Reporting on risk

The following accounts describe how hospitals in two different countries responded to the fact that some of their patients may have been exposed to Creutzfeldt-Jakob disease, an infectious and fatal neurological condition which is being increasingly documented in the West. Are these concerns remote for Indians? Given the quality of infection-prevention protocols, hospital-acquired infection is a serious problem in India.

Following her delivery by caesarean section in Hospital P, Ms Q returned home but was later shifted to another hospital when she displayed symptoms of a deteriorating neurological condition suggestive of variant Creutzfeldt-Jakob disease (nvCJD). The infant was admitted along with the mother since it was failing to thrive and appeared to have neurological signs — possibly the first case of vertical transmission of this prion-based disease.

The hospital where Ms Q delivered her baby was notified, and hospital authorities identified the kit used on Ms Q. Though they immediately removed it from circulation, they confirmed that seven other women had had caesarean sections using the same theatre kit, after Ms Q, and before the hospital was notified. The family obtained a court injunction prohibited anyone from publishing the name of mother or child or the name of any hospital at which they were treated in newspapers, TV or other media.

Should the seven patients have been traced and informed?

It was pointed out that if the authorities were sure of the instrument-disinfection process, if they could not identify the disease, but believed that it could have been transmitted from mother to foetus, and there was nothing to test or treat possible contacts, and no risk of further spread, there was no point in pursuing this issue.

Meanwhile, a local newspaper ran a feature on CJD and Ms Q's case, as well as the possibility of vertical transmission. As they could not name the hospital because of the court injunction, they created a panic reaction for every woman in the region who had recently given birth.

Public health authorities could have responded by tracing the seven women, telling them of their exposure and then putting out an announcement that no-one else need worry because the seven women had been told. They would inflict the problem on the seven women in order to save everyone else distress.

However, the authorities were advised that that this policy could cause the seven women significant harm. It could create anxiety, provoke reactions from family members, result in loss of their insurance, and so on. They recalled the early days of HIV where sufferers whose status was accidentally discovered and communicated to them without warning. Some women committed suicide.

They therefore decided to make the information available to anyone who wished to know, but giving patients the choice of knowing their particular status. A public phone line was set up. Callers not from Hospital P were told not to worry, as were for callers from Hospital P, who had given birth outside the relevant period. Callers from Hospital P in the relevant period were issued a special number at the hospital through which they reached a team of counsellors who would contact the woman and discuss her risk.

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That's how one set of authorities handled the problem. In another instance, 10 people who may have contracted the CJD as a result of a breach of infection control, were informed directly of their exposure by the hospital.

A neurosurgeon treated a patient with dementia who may have had CJD, and reused the equipment on 10 other patients, though according to the hospital's protocol for brain biopsy where there is a risk of CJD, the equipment should not be reused until a CJD diagnosis is excluded. The equipment was sterilised but the risk of CJD is not eliminated by normal cleaning and sterilisation.

The hospital made the decision despite warnings that the information could cause serious distress among some people, leading to suicide attempts. While the risk to these patients is very low (a one in one million chance), there is no test to determine whether a patient has caught CJD, and no treatment. The argument was rejected that not all patients would comprehend how remote the chances were of developing the disease, even with extensive explanations and counselling, and there was a real risk of this distress leading to suicide.

One of the 10 patients potentially exposed to CJD died of an unrelated condition. The other nine patients face a wait of up to 30 years to find out whether they have contracted CJD because there is no accurate test for the disease prior to symptoms surfacing.

The health minister said patients and the public had a right to know about such breaches of infection control procedures. "If patients, staff and the public had heard of the infection control breakdown by other means, they would have been extremely concerned. It would have also led to a potential panic or fear among other patients at the hospital."