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Cluster management and the role of concerned communities and the media

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Abstract. Public health services often have to deal with reported clusters of adverse health events. An important characteristic of disease clusters is that the involved community often is concerned about environmental factors influencing health. To facilitate cluster investigations, a stepwise protocol was developed in the Netherlands, based on international literature. Essential is the two-way approach, consisting of a disease-track and an environment-track. Attention to potential environmental exposures is as important as attention to the reported diseases, not only because environmental pollution often is the reason of public concern and thus relevant for risk communication, but also for deciding about the boundaries of the population at risk. Moreover, environmental information is necessary for judgement of the plausibility of a causal relation and for advising measures to prevent exposure. Within this two-way approach, three stages are distinguished: orientation stage, verification stage and quantification stage. Only if an increased risk as well as an elevated exposure is verified, under certain conditions a case–control study may be useful to study causality between exposure and adverse health events. During all stages of the investigation, good risk communication strategies have to be taken into account. However, even then it might be difficult to prevent conflicts, because of the differing interests between experts and the community involved. One of the most important aspects that determine judgements about risks by threatened people, is controllability; that is why community participation is essential. Therefore it can be concluded that cluster management is a mutual endeavour for experts, public and media, where experts are judged on three characteristics: expertise, credibility and empathy.

Key words: Cluster management, Community concern, Environment, Health, Risk communication, Risk perception

Introduction

Most public health services receive questions about unusual aggregations of comparable cases of a rare disease in a specific area, time period and/or population. Concerned citizens often link these 'clusters' of disease to environmental pollution, for instance to a waste incinerator, an airport, a nuclear accident, etc. Several guidelines are available to aid the investigator to manage these clusters [1, 2].

The present paper deals with cluster management as a mutual endeavour of the health agency and the concerned community. The investigator, the concerned community and the media each have their role to play in cluster management.

In the first two paragraphs Fischhoff's valuable advice is summarized, which is offered by more than 20 years of thinking and research in risk communication and risk perception, respectively. The third paragraph gives advice in dealing with the media. The fourth paragraph mentions the consequences of all this advice for cluster management. The fifth paragraph presents a stepwise protocol for investigating clusters, aimed at continuous mutual understanding, obtaining a satisfying answer and an efficient use of research methods; in the three steps the protocol distinguishes, special attention is paid to the role of investigators, concerned community and media. The last paragraph gives the most important conclusions.

Risk communication advice

In a review of 20 years literature on risk perception and risk communication, Fischhoff [3] distinguished the following developmental stages of risk communication strategies in risk management:

1. All we have to do is get the numbers right
2. All we have to do is tell them the numbers
3. All we have to do is explain what we mean by the numbers
4. All we have to do is show them that they have accepted similar risks in the past
5. All we have to do is show them that it is a good deal for them
6. All we have to do is treat them nice
7. All we have to do is make them partners
8. All of the above.

The historical perspective Fischhoff offers, can also be seen in specific risk problems. It may start with a risk analysis in the privacy of the expert's office (stage 1). At some time the results are shown to a concerned community (stage 2). In almost all instances, the numbers do not speak for themselves, because they are unintelligible to nontechnical people or because they contain basic assumptions and uncertainties. So the numbers must be explained (stage 3). Often, explaining goes beyond giving technical details and background information. It is also a matter of separating aspects of primary and secondary importance and thus of making choices. The calculated risks have to be put in perspective. This can be done by comparing risks, in which an unfamiliar risk is contrasted with a more familiar one (stage 4). At this stage, conflicts may arise. For instance, people may become infuriated if they are told that they should not worry over the risks of living in polluted air because the risk of getting cancer from it is as small as the risk of getting cancer when you smoke 0.14 cigarettes a year. The anger can go both ways, because the researcher explaining risks at a public hearing may also become irritated over a public that gets excited over air pollution with an annual risk of causing cancer of 1 in a million, while during the break they light a cigarette from their daily package with a corresponding risk of getting cancer of 1 in 200. As the conflict evolves, it will turn out that it is not only the risk that matters. The distribution of advantages and disadvantages, compensation for people who suffer losses and available alternatives also come into the picture. A full explanation of all relevant aspects may follow (stage 5). At this point, a profound change in approach may occur. The previous stages were all about the content of a message the researcher delivered to an audience. In the next stage, the researcher may realise that even perfect messages need not be perceived as such. In order to attain this, the public must be treated nice and the message must be targeted to the audience (stage 6). A well-targeted message can also be seen as a sophisticated way to ease the opposition. Being nice is only one aspect of establishing a relationship, involving people in risk management is the last, but crucial step (stage 7).

