SECTION IV

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IV. REHABILITATION OF PEOPLE

The rehabilitation of a population that has been disturbed by a major chemical accident, whether it be a sudden explosion like Seveso or a slow release of toxic substances from an abandoned dump, requires a type of care that few societies are at present able to deal with.

Problems that can be solved by engineering are relatively easy, though they may be expensive. For more than two thousand years our culture has solved water problems by building aquaducts, dams and dikes and draining marshes. It has solved problems of hunger by importing foodstuffs and developing better agriculture.

A relatively small fraction of modern budgets goes toward solving social problems. Except for education, which is almost entirely confined to sub-adult age groups, most of our social expenditures are aimed at improving the physical status of disadvantaged groups, the old, the poor, the unemployed. Very little is spent on attempts to improve social systems and many of the attempts that have been made have been dismal failures.

Social rehabilitation is not something that can be carried out by engineering technology. Our present state of knowledge regarding the reactions of the public to attempts to make things better is not nearly as far advanced as the ancient Romans' knowledge of how to bring water to the city. To a large extent we can still be blamed for trying to solve social problems by bread and circuses.

This does not mean that attempts should not be made to help people who are in trouble. Certainly food, shelter and medical aid are necessary for

victims of disasters whether they be chemical accidents or natural calamities. The next most important need appears to be that each victim needs recognition of his or her problems as individuals. Mass methods of relief are far less effective than one-on-one personal attention to individual problems. Such an approach unfortunately goes against all our training in ways to solve other, non-human problems. Because we have been very successful in solving technical problems by a mass approach, it is hard to plan social rehabilitation in any other terms.

1. Post emergency health care

With the occurrence of accidents involving toxic and potentially toxic and hazardous chemicals two very different aspects, concerning their effect on a population's health, should be considered:

- The accident may be visible but its effects on the population may not be. This is what happened at Seveso when a cland was visibly emitted into the atmosphere, but the pathological effects were unclear.

- Alternatively, pathological effects may be observed in a population without any apparent cause, chemical, microbial, or viral. In these circumstances, the first stage would be an epidemiological survey to pinpoint a chemical agent responsible which could explain the pathological effects observed. This situation arose in the case of methyl mercury at Minamata, Japan, and in the case of adulterated cooking oil in Spain.

When an accident occurs, the first imperative of the medical team is to take care of the victims. Rapid treatment of the sick or injured may be hindered by two major difficulties, ignorance of the toxic substance involved in the accident and the large number of victims or potential victims. These two difficulties will not only hamper the immediate care but may also adversely affect the phase of surveillance and secondary care of the exposed (or presumed) population.

In most chemical accidents, treatment of the victims is no different from normal treatment for sick patients and should be within the competence of the local hospitals. However, if the victims are numerous, the capacities of the hospitals in the area may be exceeded both technically and in terms of the number of beds and health personnel.

During the emergency phase, this may lead to actions (patient movements) likely to hamper the surveillance of the population (exposed or presumed) required following emergency care. During this period:

(a) the sick may be distributed to different hospitals geographically distant, with poorly coordinated care and surveillance, especially during the first few hours;

(b) patients without apparent symptoms may be returned to their homes without the minimum tests necessary to follow any future development of their condition;

(c) various forms of treatment may be applied without admission to a hospital and without sufficient recording due to the large number of cases requiring treatment.

These difficulties are often then compounded by the impossibility to readily identify the toxic substance(s) involved. Emergency treatment is usually essentially symptomatic, without specific tests having been made or specific samples having been taken.

Furthermore, the medical team may be confronted with the sudden outbreak of an epidemic. In most cases, its toxic etiology is unknown and the cause of the disorders observed is often related to a microbial or viral agent. As a result, the patients may be sent to hospitals with little knowledge of symptoms of toxic substances. Time is therefore wasted in sampling and testing for some bacterial or viral pathogen. It is often at a very late stage that a chemical is suspected.

As a result of this delay, either the epidemic has developed considerably or, in the case of punctual food poisoning, it subsides on its own as the source of the chemical agent is exhausted. In either case, the delay in starting the surveillance eliminates the possibility of prospective surveillance and permits only a retrospective study of what has happened. Sometimes it may even be impossible to procure the toxic products consumed for analysis.

