ask for charity”, as they see it, after a life of self-reliance, avoiding being beholden to anyone for anything. Others will be deterred by their adult children’s desire to help their parents through the illness as a demonstration of gratitude. Still others will not want to make a claim so as “not to be a drain” on what they know to be a cash-strapped social security system when the costs of their care and treatment are already fully-paid by their health insurance: most do not know that work accidents and recognized occupational diseases are covered by a specific scheme financed in France by employers alone and not from joint employer/employee contributions. For some (former) employees, finding out that there is a law compensating occupational cancers – meaning that society accepts that your work may kill you – is so upsetting that they cannot conceive of their (otherwise nurturing and fulfilling) job being implicated in the occurrence of their illness.

Ultimately, affected individuals who want to claim for their cancer as an occupational disease must be able to build a proper case by providing paper “proof” of their disease and their work. It seems that accessing medical records - although a statutory right – is not easy. Even more difficult is the obtention of that essential document, a medical certificate of occupational disease. Personal beliefs and the culture of the profession (putting lifestyle factors ahead of all other origins), lack of time and training which has not prepared them for it, mean that many doctors will not issue such a certificate, or fail to make it out correctly. The pressures they come under from some employers – in some cases ending in disciplinary proceedings before the general medical council –

compounds this reluctance. And with the onset of the disease occurring years after exposure, victims of an occupational cancer may no longer have their pay stubs and/or employment certificates, the only accepted “proof” of their work activity³.

2. Unsited forms of assessment

But even a reported cancer that meets the statutory criteria will not necessarily gain recognition as an “occupational disease”, for the recognition rate for the same disease varies widely even between Funds – from 8 to 80% for some disease conditions according to the chairman of the Occupational Injuries and Diseases Committee (ATMP) established by the National Health Insurance Fund for Employees’ (CNAMTS). Occupational cancer is not a separate medical category, but a disease “negotiated” (Rosental and Omnès 2009) in a highly adversarial setting.

The circumstances under which occupational disease lists are developed – the outcome of bitter, unequal power struggles between representatives of employers, employees and the state – are one illustration of this and a main structural obstacle to the recognition of occupational cancers. There is a huge gap between the state of scientific and medical knowledge and what is actually taken in consideration in the lists evolution. In France, cancer diseases (mostly bronchopulmonary) are included in 22 occupational disease lists (out of 120) and concern only fifteen or so carcinogens – while the IARC identifies 111 “confirmed” human carcinogens and 65 “probable carcinogens” (category 1 and 2A in 2013). Also, the design of these lists is totally unfitted to the real world of work: they disregard the widespread nature of multi-exposure, consider only a single carcinogen, and the often-limited nature of reckonable activities does not correspond to actual work situations and exposure. For example, the reconstruction of the Giscop93 patients’ work histories shows that not all have kept the same job but have in fact had a succession of different employers - up to 30 for some - and so may have been exposed during their actual work activities to cocktails or accumulations of carcinogens: more than two carcinogens in 70%, and more than 5 in 25% of cases. While a complementary system was established in 1993 to try and overcome the limitations of these occupational disease lists – almost 30 years after the European Community recommended it –, it manages to recognize no more than 70 “off-list” cancers a year⁴.

The conditions for Funds’ assessment of cancers as occupational diseases are another reason for the under-recognition of occupational cancers. Firstly, these bodies’ procedures have been “modernized” in a root-and-branch reorganisation that specifically

3. Which immediately rules out any right to compensation for occupational cancer for undocumented workers – who abound in the construction industry - and cash-paid casual workers.
4. The terms of reference of the assessment done by panels of three doctors working in the Occupational Diseases Recognition Regional Committees (CRRMP) are arguably particularly unsuited to the specific characteristics of cancer diseases: with a remit to establish the existence (or otherwise) of “a direct and fundamental link” between the work and the disease, these medical practitioners are more inclined to look for “causal links” - a concept that makes no sense where multifactorial diseases are concerned. As a result, they readily refuse recognition of the occupational origin of a cancer to smokers on the pretext that there is a “non-work-related factor” involved when smoking – while undeniably implicated in the occurrence of cancer – adds to rather than cancels out occupational exposures.

