PROPOSAL FOR AN OSTEONECROSIS REGISTRY IN THE UNITED STATES

H. William Gillen

Is a registry needed for aseptic bone necrosis and or for people who dive professionally? If so, where will the information come from, and then, who will pay for collecting and recording it?

The population at risk in the United States, combining professional divers and caisson workers, is perhaps 5000 men. While the number is not known precisely, it is small compared with the numbers in other industries who are exposed to similar occupational hazards. This disparity must be considered, because there is only a certain amount of time and money available to be spent in collecting data on a single group of individuals for any one purpose.

What kind of information is needed to set up a registry not only of osteonecrosis but also of employment experience in a hyperbaric environment? The person must be identified and his past medical history recorded. Because there is still no general consensus on the etiology of osteonecrosis, many factors will have to be considered so that the reasons why some people get "bone rot" and others do not may eventually be defined. Much initial information will have to be recorded.

In the United States, as is known, such information is confidential and, under normal circumstances, may not be released for public use or even analysis by the individual or organization holding the records. However, under the Occupational Safety and Health Act of 1970, it is possible to require the release of certain information. Perhaps the conditions for release could be expanded to improve the usefulness of the registry.

From a toxicological point of view, much round-figure epidemiology must be considered. Since one does not know what answers are sought after, an almost unlimited number and variety of questions must be asked. Data entries for storage purposes must be broad enough so that information of possible future use will be available.

What benefits might accrue from such a registry? First of all, it might be possible to describe the two groups primarily exposed to hyperbaric pressures — professional divers and tunnel workers — with greater accuracy than is now possible. It would then be known how many people are employed in these industries, what their jobs are, what risks they are exposed to, and what the consequences are of these exposures. Members of the professional diving industry state that their insurance rates are at the maximum because no real information exists to describe what the risks actually are.

The factors or combination of factors causing injuries under hyperbaric exposure are a second kind of information that such a data bank might yield. If the data are adequate and flexible, it should then be possible retrospectively to determine some of the causes related to injuries. There must be good descriptions of the working environments, working conditions, and work experience to make this sort of data bank at all useful.

In the United States at the present time, these data would essentially have to be provided voluntarily, which means that one cannot get the information. It must therefore be collected by regulation and made a requirement of employment. It must then be filed at some central point, so that it can be collated, analyzed, and evaluated. If the information were filed in regional offices, the result would be a dozen different offices doing the same thing. For a bone survey, for example, a man would not receive an employability certificate until X-ray films had been made and filed at a central registry. This approach will probably be necessary if such a registry is to be of any use.

If the data were collected by some form of regulation, there must be some way of protecting and restricting their use by the central registry. Perhaps some of the ideas basic to no-fault automobile insurance could be incorporated. A

major prerequisite is that there be employer protection, such as has been extended to mine operators with respect to their employees. Under the federal Coal Mine Health and Safety Act of 1969, the employee is advised if pulmonary lesions are discovered roentgenographically. He then must be moved to a less hazardous environment, above ground, which the employer is obligated to do by regulation. When certain types of abnormalities are revealed by roentgenogram, the miner is automatically pensioned. The whole system is spelled out in the regulations, with the intention of eliminating lawsuits. By contrast, in the diving and tunneling industries at the present time, the employee discusses such matters with no one except his lawyers.

In answer to the first question: yes, there should be a registry, because there is a definable population at risk in a hazardous environment that can be reasonably well described. The population is small enough that a manageable body of data might well supply a variety and quality of information not now available. We have the opportunity at this moment to do something about it.

The second question, "Who will pay for the registry?" must remain, for the present, unanswered.

DISCUSSION 10

Dr. ELLIOTT: Thanks to the initiative of Dr. Jones, a decompression–osteonecrosis data bank for divers was discussed recently in Houston. It was concluded that two separate programs were needed: first, a simplified version, not aimed at perfection, for those who already have some experience, because past history is necessarily unreliable; and, second, a lifelong diving profile on novitiate divers, aimed at completeness. One might hope eventually to have some records on a very few divers over their entire careers. Then one would be able to make a very good retrospective study indeed.

