EXPERIENCE OF DEALING WITH THE MEDIA ON CONGENITAL ANOMALY RESEARCH

Beverley Botting
Office for National Statistics, UK
David Stone
University of Glasgow, UK

In this paper I report two separate studies of congenital anomalies, one of which was generated by a media alarm, and the second that needed to disseminate research findings to the public through the mass media. There are many similarities between the two pieces of work and the process of disseminating results. Both show the importance of working with the media to share our work in an informed way to present a true evaluation of risks to the public. The first study, generated by media concern, was based on a cluster of four English babies born without a left hand. Although this original cluster on which the first part of this paper is based was several years ago, there are several important messages resulting from this work which are still as relevant today. The second study reports the findings of a collaborative study, known as EUROHAZCON, based in different locations in Europe, which tested whether living close to a landfill site was a risk factor for congenital anomalies. The media can have a huge impact both on what we do within our Congenital Anomaly Registers and in how we do it. It is useful to reflect on these studies and evaluate how the media influenced our work at the time. In particular, dealing with the media can be very time consuming whilst we are still trying to focus on the epidemiology.

STUDY OF LIMB REDUCTION DEFECTS

The National Congenital Anomaly System (NCAS) in England and Wales began in 1964 after the thalidomide epidemic. It is based on a voluntary notification system for live and stillbirths. We cover over 650,000 births per year. Between Feb 1989 and May 1990 four children with transverse limb reduction defects were born in the same town on the Isle of Wight, a small island off the south coast of England. The only common characteristic identified by the mothers was that they had swum in the sea during pregnancy. This raised the possibility that an environmental factor associated with living near to the coast and swimming in the sea might be implicated for these anomalies.

This paper discusses the analyses we undertook immediately after the alarm was raised in the British Press in January 1994, and the impact of the media reports on the work of our register, affected families and the general public. It also discusses the needs of parents, pregnant women and the media during a cluster investigation and the important role of our registers during this time. I will discuss the impact the media had on our register and how we should be prepared so that we can manage better any future media generated alarms.

This apparent cluster first came to public notice in January 1994 in the Sunday Times, a major British national Sunday newspaper with a large circulation. It was this newspaper which also broke the original thalidomide story. Given the hypothesis that this was an environmentally caused cluster, other families with similarly affected children who lived near the coast came forward in the ensuing days. A different newspaper then presented a map of the UK with these various cases shown as large dots around the coast. No affected children living inland were included, thus suggesting this condition was restricted to those living near the coast. An analysis of data from NCAS, however, showed the more usual patterns of higher density of cases in areas of higher population. This would be expected as these are the areas with higher birth rates.

Our response to the concern was to undertake a crude analysis of notification rates of upper limb reduction defects (LRD) by small areas, known as postcode sectors, by whether the area had a coast line or not. The results showed no significant difference between areas with a coastline and those without.

Studies were also undertaken in several countries to compare the prevalence of LRD in babies born in coastal areas with those born inland. The results from three Clearinghouse programmes were published as letters in the Lancet on 23 April 1994.[1-3] These reports, from

England and Wales, Italy and Latin America all found that there was no difference in the reported rates of LRD for babies born in coastal areas compared with those living inland. A further in-depth analysis investigated different risk factors over a longer time scale. This research showed similar results, with no association between LRDs and the coast.

Two months after the media coverage of the four babies born in the Isle of Wight, there were another five babies with similar anomalies born in Cornwall, a rural peninsula in the far south west of England. The National Congenital Anomaly System identified this cluster, and we worked with the local Director of Public Health to investigate this cluster. Interestingly none of these mothers had swum in the sea during pregnancy, but this finding was only was published in the Plymouth Evening News, a small local newspaper with a small circulation

The four babies in the Isle of Wight were born over a 15 months period. Only two cases, however, had been notified by the local Health Authority to NCAS, the first and the last. Since these were born more than a year apart, this was not unexpected and so did not generate an alarm. When the local Director of public health checked back to the original birth notification forms, he discovered that for the two cases not notified to NCAS, both children had been delivered by the same midwife, and in neither case had the anomaly been recorded on the birth notification form. The key message is that NCAS is dependent on every last notifier. NCAS has particular problems, as we are reliant on a tenuous notification process from 100 health authorities. British regional registers with closer local involvement and multi-source ascertainment are less likely to be affected by this problem.

As a sequel to this work, in the summer of 1999 we were asked to help investigate a cluster of 3 babies born in 1994/5 with congenital anomalies of the hand. The parents knew each other through a coffee morning, and they all lived in Northampton, a heavy industrial town in the middle of England. There was a concern that these anomalies had been a result of exposure in utero to waste from nearby steelworks. A journalist contacted NCAS through his knowledge of the EUROHAZCON study. This geographical area was under the spotlight again in 2000 due to fears about a site in Northampton where toxic waste from the Dome site (the building built to house the millennium exhibition) had been deposited. So public concerns about environmental hazards are a continuing driver for our research. Such drivers lead to the setting up of a European study of congenital anomalies in the vicinity of hazardous waste landfill sites.

EUROHAZCON STUDY

The second study reported here, reflects on the mass media response to the paper published in the Lancet in 1998, reporting on the EUROHAZCON study of the risk of non-chromosomal congenital anomalies near hazardous waste landfill sites in Europe.[4]

This study was based on data from 21 sites, provided by 7 registers in 5 different countries. There were 1089 cases and 2366 controls included in the study. The study compared the prevalence of anomalies for those living less than 3 km from a landfill site, compared with those living between 3 and 7 km from a site. There were 295 cases and 511 controls living within 3 km of a landfill site, and 794 cases and 1855 controls living 3-7 km from a site.

