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The Health and Social Consequences of the 2001 Foot & Mouth Disease Epidemic in North Cumbria

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Section 6

Conclusions and Recommendations

> ...when the community is devastated...one can speak of a damaged social organism in almost the same way that one would speak of a damaged body.
>
> (Erikson, 1991)

The studies we have examined which attempt to understand the cost to human health of the 2001 disaster have struggled to produce the kinds of evidence their methods addressed. We suggest this is because what counts is what is counted, (Bloomfield 1991) and emanates from a form of domination in knowledge production about health, described as: '...a culture, mindset and training scheme which stresses the epidemiology and science of public health' and which has for too long been '...an uncritical handmaid of an implicitly bureaucratic, rational and utilitarian approach' (Heller et al 2003). Longitudinal diary based methods have enabled the production of evidence about the human health effects of the disaster:

- Deterioration in chronic conditions and diseases due to disruption in personal routines and access to health services
- Sleep disruption, flashbacks, nightmares, uncontrollable emotion, loss of concentration
- Reported pyre effects: headaches, respiratory problems, nausea
- Sharp increase in anxiety across different sectors
- Longer term stress relating to loss of confidence
- Ongoing health fears of residents living near carcass disposal sites
- Increased number of injuries relating to handling new stock
- Workplace health: risks and hazards (short term), change, uncertainty (longer term)
- Loss of physical exercise and recreation for a year

Wider social effects found:

- Tensions and conflict within communities
- Loss of amenity and recreation
- Communities experiencing permanent changes in land use
- Loss of confidence in organisations' ability to control crises
- Loss of trust in governance
- Increased social isolation
- Uncertainty, confusion and lack of continuity in public life
- Bitterness (collective and individual) linked to lack of resolution of pain and suffering
- Increased sense of fragility in employment

Immediate distress, feelings of bereavement and ongoing suffering by many different groups is a feature of the 2001 FMD disaster. But suffering is not a health problem unless it becomes pathological, when it is re-categorised as

'depression' or 'PTSD' and subjected to treatment. If it is treated it is counted. Otherwise those who are suffering are expected to get over it, and recover using their own resources and networks (Morse 2003). In the rural communities affected by the disaster, it was the world which was disordered, not local people or those drafted in to help. Yet the effects on this large group of people were painful and disabling and there remains a simmering sense that this is not understood by 'outsiders'. The demands and expressed wishes of those who have experienced a disaster need to be given special attention because these impact on the possibilities for recovery. This is reported in a number of other studies such as the recent re-examination of Aberfan by McLean & Johnes (2000)[53]. It has been shown that when the response of 'authority' is not appropriate, or when it underestimates the scale, duration and impact of disasters, or does not acknowledge its own mistakes, recovery is much more difficult (Giner-Sorolla 2004)[54].

Our definition of trauma is therefore a situated one, within the context of the FMD disaster, and encompasses both the events and how those events were experienced by both individuals and communities. Trauma is associated with the inability to fight or flee, i.e. being trapped in the stressful environment and unable to take control over events. In this way we can see how the 2001 FMD epidemic with its severe movement restrictions on people, exacerbated the distress caused by particular events such as the culls. It is known that the length of time people are exposed to traumatic events can be a risk factor for developing enduring problems. Again, the FMD epidemic culls alone (let alone the restrictions) lasted for nine months in Cumbria, another factor not sufficiently understood by 'outsiders'; in terms of disaster studies, exposure in this case was very long indeed.

Recovery is subject to many influences and stages including how the disaster is perceived by those affected and those who are not. Erikson (1994) notes that it appears much harder for people to recover psychologically if the disaster appears to be 'produced by human hands'. McMillen et al (1997) in a study of a range of very different types of disaster, found that a community of people with existing networks of support was more likely to experience recovery from disaster than examples where ad hoc or random groups (i.e. train passengers) were hit by disaster. North & Hong (2000) found that recovery was more effective if local people received support, practical help and training from

[53] McLean & Johnes revisited the 1966 Aberfan disaster in which 144 people were killed, 116 of whom were children, buried when a coal slag tip slipped down onto the local school. Here a local chapel was used to house the bodies and was where parents came to identify their children. Later local people requested that the Coal Board (which was apportioned liability) should fund the demolition and rebuilding of the chapel as they felt they could no longer worship in a place which had such a traumatic association with their loss. This was initially refused and is given as an example of how those outside of the disaster view such requests as 'irrational', while for insiders it is a normal reaction to an abnormal event.

