Childhood leukaemia - communicating with a worried public

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1. Introduction

This presentation is a case-history of an attempt by a local health authority in the U.K. to deal with high levels of public anxiety about a cluster of childhood leukaemia in Northampton by a risk communication strategy. Usually, in similar circumstances of intense public demand and extensive adverse publicity, health authority's have responded by setting up, predictably inconclusive, epidemiological studies. Despite intense public, political, media and management pressure to do just this, we chose rather to educate the public about disease clusters and the limitations of epidemiological methods. This involved working with the community and media and producing a written report for parents and later working with the BBC to produce a programmes on disease clusters. The conference presentation will involve using video clips of television coverage to illustrate aspects of the approach taken which cannot be adequately captured in the written word, together with an evaluation of its effectiveness. This paper gives background information.

2. Background

In 1993 Northampton Health Authority was contacted by a local councillor about an apparently abnormally high number of children with leukaemia in his ward. He reported public concern that this was due to an accident on the railway line, some years previously, involving radioactive material.

Identification of cases, and calculations of the observed and expected rates of leukaemia, suggested that the "cluster" was probably due to chance and the post hoc identification of the cluster. There were no records or newspaper reports or other evidence of an accident on the railway involving radioactive material. A literature review of the epidemiology of childhood leukaemia and the investigation of disease clusters suggested that a local epidemiological study to determine the cause or causes of leukaemia in the children in Northampton would be unable to provide further answers. Reassurance was fed back to the community using local networks and community leaders informed us that public anxiety appeared to have been allayed. The matter was concluded.

Unexpectedly in July 1995 a local newspaper, published an article with the banner headline "WHY did this child die?" The article demanded "a full investigation into the causes of leukaemia on Pembroke Road". The health authority was unaware that, during the intervening year and a half, public anxiety had reached high levels. During the next days and weeks there was a barrage of headlines and articles in the local press and the start of a sustained campaign in the local community demanding an investigation. The problem was highlighted on regional and national television. There was a 4,000 signature petition handed in to Downing Street demanding an enquiry. It was clear that there was extreme anxiety in the community and the HA were facing a public relations disaster.

3. The Gulf

There was a huge gulf in expectations and beliefs between the health authority and the public. Ordinary people were convinced that "there must be a link between the cases" and that the authority should be doing something to discover what it was and protect the community. The evidence suggested that the cluster was probably a chance occurrence and that, even it were not, it would not be possible to demonstrate this. The table below contrasts the position of the HA and the families as portrayed in the first days in the press.

Table 1 - The gulf in expectations

The Families	The Health Authority
"How many children are going to die before something is done?" "There is something not right somewhere.... We want to find out what is causing these kids to become ill" "All parents would like to know the cause of it and want something to be done." "We feel annoyed and cheated the public health authority should have done something years ago"	"With most clusters of leukaemia the answer is never found. There wasn't [sic] enough cases to look at this area as a cluster. It does not mean we should not worry about it." (The Director of Public Health) "The Director of Public Health denied the Health Authority could have done any more itself when it was first alerted to the problem two years ago.... Despite pleas from the families... she said she could not launch an in-depth investigation into the reason for the cluster of cases. 'We don't know what to look for because no-one knows the causes...' ."

4. What should be done?

The traditional public health response in such situations is to set up an epidemiological study. As one professor stated at a recent Faculty of Public Health Medicine Scientific Conference on the subject of communication: "There's no point at the outset saying 'there's no point investigating clusters - they never get us anywhere' - just accept that you've got to do it and investigate it mainly by secondary investigations." (Palmer 1996) Typical secondary investigation protocol steps include:

- define the cluster (set the geographic and other boundaries)
- case finding, confirmation of diagnosis and other criteria of case definition
- assess the relative risk of the referent population
- statistically analyse disease rates
- examine potential exposures
- assess biological plausibility
- determining cluster significance and the need for further investigation
- disseminate results

These steps had already been carried out. They were repeated in 1995 and the conclusions were unchanged - the "cluster" was probably a chance occurrence. Sometimes such secondary studies will reassure the public. When they do not, formal epidemiological studies are often undertaken. These are almost invariably inconclusive. The Vice President of the Epidemiology and Statistics Department of the American Cancer Society stated at an International Symposium on Leukaemia Clustering that he did not know of *any* investigation of an individual leukaemia cluster where one could be sure *it was due to anything other than chance.* (Heath 1992) At the same meeting, another epidemiologist remarked:

"One take-home message for me is that other epidemiologists from around the world seem to agree that formal investigation of clusters have not been very productive… those of us in cancer

agencies have to figure out how to communicate these problems so that we can concentrate our efforts on what we feel would be productive work."(McLaughlin 1992)

The department of public health in Northampton felt that its aim should be to deal appropriately with public concern about a possible cluster of cases of childhood leukaemia. We considered it inappropriate to set up a scientifically useless study as a public relations exercise yet we still wanted to respond to genuine fears and concerns of the families and community. Although doing a "placebo" investigation may well have helped to overcome the perception that the authority was uncaring and did not listen and may well have convinced people that the we had responded appropriately to public concern, this would have been achieved at the cost of doing something predictably useless, which did not genuinely address the real issues, and reinforced the erroneous idea that there are always solutions.

Our key objectives were to:

- Ensure that the local health situation was fully assessed and that appropriate measures to protect the public were in place
- Ensure that the public receive accurate information about the local situation
- Listen to the needs and worries of affected families
- Make sure that people knew that the health authority was genuinely concerned about their problems and was responding appropriately to their needs.

The underlying problem behind the gulf in expectations was that the public did not understand epidemiological evidence and the limitations of current methodologies and knowledge. We felt if this was the underlying problem then this was the problem that should be addressed. Thus the best way we felt we could achieve the latter objective was by educating the public about disease clusters and taking the time to listen and explain about epidemiology. At the same time we collaborated with the local authority to investigate whether there were any local environmental hazards and whether there were protective measures that could be put in place.

We hoped such a strategy would

- Show the community that we were genuinely concerned
- Help people understand that currently there are no known protective measures that they were being denied
- Treat people with respect
- Not put out a mixed message.

The strategy encountered resistance from the health authority hierarchy who saw it as naïve and politically disastrous (not only were we refusing to do a special epidemiological study, but we were intending to advertise the fact!). One senior manager commented that it was all very well to insist on "doing the right thing" but it was actually more important to be "perceived as doing the right thing" (with the implication that in this instance the two were not compatible).

5. What did we do?

We believed that "Risk communication cannot be separated from dealing with the problem itself. Do the right thing at the right time - this is the best defence and the best practice." (Palmer 1997). However we also discovered that "The objective of informing and educating the public about risk issues seems easy to attain in principle, but, in practice, may be difficult to accomplish" (Slovic 1986)

There is a huge literature on the communication of risk and there are no simple solutions. Different people have very different attitudes to risk and process information about risks in different ways. (Ferguson & Valenti1991) However, the literature is a rich source of advice about what makes for good risk communication and there is a remarkable degree of consensus about the right approach. Important rules include: accept and involve the public as legitimate partners; plan carefully and evaluate your efforts; listen to the public's specific concerns; be honest and open; meet the needs of the media.

There is also recognition in the literature that in practice it is often handled badly. We tried to put into practice as many of the principles as possible:

- Families met local and national experts to express their concerns and ask questions
- They were invited to meetings of the health authority and to private meetings at which they were consulted on their views and what they wanted.
- I was readily accessible to families and they frequently telephoned me.
- Factsheets and press releases were prepared proactively for the media. I talked to them to explain the issues and provide them with information.
- Meetings for other interested parties e.g. local councillors and national politicians.
- A report for parents summarised what is known about leukaemia and its causes, explained the implications of having five cases over 8 years, detailed the investigation, explained why a local study would not tell us what had caused the leukaemia, described current scientific evidence on the relationship between environmental hazards and childhood leukaemia, explained that many of the important questions about the causes of leukaemia are being addressed in well-designed scientific studies.

The report was sent for external peer review and received a very positive response and widespread support. It was adopted and published by the health authority in January 1996. Evaluation shows that it has been partially successful. The report was turned into an HTML document by the Leukaemia Research Fund and is available on the Northamptonshire Health Authority's website (http://www.northants-ha.anglox.nhs.uk). A BBC2 documentary (Anxiety Attack 2 - Street of Doom) was also produced in response to this report. This programme is being used as part of the teaching programme the Royal Statistical Society and in a number of UK universities.

REFERENCES

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RÉSUMÉ

This is a case history of public health department's response to a perceived cluster of leukaemia by resisting calls for a scientifically useless epidemiological study. Instead, an intensive educational and risk communication strategy was adopted to help the public understand about the limits of scientific methods. A written report for parents and a BBC television documentary were two products of the strategy. The former has been turned into a HTML document by the Leukaemia Research Fund and is available on the Northamptonshire Health Authority's website.