

Risk communication of the transmissible spongiform encephalopathies

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Summary

Previous chapters of this review have dealt with the scientific basis of assessing the risks from transmissible spongiform encephalopathies and how those risks should be managed. The author explores the theory and practice of risk communication and sets out the basic principles for good risk communication when dealing with uncertainty.

Keywords

Bovine spongiform encephalopathy – Risk analysis – Risk communication – Transmissible spongiform encephalopathy – Uncertainty.

Definitions and goals of risk communication

The international food standards setting organisation, the Codex Alimentarius, defines risk analysis as a process with three components, namely risk assessment, risk management and risk communication (4).

a) Risk assessment

This is a scientifically based process consisting of the following steps:

- hazard identification
- hazard characterisation
- exposure assessment
- risk characterisation.

b) Risk management

The process is distinct from risk assessment and consists of weighing policy alternatives, in consultation with all interested parties, considering risk assessment and other factors for the health protection of consumers and for the promotion of fair trade practices, and, if needed, selecting appropriate prevention and control options.

c) Risk communication

This is the interactive exchange of information and options throughout the risk analysis process concerning hazards and risks, risk-related factors and perceptions, among risk assessors, risk managers, consumers, industry, the academic community and other interested parties, including the explanation of risk assessment findings and the basis of risk management decisions.

These three aspects of risk analysis are often mistakenly viewed as discrete entities, yet, to be effective, they must be fully integrated. In particular, risk communication must not be considered as the last component in a linear process, but rather as a vital element throughout the risk analysis process, specifically defined to include the explanation of risk assessment findings and the basis of risk management decisions. The agreement on definitions of these principles in Codex involved complex and difficult discussions, with considerable argument about how the principles would be applied in practice, at the national level and internationally, for consumer health protection and for the facilitation of fair trade practices.

The history of managing risk communication in the bovine spongiform encephalopathy (BSE) and associated transmissible spongiform encephalopathies (TSEs) crises over the past fifteen years is filled with examples of how 'not to do it': at best, the basic principles of risk communication have been selectively

applied or, at worse, completely ignored. The findings and conclusions of the inquiry of Lord Phillips into BSE in the United Kingdom (UK) were forthright in identifying lessons to be learned when dealing with uncertainty and the communication of risk (10). Despite these expensive lessons, identical mistakes are often repeated in one country after another when managing and communicating about the world-wide spread of BSE and TSEs. Despite being wiser after the fact, learning lessons and improving risk communication are major challenges still to be achieved.

The Joint Food and Agriculture Organization (FAO)/World Health Organization (WHO) Expert Consultation on the Application of Risk Communication to Food Standards and Safety Matters identified the elements and guiding principles for effective risk communication and examined barriers to be overcome, as well as providing detailed practical recommendations to improve communications on food safety (6).

The goals of risk communication

These goals can be defined as follows:

- to promote awareness and understanding of the specific issues under consideration during the risk analysis process, by all participants
- to promote consistency and transparency in arriving at and implementing risk management decisions
- to provide a sound basis for understanding the risk management decisions proposed or implemented
- to improve the overall effectiveness and efficiency of the risk analysis process
- to contribute to the development and delivery of effective information and education programmes, when they are selected as risk management options
- to foster public trust and confidence in the safety of the food supply chain
- to strengthen working relationships and mutual respect among all participants
- to promote the appropriate involvement of all interested parties in the risk communication process
- to exchange information on knowledge, attitudes, values, practices and perceptions of interested parties concerning risks associated with food and related topics.

Brunk cites two views of risk communication (2). The one view considers risk communication as the expert education of non-experts, i.e. the means by which regulators convince the public to adopt the reliability of the expert assessment of the risks, the reliability of the risk management and the consequent

acceptability of the risks. The second view refers to risk communication as an exchange of information between regulators and those who have a 'stake' in the process. This exchange of information is the process by which the acceptability of the risk by the lay public is negotiated and established.

These views are echoed by the Consumers' Association (UK): 'Risk communication is all too often a one-way, top-down process rather than a two-way inclusive process that enables the public to participate in decisions about what risks are acceptable. Judgements about the balance between consumer choice, on the one hand, and safety on the other, and therefore the legitimate role for government regulation, will only be socially acceptable if the public are involved at the outset' (1).