Dr. HARVEY: One group being neglected in discussions of a central registry is the huge number of amateur scuba divers here and abroad. As we learn from a data bank what the risk criteria are, we shall have to educate the public. Some long-range goals of information dissemination are thus inherent in the idea of a central registry.

Since such a diverse group of divers is affected, I think a central registry almost has to be associated with either the Department of Labor or HEW, both of which would have a vested interest. There are several data-collecting centers in the United States — for example, the Navy Diving Accident and Injury Bank at Norfolk and the International Decompression Data Bank at the University of Pennsylvania. But none is ideally suited to establish an osteonecrosis registry (nor, probably, is interested in expanding in that direction at the moment). To get the necessary legal and monetary backing to establish a central osteonecrosis registry, then, a federal agency will have to be associated with the project.

Dr. SEALEY: I have had some experience with the problems associated with the Coal Mine Health and Safety Act of 1969. The Appalachian Laboratory for Occupational Respiratory Disease does have such an organization. Although it could not perhaps legally undertake this project, its methods of identifying, classifying, and recording X-ray findings on computer-readable forms might be of use.

Dr. JONES: Several interested parties from both public and private enterprise attended the small Houston conference regarding a proposed decompression–osteonecrosis data bank. The conclusion was that a data bank established in the United States, with multidisciplinary and international cooperation, would be advantageous for several reasons.

There is a need for reliable liability information concerning the risks of developing osteonecrosis following exposure to dysbaric phenomena. For example, I understand that during construction of the third tube of the Lincoln Tunnel in New York, substantial compensation insurance premiums were paid for every $100 the compressed-air workers received in wages. In the Milwaukee project, I understand that the cost of compensation insurance has become almost prohibitive. For the BART project it was necessary for several insurance companies (Transit Insurance Administrators) to collaborate to underwrite the substantial industrial liability.

I also understand that there is a significant liability problem with private diving firms in the United States. If legislation or incentives of a preventive-medicine nature are established by the Department of Labor or HEW, it will be necessary to convince private diving firms of the advantages of such a registry.

As Mr. Galerne has pointed out, divers employed in navigable waters are considered seamen under the Jones Act and can sue their employers for negligence, rather than accept workmen's compensation benefits. There-

fore, I think we will have to start first with novitiate divers and compressed-air workers, who may constitute the first group to have compulsory, comprehensive preemployment examinations, as Dr. Elliott has suggested. If complete examinations were performed on employees of private diving firms and several lesions were found, the liability of these companies would be substantial. Because the pay scale for experienced divers is also substantial, phasing them into vocational rehabilitation or a retirement program on disability pensions would be quite expensive.

If a decompression–osteonecrosis data bank is established in this country, I believe a consulting group patterned after the MRC Decompression Sickness Panel, which has functioned so effectively in Great Britain, should be formed. Possibly we could become the American arm of the MRC group. This would mean that perhaps quarterly or semiannually the data-bank consultants would meet and review questionable cases and possibly help adjudicate compensation awards. Insurance companies might also participate and, hopefully, insurance premiums would be reduced.

Dr. McCALLUM: All one can say is that the possibility of close liaison in handling information such as this would be most welcome to us in England. I might add a point about disability pensions in England. We have industrial injury benefits, which last for six months. These benefits are distinct from the life pension that may follow in cases of permanent occupational disability.

Dr. Gillen made the point in his presentation that the many factors involved in necrosis make it difficult to decide what sort of data one wishes to collect. We have encountered this problem in determining how much detail should be included in the medical examination of divers or compressed-air workers. There is some danger of flooding oneself with data, with the result that whatever is useful might be completely buried. While the information that we are gathering may seem rather restricted, we are only trying to protect ourselves from being submerged in masses of tables.

Regarding legislative action, we in England have set up our registry on a voluntary basis; one reason is the enormous time lag between deciding if legislation is needed and getting it enacted. We got a bit fed up with talking to officials about revising our compressed-air regulations and took another tack. We are now talking in practical terms about codes of practice.

