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Ana FRUNZĂ , Antonio SANDU

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# Transparency and the Duty of Full Disclosure in Public and Environmental Health

Ana FRUNZĂ<sup>1</sup>, Antonio SANDU<sup>2</sup>

**Abstract:** For this paper, we will consider the necessity of full disclosure and the duty to inform the public of the results of public health related and environmental health studies. The focus of the paper is that the results of the research, which is related to public and environmental health can lead to risks for public health that can endanger human health, so no matter how small the statistical representativeness is, full transparency must be achieved. We chose to review and make an analysis on the public health issues related to the duty to inform the public of research results in a study of dry cleaning workers; the 10b.case as exposed by Steven S. Coughlin in his book “Case Studies in Public Health Ethics”, 2009. In supporting the theme of this paper, the necessity for full transparency of data, which could be of public health and environmental health interest – we will bring a series of pros and cons to full disclosure, followed by a construction of counter arguments and will offer possible solutions to the issue of full disclosure towards the public in the case of data or results of public health related research.

**Keywords:** transparency; duty of full disclosure; public health; environmental health.

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## Introduction

The case study refers to the possibility of dry cleaning workers being exposed to health hazards by direct exposure of the workers to Perchloroethylene in the dry cleaning process. A regional health authority commissioned a team of environmental and occupational epidemiologists in order to investigate this. The epidemiologists found evidence of early neurological changes in colour vision among a small sample of the workers. A number of the workers, who were exposed to low levels of

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<sup>1</sup> PhD - Scientific Researcher III, LUMEN Research Center in Social and Humanistic Sciences, Iasi, Romania, ana.caras.15@gmail.com, 0040740709555.

<sup>2</sup> PhD – Professor “Stefan cel Mare” University of Suceava, Romania; Senior Researcher LUMEN Research Center in Social and Humanistic Sciences Iasi, Romania; Executive Director - Romanian Unit UNESCO Chair in Bioethics, antonio1907@yahoo.com.

Perchloroethylene, experienced a temporary loss of colour vision, but their vision always returned to normal within 15 minutes of leaving their work areas. There was no evidence that the effect was permanent. Even if the research team considered the effects as not harmful for the state of health and security of the participants, eight weeks later some of the workers “were hospitalized complaining of complete loss of colour vision, blurred vision and headaches”.

The research team claimed that the temporary loss of colour vision was caused by occasional exposure to relatively high doses of perchloroethylene mist, which could be avoided by paying closer attention to the existing safety procedures. The research team submitted its results to the companies involved, but not to the individual workers. The epidemiologists believed that there was no need to alarm the workers because the employers were doing all they could to ensure that high dose exposures did not reoccur. Because the sample size was not large enough for them to draw conclusions with great certainty or precision, the researchers believed that it would be irresponsible for them to disseminate preliminary results widely and risk damaging the companies involved.

Considering Robert Elliot’s distinction of the ethics, this particular case study can be approached from a public health perspective and from an environmental ethics perspective (Elliot, 1997:284-93). Environmental ethics extends morality to all, not only to sentient creatures (Singer, 1997). The contamination with Perchloroethylene affects both the health status of humans – causing temporary or permanent loss of colour vision – and the status of the environment, as it contains a known oil contaminant, which is difficult to be removed due to its mobility in groundwater, its toxicity at low levels and its density (Ryoo et al, 2001).

In supporting the theme of this paper, the necessity for full transparency of data, which could be of public health and environmental health interest – I will bring a series of pros and cons to full disclosure, followed by a construction of counter arguments and will offer possible solutions to the issue of full disclosure towards the public in the case of data or results of public health related research.

### **1. Where Does the Transparency of Obligation Lie?**

We can identify at least two authorities, which are responsible for transparency: 1) The public health authority, which commissioned the study

and (2) the responsible persons designated by the research team who conducted the study.

Regarding the public health authority, it has the obligation of transparency in virtue of the public's interest, which represents its own constitutive value (why it was funded). As officially responsible, the institution must designate an institutional communicator who would transpose all the information of public interest into understandable adverts for the general public.

Regarding the research team, it has the obligation to report the results of the financier (authority of regional public health), publishing of partial data is not an obligation of the ethics of research to be considered a moral obligation towards the public.

From the perspective of public health and environmental ethics, we are interested in the institutional ethical obligation of the public health authority, an obligation that cannot be removed by the fact that the research team considers the data to be sufficient or unrepresentative.