The key EUROHAZCON finding was that residence within 3 km of a landfill site was associated with a significantly raised risk of congenital anomaly. The combined odds ratio adjusted for maternal age and socio-economic status was 1.33 [with 95% confidence intervals of 1.11-1.59]

To disseminate this finding in Britain, prior to publication of the paper in the Lancet, a press release was issued. There were instant national and local media enquiries. Radio, TV and newspapers interviewed several of the authors. All this interest resulted in the first wave of media coverage, which made the public aware of the key finding. Subsequently local community groups demanded action on their perceived risk to their children, the environment lobby issued statements, and local and national politicians commented on the finding. This generated a second wave of media coverage. As a result of this further media coverage there were responses from the statutory agencies – the National Health Service, the local environment health department and the Scottish Environment Protection Agency. In turn, this lead to another wave of media coverage, since which time the story has largely lay dormant. On reflection, the three waves of media response were driven by journalistic, political and professional perspectives. The reporting was

generally relevant, accurate and non-sensational. The media reporting, however, developed its own momentum.

In January 2002, a second EUROHAZCON paper was published in the Lancet, this time reporting a similar analysis of chromosomal anomalies.[5] The excess risk of anomalies in babies of mothers living within 3km of a landfill site was similar to that found in the earlier paper. The first wave of media coverage was equally intense but has subsided rapidly. Time will tell whether media interest will be sustained into a second and third wave.

DISCUSSION

Apparent clusters of anomalies genuinely scare the general public. They believe that they are being poisoned and nobody has told them, and that the truth has been concealed from them. Congenital anomaly registers and researchers, therefore, have a responsibility to investigate potential environmental teratogens and to respond to media concerns.

Parents are particularly responsive to hypotheses raised by the media. There are two types of affected parents, those with similarly affected children, and those women who are currently pregnant. Parents of affected children want an explanation of why their child is affected by the anomaly, so are keen to explore every possibility raised by the media. Pregnant women are concerned that their baby be similarly affected if they have been exposed to the hypothesised teratogen. Parents need to be believed, and if they feel they are not being taken seriously by the health professionals, they are likely to turn next to the media. Second, they seek reassurance, which we can only give if we have scientific evidence to disprove the hypothesis. Otherwise we need fast simple analyses to test the hypothesis.

The day after the media story about the handless babies broke in Jan 1994, NCAS received many telephone calls from pregnant women who had swum in the sea asking whether their baby would be born with similar anomalies. Much time and hence resource, was spent discussing issues with these women, trying but being unable to reassure them before hypothesis testing was complete.

The media want fast answers to the concerns they have raised. This is a real problem as most good hypothesis testing takes time. Even with sufficient financial resources, time is needed to extract and examine case notes, to collect more information on the cases or to examine the cases themselves, plus to undertake the statistical analysis

The media also want a good story to sell papers, as newspapers need to be profit making. The Cornwall apparent cluster where none of the women had swum in the sea was not considered a nationally newsworthy extension of the original story. Similarly, a more in-depth analysis of the Isle of Wight cases showed that they were of different etiology - 1 genetic, 1 amniotic band amputation etc. Positive and negative associations were not given equal numbers of column inches. As a result the public may be exposed to biased unbalanced reporting and this can affect public opinion of the real risk and the scientific results which eventually are released. It is therefore important that we work with the media whenever possible to ensure balanced reporting. This happened to an extent with the reporting of the EUROHAZCON study, although the longer term implications remain unclear.

CONCLUSIONS

It is crucially important that

- We have active good quality monitoring systems so that we can pick up any increase before the media and in discussion with local Public Health colleagues discuss possible hypotheses and begin to test them before people and pressure groups raise unsubstantiated hypotheses with the media.
- We can recall cases as usually it is very difficult to collect initially every piece of information that might be needed to test a given hypothesis.
- results of our analyses are published in peer-reviewed journals so they are unbiased
- we work together with other registers within our countries and internationally. The simultaneous analysis of data from different Clearinghouse programmes in South America and Italy showed no coastline clusters. The Italian analysis also examined occupations related

to the sea, for example. Fishermen, and found no association. There is power in having results corroborated internationally.

- We have a caring attitude to distressed public, parents and pregnant women so that they trust we have their interests central to the work of our programmes. We also need to build trust with our public health colleagues since they are our local people on the ground.

- In conclusion, media interest in public health research is inevitable. Public health scientists and professionals have an obligation to interact with the media. A proactive approach is probably preferable. It is difficult for scientists to talk with the media as the media want fact, but much epidemiology is about probabilities, caution, hypotheses and evidence. We must build up trust with the media so that they know they can discuss concerns with us & we will take them seriously & give advice which maintains our integrity - so that we are a first point of call with a view to more unbiased media coverage. All these factors have implications for dissemination and training.

REFERENCES

1. Botting, B.J. Letters to the Editor, *The Lancet* 23 April 1994, 343(8904):1033-4.
2. Castilla, E. E. & da Graca Dutra Letters to the Editor, *The Lancet* 23 April 1994, 343(8904):1034-5.
3. Mastroicovo, P., Botto, L., Fusco, D., Rosano, A. & Scarano, G. Letters to the Editor, *The Lancet* 23 April 1994, 343(8904):1035.
4. Dolk, et al. (1998). "The EUROHAZCON Study" multicentre case control study of the risk of congenital anomalies near hazardous-waste landfill sites in Europe. *The Lancet, 352,* 423-427.
5. Vrijheid, et al. (2002). *The Lancet 359,* 320-22.