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### The Distribution of Hypersensitivity

### The Sudden Appearance of People with Electrical Hypersensitivity in the Public Space

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Abstract:

The recent evolution of health and environmental controversies in industrialized countries has produced the emergence of new illnesses, often categorized as unexplained syndromes. This article examines how the collective movement of people with electromagnetic hypersensitivity has elevated the issue of electromagnetic waves to the point where it garnered, in the winter of 2007-2008, as much media impact as major issues such as asbestos, radioactivity, genetically modified organisms, or pesticides. This research, based on the study of the various actors, arguments, and accounts of people with electrohypersensitivity, proposes a reformulation of the theme of intuition in the world accessible to the senses, an indispensable step in the symmetrical analysis of controversies about medical categories and the distribution of individual and collective experiences.

Key words:

health scares, medical controversies, hypersensitivity, electromagnetic waves, pragmatic sociology, victims

March, 2009. Pascale told us about the long conversation she had the day before yesterday with the superintendent of the building next door. In the middle of a discussion she called "completely banal," Pascale brought up her nonstop migraines, which repeated medical tests were unable to diagnose. Jumping in, the superintendent told her about her own problems: insomnia, ringing in her ears, and headaches that did not go away until she went far away from the neighborhood.<sup>1</sup> For her, there was no doubt: the base station antenna was the cause of it all! Fixed to the roof of a building, the antenna, about a hundred meters high, loomed over the area. "It's true," she had said, "they talked about it on TV – there are people who can't tolerate these electromagnetic waves." After years of worries and medical problems that doctors attributed to a psychosomatic disorder, she finally had identified the source of her illness and undertook to investigate it further. Afterwards, as much as she had tried to resist it, for instance, by attributing the cause of her migraines to an excessively strong detergent, Pascale found herself wrapped up in the cause of "electrohypersensitivity!" She educated herself, rapidly finding the web site of the Robin des Toits association,<sup>2</sup> then a link to an electrosensitivity blog<sup>3</sup>, through which she joined ARTAC (Association for Therapeutic Anti-Cancer Research), an association of doctors and researchers working for the recognition of environmental causes of cancers, led by the famous Professor Dominique Belpomme.

Starting with a simple anecdote, as we have shown here, one thing led to another, right to the problem of health scares and the controversies they entail. The phenomenon is not new for sociology: a category accompanied by a semantic network favoring a group of suggestions and interpretive operations is inserted into the heart of the most ordinary of conversations. Thus, over the last 15 years, in the wake of large health and environmental crises, common sense has become constantly attuned to earlier scares converted into prototypes (contaminated blood, asbestos, radioactive fallout from Chernobyl, mad cow disease, etc.), and aware of related concepts implemented by the government (precautionary principle, health and safety, traceability, weak signals, and so on).

Dominique Belpomme is well known among those with an interest in following questions of public health over the last few years. After becoming a public figure through multiple speeches about pesticides, he began to suspect that carcinogenic effects could be attributed to electromagnetic fields. Without having indisputable evidence at his fingertips, the oncologist encouraged the collection of victims' accounts of their experiences and supported their joining forces to have electrosensitivity syndrome recognized by the government. In this way, the interpretation of signs carried out by ordinary people in multiple localities cut across a process of questioning, which, in turn, reinforced the intuitions underlying a form of "popular epidemiology."<sup>4</sup> Voices from all over made it clear that a syndrome, not just individual singularities, existed, and pointed to an invisible world, that of electromagnetic fields and waves (Granlund-Lind, 2004). On the ground, numerous actors considered that the uneasiness was well founded, since people were exposed to electromagnetic waves all the time, and this exposure had been growing since wireless communication systems became common – all the more worrisome since scientific controversy about the non-heat-related effects of electromagnetic waves was in full swing. It must also be noted that reference to the precautionary principle had been a constant in the public debate about this issue since the early 2000s (Burgess, 2004).

<sup>&</sup>lt;sup>1</sup> Recalling an illness often leads people into discursive configurations marked by a sort of expressive exaggeration of the experience of pain (Augé, 1994).

<sup>&</sup>lt;sup>2</sup> "Robin des Toits," or "Robin Roof," is a play on "Robin des Bois" ("Robin Hood") which is also the name of a well-established French organization for the protection of nature.

<sup>&</sup>lt;sup>3</sup> http://www.electrosensible.org.

<sup>&</sup>lt;sup>4</sup> The concept of popular epidemiology was developed by Phil Brown, see Brown (1997 and 2002. In the French context, multiple labels (Popular, ordinary, lay, civil, socially aware) have been current in the social sciences in recent years to designate these processes of collective inquiry through which actors recount experiences with the aim of simultaneously making institutions accountable and changing scientific research. See Fromentin (2008) for the use of the notion of "laity" in the social sciences.

In the majority of health and/or environmental controversies, the dynamic of scares and the social organization of victims produce a reorganization of the sets of actors and of arguments that involve authorities on the ground of lawsuits for damages. This phenomenon can also be seen when the issue is in the process of normalization.<sup>5</sup> Quite often, according to the doctrine founded on the principles of risk assessment and risk management, the fact that a potential public health problem was put on the agenda, and that it resulted in regulations or legal measures, making continual worries and complaints about it seem illegitimate, or even a little irrational (Borraz, 2008). Nevertheless, attention to the interpretive activities of the actors in their contexts shows that official attention cannot reduce the intersubjective processes governing the sharing of experiences, and, in particular, the elaboration of a common sense of illness and health (Herzlich, 1984; Dodier, 1993). Better still, the serial connection of interpretations and local interactions result in proto-collectives or interpretive communities – today particularly visible on the web<sup>6</sup> – and, sometimes, true collective causes. This kind of interpretive operation frequently appears in the course of ordinary interactions. In fact, the production of an unexplained syndrome like electrohypersensitivity receives a minimum of social support, with every interaction relying on individuals to be simultaneously capable of both subjectivity and an intersubjective competence, or at least a capacity for trans-individual action (Simondon, 1989). A causal association may not necessarily be shared, but health and illness are commonly activated as ethnomethods of conversation. At the same time, when the political and media attention to an issue reaches a critical mass, that is, a degree of collective action sufficient to create, if not a precedent, then at least a minimum of irreversibility, the individual construction of disease begins to feed on the public process of the socialization of experience. This was the case in 2008 for electromagnetic waves. The accumulation of victims' accounts finishes by reinforcing the choices of causal attribution made by individual subjects. The government and professionals concerned therefore do not have any other choice but to take into account the existence of the cause – even if they essentially refute its premises.