[54] In their ESRC funded study into the after effects of the Prestige oil spill off North West Spain, Giner-Sorolla et al reported: 'Compensation without feelings can be seen as an insulting hand-out or buy-off; but expressing appropriate emotions of shame, guilt or compassion sends the message that the compensation is based on a genuine social relationship'. Anderson 'Lessons Learned' Inquiry report says 'a first step is for DEFRA simply to admit that government made mistakes during its handling of the crisis and that all involved are determined to learn from these mistakes'.

professionals to counsel *each other*, rather than experience the direct intervention of 'outside' health practitioners or social workers.

We have shown that the post FMD suffering is accompanied by fear of a new disaster, by loss of trust in authority and systems of control, and by the undermining of the value of local knowledge. This legacy is ominous, and one which we have endeavoured to make visible to those agencies who will read, reflect and act on our findings. Just as suffering has to be *documented rather than counted*, our conclusions imply recommendations for change mostly in attitude and emphasis, rather than the creation of new bodies or yet more specific targets and protocols. We want to argue for *more flexibility* in e.g. disaster planning, and for *less tightly coupled systems*, since such systems arguably themselves carry further and more elaborate risks as Charles Perrow in his study of risk and accidents (1999) has shown. For this reason, not all the insights provided by the research translate neatly into recommendations for operational change, however we urge the authorities and agencies who have a role in disaster management, care and recovery to assist in this work of 'insight translation'.

Nine conclusions and recommendations were drawn up in consultation with the project steering group:

1. Conclusion
Many human reactions to the disaster, such as experiencing of flashbacks; emotional triggers; life now measured by pre and post FMD events; irretrievable loss; anxiety about new problems, are *normal reactions to abnormal events.* (See Section 5, Trauma & Recovery p50)

Recommendation
Organisations in healthcare, recovery and those working on the Rural Stress Action Plan need to disseminate this message widely so that those who seek help, whether practical, financial or emotional, realise that this is because of external circumstances and not because of personal failings or pathologies. RSAP working group has contributed to the current DEFRA FMD Contingency Plan and the Haskins Rural Delivery Review to raise awareness about stress. But existing plans still talk in pathological terms, therefore the work of this Group should be extended to *develop a non-pathological understanding of trauma* as indicated in this report.

2. Conclusion
During the crisis voluntary sector helplines were inundated with distressed callers. Statutory agencies seemed paralysed by a new and complex phenomenon which they did not recognise as a 'disaster'. (See Summary p6)

Recommendation
Health, social care and voluntary organisations need to review jointly *what counts as a disaster* and how this is recognised. The definition should be broadened beyond professional definitions or what can easily be counted or measured and should include developing and long-term phenomena. In crisis situations, practitioners from all agencies need support so that they can take initiatives according to needs which they encounter on the ground.

3. Conclusion
During the crisis, voluntary sector organisations rather than statutory agencies responded quickly and flexibly to help alleviate severe practical and emotional needs. They understood that practical needs, e.g. fodder to prevent animals starving, were inextricable from emotional distress. (See Section 5, Knowledges in Context, Appendix 3)

Recommendation
Health services and voluntary sector organisations need to develop '*ways of sharing 'intelligence'* about needs. Ways to do this without breaching confidentiality should be developed. The sectors have different, but closely related roles, both during and after disasters.