We consider that the only obligation, which the research team may undergo, from the perspective of the ethics of research, is not to change the data, but to report it correctly and completely to the authority, which commissioned the research. This approach will not be covered in this article.

In the following paragraphs, we will refer to the institutional obligation of transparency.

## **2. Pros to the Full Disclosure of Data/Public Health Research Results**

- *Creating public trust in the public health authorities.*

Constructing a trust-based relationship, between the public health authorities and society is one of the primary conditions for the functioning of the public health system. Transparency is essential for maintaining public trust. It allows the general public to understand the information gathering process, as well as the risk-assessment and decision-making processes (ECDPC).

Communication of the public health system with the public is addressed in terms of the necessity of transferring the traditional public health values to those who can develop the system (Susser & Susser, 1996). The improving of public health as a primary value would be, in the authors' opinion, the primary one. The relationship between epidemiologists and

society would be a reciprocity-based one, while “society confers on them an autonomous and privileged function based on their specialized training”, this “autonomy carries with it reciprocal obligations of service to individuals and to society” (Regidor et al. 2007).

A fair communication of public health information towards the public could be a matter of improving the system and to strengthen the relationship between the public health representatives and society.

- *Similar research in other areas with similar potential risks can be initiated, and the effects of the same substances, or other similar substances, on public health and the environment can be identified;*

After analyzing the results obtained in the initial research on the possibility of endangerment to public health - repeated exposure to toxic substances in the workplace of the individuals and the environmental health, the epidemiologists can take notice or be contracted by other regional or national public health authorities to repeat the research. If similar results or substances whose toxicity is too high to allow people to work in such a toxic environment are identified in the future, measures can be taken to improve the already known effects on public health and the environment. These measures will aim to inform the general public and the industry representatives in the field, and involve action to stop any exposure to environmental pollutants and of future use of toxic substances, which may be identified.

- *Fully informed stakeholders could become policy makers who can make decisions, which can determine future public policies.*

In this case, employers and owners of dry cleaning businesses may decide to change the chemicals used in cleaning. Moreover, in case of a lack of a quick response from the employers and owners or representatives of such services, other stakeholders, such as community members, environmental organizations, consumer organizations, or trade unions can put public pressure on those who decide what substances to use in dry cleaning businesses (owners, shareholders, etc.)

A global assessment of the burden of disease from environmental risks published by the World Health Organization exposes how significant the impact of the environment on health is, publishing on their official website that, at the global level, “an estimated 24% of the burden of disease and 23% of all deaths can be attributed to environmental factors”. In order

for these percentages to be reduced, public and environmental health policies should be supported. One important action is the assessment and management of risks to public and environmental health. Evidence-based norms and guidance on major environmental and social hazards to health are also formulated (Prüss-Ustün et al, 2016).

The individuals that the regional health authority ought to inform could represent at least one of these categories: workers in such polluted environments, clients of such services, dry cleaning business owners, public health policy makers and public health agencies. All of them are, in fact, stakeholders who could contribute directly or indirectly to the possible degradation of a healthy environment and to the development of health hazards. A correct disclosure of information on the effects to health of repeated exposure to toxic chemicals, such as perchloroethylene, could be a step forward for increasing the responsibility of the public, for both public health, as well as for environmental health. The co-action of the society members, policy makers, representatives of the cleaning industry, public and environmental health authorities, could strengthen and sustain improvements to human well-being and quality of life via multiple social and economic co-benefits.

- *Legislative regulation of the acceptable toxicity level of substances in human activities, not only in human consumption*

Following the disclosure of research findings on the effects of exposure to chemical cleaning products, which have a level of toxicity that endangers the health of individuals, action for better legislation on the acceptable toxicity level of certain substances in human activities, not just in human consumption, will be formulated.

In this area, there are already initiatives, which have been internationally agreed by the WHO. This legislative resizing can be corroborated with similar surveys conducted in different regions, and proposals for legislative change may be made gradually, starting at the regional level and developing to the national, international and global levels.

Researchers approached a cross-sectorial policy framework in 2013, for primary cancer prevention, through environmental and occupational interventions, based on a prior policies analysis in the field (Espina et al, 2013). Based on a more extensive identification of the hazard of exposure to toxic substances in such services, similar interventions can be developed to reduce the risks to public and environmental health.

At the European level, efforts to reduce the use of toxic substances in human activities have been made in England since 2000, in response to discoveries made on the effect on the body's endocrinal system of using alkylphenol ethoxylate chains (APEs) as detergents . However, there are no legal regulations about reducing or eliminating the usage of this product from the cleaning products industry.