From this still unstable sociopolitical configuration, we will retrace the emergence of electrosensitivity in the case of electromagnetic waves. The way in which this health problematic emerged in the public arena will allows us to explore two principal questions: on one hand, the formation of diagnostic categories, such as unexplained syndromes, and, on the other, new dividing lines among intuition, representation and the public expression of a health-related issue.

# **1.** A brief history of the controversy about electromagnetic waves

Compared to the health and environmental issues that came before it, the case of electromagnetic waves has several notable characteristics: it is, in effect, the product of a long period of development, marked by local conflicts about mobile phone base station antennas beginning in 1999-2000, and by the slow growth of concerns about mobile phones themselves, warnings emphasized by the publication of contradictory studies and reports. When the trajectory of this issue is traced, above all, it is the antennas that gave rise to the biggest protests (Borraz, 2004). In 2006, telecom companies launched a defamation suit against Étienne Cendrier, spokesperson of the Robin des Toits association (Cendrier, 2008), preparing the conditions for the unification of causes, that is, a

<sup>&</sup>lt;sup>5</sup> The case of asbestos, often cited by the actors themselves, now serves as a prototype used to characterize issues in which public support did not lead to the eradication of the hazards in question, but instead made the scope of the disaster worse (Chateauraynaud, 1999, 99-194).

<sup>&</sup>lt;sup>6</sup> See, for example, the thread "Electromagnetic pollution – Waves" (« Pollutions electromagnetique – Ondes ») on the Doctissimo site – the 11<sup>th</sup> most visited forum in the world, according to big-boards.com! The number of forums and of discussion threads in general (blogs, mailing lists, etc.) that develop around questions of health and illness from an intersection of heterogeneous points of view have grown nonstop over the past ten years, to the point where governments and medical associations should become alarmed. See Akrich (2004) on the analysis of illness-related forums.

convergence of critical processes that were separate until then. This convergence was accelerated in August of 2007 by the publication of the BioInitiative report. At the end of 2007, the cell phones for kids scandal, which got consumers' associations involved, ended the process of transformation. The questioning of the Minister of Health by critical actors marked a turning point, after which this issue has never left the public arena.

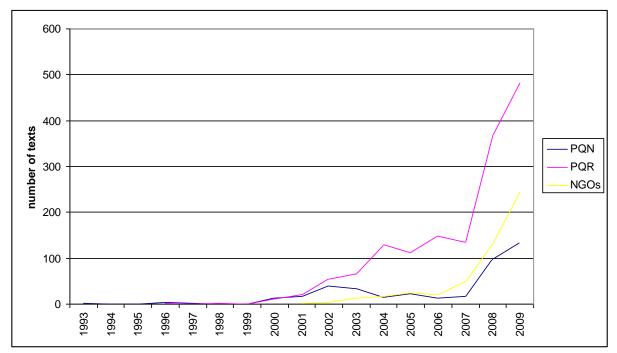


Fig. 1. Temporal distribution of texts about mobile phone controversy, separated into three series: the regional daily press (PQR), the national daily press (PQN), and documents produced by associations (white papers). It is clear that local protests preceded the rise of the issue to the national level. Source: Observatoire socio-informatique des alertes et des controverses.

At the end of the 90s, in the middle of the expansion of mobile phone use, the question of the dangerousness of electromagnetic waves exploded onto the already long list of subjects of health scares and controversy. Sometimes categorized as an "emergent risk," this issue borrows multiple elements from the oldest problem of the impact of electromagnetic radiation, that of high voltage power lines, which were protested since the 1960s. Studies have not been able to definitively answer the question of whether negative biological effects are associated with these lines, in particular, whether they raise the risk of brain tumors (Brodeur, 1989). In April 2000, anticipating a possible health crisis, doubtless because of the impact of the Independent Expert Group on Mobile Phones commission directed by Sir William Stewart and launched in February in Britain,<sup>7</sup> the Council for the Applications of the Academy of Sciences and the Academy of Medicine organized a conference called "Mobile Communication: Biological Effects" (Paris, April 2000), in which social science researchers also participated (Académie des sciences, 2001). The majority of papers underlined the insufficiency and contradictory character of studies, and the necessity of prolonging research, favoring the convergence of questions of dosimetry, in vitro experiments, epidemiological inquiries, and health standards – in other words, a fuller expansion of the "precautionary principle."<sup>8</sup> Despite the regular publication of new studies, in particular from the international Interphone program, a decade later,

<sup>&</sup>lt;sup>7</sup> The Stewart Report became public on May 11 (IEGMP, 2000).

<sup>&</sup>lt;sup>8</sup> Tracking the corpus of texts and discourses on the risks of mobile phones over time shows a sharp upswing in the number of references to the precautionary principle from 2000-2001, simultaneous with the growth of the issue itself.

uncertainty continues to be the dominant theme of scientific texts. Nevertheless, studies suggesting that base station antennas or mobile phones have biological effects were circulated widely by key players who claimed to be alarm raisers<sup>9</sup>

In France, the series of reports that followed,<sup>10</sup> as well as the critiques they generated, put into doubt the independence of expertise and strongly influenced the trajectory of this issue. First, there were intense controversies about the manner in which the question of thresholds of exposure to radiofrequencies is discussed and used (Dillenseger-Honoré, 2004). The argument that multiple sources of exposure play an essential role was among the elements that paved the way for the entrance of people with electrohypersensitivity onto the scene, since cell phones are integrated within a constellation of telecommunication networks. More recently, the argument for the harmlessness of electromagnetic waves is in conflict with the increasing superposition of multiple electromagnetic fields as WiFi hotspots become more widespread. For many actors/authors, problems of the metrology used, of the duration of exposure taken into account, and of the a priori sensitivity attributed to people, are not addressed well in official studies. The most powerful critique focuses on the fact that studies until then were run on populations exposed to single sources, excluding analysis of the impact of both overlap and interrelations. This stands in contrast to the testing of chemical products that applies under the new European REACh-type rules (Registration, Evaluation, Authorisation and Restriction of Chemical substances), which allows for taking interactions among multiple exposures into account (Narbonne, 2007). From this point of view, the issue of electromagnetic waves constitutes an excellent way to analyze the process of rebuilding the "health/environment" problematic, starting from the constellations of sources in continuous interaction with one another.

