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Aspects of Studies on the Functional Impairment Electrohypersensitivity

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Abstract. Persons, claiming to suffer from exposure to electromagnetic fields, have been described in the literature. In Sweden, electrohypersensitivity (EHS) is an officially fully recognized functional impairment (i.e., it is not regarded as a disease). Survey studies show that somewhere between 230,000– 290,000 Swedish men and women – out of a population of 9,000,000 - report a variety of symptoms when being in contact with electromagnetic field (EMF) sources. Swedish electrohypersensitive people have their own handicap organization, The Swedish Association for the Electrohypersensitive, which has its own website in both Swedish and English. This organization is included in the Swedish Disability Federation (Handikappförbundens SamarbetsOrgan; HSO). One aim of our studies has been to investigate possible alterations, in the cellular and neuronal systems of these persons' skin. In summary, it is evident from our preliminary data that various alterations are present in the electrohypersensitive persons' skin that are not indicated in the skin of normal healthy volunteers.

1. Introduction

In Sweden, electrohypersensitivity (EHS) is now an officially fully recognized functional impairment (i.e., it is not regarded as a disease). Survey studies [1] show that somewhere between 230,000– 290,000 Swedish men and women – out of a population of 9,000,000 - report a variety of symptoms when being in contact with manmade sources of electromagnetic fields (EMF) [1].

2. Rights for Electrohypersensitive Individuals in Sweden

Swedish electrohypersensitive people have their own handicap organization, The Swedish Association for the Electrohypersensitive [2], which has its own website, <http://www.feb.se>, in both Swedish and English. This organization is included in the Swedish Disability Federation (Handikappförbundens SamarbetsOrgan; HSO). HSO is the united voice of the Swedish disability associations towards the government, the parliament, and national authorities, and is a cooperative body that today consists of 43 national disability organisations (with The Swedish Association for the Electrohypersensitive being 1 of these 43 organisations) comprised of about 500,000 individual members. It has its own website in Swedish, parts of which are also in English [3].

Swedish municipalities, of course, have to follow the UN 22 “Standard Rules on the equalisation of opportunities for people with disabilities” (“Standardregler för att tillförsäkra människor med funktionsnedsättning delaktighet och jämlikhet” [4]. Since 2007 they have been upgraded into the UN “Convention on Human Rights for Persons with Functional Impairments”) [4]. As a result of this, all people with disabilities shall, thus, be given the assistance and service they have the right to according to the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (“LSS-lagen”) and the Swedish Social Services Act (“Socialtjänstlagen”).

People with disabilities, thus, now have many different rights and can get different kinds of support. The purpose of those rights and the support is to give every person the chance to live like everyone else. It is intended that as a result of this everyone who lives in the Swedish municipalities shall be able to lead a normal life and the municipalities must have correct knowledge and be able to reach the people who need support and service. People with disabilities shall be able to get extra support so that they can live, work, study, or do things they enjoy in their free time. The municipalities are responsible for making sure that everyone gets enough support. Everyone is required to show respect and remember that such men and women may need individual and different kinds of support.

3. The Environment, Impairments and the Individual

In Sweden, impairments are viewed from the point of the environment. No human being is in itself impaired, there are instead shortcomings in the environment that cause the impairment (as with the lack of ramps for the person in a wheelchair or rooms requiring electrosanitisation for the person with EHS). This environment-related impairment view, furthermore, means that even though one does not have a complete scientifically based complete explanation for the impairment EHS, and in contrast to what many individuals involved in EMF discourse at present, the person with EHS shall always be met in a respectful way and with all necessary support with the goal to eliminate the impairment. This implies that the person with EHS shall have the opportunity to live and work in an electrosanitised environment.

This view can fully be motivated in relation to the present national and international handicap laws and regulations, including the UN 22 Standard Rules/UN Convention and the Swedish action plan for persons with impairments [5]. Also, the Human Rights Act in the EU fully applies.

4. Implications of Electrohypersensitivity

Many people who are electrically hypersensitive in Sweden, as well as elsewhere, have a living hell today. They may be dismissed from their jobs, refused housing adaptation, denied sick leave, compelled to move, etc. While this is happening, a lot of people are talking about the necessity of taking EHS seriously. This talk, however, is not generally leading to anything since it is action that is required. In the first place, working and housing environments must be created where people who are electrohypersensitive can live and work.