Cases such as this can become precursory to the development of legislation to support public health and environmental protection, and their disregard contributes to public ignorance towards the long-term effects of environmental pollution and a public health ethics violation.

- *Informed choice for the public – the workers or potential future workers in dry cleaning businesses*

Occupational health risks are mostly directly related to physical, chemical and biological factors in the environment and related behaviour, and are included in the definition of the environment. In the case discussed, the health risks are associated with the direct long exposure of the dry cleaning workers to the toxic chemical substances used in the daily cleaning procedures.

In this particular case study, but also at the general level, the workers from the dry cleaning industry should be informed about any endangering factors from their work place, whether this information comes from the results of the research or not, in respect of their autonomy. The information should be addressed especially to the workers who were not subjects of the research, because they were not informed at all of the potential side effects of major exposure to the possible toxic substances, so they might continue to be exposed to the toxic substances thus causing a health risk.

Employees in industries with potential risks, - in this particular case, the dry cleaning industry, which uses perchloroethylene - can then make an informed choice on whether to continue working there or to leave that work place. Unions could then possibly negotiate more favourable working conditions, customized health insurance or risk premiums. Then, the decision to stay or to engage in such a job becomes an autonomous one.

What are the conditions that can permit a research team, or a company which commissions the research team, to develop environmental or public health research to keep the results away from public access? As long the research is addressed to the interests of the public, the data should be made available to the public in a manner that the general public can

understand and, therefore, behave pro-actively. The situation of workers in the dry cleaning industry is even more problematic ethically, when more information on the health risks is known both by those responsible for the research and the company who requested the study, but when it is not made available to either the workers in order to warn them of the risks of future exposure, or to the dry cleaning business owners. Both the workers and the owners have the right to know the risks they face.

- *Fair compensation for those already harmed by exposure to toxic substances*

Compensating those already harmed by the exposure to toxic substances can be made based on an analysis of the injury caused, after determining that it has endangered health (such as, permanent loss of colour vision), and was caused by exposure to chemical substances (such as, perchloroethylene). Once it is clearly determined that the loss of colour vision was caused by exposure to Perchloroethylene, then specialized services must be offered to those affected, in order to improve their health condition. A compensation system should have been considered and applied to cover the treatment expenses and the financial damage caused by the employees' absence from work. Furthermore, the people who have not been identified as victims of the exposure to a pollutant environment, but who are potential future victims, should be compensated for the risks to which they can be exposed and cannot be excluded from, or those that are very difficult to avoid.

Albert Lin proposed a risk-based administrative system of liability and compensation for exposure to environmental pollutants. The system he developed implied that the individuals whose health was endangered by exposure to the pollutants received compensation from the pollutant emitters who had to pay levies for their actions. The affected individuals would be compensated according to the health risk borne by each person as a result of their exposure to the pollution (Lin, 2004). Lin's proposal could be acceptable for conditions involving a mutual agreement between the parties implicated, on the risks that the victim was exposed to. This understanding will have to be based on the informed consent of the potential victim. This approach can be acceptable from the perspective of utilitarian ethics, while it can be criticized from the perspective of a Kantian ethics, since the victim rather becomes a means and not a purpose.



### 3. Cons to the Full Disclosure of the Data And Public Health Research Results

- *Full disclosure will create public panic*

Panic can be considered to be a perverse effect of transparency of data and research results with the potential to impact public health. Public panic can lead to a negative chain of reactions to all similar services, regardless of the active substance used. This could lead to the bankruptcy of firms in the industry, job losses, damage to the public image of companies, including those who are not guilty. It can also affect the level of public trust. The lack of people's trust may extend to all public institutions in the area.

- *Public reluctance in accepting public information from the public health authorities*

This attitude can be generated from a general public distrust towards the honest activity of the authorities. In this case, the research whose results are made available to the public can be considered unrepresentative and are, therefore, treated as such and disregarded. The public understanding of the situation can be influenced by the fact that further serious side effects can appear and research participants suffer complete loss of their colour vision, or have blurred vision and headaches. If there is poor communication, the trust of the public towards the health authority would be at least diminished.

- The abundance of information of public interest on environmental and public health risks can lead to the creation of resilience towards such information and inappropriate reactions, or by lack of reactions in similar situations.

Because the public are subject to continuous media reports, which expose health and environmental risks, they may develop a strategy of coping that aims to reject any information, regardless of whether it contains prevention measures.

- Partial disclosure may be advantageous, in detriment of the integral one, because it does not generate public panic, or it diminishes it. The public might be insufficiently educated to understand the information provided.
- Sampling representativeness is limited.