A major turning point occurred on the 15<sup>th</sup> of June, 2008: the *Journal du Dimanche* (Sunday Journal) published an appeal put out by scientists, including respected oncologists, "against the dangers represented by mobile phones." Coordinated by David Servan-Schreiber, professor of psychiatry at the University of Pittsburgh, the text enumerated ten principal recommendations.<sup>11</sup> For example,

"Children under 12 years old must not be allowed to use a mobile phone except in emergencies. Mobile phones must be kept more than a meter away from the body when in use, by turning on speakerphone or using a hands-free kit or an earphone, and carrying a mobile phone on one's person should be avoided as much as possible, even when it is in sleep mode. The appeal also recommends communicating mostly by SMS, since this limits the duration of exposure and the proximity of the device [to the body]."

All these recommendations came out after more than a decade of intense mobile phone use. Also, according to the *Journal du Dimanche:* "Scientists agree on two things: there is no formal proof of the harmfulness of mobile phones, but a risk exists that long term exposure to them promotes the development of cancer." Thierry Bouillet, an oncologist, and a signatory of the appeal, does not hesitate to compare this issue to those of asbestos and tobacco, an analogy spread rapidly by multiple media outlets: "We are today in the same situation we were in 50 years ago with asbestos and tobacco. Either we do nothing, and accept a risk, or we admit that there is a body of disturbing scientific evidence." A body of evidence is not tangible proof, but, in the logic of precaution used by the protagonists, it allows one to act as if this proof existed, and to infer from it all the consequences. Hence, when actors construct a case by making a set of signs the potential equivalent of a proof that

<sup>&</sup>lt;sup>9</sup> In France we distinguish whistleblower and alarm raiser (lanceur d'alerte). In the first case, people denounce a rule violation or a scandal, whereas in the second one, the main problem is to obtain recognition for a new danger or uncertainty and to act upstream before the catastrophe. On this point see Bernstein and Jasper (1996) and Chateauraynaud and Torny (2005).

<sup>&</sup>lt;sup>10</sup> As Zmirou Report (2001), the Parliamentary Office of Evaluation of Scientific and Technological Choices (2002), and the expert reports mandated by AFSSE (March 2003 and April 2005).

<sup>&</sup>lt;sup>11</sup> « L'appel des vingt contre le portable », *Journal du dimanche*, June 15, 2008.

one cannot expect to see manifest before acting, they increase the likelihood of switching from a logic of controversy to a political logic. The alignment that results generally produces serious inflections in the trajectory of an issue. In this case, the question of the risks associated with electromagnetic fields certainly changed appearance, as a press release from AFSSET attests: reacting to the appeal of the oncologists, the health agency welcomed "seeing its recommendations taken up by other scientists."<sup>12</sup> It became more concerned with the development of this issue than it had been in 2005, when polemic raged about the independence of the agency with respect to Telecom Companies.<sup>13</sup> This polemic helped give weight to radical accounts and greatly fed the growing power of "anti-wave" groups and associations in the public sphere.

### 2. The slow percolation of an invisible cause

In the social sciences, the ontological status of pollution varies according to its degree of visibility. Within the model of actor used by scholars and its corresponding epistemology, people are granted or denied the ability to rationally construct a social topography of invisible entities. The salience of these invisible entities depends on the type of shared cosmology (Descola, 2005). Three things are clear: either the objects or phenomena are constituted by science or medicine and belong to the list of issues taken up by, or capable of being grap by anyone;<sup>14</sup> or the entities exist for certain protagonists and do not exist for others;<sup>15</sup> or the players agree on a form of undecidability by putting forward a scheme of uncertainty. These ontological splits are of concern not only to the actors who bring forth the causes through alerts and controversies; they are also of interest in professional circles. This is notably the case with insurance companies, who consider the health effects of electromagnetic waves as "phantom risks" (Brauner, 1997); public health experts see them as a "non-assessable" reality. In reasoning based on the idea of "risk perception", the spontaneous interpretations of symptoms are reduced to a diagnosis of hyper-vulnerability, which was prompted by the belief itself. This permits an expert to write that, "the simple perception of a risk can induce medical effects."<sup>16</sup>

It is as if the rising power of people hypersensitive to electromagnetism in the public arena acts as a source of ontological disturbance as much as it constitutes an epistemological disturbance. This is often the case in socio-technological controversies when they give rise to an intense effort of public explanation and justification (Jasanoff, 2005). Not only are the entities and relations that make up the world affected by the inclusion of electromagnetic hypersensitivity, but the space of epistemic controversy, more precisely, the confrontation of degrees of conviction associated with collective metrologies, is transformed. In terms of values, electromagnetic hypersensitivity alters the boundaries of dominant categories by expanding the definition of victim in a sense that certain commentators refer to as "hyperindividualism" (Ehrenberg, 1995). What unites these different sets of values depends on the manner in which invisibility itself is treated by the players. Electromagnetically hypersensitive people who speak publicly carry with them the idea that invisibility will not last forever, and that they are the precursors of an objectification of dangers that were until now unknown, denied or scorned. In doing so, they are the promoters of new protocols of measurement and evaluation suited to the realm of the imperceptible. Rather than sustaining an

<sup>&</sup>lt;sup>12</sup> AFSSET, "AFFSET calls attention to the recommendations it has been developing since 2005 for mobile phones," press release, June 16, 2008.

<sup>&</sup>lt;sup>13</sup> IGAS/IGE report, "Evaluation of scientific research methods at AFSSE," January 2006.

<sup>&</sup>lt;sup>14</sup> On the history of the Spanish flu seen through the arguments of scientists and physicians, see Rasmussen (2007). The author describes the uncertainties and controversies relative to the identification of the infectious agent; the notion of "virus" had not yet been stabilized.