As far back as 1996, a report to the UK Health and Safety Executive on risk communication by government departments identified key factors for the success of risk communication (3), including:

- consultation processes, particularly the extent of involvement by interest groups and the public in policy-making and the way in which the governments involve them
- public scepticism about government messages in the light of the history of earlier communication about a risk, compounded by low trust in government generally
- difficulties that non-scientists have in understanding scientific information and methods, compounded by suspicion of science and technology generally
- public preferences about different types of risk, which often lead to very different judgements from those in technical risk assessments
- inadequate or inconsistent articulation or explanation by departments of their assessment of risk, sometimes reflecting more fundamental differences in decision frameworks.

Recent examples of risk communication about TSEs show that implementing these principles presents a major challenge for most food regulators.

The importance of risk communication and consumer perceptions

Communicating about risk is critically important since this is a process whereby acceptance of risks is acknowledged or not, as the case may be. Consumers are most concerned about those risks that directly affect their lives and families. Food safety,

particularly in regard to BSE, the human form of the disease, variant Creutzfeldt-Jakob disease (vCJD) and the impact on public health is a case in point. Safety is a negotiation about the acceptability of risks by those who are the bearers of the risks. Concerns about the risks from BSE and TSEs are heightened since consumers have little control in dealing with these risks.

Consumers have often been very confused about the risks from BSE and TSEs and have rejected and mistrusted risk communications. Research by the Consumers' Association (UK) in 1998, specifically considering BSE, demonstrated confusion and lack of trust of consumers in the information they had received about the disease (1). Four out of five people (81%) felt that information about whether meat was safe to eat changed constantly and 39% were confused about whether they could safely eat beef. More than half the consumers (60%) said that they did not have enough information about BSE or wanted to know more about the risks associated with the disease (51%). The majority of those interviewed (57%) stated that they did not take any notice of BSE anymore. The study also suggested that reports on possible transmission to sheep had had a small, but significant, impact on the consumption of lamb.

The perception and reactions of consumers to risk are often very different from those of experts and depend on factors such as:

- the nature and magnitude of the risk
- the uncertainties of the risk
- the 'fear factor'
- the nature of any benefits
- trust in those assessing and managing the risks.

Experts tend to focus on the quantifiable aspects of risks, while non-experts tend to be more concerned about qualitative aspects. Consequently, experts are often frustrated by the response of consumers to risk, complaining that if only they understood probability better, they would view risks as they really are and would not respond so 'irrationally', especially to food safety scares as 'exposed' in the media. Clearly, there is often a mismatch of risk perceptions between experts and consumers. Nevertheless, acceptance of the concerns, views and attitudes of consumers towards risk, however 'apparently unreasonable', is key for risk communicators. Without this fundamental understanding (which has to be developed through constructive, two-way iterative dialogues), there will be little if any trust in the messages or the messengers of food safety risks. Trust in risk communication can only be built on the credibility of the process whereby risks have been assessed and managed and the extent to which consumers and other stakeholders have been involved throughout the process.

The UK Food Standards Agency (FSA) set up a BSE Stakeholders' Group in 2001 comprising scientists, farming,

food industry and consumer group representatives. This group considered risk reduction measures for the theoretical risk of BSE in sheep and advised the FSA on the application of precautionary measures. The process was open, transparent and inclusive, and perhaps most significantly, there was little if any media hype or hysteria about the proposed outcomes and little impact on the consumption of lamb. The public and the media appeared to trust the resulting communications from this forum.

Dealing with uncertainty

Previous chapters of this review have dealt with the current state of scientific knowledge of TSEs and have identified areas where there is lack of scientific evidence, or uncertainty, requiring further work. Whilst the enormous scientific efforts made over the past decade are recognised, there are still many 'uncertainties' concerning scientific evidence about BSE, TSEs and vCJD. However, even when faced with uncertainties, regulatory decisions and communications have to be made. The public has a right to be informed and expects governments to carry out their role in reducing food risks and exposure of consumers to these hazards. Regulatory authorities must adopt practices to ensure that food is safe to eat, based on available scientific knowledge, and ensure that any decisions are properly communicated to consumers, which could possibly be before sufficient scientific data is available. Communicating uncertainty is one of the most difficult and critical aspects of risk communication about TSEs.