Fischhoff argues that good risk communication invokes all the above-mentioned stages. But he emphasises that even with all these stages taken into account, good risk communication will not prevent all conflicts. Avoiding conflicts is not a realistic, or even a legitimate, goal for risk communication. Conflicts based on misunderstandings or unacceptable solutions can be avoided. Conflicts based on differing interests and values remain, but these are real issues in a democracy. In the end it could be said that good risk communication leads to fewer, but better conflicts.

Risk perception advice

The stages in the history of risk communication can be well understood if we look at some basic insights obtained in the related field of risk perception. The risk perception literature mentions dozens of demographic, psychological, social and cultural factors which determine judgements about risks. In Table 1 some important factors are mentioned together with the way in which they influence risk perception. These different factors can also very well explain why and how conflicts as described above occur. Experts and people who feel threatened themselves judge a risky situation differently, because they judge the same situation on the basis of different factors.

A striking absentee from the list in Table 1 is an aspect that is most important to the expert: the expected annual mortality or morbidity. It is by now a well-established fact that lay people's risk perception is only slightly determined by this [4, 5]. This is a striking conclusion, because risk policies in several countries and many experts' perceptions are predominantly based on data like expected annual mortality or morbidity.

The explanation for the different perceptions of experts and lay people of environmental threats is very straightforward and seems rather simple. Nevertheless, different perceptions do occur and they lead to misunderstandings and disagreements. Different perceptions can be overcome if experts and responsible authorities take the factors of the table into account. In each specific situation other factors can be dominant. Discovering which factors are most important in a specific situation therefore is not achieved by automatically going through a checklist, but shows more resemblance to the construction of a story.

In many situations, the factor controllability is very important. If the community is involved in decision making from the beginning, risk communication will almost always be successful.

Involved and motivated members of a concerned community can acquire technical skills which equal those of experts. They become experts themselves. Most people, however, do not have the time or the

Table 1. Determining factors of risk perception

Aspect	Makes more afraid	Makes less afraid
(assumed) Controllability	Low	High
Voluntariness	Low	High
Advantages of the activity	Few	Many
Origin	Industry	Nature
Catastrophic potential	High	Low
Trust in responsible authorities	Low	High
Openness of responsible authorities	Little	Much

motivation to become an expert. To get hold of the situation, they judge the messenger more than the message. In doing this, the public poses the following demands to experts and responsible authorities:

1. expertise: being knowledgeable, but also able to deal with uncertainties and premises;
2. credibility: being credible and trustworthy;
3. empathy: being receptive to emotions.

Risk communication, risk perception and the media

It is not an easy job for responsible authorities and experts to take all relevant factors of a risk problem into account and to live up to the three demands posed above. The job is even more difficult if media follow and cover the story meticulously. The majority of the public gets their information about risks from the media. At the same time, the media do not constitute the most credible source for people. Several studies [6, 7] have shown that media rank first as used source, but much lower as credible source. This suggests that the public is not an innocent victim which can be infected by media messages in all wanted directions. People can be critical about what they learn from the media and judge its credibility and reliability by consulting other sources, especially when media messages have implications for their own lives.

It can be questioned whether media can create a risk controversy [4]. Media coverage is determined by health, political and other consequences of a risk issue and not the other way around [8]. Nevertheless, media can make risks real, vivid and look fearsome. Since judgements of risks are influenced by imagination, dramatisation and memorability, media can influence risk debates to a large extent [9].

Wilkins and Patterson [10] note several ways in which media can complicate risk communication. The most important complication is that the sender has no control over the message delivered. The loss of sender control is exacerbated by the lack of feedback. Risk communication advice emphasises the importance of interaction. Communication through the media is often a one-way process, with no opportunity for direct intervention and very little opportunity for reactions. Several authors [4, 5] offer advice to deal with the complications caused by the media. These advices range from simple rules of thumb to keep media messages focused, simple and clear to outlines of proactive media strategies. In all advice the importance of credibility and being receptive to the needs of journalists is emphasised. The manual written by Hance et al. [5] stresses the important point that, although it is important to inform journalists as soon as possible, involved parties, including the affected community, must be informed before a story gets to the media. The only exception is when the affected community is so large that they can only be informed through the media.

Risk communication advice for cluster management

In the foregoing a lot of lessons to be learnt from risk communication and risk perception have been given. What does all this mean for cluster management?