Partial information studies may be irrelevant scientifically and are, therefore, inconclusive. Because the sample size was not large enough for

them to draw conclusions with great certainty or precision, the researchers believed that it would be irresponsible for them to disseminate the preliminary results widely and risk damaging the companies involved.

- The distortion of the message by the media, by the exaggeration of the public hazard, without presenting the real dimensions of the risk and their mitigation measures.

#### 4. Rejecting Counterarguments

The argument against full disclosure, because it might create public panic, can be rejected by considering how to bring the information in the most appropriate manner to the interested public.

The idea of creating public panic can be associated with the epidemiologists' position in the case study, who believed that "there was no need to alarm the workers because the employers were doing all they could to ensure that high dose exposures did not recur. Because the sample size was not large enough for them to draw conclusions with great certainty or precision, the researchers believed that it would be irresponsible for them to disseminate preliminary results widely and risk damaging the companies involved."

I consider that the health authority spokesperson or the person responsible for the public communication of such public health research should consider the appropriate manner of spreading the information to the public, so as not to install panic among the public. Full disclosure of the information should be made, so the people interested by this particular issue are able to discern on the existence of the potential risks and the possibility of the appearance of negative effects. It was brought into discussion a change of orientation in the American public health communications, on focusing on improving the health of communities and populations and on deconstructing the underlying mechanisms of communication. He saw public health communication as inherently interventionist, seeking to promote and protect health through change at all levels of influence (Bernhardt, 2004). Communicating a possible health hazard caused by exposure to chemical substances that are capable of endangering life or causing harm to individuals who have repeated exposure to them must be subject of well-conceived and carefully implemented public health communication strategies. This type of informational strategy – sustained over time – will have "the capacity to elicit change among

individuals and populations by raising awareness, increasing knowledge, shaping attitudes and changing behaviours” (Hornik, 2002).

In addition, prior to the public announcement of such information, the public health authority representatives will inform representatives of the dry cleaning businesses, in order to identify solutions to stop, or at least, reduce pollution. Public information could be corroborated with the presentation of the solutions made by the dry cleaning representatives. In this way, by giving them a correct assessment of the facts, the public will have the necessary information to judge both the public health authorities involved and the dry cleaning companies as being of good faith, orientated for the common good.

The presentation of measures that have been taken, or will be taken, for preventing future possible pollution will be conducted using honest and widely available media. Indeed, the lack of trust by the public in the public authorities can determine the public delayed reaction to the call to responsibility through public information, especially when announcements on potential crisis situations are exposed to the public, which is already reluctant. In fact, the transparent communication of any data, which have a preventative role in the case of possible crisis situations in public health and environmental issues, is the responsibility in action of the authorities in relation to the public.

The reluctance of the public to be informed of the actions of the authorities can be reduced by campaigns to increase the credibility of the public health authorities, campaigns which can be corroborated with exposure of the public risk situation identified, together with intervention plans, possible solutions at the exit from the crisis situation and an awareness about the effects of ignorance of possible determinants of health hazards. No public announcement should have any misinformed character, and the establishment of effective communication strategies should be a priority in the public authorities’ health agenda.

Regarding the possible negative effects of too much information being addressed to the public, I believe that the communicator should be aware of the target audience of its announcement. The information will be addressed to those who will need to be informed – the potential population who are most affected by the information or by further decisions being taken. In these regards, the information should not be lacking in transparency. Public information that may prevent future crisis situations must be communicated whenever necessary. In fact, the information should

be addressed to those stakeholders whose view is relevant to be included in subsequent action, in the decision-making process of creating policies for public health and the environment. Such stakeholders are among the workers in industries based on working with toxic substances, owners of dry cleaning businesses, shareholders in the business field, and environmental protection organizations. These people could be those who are most affected by the decisions being taken, as well as their proxies, including leaders of representative organizations and the news media (O'Malley et al. 2009).

When we consider the relationship between transparency and trust, a precautionary approach would support disclosure, rather than withholding information. The idea of informed prudence underlies the two formulations of the precautionary principle (Jordan, & O'Riordan, 2004). First, this principle is an expression of a need by decision-makers to anticipate harm before it occurs. In this regard, the responsibility of an activity-proponent is manifested to establish that the proposed activity will not (or is very unlikely to) result in significant harm (Jordan & O'Riordan, 2004). In the mentioned case study, we analysed the public health authorities who should manifest their responsibility of informing each potential party who could be harmed in future and those who had already been harmed about the risks that emerge for the long term use of toxic substances in dry cleaning businesses.