The Joint WHO/FAO/Office International des Epizooties (OIE: World organisation for animal health) Technical Consultation on BSE addressed the issue of uncertainty in risk communication and concluded that there were four contexts for typical risk communication messages (9), as follows:

- issues where the answers are thought to be known (high certainty contexts), recognising that new data can change the conclusions in which the highest confidence has been placed. For example: whether food exposure is the cause of vCJD
- issues where the answer is not known (high uncertainty contexts). For example: how many people might be affected by vCJD in the future
- issues where debate or controversy exists (moderate uncertainty). For example: whether BSE has spread to the rest of the world
- new emerging issues of potential risk. For example: sheep and goats may have been infected with BSE.

Risk communicators should identify a given situation and adopt appropriate strategies for explaining these contexts to the public.

The Joint WHO/FAO/OIE Technical Consultation on BSE identified principles to adopt in an attempt to overcome some of the major problems that have occurred in risk communication (9). Regarding uncertainty, it was considered important to frame the question and address the full range of concerns about the risks, ensuring that the response is given in the context of the full story. Translating and summarising the story for different audiences are also important.

When faced with scientific uncertainty, good risk communication should address the following:

- what measures are being taken to reduce the risks, and why
- what is known
- what is unknown and explain why this is the case; be open and honest
- what is being done to fill the knowledge gap
- what precautionary measures are being taken in the interim.

Regular updates are necessary, even when there is no new information. Risk communicators need to be proactive, to take the initiative to communicate new information about risks, even though this may be unsettling to the public, explaining what is being done to address the risks. A proactive, open policy should be adopted for all aspects of risk communication.

The Phillips Report on the BSE Inquiry in the UK firmly concludes that, based on experience, a policy of openness is the correct approach. 'When responding to public or media demand for advice, the Government must resist the temptation of attempting to appear to have all the answers in a situation of uncertainty' (10). The authors of the report are of the firm opinion that food scares thrive on a belief that the Government is withholding information. The evidence from consumer research supports this view. Withholding, or being perceived to be withholding information can cause more harm than good, fostering a climate of uncertainty and fear. A Consumers' Association survey conducted in April 1996, following the announcement of a possible link between BSE and vCJD (after years during which beef had been pronounced as safe to eat), demonstrated that 71% of consumers thought that the government had withheld information regarding the risks associated with BSE (5). The Phillips Report recommended that 'if doubts are openly expressed and publicly explored, the public is capable of responding rationally and is more likely to accept reassurance and advice if and when it comes' (10).

Building confidence and trust

Effective risk communication should build public confidence in regulators. The public should be reassured that their concerns and fears have been heard and addressed and consequently, then will be more likely to trust any information provided.

Involving consumers or consumer organisation representatives in the risk analysis process, and especially in risk communication, will improve confidence, and should ensure that there is more chance of 'one' clear message being communicated to the public.

The media will have less opportunity to cause confusion and exploit any weakness in communications if the regulators and all stakeholders are communicating the same message to the public and to their respective sectors.

Conversely, there was a complete lack of trust in the UK when many of the reassurances about the 'absolute' safety of beef issued from the Ministry of Agriculture, Fisheries and Food (MAFF) were demonstrated to have been unfounded. Public trust in government and in science was severely shaken when fears about the threat of the BSE epidemic in cattle for human health were confirmed in March 1996. The UK Government announced, despite previous strong reassurances to the contrary, that a human form of BSE was suspected, ten cases of new vCJD having been identified. For over ten years, there had been public concern about the risks to human health from the epidemic of BSE in cattle and these worse fears had been confirmed.

Public reassurances about the safety of beef were shattered. The UK beef industry plunged into crisis, consumption of beef slumped and exports were prohibited. In February 2002, research of the UK Food Standards Agency showed that 55% of consumers were still concerned about BSE (7), although this figure had fallen 6% from the previous year. Uncertainties about the future development of vCJD in the population and the problems of trying to eliminate the risks of BSE from the food and feed chain world-wide now have to be faced. Given the scientific uncertainties, communicating about the risks to human health against this background is indeed a major challenge. However, there are lessons to be learned and good practices to follow. Guidelines to regulators for good media communications were developed at the Joint FAO/WHO/OIE Technical Consultation on BSE and are included in the Appendix below.