Most advice can be used directly. Probably the most important advice is that cluster management leaves ample room for *community involvement* [11]. Investigation of a cluster often starts with questions from worried citizens or citizen committees. A reported cluster is best seen as a common problem for the involved community and the responsible authorities and experts. Cluster management then becomes a common endeavour as well. The interests of the concerned community and the responsible authorities and experts should coincide as much as possible and in order to achieve this they should work together as much as possible. The box shows a famous example in which interests of the researcher and the affected community did not coincide.

> In the Turkish village of Karain an unexpected large number of people acquired and died of a specific form of mesotheliome. A competent Turkish researcher, Bariş, discovered after a series of inventive investigations that the mineral erionite was responsible for the large number of cases. Erionite is a mineral that resembles asbestos. It is found in abundance in the rocky soil of Karain. People used the material to build their houses, pottery and other household products. They were living in the midst of a mesotheliome causing mineral, breathing it in continuously.
> After Bariş had discovered the link between erionite and mesotheliome, the village was struck with disaster. The people from neighbouring villages no longer bought products from Karain. Also, nobody wanted to marry the young men and women of Karain anymore. In the words of the villagers, Karain was 'cursed'. The curse could not be removed, because the Turkish government said to have no money to solve the problem.
> Bariş of course did not intend to inflict this misfortune on Karain, but the net effect of his skilful investigations was that he became the enemy of the people of Karain.
>
> Based on Neutra 1990

As a corollary of the advice previously given, it is important to find out which factors determine judgements of risks in the specific cluster at hand. These factors can be the ones mentioned in the table, but they can also be other factors or even unsolved controversies and problems which have nothing to do with clusters at all. The US Centers for Disease Control (CDC) published a manual with guidelines for investigating clusters of health events [1] which

also states that cluster investigators should understand the various ways in which individuals respond to stressful situations and react to uncertainties. Investigators also should be able to recognise the source of inevitable community suspicions and demands. They should respond to these without hostility and should be able to diffuse them. Finally, investigators must be aware of and responsive to the fact that a perceived problem must be resolved responsibly and sympathetically, even if no underlying community health problem or cluster of disease truly exist.

In general, there is a need for a fuller recognition of the role of social and cultural context of cluster research, which may require the adoption of combined qualitative and quantitative research approaches [12].

The CDC manual [1] also offers advice to deal with the media in cluster management. A lot of this advice resembles the advice given in Hance et al. [5] and the National Research Council [4]. The CDC manual emphasises that public health agencies must be aware of media 'imperatives'. Investigators must understand the factors that influence the various media in their selection and presentation of stories: e.g. the desire for a pictorial/visual component, the presence of conflict or controversy, the presence of strong emotive content and the availability of target for blame. Similarly, investigators must recognise that the media tend to simplify complex, technical explanations, thereby losing subtle distinctions or qualifications. Thus, investigators should distill the messages they wish to convey and present them in the way they are most likely to be transmitted without confusion or distortion. Investigators must be prepared to stress key points, provide background necessary for understanding and be straightforward regarding what is fact, what is speculation, and what is not known. Most of all, investigators must remain co-operative and responsive and must be prepared to provide needed information rapidly, before distortion and discord have been introduced into the public exchanges.

Stepwise protocol for dealing with clusters

To facilitate cluster research, a model was developed which contains three steps: exploration, qualification and quantification [2]. In each of these three steps, questions have to be answered about the cases ('disease track'), about the suspected exposure ('environment track') and about the plausibility of a causal relation between these two (see Figure 1). After the second step a decision has to be made to stop or continue the investigation.

Attention to possible environmental exposures is as important as attention to the reported diseases, not only because environmental pollution often is the motive for public concern and thus relevant for risk