<sup>&</sup>lt;sup>15</sup> This type of division concerns the adversaries of pseudoscience. On the "dialogues of the deaf" that result from this, see Doury (1997).

<sup>&</sup>lt;sup>16</sup> Luis Miro, cited in «Le casse-tête des champs électromagnétiques » ("The puzzle of electromagnetic fields,") *Travail et sécurité*, November, 1997, p. 29.

opposition between the rationality of the visible world and the imaginary irrationality of the invisible one, it is better to conceive of this process – which, since then, has taken on the form of a political campaign - in order to distinguish several forms of invisibility. The first form of invisibility refers to that which is literally incapable of being applied to any exterior element, that which exists only in an act of speech, for example, a discomfort or kind of suffering mentioned by a subject without any external indication or possibility of confirmation by others. Then there is that which is potentially produced by a source visible in the world, but for which there is no instrument that would allow its effects to be measured objectively. This configuration is at stake when actors focus their attention on an object present in the environment and suspect it to be the source of environmental pollution, without connecting the links in a causal relationship. At a higher level, perfectly visible objects (a field of corn, for instance, or a base station antenna) have available a greater number of metrologies capable of evaluating the flux they generate (pollen released, electromagnetic waves or radioactivity emitted, etc.); invisibility comes from measures that remain at levels below the threshold of detection (e.g. a radio belonging to a smoker in good health). Finally, there is everything that is not visible yet but that will become visible later. Invisibility is thus defined by a shorter or longer temporal horizon. In public health, this is the classic problem of latency time (e.g. the famous thirty years for malignant mesothelioma, the cancer caused by asbestos).

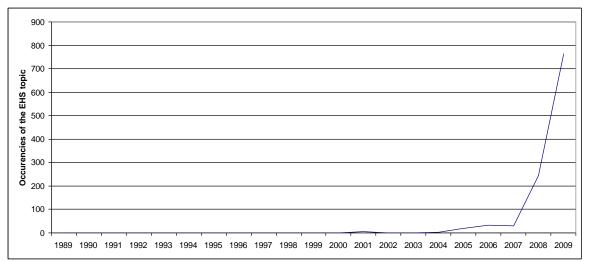


Figure. 2. The growth in the number of times people hypersensitive to electromagnetism were mentioned in the corpus. The dotted line shows that growth began to take off at the end of 2008. The Y-axis shows the number of times the theme appeared in the files.

In order to break the interpretive circle created by the disturbing invisibility of phenomena, players need a common space of reasoning: they must share the way that the issue or environment are seen to exist, the techniques of measurement, the concerns that the people involved have, and the things that they perceive (Chateauraynaud, 2004). One difficulty for people lays in the long detour imposed by public speech on the expression of a personal experience. How can a person express a hypersensitivity when the people he or she is speaking with not only do not recognize this category as a public category, but do not have the ability to access the same experience? In other words, how is it possible to communicate a personal experience when there is no common ground? The most important aspect of emotional and cognitive stress comes from the need to bring players (close relatives, witnesses, doctors, and designated speakers of collectives) to understand sensory suffering to which they do not have access. But would that mean a direct comprehension of another person's hypersensitivity (Austin, 1971)? We know that the interchangeability of roles is one of the fundamental conditions of social interaction, and that it is precisely the reference to internal states that is an obstacle to this natural exercise of understanding one another (Mead, 1963). Hypersensitivity appears as a radical form of sociological test or social experiment: on which grounds can we base an agreement when the motives rest on perceptions, and mental states are described in the language of emotion? Electromagnetic hypersensitivity as a cause engages the actors in a process of comprehension, in terms of both overcoming the gap between experience of an influence inaccessible to others, and developing protocols of objectivity founded on normalized metrologies. One of the possible solutions requires the electrohypersensitive people to transform themselves into environmental testing instruments using their powers of detection. But it is precisely in the assertion that they have such powers that electromagnetically hypersensitive people open the door to rationalist criticism. The structure of medical space, however, allows for a plurality of options, as when patients can negotiate the meaning of their symptoms with doctors.<sup>17</sup>

On the AFIS site,<sup>18</sup> an exchange dated January, 2009, illustrates the phenomenon of mutual incomprehension. It occurred at the precise moment when the cause of electrohypersensitivity reached a new level of visibility in the public eye:

"The article on electromagnetic waves on your site is a model of misinformation. In the first place, it's an insult to EHS (electrohypersensitive people), of whom I'm one. EHS sensitivity is simply 10, 100 to 1,000 times higher than that of the average person. To call EHS people sick with an imaginary illness is hypocrisy and intellectual dishonesty. [...] Scientific proof of the dangerousness of pulsed microwaves was amply confirmed by independent studies, notably the Bioinitiative report [...] The recent Belgian study by Dirk Adang on lab rats yielded disturbing results. [...] The irradiation of the entire population, occasionally against its wishes, is probably going to be the biggest health scandal of the 21st century."

Aside from the polemic in the preceding extract, there are two points made: the reference to a scale for measuring sensitivity, and reliance on laboratory experiments. The response of the editors rests essentially on refusing to associate the two, that is, the undisputed suffering experienced and an evidence based statement.

"To say that symptoms called electrohypersensitivity are not linked to electromagnetic fields does not deny their existence, or denigrate those who are suffering from them, or treat them as people suffering from imaginary diseases. Quite simply, no study has been able to establish such a link between these symptoms and electromagnetic fields. [...]"

Aside from these snippets of controversy that hint at parascience or pseudoscience, the public success of the electrohypersensitive cause depends on two types of conditions: the elaboration of a set of language in which people can share their feelings of sensitivity, and the construction of the body itself as a public laboratory (stress is a recent example of a successful transformation). The idea of sensitivity is an intermediary between the world of instruments and the lived world. What the cause of electrohypersensitivity does to these two forms of expression is to the overcome a deep divide or at least force to a redefinition of the lines. Despite the reservations of rationalists, the set of language that combines bodily functions and sensory perception has a long history. The objectification of illnesses, their causes, and their clinical presentations has allowed for the institution of hygienic programs on the basis of foundations little contested today. Someone who, during a meal, makes a gesture to indicate that he must not add salt, produces, in interactionist terms, an effect of adjustment on the part of his co-interactors, who do not demand long explanations. The degree of *accountability* is high because it rests on medically and socially established grounds. We see that, with the same logic, one can imagine a social world in which, when someone takes out a mobile phone, a hypersensitive person could legitimately ask him to put it away

<sup>&</sup>lt;sup>17</sup> General practitioners who assert the existence of a global scope for medicine have the confirmed tendency to take unexplained syndromes seriously (Baszanger, 1983; Arliaud, 1987; Eeckeleers, 2009).