4. Conclusion
Rural health services were disrupted and many patients and clients did not access help for chronic conditions. (See Section 5, Discussion)

Recommendation
***Enhanced outreach working* initiatives in rural areas would help alleviate some of the ongoing problems resulting from poor access during the disaster. Additional funds to support this should be made available through regeneration agencies so as not to damage existing provision in other areas. 'Health' and 'non-health' agencies need to work within a broad definition of health to facilitate this.**

5. Conclusion
Health consultations became more complex and lengthy during the crisis. Rural health practitioners had to improvise new ways of working. (See Section 5, Occupation)

Recommendation
Practitioners 'on the ground', e.g. health visitors and community nurses, should be consulted regularly **during a crisis to see what changes in working practices need to be accommodated (extra visit time, phone time, home visits), as it may be more effective to adapt existing networks of trust rather than draft in new 'emergency' workers.**

6. Conclusion
FMD Front-line workers were recruited at speed for the emergency. Some were transferred or seconded from existing unrelated posts, or hired through agencies/employment service. They had little or no training for what was an unprecedented situation. They amassed critical expertise, 'learned on the job', which is still not being sufficiently recognised or recorded so that it may be used in future contingency planning; e.g. veterinary; emergency planning; community health; transport; police. Lack of recognition of this knowledge has contributed to poor morale. (See Section 5, Recovery; Local knowledge and control)

Recommendation
Agencies that employed front-line workers should *make a record of skills and expertise acquired* and ensure ways to access this in future. Strategic and operational knowledge and experience about FMD should be brought together, rather than separated hierarchically.

7. Conclusion
Many respondents reported how taking part in the research provided a sense of relief and release within a 'safe conversation' (in diaries or interviews). There is little evidence of de-briefing and counselling offered to *workers* who undertook horrific tasks over long periods of time. Positive regular mental health promotion for workforces should have higher priority within the larger organisations, and be available also for sub-contractors. (See Appendix 7)

Recommendation
All agencies need to review this aspect of provision. In particular, where a temporary workforce (or seconded one) is concerned, these can be the people worst affected, but receive the least care. Great care needs to be taken over the kind of support which is offered, with *emphasis on guided de-briefing models and peer support*, rather than stigmatising or pathologising approaches.

8. Conclusion
Residents living near disposal sites have had their environment affected and changed in ways about which there is little knowledge or precedent. Anxieties

prevail, and currently the extent to which residents and communities are consulted and involved varies greatly between inclusive and exclusive practices. (See Section 5 Trust in Governance)

Recommendation

A need for *greater community involvement in disposal site management* and contingency planning more widely. Those involved in such planning (local government and other agencies) need a regular programme of outreach meetings, held within local community centres at times which most suit a working population. These need to be *strongly focused on listening, negotiating and learning, rather than 'imparting information.* Local residents may be willing to act in an advisory capacity on decision making bodies with post-FMD remits. Such community involvement may help alleviate some of the mistrust, particularly of government agencies, that has followed the epidemic and the fears about future animal disease outbreaks again becoming disasters.

9. Conclusion

Post FMD regeneration funds have been widely publicised in affected areas but the experience from individuals and small local organisations is largely negative. Small businesses have great difficulty finding their way around the recovery funding, and in some cases, feel excluded by their geographical location. There are too many 'new', unrecognisable organisations and little continuity, ironically making help seeking itself stressful. Eligibility criteria are perceived as stringent, even punitive, inviting applicants to make themselves into 'victims' to qualify, or transform their activities in ways that are alien to their purpose. (See Section 5, Trust in Governance)

Recommendation

Post FMD rural *regeneration support needs to be simplified, made more accessible and with less stringent/punitive eligibility criteria.* A greater recognition is needed of inequalities and of how differences in location may influence the rate of recovery. One-stop events, with advisors to hand can save time and anxiety. Regular events for voluntary and community groups, but which also focus on local businesses and recognise the inter-relatedness of rural economies, would create more meaningful access, than expecting applicants to struggle with complex criteria alone.

The above is a verbatim extract from the full report available on:
http://www.lancs.ac.uk/fss/ihr/publications/maggiemort/fmdfinalreport.pdf

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