Ideally, organizing secondary surveillance and care of the poisoned need, as prerequisites, accurate knowledge of the following elements:

- the nature of the toxic substance and its short, medium and long term hazards;

- the appropriate medical treatment, its effectiveness and possible difficulties;

- the medical facilities available (hospitals, dispensaries, physicians, laboratories);

- the budget available for that task.

In practice, implementation of a post emergency health care programme often occurs while only partial information is available (and a state of emergency still exists).

4.4. Surveillance

In any accident, as has already been mentioned, surveillance systems must be set up immediately (Foege 1980). Such systems should re-evaluate the hazardous substance and also the expected (and demonstrated) health effects.

It is obviously difficult to ascertain exactly when the emergency stops and the post emergency period begins. It is therefore advisable to set up a surveillance system as soon as possible. This is necessary to ensure that the source of the emergency has been adequately contained or if some had escaped during the emergency and is still unaccounted for.

If some hazardous material is believed to be still at large and has dispersed into the natural environment, it is necessary to determine the following:

- how did the chemical reach the environment (pathway)
- what is the probable extent of contamination (zone of contamination)
- how large a population may be at risk
- what are the foreseeable health effects
- how can the population be protected from the danger
- how can the possible adverse health effects be minimized.

The scope of the surveillance system varies with the chemical. If its health effects are already well known, it might be decided to follow-up only the exposed people for only the relevant effects, mainly for compensation purposes. In the majority of cases there is some knowledge to be gained by planning and implementing a full surveillance, i.e. including people exposed to different degrees and appropriate controls, and looking for several end points.

Depending on the type of chemical accident, surveillance of the population and the environment may be undertaken by industrial hygiene and food inspectorates or the environmental protection (and inspection) services. These may be assisted by scientific or research establishments to provide theoretical and methodological bases for the work.

The major points to be considered in planning a surveillance system are: definition of the population to be followed (exposed and controls), level of exposure definition, choice of the balance between intensive monitoring follow-up and "routine" health information system surveillance, and organizational features, including the relationships with the local health services.

Here attention will be focussed on the problem of area-wide chemical accidents (of the Seveso type). Long term epidemiological investigations of chemical accidents in closed work environments are not conceptually different from the usual investigation of other occupational exposure, for which there exists already good methodologies and experience.

In cases where people have contacted toxic substances which might lead to chronic poisoning, the diagnosis and treatment of such cases should ideally be performed by specialists familiar with industrial poisons or by poison control centre staff. Such personnel should, once again, receive the support of scientific or research oriented institutions, particularly when epidemiological studies are involved.

The length of surveillance experience depends on the more or less chronic nature of the chemical action. If oncogenic effects are suspected, the "routine" information system (q.v.) must be kept under quality and completeness control for decades. Some factors affecting any surveillance programmes are listed in Table IV.1.

1.2 Initial census

It cannot be overstressed the importance of registering the exposed population early, before they scatter or become infiltrated by people who are simply seeking compensation (Beebe 1979). However, it is not surprising to realize how seldom this has been done, because many other less essential activities are felt politically and psychologically as more important. It is absolutely essential, however, that the census taken during the emergency be carefully verified and updated.

An ad hoc census is particularly important in area-wide chemical accidents, when it should concern not only the people who have certainly been exposed, but also the population of the surrounding area. It is less important in accidents in a closed working environment, where it is likely that adequate records are available.

Only a few items of information have to be collected. A census of this type has also been defined as a minicensus, as the amount of information collected is kept to a minimum and aimed at a specific purpose.

TABLE IV.1 FACTORS AFFECTING SURVEILLANCE PROGRAMMES

1) NATURE OF THE TOXIC EFFECTS

- Information on toxicity of the chemicals involved
- Acute or chronic effects
- Effects due to direct exposure or mediated through pollution of the environment or food
- Number of cases
- Gravity of cases

2) EFFECTIVENESS AND DIFFICULTY OF THE MEDICAL TREATMENT

3) AVAILABLE HOSPITALS, DISPENSARIES, PHYSICIANS, AND LABORATORIES

Since the main purpose is to provide denominators on which to base future incidence rates of exposed, less exposed and unexposed individuals, it is tempting to ask a lot of information about the intensity and the possible sources of expositions (eating and drinking patterns, dust exposure and so on). This decision may be appropriate for a small subsample of the likely most exposed people, in order to quantify different levels of exposure among them; but it must be considered that the information given may be severely biased by the hopes of compensation or the desire to avoid guilt feeling because of carelessness.