<sup>&</sup>lt;sup>18</sup> Association Française pour l'Information scientifique (French Association for Scientific Information) : http://www.pseudo-sciences.org.

- the case of secondhand smoke has, from this point of view, changed the rules of interaction among smokers and non-smokers. At the same time, the goal is not to establish electrohypersensitivity as a parascientific theme, but to instead place it in a process of socialization of sensitive experiences, that has no more and no less of a likelihood of happening than any other, in the same way that one thinks of allergies, stress, work-related suicide or even vasovagal syncope. Every sensory manifestation which, at the moment it occurs, requires a test of comprehension, cannot become, as evidence shows, a collective cause. The emergence of electrohypersensitive people therefore constitutes a revelation of the capacities of actors to redefine their common world, which always appears under construction or, more precisely, as a provisional state of the distribution of the sensible.

Another dimension of the problem, well known in the social sciences of health, had long been established under the concept of "the whole person." "Alternative medicine" very quickly became the antithesis of "mainstream medicine" (Gomart, 1996). At the same time, the strong growth of genetics and predictive medicine in the public space in the past twenty years vigorously pushed interpretive procedures founded on traditional medicine to the fringes (Gaudillière, 2002); 'Show me your DNA and I'll tell you how healthy you are!' At the same time, the oft-cited crisis in clinical medicine in the face of the growth of "evidence-based medicine" awakened old epistemic tensions (Dodier, 2003). Although in their recent formulations, electrohypersensitive people do not seek to ground their cause in "alternative medicine," they wish to rebuild the meaning of the sensitive. The notion needs, in effect, to be situated in relation to other accepted uses of the term, such as "sensitive zones," "sensitive individuals," "sensitive populations," as well as "sensitive organs."

### 3. Tests and proofs of visibility

The different turning points undergone by the trajectory of electrohypersensitivity permit us to make explicit three forms of public visibility. First, we see various attempts to construct a complaint, whether by the recourse of individuals to court procedure, or by the formation of victims' associations (Barbot, 2002). Second, we see the promotion, also experimental, of a new ecological regime, via the creation of ecovillages or camping sites in "white zones" made to house the electrohypersensitive. Finally, the progressive organization of a militant medical study, initiated by ARTAC, contributes to the creation of a new repertoire of studies and research on the environmental origins of chronic illnesses such as cancers.

#### An electrosensitive person dismissed by the court

An individual isolated because of distance from all social networks capable of relaying his worries or claims, or because the organization in which he or she operates pushes him or her to the fringes, looks for a device allowing him or her to express the causes of suffering, but, also, inseparably, to gain recognition of the wrongs done to him or her. The legal route therefore marks a dramatic change in the settlement of a complaint. Let us open here the Rinckel legal trial:

"The district court of Strasburg was opposed to a woman who claimed to be hypersensitive to mobile phone base station antennas in a case she filed against her landlord, CUS Habitat. Sabine Rinckel, 42 years old, claimed to suffer from electrohypersensitivity (EHS), a condition recognized in Great Britain and in Sweden, but not in France, and she accused her landlord of not having sheltered her from the effects of base station antennas, despite previously being resettled in another neighborhood in Strasburg in 2003. [...] The court held that the 'problems presented by the plaintiff are inherent to her person, given that the new tenant (of the housing that she occupied) does not have any problem.' The tribunal also held that the problems invoked were 'subjective' and that the landlord cannot be held 'responsible for external factors.' The judge also held that the conclusions of a study by the French Agency for Environmental and Occupational Health (AFSSET), put forth by the landlord, according to which, magnetic waves emitted by mobile phones are no stronger than those of television antennas." (AFP, September 29, 2006)

We note that this ruling allows for parallels among the French case and other national situations, such as those in Great Britain and in Sweden, using a process of comparison extremely frayed during the construction of contemporary causes. AFSSET is cited by the defense and the lack of ties is underlined by the court, which is led to reject the demand. Nevertheless, on appeal, we will see a change of reasoning marked by the tacit recognition of electrohypersensitivity despite of the absence of a causal link in this case.

"In their judgment, the magistrates of the court of appeal confirmed the first judgment in upholding 'the requirement to produce medical certificates' which, with one exception 'make no mention of the medically aforementioned problems of hypersensitivity.' Mrs. Rinckel, who had undergone operations to put metal plates in her face, declared that, since 2003, she has been electrohypersensitive (EHS) to electromagnetic waves and said she has tingling, headaches, tintinnus and pain in her cervical vertebrae because of the proximity of the antennas. For the court, which does not deny the existence of electrohypersensitivity, 'Mme Rinckel did not demonstrate that it is imputable to base station antennas.'" (AFP, October 15, 2008)

The Rinckel affair did not seem to produce a ripple effect and was not intensely supported by the collectives under construction. For them, the issue at stake resides much more in the modification of a category, like that of the sensitive population, which would permit the extension of the notion of sensitivity to different classes of people without getting into their personal experiences. This sparks a quest for objective criteria of sensitivity, following the example of what is in place for children or pregnant women. We know that an active association of victims supposes the existence of spokespeople given the power of clear expression, capable of acting on a media and political configuration.

"The principal victims of this type of technological disorder caused by the technical group of mobile phone providers, and who are known as victims of EHS – electrohypersensitivity – got together during the week of July 13 to 17, 2009. They decided to give themselves a social existence and form a national collective. They published a declaration in which they demanded that the government officially take into account the very serious consequences of the near total absence of regulation in this area. They called for an end to local decisions made in total disregard for the present state of scientific knowledge, and also total contempt for the population from which they are holding back all real information, and who do not have any right except to the fatuous remarks of the telecommunications companies." (Press release, EHS network, "The movement for a life without electromagnetic pollution calls for medical surveillance and electromagnetic wave-free zones," July 23, 2009)

As long as the construction of victims is not stabilized such that their situations are made equivalent and interchangeable, as in the case of AIDS patients (Dodier, 2003), the controversies and the polemics take on sawtoothed trajectories. A continuous effort of presence on the political and media agenda is therefore necessary to obtain the support of claims (Hilgartner, 1988). From a pragmatic point of view, electrohypersensitive people therefore remain a sociological category under construction.