affects the direct interface with users. Their management has been largely computerized or outsourced, while most of the public first-contact points have closed. Insured individuals now have to submit their queries over the Internet or by phone to customer advisors in call centres, where call handlers who are not trained in the difficulties faced by people living with cancer are assessed on the basis of response times. Rather than feeling that they have been treated as sustaining an occupational injury and given caring support in accessing their rights, claimants who are already badly afflicted by disease, rendered insecure by the complexity and lack of transparency of the procedures and the legalistic language of the letters sent out by the Fund may experience these relations as dehumanized and degrading to the point where they drop their claims.

Then, too, the sickness insurance funds are under-resourced and ill-equipped to perform the kind of assessment required for cancers properly within the regulatory 3 - 6-month timeframe: a lengthy and painstaking investigation into all the ins and outs of an entire work history, collating all if any traces of carcinogenic risk in the relevant jobs and firms. This means going back over 20 to 30 years, and it is not uncommon to find that firms and work processes have disappeared or been radically changed. If still in operation, firms take part in the assessment on an adversarial basis, meaning that victims and their employers both make submissions and are told of the facts of any complaint against them. Again, the balance of power between a (past) employee, weakened by illness, with an inexpert grasp of the terms and nature of the procedure, and an employer's highly-qualified legal department is particularly unequal. While the insurance funds may also look to other sources (health and safety inspectors and safety engineers) to identify potential carcinogenic exposures dating back 30 to 40 years, they also face the gaps in the institutional memory of exposures: if the risk cannot be "established", it will not be recognized. Little surprise, then, that most recognized claims (90% in the Giscop93 survey) are established on the basis of exposure to asbestos, a carcinogen that mobilized widespread labour action and was the focus of a number of studies commensurate with the scale of the health scandal for which industrialists and employers are mainly to blame, facilitated by the shortcomings of the authorities to prevent toxic risks.

These non-reporting and non-recognition factors penalize women even more at all stages. Research on cancer risks – both toxicological and epidemiological studies – has long focused only on male populations. As things go, the Giscop93 experts identifying exposures to carcinogens in the survey patients' work histories find it harder to analyse the work histories of women than men: only 26% of women receive a referral to report their occupational disease (against 64% of men). Asbestos aside, the carcinogens most frequently encountered by women - formaldehyde, chlorinated solvents and passive smoking – are not such as to allow of recognition as a listed disease. Where lists do exist, the limited listing of work activities is patterned on an often inappropriate model of male work. Finally, over and above these structural obstacles to reporting and recognition, women are seen to be "going it alone" more than men in claiming recognition of an occupational disease. As a result, only half of women who reported their cancer as an occupational disease are found to have won recognition compared to 76% of reporting men.

Paradoxically, while women suffer from a lack of recognition of their own occupational cancer, they are the “real” beneficiaries of compensation awarded to their ailing spouses. So short is life expectancy with the disease (50% of patients die within a year of diagnosis) and so protracted are the procedures that the patient often dies before the claim is settled, or even before the occupational disease is reported. It then falls to the spouse to initiate a claim or – in the event – press on with a claim already initiated in the hope of being awarded a portion of the pension the victim would have got if his cancer was recognized as an occupational disease. They then face the same difficulties as encountered by the victim described above but further exacerbated by their bereavement (difficulty making sense of the process, very hard to gain access to medical records).

Seemingly, then, reporting an occupational disease is much less about simple paperwork than “an issue of struggle” to borrow the title of an article on work accidents by the French sociologist Rémi Lenoir. There can only be effective recognition of work cancers through a collective approach, not by dint of individual cases. Likewise, the burden of proving carcinogenic exposures must not lie with the victims of work-related cancers alone. As an issue of struggle, the right to recognition of occupational cancers in the final analysis requires the labour movement to take a long look at its power to act on the combined improvement of cancer compensation and the prevention of occupational cancer risks.

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