The same problem exists when asking people about symptoms; people perceive their health in relation to what they think the exposure might have been, so that bias creeps in.

It is advisable to limit the exposure information to where the people were during the likely period of exposure (in acute area-wide accident, if they were away, e.g. on holiday, and if they moved out their office or home). In very acute episodes, it might be useful to ask also what they did during the accident, so that it might be possible in the future to determine whether certain behaviour has a protective effect.

Since for most chemical accidents, it is impossible to exclude the confounding or modifying action of occupational exposure, it might be useful to question everyone on their place and type of work. This information not only might be used to analyze better and interpret the results, but it offers other possible epidemiological research outcomes to the expensive surveillance systems, because it might throw light on other professional risks. This might increase the motivation of the epidemiologists involved in running the surveillance system, who might otherwise think that they are simply doing a post-mortem exercise with uncertain hopes of clearcut conclusions.

Taking a minicensus might also have a beneficial psychological effect for the population, if the interviewing is undertaken by members of the population who were exposed themselves (Beebe 1979).

1.3 Assessment of extent of exposure

The level of exposure very seldom may be measured with biological tests in the exposed individuals. Questionnaires, as mentioned earlier, rarely provide unbiased and accurate answers. In most cases it becomes necessary to quantify the level of exposure taking only into account where the person was and where he/she worked during the period of possible exposure.

This raises the problem of how to quantify the exposure level of different areas: chemical determination, animal morbidity and mortality and the onset of human gross pathology (like chloracne) may be all useful indicators, but sometimes give not consistent results.

In this case too, due to the difficulty of providing the sophisticated analytical method often necessary soon enough, the possibility of keeping samples of contaminated material should be considered (e.g. dust or earth), in order to be able to repeat at a later date the determinations, or to assess other chemicals previously not thought of. This is relevant only if it is possible to keep the chemicals involved in reasonably stable conditions.

Some parameters facilitating the assessment of exposure are listed in Table IV.2.

1.4 Biological tests

It is not uncommon to invite large groups of people to give blood or urine specimens, and to perform on them a large variety of biochemical analysis without having paid due attention to the problem of quality control in the laboratories involved. Some of the tests performed (occasionally expensive) may be useless or at least not the best ones for that particular accident. This approach has several disadvantages.

- Blood samples or biopsy specimens are not likely to be obtained for some ten thousand or even a few thousand people; the group examined will not be representative and may be biased to an unknown extent with people who had already had, before the accident, psychological or physical symptoms.

- The lack of laboratory quality control, especially if several laboratories are involved, jeopardize the reliability of results and make their interpretation difficult if not impossible.

For all these reasons, the following may be recommended:

- focus efforts in obtaining compliance of all members of a relatively small population including people with different levels of exposure. This obviously does not apply when biological tests are used to directly measure the degree of exposure (e.g. serum lead concentration analysis);
perform immediately only tests of clear short-term utility;
implement a comprehensive quality control programme;
freeze and store biological specimens, each in at least two separate containers, in order to be able in the future to perform tests both of better quality and with clearer indications (e.g. to compare differences between people who eventually may develop complications with those who do not).

It may also be useful to store tissue specimens (e.g. adipose tissue) taken at random from surgical operations.

1.5 Re-evaluation of initial diagnosis and treatment strategies

As in all medical care programmes in "intensive care units", the course of treatment has to be constantly re-evaluated on the basis of results. This of course requires a team of experts who can evaluate the results objectively. If warranted, strategies of treatment should be modified.

TABLE IV.2. PARAMETERS FACILITATING THE ASSESSMENT OF EXPOSURE

- Clinical effects observed
- Measurements of the released substances in biological fluids
- Measurements of disturbances in biological fluids
- Measurements of the released substances in the contaminated products
- Pattern of chemical release

The decision to continue or terminate or change the course of treatment will rest upon the evaluation of results. When hospitalization is discontinued, the patients must be advised to report to the unit periodically or at least their location should be known so that they can be tracked for any unexpected manifestations. When treatment at home is suggested, schedules of treatment and a supply of medicine should be provided.

1.6 Re-assessment of health effects

Monitoring and surveillance are indispensable components of the process of rehabilitation. The need for this is discussed more thoroughly in the sections dealing with monitoring and feedback of information. It is expected that more and more information will be fed back to the treatment process by the monitoring units. New health effects noticed, if any, or side effects of medication uncovered will have to be assessed and appropriate remedial action initiated. Besides clinical toxicological studies to evaluate the fate of the delayed response chemicals on the victims, animal experiments may have to be initiated to determine the mode of action, biotransformation and disposal. Besides studies using blood, saliva, urine, sweat or semen for detecting either unusual changes in body's chemistry, sensitive and sophisticated analytical techniques may also have to be developed.