# The admission of electrohypersensitive people into a participatory democracy

The organization of the dialogue and the public debates about electromagnetic waves during the spring of 2009 provides a measure of the weight of the cause of electrohypersensitive people. Actually, in the Grenelle of waves<sup>19</sup> and in the Paris citizen conference on electromagnetic waves, electrohypersensitivity played as much of an essential role. Citizens' views produced at the City of Paris's "Waves, Health, Society" public meeting on electromagnetic waves brought up electrohypersensitive people on many occasions and dedicated the tenth recommendation entirely to them. It reads:

"Toward a recognition of the intolerance to electromagnetic fields: whether or not these symptoms are linked to electromagnetic waves, the City of Paris must implement appropriate and personalized care in collaboration with the associations specifically dedicated to people with electrohypersensitivity. One part of the group recommends that electrohypersensitivity should be recognized as a handicap. Finally, as an employer, the City of Paris should consider ways to support the work of people affected by these symptoms."

For their part, the Grenelle spokespeople brought up the possibility of taking responsibility for electrohypersensitivity:

"Appropriate care for hypersensitive people:

collaboration with teams from the Cochin Hospital from the perspective of developing a protocol for receiving and caring for these patients will be followed; research into the causes of these symptoms will be undertaken."

Finally, in July 2009, an additional obstacle was also overcome by the collective cause when the second National Plan for Health and Environment provided the "Action 24", called "improving the care of illnesses potentially caused by the environment," targeting, in particular, "people affected by hypersensitivity to environmental factors, notably electromagnetic waves."

### 4. A series of unexplained syndromes might hide many others

After many years of record growth of the issue of electromagnetic waves, the cause of electrohypersensitive people acts as a reconfiguring force. Thus, the health field must face the advent of a proto-category of victims, already made public in other countries. From a formal point of view, the rise of this new entity in the set of dominant actors presents certain analogies with preceding public constructions of victims: people with thyroid disorders linked to radioactivity, Gulf War syndrome veterans, people living near incinerators, people living near highway interchanges, victims of sick building syndrome.<sup>20</sup> In contemporary political analyses, it is normal to classify or dismiss the process of construction of individual and collective causes as a byproduct of a

<sup>&</sup>lt;sup>19</sup> This label was derived from the 'Grenelle de l'environnement' (the Grenelle of Environment) which was held in 2007 France and based upon an open multi-party debate that brings together representatives of government, classical social organizations and non-governmental organizations around the key points of public policy on ecological and sustainable development issues.

<sup>&</sup>lt;sup>20</sup> On the appearance of unusual victims in different cases (exposure to radioactivity, benzene and sick building syndrome), see Michelle Murphy Sick Building Syndrome And the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers, Duke University Press, 2006; for the French case see F. Chateauraynaud (director), For a computerized observatory of alerts and environmental crises. An application of the concepts developed during research on whistleblowers, Convention CEMAGREF/GSPR-EHESS (Programme EPR 2000), February 2003.

transformation of the law that tends to give the spotlight to victims – the "American model," spontaneously associated with the idea of legalization (Israel, 2009). The comparison of multiple critical processes shows that the way of constructing victims depends on the space of calculation in which they find themselves, as in the way that complaints are reduced to a logic of damages and interests. In the case of electrosensitive individuals, the public expression of problems can evoke other cases, such as work stress or sick building syndrome, that lead to psychologization of distress. In the same movement, electrosensitivity is contemporary with the appearance of other "unexplained syndromes" which we are taken into account by sanitary agencies.<sup>21</sup> This process corresponds with that noted for other simple or multiple hypersensitivities that have emerged in recent years with respect to certain molecules. If the care of electrosensitive people at the local level becomes more and more effective, it is not yet clear how this problem will be taken in a chain of responsibility because of the divergence in interpretation of the links between their symptoms and the environment.

While the interpretive difference of opinion is at its peak, which is the case so long as one person claims to have a condition that the medical establishment is not disposed to recognize as such, the reduction of the problems to "psychological stress" remains the dominant strategy. But, paradoxically, the lay use of medical categories is constantly criticized by professionals, who put strong constraints of specification on descriptions and on diagnostic terms. Thus, a patient who uses a phrase such as, "This is certainly psychosomatic," will find himself facing a counteroffensive reaction of the type, "Psychosomatic doesn't mean anything!" Many categories that have cropped up in the history of medicine have thus changed into a sorts of fallacies associated with "common sense." It is striking, therefore, to see how, in controversies about risks, reference to a "collective psychosis" remains an ordinary way of publicly dismissing behavior.<sup>22</sup> We present the following table as a heuristic way of looking at how certain categories can be validated or invalidated:

Conditions with an identified source that is not psychosomatic	Emerging or reemerging conditions	Conditions attributed to psychopathological profiles: somatoform problems
Asthma	Panic disorder with tetany	Somatoform disorder
	(spasmophilia)	(Briquet's syndrome)
Allergies and intolerances	Stress	Hypochondria
Post-traumatic stress disorder	Electrosensitivity	Phobias

This table presents the contents of a collective discussion during a seminar devoted to electrosensitivity (March 2009). Each participant was invited to categorize the types of symptoms which he or she spontaneously associated with hypersensitivity. This yielded a cognitive map that had only the function of serving to engage the reinterrogation of the origins of these liminal categories.<sup>23</sup>

We can situate the variation in electrohypersensitivity between two limits: at one end, a successfully completed and no longer controversial process of medical reification, and, at the other, a clinical diagnosis of one or more psychological conditions. The fact that it belongs neither at one end of the spectrum nor at the other leaves the issue in a constant state of flux.