Based on the second formulation of the precautionary principle, the public health authorities, together with representatives of the possible pollutant industries and other stakeholders should consider the concept of proportionality of the risk and the cost and feasibility of a proposed action. Indeed, at first sight the partial disclosure could be more advantageous, given the possibility that the public, who will receive the information in all its details, could panic so they may not actually analyse the situation they ought to understand in order to react effectively. But, what information can be made publicly available and what should not? By exposing only partial information, the principle of transparency will no longer be respected, as the information omitted could be of interest for particular individuals and stakeholders, so by not receiving all the data they need to consider, proactive behaviour may not be the result.

Of course, there can be two forms of transparency invoked, at a minimal level, by simply publishing the data as a report on the authority's official website, which is only formally fulfilling the obligation of transparency and the communication of the results to the media (and

further, to the population), along with explanations regarding the risk gravity, but also its limitations. Only this way of action can be fully considered as supporting the transparency of the information of public interest.

Regarding the representativeness of the sample and the preliminary results, it should be considered as a risk cost-benefits analysis to be done before releasing any public announcement (Adams, 1995; Fischhoff, 2015). This analysis must consider the effects of possible risks on the social, economic, public health and environmental health contexts. Also, the scientific relevance may become a secondary aspect in the analysis when the health and environmental hazards may occur. Scientific proof is important and relevant for further development of the field, but as a first measure in the best interest of the potential directly affected population is to inform them of the effects of the toxic substances on human and environmental health, so that the population becomes aware and is prudent about the situation.

The damage to the companies involved because of distortion of the message by the media by exaggeration of the public hazard, without presenting the real dimensions of the risks and their mitigation measures can be counteracted by the cooperation of the health authorities, epidemiologists, cleaning industry representatives, workers in the dry-cleaning industry and the media.

### **5. What Are the Risks of the Result of Non-disclosure?**

In the absence of public pressure to amend procedures for cleaning, companies using the same type of chemicals, who are unaware of the risks, or even know them, will continue exposing employees to a polluted environment, with the risk of jeopardizing public health. As a result, severe work injuries or occupational diseases may occur or be more frequent. Trust in public health authorities may diminish considerably when the information gets to the public by other means than through official communication or is delayed. Therefore, the public health authorities may be involved in a lawsuit for damages by individuals who have suffered illnesses caused by exposure to toxic environments.

### **6. Possible Solutions**

Solutions in such cases can be listed as follows:

- Informing and counselling of industry representatives on measures to reduce risks to public and environmental health shortly before making the information public.
- Reparative actions proposed by industry representatives could, and should, be disseminated simultaneously with information by the public health authority on the public health risks determined by prolonged and repeated exposure to Perchloroethylene.
- For preventing further exposure of workers to toxic environments without being informed of it, the management of dry cleaners and services in the cleaning industry should offer specific and clear information about the toxicity of the active substances used in the cleaning process. The development of information campaigns inside all workplaces in the cleaning industry can be proposed by exposing informative banners.

## Conclusions

Considering the pros and cons of the theme of the paper, we support the initial thesis according to which in case of results of research related to public and environmental health that can lead to risks for public health that endanger human health, no matter how small the statistical representativeness is, full transparency must be achieved.

The main arguments for full disclosure of the data/results of research in public and environmental health studies were:

- *Creating public trust in the public health authorities.*
- *Similar research in other areas with similar potential risks can be initiated and the effects of the same, or similar, substances on public health and the environment can be identified.*
- *Fully informed stakeholders could become policy makers who can make decisions, which can determine future public policies.*
- *Legislative regulation on the acceptable toxicity level of substances in human activities, not only in human consumption.*
- *Informed choices for the public – for the workers or potential future workers in dry cleaners.*
- *Fair compensation of those who have already been harmed by exposure to toxic substances.*

Full disclosure of data/results from studies in the public health field should be considered as paramount in establishing a trustful relationship between the public health authorities and the public. Full disclosure should

be made considering the specifics of the population that the information addresses, the impact on the socio-economic context, the risks to public and environmental health, the appropriate channels of announcing the information, etc. Responsible behaviour of the authorities that are involved in the research, or have access to the data, indicating the potential risks for the health of the public, should target the exposure of information of these risks at the same time as the dimensions of risk exposure, taking all measures to reduce public panic. Through information and full disclosure, the informed public will become part of the decision-making process regarding further action and health policies.

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