The design of our physical, intellectual and social environment is not something laid down in the constitution or divinely ordained. It is not a law of nature that everyone has to have mobile telephones, to use high-frequency lighting apparatus and wireless Internet. However, if someone might say, we have “diversity” in Sweden – surely that applies to everyone? We may all listen to our favourite music, dress according to taste, and vote for the party of our choice. But, unfortunately, when it comes to disabilities, adaptation and assimilation generally still take priority over the minority’s right to access – despite the electrically hypersensitive, and others with disabilities, having other requirements that need addressed.

This interdisciplinary issue with regard to those with disabilities applies internationally right across the scientific divide, the healthcare sector and social services, and into user-focused lifestyle and design initiatives. There is a need to educate and design for all to ensure that consumer products, the built environment and all its components (as designed and specified by architects, engineers and others) to positively allow for the inclusion of those with disabilities. As part of this it is also suggested that current building standards, regulations and guidance documents should be developed to incorporate guidelines on how to create suitable environments for those with EHS, as are now generally given for a number of other disabilities.

It is necessary to encourage the necessity and benefits of good EHS research to policymakers and the developers of new technologies to address the major concerns that presently exist. It is also necessary to adequately fund more multidisciplinary work in this field to allow for the research and development of more 'user-friendly' environments, particularly as related to biological effects.

5. Cellular and Neuronal Studies of Electrohypersensitivity

We have investigated the presence of intraepidermal nerve fibers in normal human skin from healthy volunteers using the new marker PGP 9.5 [6-8]. The intraepidermal nerve fibers are found as close as 20–40 μm from the surface, which makes it highly possible that weak electromagnetic fields may affect them.

In facial skin samples of electrohypersensitive persons, the most common finding is a profound increase of mast cells. Nowadays we do not only use histamine, but also other mast cell markers such as chymase and tryptase, but the pattern is still the same as reported previously for other electrohypersensitive persons [9]. From these studies, it is clear that the number of mast cells in the upper dermis is increased in the EHS group. A different pattern of mast cell distribution also occurred in the EHS group, namely, the normally empty zone between the dermo-epidermal junction and mid-to-upper dermis disappeared in the EHS group and, instead, this zone had a high density of mast cell infiltration. These cells also seemed to have a tendency to migrate towards the epidermis (=epidermotrophism) and many of them emptied their granular content (=degranulation) in the dermal papillary layer. Furthermore, more degranulated mast cells could be seen in the dermal reticular layer in the EHS group, especially in those cases which had the mast cell epidermotrophism phenomenon described above. Finally, in the EHS group, the cytoplasmic granules were more densely distributed and more strongly stained than in the control group, and, generally, the size of the infiltrating mast cells was found to be larger in the EHS group as well. It should be noted that increases of similar nature later on were demonstrated in an experimental situation employing normal healthy volunteers in front of cathode ray tube (CRT) monitors, including ordinary household television sets [10].

In one of the early papers [11], we made a sensational finding when we exposed two electrically sensitive individuals to a TV monitor situated at a distance of 40-50 cm away from them. When we looked at their skin under a microscope, we found something that surprised us. In this article, we used an open-field provocation, in front of an ordinary TV set, of persons regarding themselves as suffering from skin problems due to work at video display terminals. Employing immunohistochemistry, in combination with a wide range of antisera directed towards cellular and neurochemical markers, we were able to show a high-to-very high number of somatostatin-immunoreactive dendritic cells as well as histamine-positive mast cells in skin biopsies from the anterior neck taken before the start of the provocation. At the end of the provocation the number of mast cells was unchanged, however, the somatostatin-positive cells had seemingly disappeared. The reason for this latter finding is discussed in terms of loss of immunoreactivity, increase of breakdown, etc. The high number of mast cells present may explain the clinical symptoms of itch, pain, edema, and erythema.

We have compared facial skin from electrohypersensitive individuals with corresponding

material from normal healthy volunteers [12]. The aim of the study was to evaluate possible markers to be used for future double-blind or blind provocation investigations. Differences were found for the biological markers calcitonin gene-related peptide (CGRP), somatostatin (SOM), vasoactive intestinal polypeptide (VIP), peptide histidine isoleucine amide (PHI), neuropeptide tyrosine (NPY), protein S-100 (S-100), neuron-specific enolase (NSE), protein gene product (PGP) 9.5, and phenylethanolamine N-methyltransferase (PNMT). The overall impression in the blind-coded material was such that it turned out easy to blindly separate the two groups from each other. However, no single marker was 100% able to pin-point the difference, although some were quite powerful in doing so (CGRP, SOM, S-100). In our ongoing investigations, we have also found alterations of the Merkel cell number in the facial skin of electrohypersensitive persons [13]. However, it has to be pointed out that we cannot, based upon those results, draw any definitive conclusions about the cause of the changes observed. Blind or double-blind provocations in a controlled environment [10] are necessary to elucidate the underlying causes for the changes reported in this particular investigation.