In the UK, where public trust in food controls was most dented, issues about the theoretical spread of TSEs to sheep and goats have not been received with the same public outcry as was the BSE situation. Many factors have no doubt contributed to this change in public response, for example, the establishment of an independent FSA. However, the way in which information about the possible risks of BSE in sheep and goats has been communicated to the public has clearly changed. Stakeholders were involved in advising on precautionary measures against the theoretical risk of BSE in sheep. The advice of the FSA was unchanged against a background of uncertainty and was communicated clearly and openly, with consumers being advised about informed choices that could be made to reduce the risks. Good risk communication was highly appreciated.

This was especially so since a special briefing was held with representatives of the Muslim, Asian and African-Caribbean communities, which traditionally eat meat from older sheep and goats. One delegate commented 'It is a difficult situation, but one that we now have some knowledge about to be able to make personal choices.' (8)

Principles for good risk communication

In summary, much has been written about the problems of risk communication. When faced with scientific uncertainty, and when human health is at risk, the media always look for a new food scare to exploit. In the past, there was much to criticise about the way risks from BSE were communicated. However, lessons have been learned from earlier mistakes. The principles of good risk communication are clear and need to be steadfastly employed.

In conclusion, reiterating the principles identified as a result of the Joint FAO/WHO/OIE Technical Consultation on BSE is important (9). These are as follows:

1. Consult all stakeholders at the outset to address their concerns in an open and transparent dialogue.

2. Frame the question and address the full range of concerns about the risk.

3. Frame the response in the context of the full story. The audience may be poorly or well informed. It is important to translate and summarise the story for different audiences.

4. Explain:

- what measures are being taken to reduce the risks, and why
- what is known, what is unknown and explain why this is the case; be open and honest
- what is being done to fill the knowledge gap
- what precautionary measures are being taken in the interim.

5. Give regular updates, even when there is no new information.

6. Be proactive, take the initiative to communicate new information about risks, even though it may be unsettling to the public. Explain what is being done to address these risks.'

Confidence in food regulators – to protect consumer health and to ensure fair trade practices throughout the risk analysis process – must be negotiated by applying these fundamental recommendations about risk communication.

Appendix

Guidelines to regulators on good media communications (9)

- Simplify the scientific message but maintain accuracy
- Use the media as partners to achieve your goal of communication; develop, seek a dialogue and an ongoing relationship
- Respond quickly, be candid and understand how the media work; if you decide not to discuss an issue during an interview, explain why
- The media want 'news', so know how to frame the message without allowing the process to distort the message
- Be consistent, but be prepared to revise your message in the light of new data
- Prepare a written statement to ensure the media get the message and be able to respond to questions
- Try to get journalists to repeat back the message to see that they have understood and that you have communicated your points clearly.'

La communication sur le risque des encéphalopathies subaiguës spongiformes transmissibles

D. McCrea

Résumé

Le fondement scientifique de l'analyse du risque lié aux encéphalopathies subaiguës spongiformes transmissibles et les modes de gestion de ce risque sont traités dans les chapitres précédents de cette revue. L'auteur aborde les aspects théoriques et pratiques de la communication relative au risque, et il énonce les principes de base d'une bonne communication en cas d'incertitude.

Mots-clés

Analyse du risque – Communication relative au risque – Encéphalopathie spongiforme bovine – Encéphalopathie subaiguë spongiforme transmissible – Incertitude.



Comunicación sobre el riesgo de encefalopatías espongiformes transmisibles

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Resumen

En capítulos anteriores de este volumen se han expuesto los fundamentos científicos en que reposa la evaluación del riesgo de encefalopatías espongiformes transmisibles, así como la forma en que convendría gestionar dichos riesgos. El autor examina aspectos teóricos y prácticos del proceso de comunicación sobre el riesgo y sienta los principios fundamentales por los que ha de regirse esa labor en situaciones de incertidumbre.

Palabras clave

Análisis de riesgos – Comunicación sobre el riesgo – Encefalopatía espongiforme bovina – Encefalopatía espongiforme transmisible – Incertidumbre.



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