<sup>&</sup>lt;sup>21</sup> Hypersensitivity gave rise to various medical constructions, for instance, the syndrome of intolerance to chemicals. See the thematic issue « Les syndromes psychogènes: connaissances acquises et études de cas » in the *Bulletin d'Epidémiologie Hebdomadaire*, April 24, 2007, numbers 15-16.

<sup>&</sup>lt;sup>22</sup> On the origin of the psychology of crowds and "collective behaviors," see Cefai, 2007.

<sup>&</sup>lt;sup>23</sup> The exercise merits being extended, for example, to the categories at the heart of the strongly condemned DSM IV (American Psychiatric Association, 1994 ; Kirk 1998) and the upcoming DSM V.

# Constructing a sensitive population: the precedent of chemical hypersensitivities

Electrosensitivity can build on the precedent of hypersensitivity to chemicals, which has a very long history of illuminating the complexity of the human body's reactions when faced with a multiplicity of sources of exposure in the environment (Frickel, 2004). The literature speaks of chemical sensitivity when the response of the organism is immunological, and chemical intolerance in other cases (Ashford, 1998). This issue has given rise to institutional plans guaranteeing the monitoring of particular populations sensitive to low doses, that is, below the recommended thresholds and limit values of exposure. Unlike the case of electromagnetic waves, the universe of chemistry has allowed for a questioning of dogmas founded on dose-effect relationships by taking into account atypical responses to diverse substances. Experts now admit the possibility of reactions to very low doses – at the limit of what is measurable – as well as the existence of reactions to a given substance caused by massive exposure to another substance, such as when the chemical sensitivity or intolerance produced by a form of carrier or vector gives rise to causal links between heterogenous sources. (For instance, stress brought about by a traumatic experience of being laid off might itself create a vulnerability making a divorce unbearable!) We see that aspects of complexity stand out in a universe characterized by standards of assessment and calibrated instruments of measurement. In this context, medically unexplained illnesses cannot so easily be reduced to psychogenic factors. Electrosensitivity appears against a very different backdrop than just the simple public display of emotion provoked by the issue of electromagnetic waves. The range of notable situations in which analogous processes are at work is very long because of the case of industrial workers, among whom long term exposure has been the subject of a long process of codification, even if controversies persist (Thébaud-Mony, 2007). It also includes the occupants of "sick buildings" and inhabitants of contaminated sites, or populations exposed to toxins through accidents or natural disasters. The rise of sick building syndrome (Kreiss, 1989) is part of the class of emerging causes that feed into current controversies in the field of expology.<sup>24</sup>

### 5. Recovering intuitions, socializing interpretations

Witness: It's that, clearly, I had identified that, at certain moments, in certain places, I wasn't well, and when I went away, the phenomenon got milder... But the feeling at those moments, now I would say the fact of feeling stunned, or clear-headed, the pain that comes on... Back then, it was basically in the head, that's the most receptive part.

Questioner: First was it mostly muscular, and it became maybe more of a migraine?

Witness: No, but muscular pain, that was really at the beginning. Afterwards it was more diffuse, I felt bad until, I'll say, mid-2007, that's when, clearly, the perception that I had, it was really muscular contractions. But here, it was also in the head as well as arms, feet, different parts of my body. It depended on the context. So I never got to understanding which part would go at which moment. Here I really felt it, I made the connection between a muscle, a pain, and being ill, I would say. But a whole period, it was pain, headaches. . . So there were moments where the headaches, it was more to the right, then to the left, then at the front, bizarrely, a bit like a compass. *I had a pain on one side, and I turned and I found the source, at least a device that could emit rays.* Back then, in June, I thought I had already made the connection, so I talked about it with doctors, and they told me, "Well, not really." I had the impression that the temperature of my head, but this is just a perception, I was hot, I had the impression my head was

<sup>&</sup>lt;sup>24</sup> The notion of expology (analysis of environmental health risks) is defended in particulary by the members of the RSEIN network (Recherche Santé Environnement INtérieur).

boiling [...] Not boiling, but really a higher temperature than normal [...] I mean I had the impression of my head cooking, but, weirdly, when I touched it with my hand, I had the impression of my head being really hot" (Interview with an electrosensitive person, April 15, 2008, Eure-et-Loir, France)

The multiplication and intensification of percepts install a kind of interpretive loop in time, creating a quasi-permanent state of concern, extending beyond the limits of everyday life and making it unbearable. The electrohypersensitive people we met described a sort of "colonization by pain," coupled with worries about their own true capabilities of perception and reasoning. Without plunging into a radical experience of illness, like the one described above, everyone who has a sensation of discomfort engages in interpretive work. The series of acts of overlap and convergence of heterogeneous signs can increase the links with points of recovery of memory and perception. Once we have reached this level of description, which relies on the self-analysis of actors or, at least, on their attempts to explain the processes that affect them, a fundamental question is posed in terms of practical inquiry: which concept or model of intuition must we use in order to treat ordinary experiences and public expressions symmetrically? Under ordinary circumstances, the analysis of sets of actors and arguments tends to override the circumstances of the formation of sensory experiences which people rely on to create their testimonies, to solidify evidence and hone arguments. In this exploratory contribution, we can only underline the forms of vigilance that people assert since there is uncertainty both about causal links and about the likelihood and degree of danger.

The relation between public argumentation and private emotion remains very difficult to articulate. There are contexts in which it is legitimate to subordinate reason to emotion (in all cases of mourning, for example), but, globally, reference to pathos generally serves to discredit forms of expression that put difficult-to-separate experiences of feelings first. Even in a society in which the individual serves as the main point of reference, tropes of irony and scorn are invoked whenever a propensity for egocentrism or an inflated sense of self are detected. We nevertheless see attempts to alter the boundaries of judgment and to change the status of intuition in the world accessible to the senses. It therefore suffices to reverse the dominant strategy, which underlies the calls for vigilance put out regularly by the authorities: if vigilance describes the movement of opening up to possibilities, and not the attention centered on a predetermined goal, it presupposes a capacity for exploration that has not yet found its object. Actually, this process is permanently going on in the continuous production of being in the world (Merleau-Ponty, 1945).