6. Discussion

As previously mentioned Sweden has officially recognised EHS as a disability. However, a lot of work still has to be carried out by the electrically hypersensitive, as well as for them, and their disability organisation, the Swedish Association for the Electrohypersensitive (FEB) to achieve complete equality. Accessibility and adaptation are key issues for allowing EHS, and others with recognized functional impairments, to gain/regain their rightful independence. Such support can also benefit society in general.

Society must recognise in practical applications the right of the electrically hypersensitive to be different, to their distinguishing feature. Society must recognise the right of the electrically hypersensitive to have an equal life in a society based on equality. Treating members of the community equally is not something that should be done as a favour; nor is it something that any parliament or government should politely request other inhabitants to provide others with. Equality is not something to be done “out of the goodness of one’s heart”. It is something one does because it is expected of every citizen, because inaccessibility and discrimination are prohibited by law.

Some doctors and dentists have described at an early stage the electrically hypersensitive as “old crones in the throes of the menopause”, “the poorly educated”, “hypochondriacs”, “radiation ladies”, etc. These prejudiced care-providers used these terms despite often never having met an electrically hypersensitive person or carrying out research in the field.

At times, the view taken of the electrically hypersensitive resembled a medical pogrom with frightening overtones. Even more frightening is that the situation today, well over two decades later, is allowed to be much the same – and not only in Sweden. The entire public debate has been characterised by various degrees of acceptance and dismissal, grand words, commitments and far-reaching promises, which have often been shown to lack the necessary effect. This nonchalance and lack of commitment has per se been particularly insulting to those that are afflicted, particularly when there are often simple measures, such as not using wifi in buildings, which can be readily undertaken that could often greatly help ease the situation [14]. Is all this inaction something that we should be proud about? How much simpler, cheaper and more creditable it would have been to have provided the electrically hypersensitive immediately with the assistance and solidarity that we like to boast about and seek to create more biologically friendly environments? An immediate decision on a housing adaptation grant, disability allowance, etc., would have been self-evident as would increased dialogue with those creating electronic devices. Now we have instead endured almost three decades of hostilities and denial with big losers, namely the electrically hypersensitive and their next-of-kin.

There is much that could be done: educating architects, planners, scientists, technologists and the general public more effectively about EHS, its causes and how it can be minimized; undertaking properly funded independent multidisciplinary research into EHS and showing that such work can

make a difference. Creating work, home and general environments that are more user-friendly for EHS sufferers so that they feel included and not excluded in the rich tapestry of life.

6.1 The Need to Empower the Individual

It is proposed that, as with those with other recognized disabilities, the electrically hypersensitive must therefore, in every situation and by all available means, demand respect, representation and power. They shall very clearly reject all approaches which reflect a mentality of “feeling pity for them” or “caring for them”. Inaccessibility is not a personal problem. It is a problem for society. Inaccessibility is not about attitudes. It is about discrimination. And discriminatory actions and conduct shall not be dealt with by well-meaning talk about treatment. Discrimination is already illegal!

6.2 Disability Plan Policies

The former Swedish Prime Minister Göran Persson has declared that 2010 should be the final target year for the “National Disability Plan Policy” – “From patient to citizen” – adopted in 2000, according to which the whole of Sweden is to be completely adapted to those with disabilities [5]. In addition, there is the EU “Human Rights Act” and the UN “Standard Rules on Equalization of Opportunities for People with Disabilities”, nowadays updated to the UN “Convention on Human Rights for Persons with Functional Impairments” [4].

One of the most important ideas in these documents is the “principle of accessibility” stating that people with disabilities are to have full access to public services. This is the basis for the fast introduction in Sweden and other countries of kneeling buses, wheelchair ramps, hearing loops, automatic door-openers, beveled pavement edges, etc. However, it has to be asked where are the measures for the electrically hypersensitive?

How are they to be able to be a normal part of the community with complete access to council offices, post offices, means of transport, cinemas, restaurants, hospital care and other facilities when electromagnetic pollution can affect them detrimentally? Providing every electrically hypersensitive person with individually designed assistance, good care and stimulation to create participation in the community are very responsible tasks that require a high level of skill.