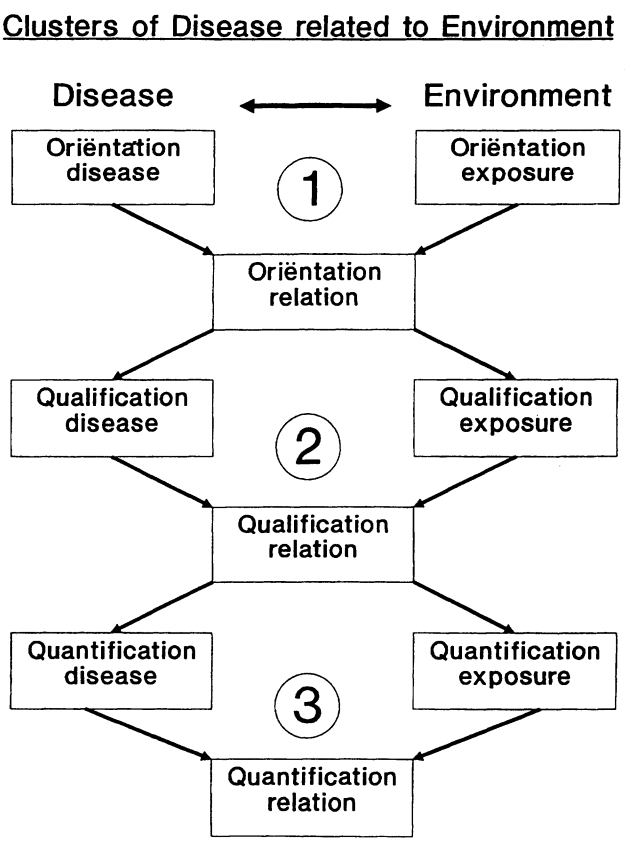

Figure 1. Clusters of disease related to environment.

communication, but also for defining the population at risk. In fact it is inaccurate to define the population at risk only on the basis of the reported cases, a phenomenon that is called 'Texas sharp shooting'. Moreover, environmental information is necessary for advising preventive measures and for judgement of the plausibility of a causal relation.

In the remainder of this paper, the three steps are explicated. The roles of investigator, concerned community and media in each step are discussed.

Exploratory step

The exploratory step only consists of the *preparation* of the visit to the person who has contacted the health agency with his worries. General information is gathered about the expected frequency of occurrence of the disease, the potential risk factors, the local exposure possibilities (by visiting the area) and the biologic plausibility of a relation between exposure and disease (by reviewing literature).

Qualification step

The qualification step consists in the first place of a *visit* to the person who represents the concerned community. Personal communication with the concerned persons in their own environment is essential for many reasons [13].

Firstly, it is important as a sign of genuine interest and shared concern.

Secondly, it enables a first rough assessment of the social context. Is worry widespread, how worried are people and why are people worried (are there other problems besides the cluster)?

In the third place, a visit is important to get an impression of the neighbourhood and its socio-demographic characteristics, especially age and the presence of children. This impression may help to understand why people are worried. An impression of socio-demographic characteristics may also help in the setup of communication at a later stage.

A fourth reason why a visit can be important is to exchange information which is basic to the investigation and management of the cluster. Local residents have basic information on the number of cases and possible routes of exposure to an environmental pollutant. It may be very worthwhile to ask concerned persons to list the number of health events (the number of ill or deceased persons) together with basic data like address, years of residence, gender, age, year of diagnosis or death, sort of disease, occupation, smoking habits, etc. It may be helpful if the health agency supplies forms and answering envelopes, enabling local residents to fill in the answers as easy as possible [11]. The filled-in forms are returned to the investigator at the health agency, who can compile the list.

Lastly, a first personal visit can be used to provide people with some general oral and written information about the disease of concern and its causes. In this information, it can be made clear that most diseases are not the result of one particular factor, but result from an interaction between natural disposition and a complex of environmental factors. This means that it is very difficult to prove a causal relation between a disease and local environmental factors. Misunderstandings of the plausibility of a causal relation between environmental factors and health effects are common. Many people do not sufficiently realise that substantial exposure to a risk factor is essential to become ill. Care, however, must be taken that this information is not considered as a definitive answer. To a limited extent, attention should also be given to problems which have nothing to do with the environment. The least an investigator can do, is to understand such problems.

At the end of the visit, agreements can be made about the next steps in the management of the cluster.

The data collected by or with the assistance of concerned community members can, together with some crude count of the number of houses and people in the neighbourhood of concern, or population data from local authorities, be compared to the national or regional expected frequency of occurrence of the disease. In some situations additional medical information from general practitioners with patients in the neighbourhood of concern may be helpful to consider whether the suspect cases constitute an aetiologic entity. With the available data, a back-of-the-envelope assessment is possible: higher or not higher than expected.

Often, assessments (especially in clusters of adult cancers in an ageing community) will have the conclusion that no excess number of ill or deceased people can be demonstrated. Many persons in the concerned community may not believe this conclusion. The investigator should not expect that one visit, one telephone call, one letter and one meeting with maybe a very clear overview and assessment of the cluster can take away worry that has been present for many years. The investigator can offer to keep in contact with the community representative.