Many critics can score points against a too-charitable account of the cause of electrohypersensitive people. The first point against it, and the most evident, consists in saying that their suffering is actually endogenous. They are victims only of themselves, of their own lack of adaptation to a world that remains foreign because of unfinished socialization, which further increases a resistance to change or fear of the unknown. Physical problems are therefore only the expression of this non-socialisation to the modern world, of being subject to continuous assaults. Another criticism has weight regarding the confusion between manifestation, correlation and causal relation – a criticism frequently invoked in epistemological controversies. The existence of an underlying factor that could explain both the exposure and the health problem always remains possible; closing in on a unique causality is rapidly deconstructed (Beale, 1997, 273-288; pp. 278 and 283 in particular).

In fine, the position of a pragmatic inquiry must endeavor to maintain coherence of the model of the initial actor consisting of giving credit to the people and groups for having a minimum sense of reality. To account for the production of tangible signs, we had to define intuition as a perception that lasts beyond the context in which it appeared, and which has not yet found its space of calculation (Chateauraynaud, 2004). Whatever critical proof is demanded from people who declare themselves to be hypersensitive, we cannot deny them their experience of a degree of perception so fine that it is imperceptible to others. We must therefore take seriously their difficulty in qualifying what they truly feel in adequate formulas and expressions. In order to provide a language to this level of experience, without reducing it to terms proposed by the cognitive sciences, we propose a sociological reformulation of intuition, enriched by the experience of hypersensitive people: *intuition is a vision that, in a microcosm that stays open, informs the senses that a process not yet represented is already at work, and is co-produced by deploying its trajectory in space and time.* In this conception, the person with electrohypersensitivity is a researcher, in the Proustian sense of the term (Deleuze, 1969), that is, a being sensitive to microvariations, tending toward the transformation of signs in a way communicable to others.

### Conclusion

The cause of people with electrohypersensitivity shows how the public trajectory of an issue, in changing configuration, modifies the conditions of access to public discourse of actors struggling with events and experiences that they cannot link together. These experiences cannot be communicated except through interpretive elaborations that have little chance of convincing others outside of their immediate circles of influence.<sup>25</sup> From this point of view, the process of establishing electrohypersensitivity in the political and media arenas meets the specifications of one of the most important tropes of sociological interpretation, that which Max Weber developed around the social conditions that enable the felicity conditions of a prophet or charismatic leader. Under such conditions, in order for the discourse to have a substantial impact, social and economic conditions must be changing, and, simultaneously, existing institutions – religious leaders and functionaries – must not be able to mount a response that makes sense in the experience of everyday life. The difference between these situations – and it is huge – resides in the fact that the charismatic leader has given way to networks of advocates and witnesses, and that the technologies of publicizing the causes have radically changed, now assuming collaborative and participative arrangements rather than authoritarian and centralized forms.

Despite constant reference to a society of risk, it is always difficult to separate out an alarm, a sign or indication, from the background in which all sorts of sensory experiences are blended, and the comprehension of which requires going beyond the division of subjective and objective (Bessy, 1995). A political work is necessary to produce public support for bringing together different causes to give to the mobilization a public legitimacy. If official insitutions, and associations or health care professionals, from now on collect all sorts of complaints and observations, does the new paradigm of expertise, regularly invoked when talking about the precautionary principle, give a greater place to sensory experiences developed by people in their "milieu"? In a society of risk in which models of regulation are organized around the explicit management of uncertainty, and in which attention to "faint signals" and the collection of all warning messages are a normal part of public office, the actors involved are led more and more to suspend judgment of normality and to develop an "ear to the ground," supposedly substituting understanding for reductionism. When we questioned professionals, clinical researchers or experts in public health, we saw that they know how to deal with "foot in the door" problem: how to cut off interactions with people inclined toward feelings of failure, mixing resentment and a sense of persecution, who look to share their indignation? It is always difficult to find the right approach now that the famous clause of ethical appeal is in effect (Lévinas, 1987, 203-283). Beyond the cause of hypersensitivity, we also find pragmatic conditions of the expression of worry or doubt, of suspected causality or of causation. The impact of a cause, such

<sup>&</sup>lt;sup>25</sup> The case of suicides at work, which have not stopped in recent years, follows the curve traced earlier by stress cases. In doing so, it forms another figure of desingularization of phenomena anchored in intersubjective spheres, which are *a priori* difficult to subject to objectification. The case of suicide is precisely the terrain chosen by Durkheim for his sociological demonstration. But the founder of French sociology wanted to construct a total social fact, detached from individual circumstances, so in the configuration that recently emerged, aside from the multidimensional aspect of the public approach to the suicides (involving psychology, work medicine, sociology, management, laws, etc.), multiple notions and descriptors push the analysis into the details of the clinical situations considered revealing of organizational tensions. See Huez (2007) and Clot (2010).

as the cause of people with electrohypersensitivity, can also contribute to the redefinition of psychopathological diagnosis as an intervention of last resort. The topic of dismissal or discredit supposedly implied by the use of psychological categories is a big concern for actors who seek to protect whistleblowers from ill-treatment in order to give substance to the idea of sanitary democracy.<sup>26</sup>

## Methodological note

This paper is based on a body of work linked to a Socioinformatic Observatory and based on a research convention with a public health agency in France (AFSSET). This research focuses on "The process of warning and mechanisms of expertise in health and environmental issues." The corpus analyzed, made up of more than 4,000 texts, contains newspaper articles, documents from advocacy associations, reports and warnings from institutions, legal and parliamentary texts, as well as standpoints from political actors and citizens. This tool was completed by a series of interviews conducted with actors in the controversy about electromagnetic waves and with people suffering from electrohypersensitivity. The analysis of the arguments was done by using the Prospero software, which allowed us to follow the sets of actors and arguments over time and the way in which a cause or a controversy played out across multiple arenas. It is by a close examination of the events that reconfigure the corpus that the question of EHS came to dominate the analysis.<sup>27</sup> It led us interrogating the forms of articulation between two types of sets of language-games: public arguments and the language of emotion.

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<sup>&</sup>lt;sup>26</sup> See the contributions to the meeting called "Lanceurs d'alerte et système d'expertise : vers une législation exemplaire en 2008 ?" Paris, Sénat, March 27, 2008.

<sup>&</sup>lt;sup>27</sup> For the methodological aspects of using Prospero, see the contributions published in the report on research at http://socioargu.hypotheses.org.

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