The cumulative effect of a chemical product is important to determine so that unknown effects could be discovered.

There are several situations, each requiring a different approach. For example:

The main health effects of the chemical well known:
Similar accidents may have taken place in different areas around the world and cases, well monitored, have been published. This is the easiest situation. The team, along with experts, may then decide to follow the published rehabilitation procedure.

The main health effects not well known (acute):
Experimental data show some acute toxicity with no chronic toxicity. Surveillance should be carried out continuously for 2 to 3 months followed by annual examinations on certain patients.

The main health effects not well known (chronic):
Experimental data show a chronic toxicity. Long term monitoring and epidemiological studies are required.

1.7 Post-emergency medical care

Medical rehabilitation follows directly from emergency care to whatever extent of recovery is possible for each individual patient. It is conceivable that an appropriate treatment for mercury or cadmium in the soil might be to supplement the diet of the area with selenium, analogous to the use of iodized salt in goiter areas. However, such a treatment would be very difficult to institute in modern cultures and could lead to societal repudiation. Medicine does its best work by the one-on-one system and even if the strictly medical aspects are essentially ineffective personal attention from the doctor and others concerned can have great healing effects.

After the emergency phase is over, the treatment covers several areas

- treatment according to symptoms of a pathology initially caused by the toxic substance, but which later develops on its own. Such is the case, for example, of kidney deficiencies, skin or neurological pathologies. According to the pathology, its severity and its spontaneous evolution, this treatment can be of short duration or, on the contrary, extend up to the end of the patients' life.

- changing the elimination process of the toxic substance by facilitating this elimination by means of chelating agents. But this form of therapy is not necessarily satisfactory for all cases.

- discussion on, and eventually termination of pregnancy in cases of high foetal malformation risk.

This medical care however should not be the only remedy to an accident caused by chemicals. In fact the very first consequence of an accident like this is a surge of panic among the population, after monge by contradictory information given by the mass-media. The fears of the population often exceed the actual risks stemming from the accident. Pos emergency care therefore has the added responsibility of giving clear information to the population in order to play down the dramatic side of the accident's consequences, and that of supplying precise details on th pathology which could appear. The aim of this would be for a population to keep a watch on itself and to get in touch with the medical professic if even an abnormal phenomenon appears.

The treatment following the emergency phase should still be the r ponsibility of the medical staff normally performing on the site of the accident, in order to avoid indue anxiety among the population.

1.8 Intensive monitoring versus "routine" health information system surveillance

Intensive long term comprehensive clinical monitoring of wide groups may not always be an appropriate approach (Table IV.3), although

necessary for the occupationally exposed people and for individuals who had shown early signs of intoxication (e.g. chloracne in organochlorinated compound accidents). It is certainly appropriate when there is epidemiological evidence that early detection procedures are effective. However, it might not be really necessary in the absence of suitable evidence.

Programs with a strong clinical emphasis should be sanctioned only on the basis of a cost-benefit analysis, when a suitable medical monitoring programme has been deemed necessary.

A good strategy might be as follows:

1) Merge the special clinical monitoring system as soon as possible into the normal local health services, except for the categories and circumstances already mentioned. Efforts should be concentrated towards restoring and improving such services, without creating a parallel system. Collaboration with local services is very important and has to be built up between local physicians and the epidemiological team.

2) Intensive clinical follow-up might be limited for research purposes to small selected groups of heavily exposed people and suitable controls. It is worth repeating that only proven screening techniques should be performed on a wider population.

3) It is essential to establish as soon as possible a health information system so that basic end points might be provided on a routine basis.

1.9 Health information system (cohort studies)

According to the magnitude of the accident, the kinds of hazardous agent action and the state of information on the biological effects of exposure, the need to undertake epidemiological cohort studies may arise.