Concerns about exposure to environmental pollutants need independent attention. So in addition *environmental data* have to be collected from local authorities to verify or falsify the suspicions.

In the qualification step, contacts with the media need not take place, except when they are involved already. In the latter case, it is likely that media have been influential, for instance in getting the cluster on the public or political agenda. It is important then to contact the media as soon as possible to make agreements about the information that will be provided to them. At the same time appreciation can be asked for the need to inform the concerned community before the media are informed. Most media will understand this as long as it is made clear to them that no information will be held back.

Quantification step

If the signal is not rejected so far, a more extended investigation is necessary. Examining the 'disease track' and the 'environment track' simultaneously is obligatory for a correct definition of the index and reference population. The availability of disease and environmental data at the desired (geographical) level may influence these definitions and therefore the results.

The frequency of occurrence of the concerned disease in the possibly exposed population has to be compared (age standardised) with adequate reference data to decide whether or not the cluster is verified and needs further attention. Preferably, national registers have to be used for index as well as reference data.

The complexity of quantitative research makes investigators incline to do their research in a sort of solitary confinement. After weeks or even months of collecting data, performing calculations and reviews by colleagues, a well-calculated conclusion is presented to the concerned community. In many cases, this conclusion learns that *no significant increase* in the number of cases can be demonstrated or that an observed increase can be best explained by coincidence. Often, the impatient public is not amused, does

not believe the conclusion and may become outraged. Instead of the original problem of an alleged excessive number of ill people, now the problem of the health agency quickly becomes how to ease the concerned community. Valuable time and money must subsequently be spent on solving this problem.

So, whatever the conclusions and the following investigations are, they should be shared with the community. The CDC manual [1] repeats some of the advice that was given before: simply presenting the numbers will not suffice.

As a reported cluster is not selected at random, the probability that an excess would have come to attention by chance alone cannot be assessed [14]. Therefore the magnitude of increased risk may be more important to decide for further research than the results of advanced statistical significance tests [15].

If there is a biological plausible and temporal logical relation with an environmental agent, further investigation of routes and amount of exposure should be done in addition (step 3: exposure track).

Even if no indication of an excess number of ill or deceased people is obtained, an *environmental risk assessment* is essential to decide if accepted exposure limits are exceeded. Exceedance of reference values for pollutants must be managed, preferably by sanatation of the source of exposure: 'first clean up the mess!' [16]. Such an environmental intervention may be more important for the community than proving a causal relation! Planning and implementing preventive actions can be done without having proved a causal relation, because an inability to give a proof of hazard is not to be taken as a proof of safety. The latter is what the public asks for, but this requires much higher numbers [17, 18].

If an *increased risk* is found that cannot be explained by artefacts (as reporting bias by publicity) *and* if an elevated *exposure* is determined, a causal relation can only be made plausible by conducting a *case–control study* to measure (a proxy of) the individual exposure and possible confounders. However, a causal association can only be made probable if this case–control study meets several conditions [16, 19]:

1. minimal 5 patients with a homogeneous disease;
2. minimal relative risk of about 10;
3. sufficient variation in well-quantifiable personal exposure;
4. minimal publicity to minimalise exposure suspicion bias.

Because of the last condition the study has to be carried out preferably in another population than the concerned one, unless local exposure is too specific. An example of the latter is a case–control study on the association between a cluster of childhood haematopoietic malignancies and local exposures to pesticides in a horticultural community [20].

An extended study will take a long time. At several points choices and assumptions must be made. The least an investigator should do is to *inform the community* about the progress of the study. Still better is to have meetings at regular intervals. At these meetings, community members can be informed on the progress of the study, but they can also participate in deciding about basic assumptions. According to Graber and Aldrich [13] and Neutra [11], local residents have a number of potentially valuable roles to play and working with a community can improve the scientific quality of an epidemiological study. Meetings can be formalised by having the community form a citizen advisory committee which follows the study and meets at regular intervals [11, 13, 21]. The advantages of close co-operation with the community are many: developing stable relationships, creating mutual understanding, deeper understanding of the scientific aspects by community members and of public concerns by investigators, increased opportunity for the exchange of information and early notification of the community. There are also pitfalls in working with a citizen advisory committee. The most important one is that the committee can become elitist and lose touch with the community at large. There is also a danger of delay, but the time which is lost in working with a committee during an investigation is often more than won at the end of the investigation when the concerned community has to be informed.