Considerably greater demands must be made on education, training and work supervision than has been the case to date. Sharing experiences between different activities must take place much more smoothly and in a way that is completely free of prestige.

6.3 Future Research

The task of medical research must be to increase knowledge about different disabilities, as is in fact clearly defined in the Karolinska Institute’s policy declaration, among other places. The over 200,000 people with the disability EHS in Sweden, as well as all the millions around the world, can only be provided with the right tools by our acquiring knowledge about their disability and immediately putting this knowledge to use to adapt accessibility and develop safer technology. Examples of the organisations that have responded to this challenge are TCO Development (Swedish Confederation for Professional Employees), Sif (Swedish Union of Clerical and Technical Employees in Industry) and FEB. But are all those who can make the necessary changes prepared to commit to such measures?

I have said it many times: It is a true must that fully financed and truly independent research projects should be initiated immediately to ascertain the effects of EMF on public health particularly on vulnerable sectors of the population, and help allay concerns over potential perceived biases in findings. Ideally, the participating scientists *would be* completely devoid of commercial interests of any sort to further reinforce the integrity of their findings and their neutrality. Of course, the determination of such matters are the responsibility of each elected government in each country, and is of special importance for people with the functional impairment electrohypersensitivity (EHS).

We must, here and now, decide how we shall build human bridges of knowledge, for persons with EHS, and others with recognized functional impairments, as well as for all future groups asking and begging for our professional assistance. Should science be perceived of in the form of problem-solving research, or rather a playground for careerists and big industry? Is it the general view of this conference held at the Institute of Physics, as well as the one, "EMF and Health – A Global Issue --- Exploring appropriate precautionary approaches", held just before, September 8-9, 2008, at the Royal Society, London, U.K., that we only shall build half- or three-quarter-ready bridges of knowledge...? Or shall we rather build complete bridges...? It is a truly international issue that we should embrace together.

As President Obama noted when President-elect, "The truth is that promoting science isn't just about promoting resources – it is about protecting free and open inquiry. It's about ensuring that facts and evidence are never twisted or obscured by politics or ideology. It's about listening to what our scientists have to say, even when it's inconvenient – especially when it is inconvenient. Because the highest purpose is the search for knowledge, truth and a greater understanding of the world around us." [15]

7. Conclusion

People with the disability EHS have an exciting future ahead of them. Work has already started to produce results on a number of these issues, including building planning and construction [14]. However, a lot more can and must be done. There are still many years of hard, constructive and consistent work waiting. I hope that everyone with the functional impairment EHS all over the world can find a common platform for this work, and help move the work forward through community and solidarity in the interdisciplinary work that is required.

It is now so important for everyone to decide on the continued direction of their activities as well as their focus and for people to work together with integrity as a team. A continued energetic action plan for the next few months and years together with a broad collaboration with other disability associations are of the utmost importance here. As clearly stated by the UN [4], there must be an end to nonchalance, lack of consideration, indifference and lack of respect on the part of society for those with disabilities for all our sakes. As moral human beings we should never accept negative discriminatory treatment or an insulting special treatment of those with impairments.

Furthermore, another very important issue is the one about how persons with the functional impairment EHS should be met and respected... and how they want themselves to be met and respected? Are they to be viewed as psychiatric patients? As somatic patients? Or as persons with a functional impairment? In Sweden, the latter is true, but will people with a fully accepted impairment in Sweden find it written off as psychological should they travel to the UK, or elsewhere in the world? This would not only be contrary to their human rights, but also a major scandal!

In particular, as levels of individuals with EHS is predicted to increase [16], it appears that this is a problem that must be openly addressed in far greater detail by governments and parliaments, working in conjunction with scientists and those involved in industry and related fields, so that solutions can be found and complete accessibility achieved.

Mother Teresa's Nobel Lecture contained a simple message: "the poor must know that we love them". I now say about persons with the functional impairment EHS: "they must know that we respect them, and that we respect and follow the regulations, laws and conventions already decided upon". If it is difficult for you to take a stand on this, just put yourself into the situation of waking up one morning, realizing that you, a family member, a relative, a friend or a colleague has become electrohypersensitive – how would you like to be met? And how do you want to see them? Would you want us to seek the answers to it?

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[For additional reading and references to the relevant scientific literature, please contact the author by e-mail at olle.johansson@ki.se].