TABLE IV.3. INTENSIVE MONITORING VERSUS "ROUTINE" HEALTH INFORMATION SYSTEM SURVEILLANCE

1) THE CHOICE IS GUIDED BY:

- Number of individuals presumed to be exposed
- Existence or absence of clinically or biologically visible pathology
- Information on the toxic effects of the substances
- Acute or chronic nature of the expected disorders

2) INTENSIVE SURVEILLANCE

- Possible if the number of exposed individuals is low
- Indispensable for all persons suffering from an initial pathology
- Indispensable for all pregnant women
- Indispensable for highly toxic or not well known chemicals

3) "ROUTINE" TYPE OF SURVEILLANCE

- The only solution when a accident involve a large population (could be combined with intensive surveillance in a test group)
- Could complete the intensive surveillance in a sample group
- Could follow intensive surveillance

The procedure in epidemiological cohort studies should not differ from the generally accepted scheme i.e. should allow for three basal phases of this type of study:

- A planning phase spelling out: the objectives of the study, premises, assumptions, detailed hypothesis, methods of variable measurement, definition of population subject to the study, justification of the methodology of studies, verification of results of studies, evaluation of completeness of material, selection of control group, plan of statistical analysis and plan of setting up the studies.

  In the planning phase, an analysis to eliminate systematic error and to determine the magnitude of the incidental error should be carried out.

- Field phase - should include pilot study along with verification of the methodology of the study and plan of setting up the study. It should lead to unification of the methods applied. The field phase terminates with the obtaining of results of full epidemiological study and the transfer of the data for elaboration.

- Phase of elaboration of the results of the study relates to statistical analysis of the data collected during field phase, comparing the results with the present state of knowledge and the formulation of the conclusions.

The main sources of end points for the populations defined as the cohorts to be followed-up will be hospital discharge data and mortality data.

If not already present, a hospital activity analysis, with individual forms completed for each in-patient, should be introduced in all hospitals of the affected area. Such forms should be completed also for people resident of the area admitted to hospital located outside.

If reproductive damage is suspected, special attention should be paid to birth, early death notification and abortion information systems.

As far as mortality data are concerned, the importance of having a local (or, better, regional or national) central register where all death certifications are collected and checked, cannot be overstressed.

Morbidity, malformation and cancer registries may also be created depending on the outcomes suspected. Input data for registries should also come from normal health services.

Special provisions anyway will be necessary to stimulate completeness and accuracy of reporting. This is already well known for morbidity registries but applies also for mortality and hospital discharge data.

Most of the hospitals today have some form of registries of health records of patients admitted and discharged. In principle the system can be adapted to the needs of recording data on rehabilitation. The records are mostly based on questionnaires and as such the questionnaires must be properly designed, allowing scope even to record and quantify subjective statements made by the victims. The personal dossier of every patient treated is bound to grow in size and hence there must be a system to retrieve the information. There is considerable expertise available on computerizing data of health care in hospitals and this must be utilized to evolve an adequate register.

Accidents in factories are reported and recorded in some countries by the factory inspectorate system required under legislation for labour welfare. National safety councils operating in some countries maintain their own records of accidents. All this experience should be used for constructing a useful register.

Since long-term rehabilitation programmes are expensive and the funding agencies would expect accountability from the rehabilitation team, it is essential to evolve an objective reporting system where the experts make unambiguous statements on the performance of the rehabilitation programme.

1.11 Organization

a) An epidemiological team with local physician representation should be made responsible for the planning, implementation and analysis of the cohort study. The separation between the epidemiologists who plan the study and the ones who do the work on the field has proven to be counter productive. At least one member of the team should have practical experience of health information systems; the temptation must be resisted to give too much importance to techniques. Surveillance plans can be slowed down and confused by gradiose computer programmes. Since epidemiologists with practical experience are rare in some countries, it is suggested that an international research agency is identified where initial advice and help might be obtained. No existing international agency at present seems to have all the required expertise.

b) Any intervention programme should recognize the normal services of an area and try and help them to re-establish full responsibility for routine diagnosis and treatment following the emergency phase.

External agencies might continue to be involved in: a) training and re-training activities; b) helping to conduct clinical trials of new therapeutic agents of uncertain effectiveness and toxicity; c) following specific research studies of selected groups of people in which relatively sophisticated special tests have to be made (e.g. nerve conduction measurements, chromosome studies and so on).

c) Adequate importance should be given not only to the collection and quality control of epidemiological data, but also to their statistical analysis. Statistical results, if obtained in good time and communicated widely, will do much to increase the credibility of the surveillance system and in most cases also to allay the anxiety of the population involved.

A slow chart showing a possible organisation scheme of post emergency health care is shown in Fig. IV.1.