The moment a conclusion is drawn and the concerned community is informed, it is also necessary to *inform the media.* A proactive media strategy, using the advice in for instance Hance et al. [5], can be planned. Preferably, this strategy is devised together with representatives of the concerned community. Contacts with the media are less fruitful during an investigation. Media will mainly be interested in conclusions and not in procedural aspects or discussions on details. The media may be interested in disputes about basic assumptions, especially if a citizen advisory committee is involved and differing opinions exist. Care should be taken that responsible authorities and the citizen committee do not try to prove their right through the media. This could result in a war which the media will be more than glad to feed. Whenever possible, responsible authorities and citizen committee should say the same things. To attain this, they should prepare media contacts together. Written communications could even be devised in a joint effort. At last it may be worthwhile to go to the media through a spokesperson of the community or together with such a person.

Conclusions

The fields of risk communication and risk perception offer valuable lessons which can be very useful in cluster management. The present paper mentions a few of these lessons and directs the interested reader

to the relevant literature in which more extended and detailed advice can be found. The most important lesson is that a cluster is a common problem of the concerned community, responsible authorities and involved experts and management of a cluster is their common enterprise. Cluster management can be divided into three steps: exploration, qualification and quantification. The aforementioned parties and the media each have their specific role to play in the subsequent steps. As cluster management progresses to later steps and investigations become more complex epidemiologically, community involvement should remain high. If the community is fully informed and involved in decision making from the beginning, risk communication and thus cluster management will almost always be successful.

References

1. Centers for Disease Control. Guidelines for investigating clusters of health events. MMWR 1990; 39: 1–23.
2. Drijver M, Melse JM. Disease clusters and environmental contamination: A guide for public health services (in Dutch). T Soc Gezondheidsz 1992; 70: 565–570.
3. Fischhoff B. Risk perception and communication unplugged: Twenty years of process. Risk Analysis 1995; 15: 137–145.
4. National Research Council. Improving risk communication. Washington, D.C., USA: National Academy Press, 1989.
5. Hance BJ, Chess C, Sandman PM. Industry risk communication manual. Improving dialogue with communities. Lewis Publishers, 1990.
6. Liston AJ. Risk communication and health protection. In: W. Leiss (ed), Prospects and problems in risk communication. Waterloo, Ontario, Canada: University of Waterloo Press, 1989.
7. Slovic P, Flynn J, Mertz CK and Mullican L. Health-risk perception in Canada. A research report to the department of national health and welfare, Canada 1993.
8. Renn O, Burns WJ, Kasperson JX, Kasperson RE, Slovic P. The social amplification of risk: Theoretical foundations and empirical applications. Journal of Social Issues 1992; 48: 137–160.
9. Forsythe RH. Risk: Reality versus perception. Poultry Science 1993; 72: 1152–1156.
10. Wilkins L, Patterson P. Risky business: Covering slow-onset hazards as rapidly developing news. Political Communication and Persuasion 1990; 7: 11–23.
11. Neutra RR. Epidemiology for and with a distrustful community. Environmental Health Perspectives 1985; 62: 93–97.
12. Cole DC, Tarasuk V, Frank JW, Eyles J. Research responses to outbreaks of concern about local environments. Archives of Environmental Health 1996; 51: 352–358.
13. Graber DR, Aldrich TE. Working with community organizations to evaluate potential disease clusters. Soc Sci Med 1993; 37: 1079–1085.
14. Thomas DC. The problem of multiple inference in identifying point-source environmental hazards. Env Health Persp 1985; 62: 407–414.
15. Melse JM, Drijver M. Disease clusters and environmental contamination: Inventory of statistical methods and backgrounds of cluster research (*In Dutch*). T Soc Gezondheidsz 1992; 70: 624–630.
16. Rothman KJ. A sobering start for the cluster buster's conference. Am J Epidemiol 1990; 132; S6–13.
17. Bross ID. Why proof of safety is much more difficult than proof of hazard. Biometrics 1985; 41: 785–793.
18. Millard SP. Proof of safety versus proof of hazard. Biometrics 1987; 43: 719–725.
19. Neutra RR. Counterpoint from a cluster buster. Am J Epidemiol 1990; 132: 1–8.
20. Mulder YM, Drijver M, Kreis IA. Case–control study on the association between a cluster of childhood haematopoietic malignancies and local environmental factors in Aalsmeer, The Netherlands. Journal of Epidemiology and Community Health 1994; 48: 161–165.
21. Lynn FM and Busenberg GJ. Citizin advisory committees and environmental policy: What we know, what's left to discover. Risk Analysis 1995; 15: 147–162.

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