The basis of this approach is to get professionals in the field to agree to basic minimum standards much higher than government agencies would normally set. Then there is a fair chance of pushing through certain standards as accepted practice. Among these is the use of radiographs of major joints in preemployment examinations. It is already routine for U.K. divers, and we are hoping to persuade civil engineering contractors that it is part of the job to have men X-rayed before they start work.

Legislation may come later, but I do not see how it can ensure follow-up films. Once a man has left a contract, how can one make sure by law that he has his bones X-rayed in two years' time?

Amateur scuba divers present a real problem. We have some contact with them and we will keep information on them in the registry. But they are such unpredictable people that it is difficult to get useable data.

One point that I want to emphasize is the difficulty involved in framing legislation on occupational standards which will ensure the acquisition of data on the problem of osteonecrosis. I suspect that you will have the same troubles in the United States that we encountered in England. When I was here in 1952 there was great pressure to get legislation passed to protect coal miners' health, and it has taken until 1970 to effect it.

Dr. WALDER: As Chairman of the MRC Decompression Sickness Panel, I should like to say that I feel a bit like the young lady who goes out with her boyfriend and instead of being raped receives a proposal of marriage — it is a very pleasant surprise. Of course we would be delighted to help you in any way that we can. I think it is a very good idea because we can each benefit from the other's experience.

I should also like to emphasize what Dr. McCallum has said about legislation. I have a rather gloomy regard for it. Legislation always seems to be terribly cumbersome; and once it's done, it's there for many years. Everyone is loath to alter it in any way. In Great Britain some of us have recently started trying to avoid the need for further legislation by introducing codes of practice. One for diving has just been published, entitled *Principles of Safe Diving Practice*, and another is being prepared *(Medical Code of Practice for Compressed Air Workers)*. The idea is to make it clearly known what should be done. Then, it is hoped, those who do not comply with the standards will be sneered at and, even worse, may suffer in a court of law if action is ever taken against them for negligence.

Mr. FARAH: I represent the International Association of Professional Divers, whose membership numbers somewhat over 400. We have been looking toward some kind of licensing of divers, such as has been discussed here, and of course we would very much like to see something done to stop necrosis. But anybody who has been around our profession at all knows that relations between management and employees have been rather strained, to say the least, over the past few years. It's fine to go around surveying divers for medical and research purposes; but I do not think you are going to convince them that these are the sole purposes for which the information will be used. Divers have seen too many instances when such information has been used in ways other than for their benefit.

Dr. MILES: Our labor unions seem to think that requiring preemployment roentgenograms is like making a man testify against himself. Unions and other organizations in this country would be strongly opposed to preemployment examinations.

Mr. GALERNE: We also face the cost of this physical inspection. Many divers move around from one company to another, and one cannot X-ray every man who is to be employed for only a few days. As an example of another problem, we have in New York absolutely nobody within a radius of maybe 200 miles who is able to look at our X-rays and say definitely if they are all right or not.

In this Symposium I have listened to you gentlemen talking about whether a problem does or does not exist; even *you* do not always agree. If I have a problem some time and go to you, will you give me a positive yes or no? If you say "maybe," I have no choice. I cannot engage the man. He may have a family and need work; but if I give him an X-ray and then take it to somebody who is not sure, I must protect myself and say no. This is a human problem, too. I think we need to work on prevention, because you have not yet said to me what I must do to avoid injury.

Dr. PURDY: We are presently using some of the West Virginia computers for the storage of data in our current occupational health survey of coal miners, and I think the unions are beginning to trust us. NIOSH expects to get its own computer, so we could treat any available osteonecrosis records as confidential. I might add that the amount of data to be stored is less of a problem than actually getting it into the computer. With modern computers there is plenty of space; but you have to figure out

how to get the information into storage easily, which may mean using special forms.

Dr. McCALLUM: I think it is quite clear that we must have some sort of central system, from the employer's point of view as well as from the man's, because he cannot be X-rayed by all and sundry every two or three days. Underlying this discussion has been the different social backgrounds in Britain and the United States. Our unions have a different approach. Compressed-air workers have no specific union in Britain, but the unions representing them do not oppose preemployment examinations. They take the view that such measures are designed to put a man in the right job, depending on his physical capability.