SKIN FAILURE AND LYMPHEDEMA*

Lymphedema is largely a cutaneous problem and the gross deformity that causes such severe disfigurement is an example of skin failure. The World Health Organization concept of “Health for All” includes physical and mental well-being, which means contentment and confidence. In the Proceedings of the 10th International Congress of Lymphology held in Adelaide in 1985, I was responsible for coordinating the section of the Consensus Document devoted to “Goals of Treatment and Criteria of Success or Failure” (1). The concept of the Greek ideal of beauty “The Confident Nude” as someone whose condition was so improved that no external supports were needed and who was confident that the condition would not return was debated. More recently, as a member of the International Committee on Dermatology, I have been concerned with the problem that the documents from the World Health Organization concerned with “Health for All” include very little about the skin. A series of chapters under the heading of “Healthy Skin for All” (2) have therefore been prepared on behalf of the International League of Dermatological Societies. These are aimed in part at providing advice to those who have an influence on the provision of resources. It takes into account that all Health Care professions now have to be more concerned with prevention, they have to look at quality, and consider the poor, women versus men, vulnerability or susceptibility to diseases like infections and cancer, and they also have to look at good practice. The latter includes the efficacy of treatment, safety issues, the satisfaction of patients and the cost of therapy. One has to examine those treatments which are locally available at low cost, many of which may be traditional health systems.

In the content of World Health Organization documents, one has to consider “Disability, Impairment and Handicap.” In this context, one is talking about loss of function. We all know about heart failure, respiratory failure, liver failure and failure of other organs, but in general, no one speaks of skin failure. Most textbooks consider the functions of the skin as protection, containment of body fluids, thermoregulation and sensing the environment. More recently, major textbooks (3) have included the important function of “Display” and contemporary good management of, for example, a sick child with generalized skin disease in whom septicemia, prerenal failure, loss of body temperature are a threat to life, will examine the special needs of the child, which will include the ability to play. In the case of a child with severe deformities due to congenital lymphedema, there is recognition that in order for the child eventually to achieve its potential, there has to be confidence in appearance, and probably the most important occasion to effect such confidence will be the first introduction to a new class at school.

Vulnerability is an important problem. As I wandered round the streets of Recife, I

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noted albinos who have no pigment and are at risk for ultraviolet irradiation. The many albinos in Tanzania where dermatologists are trying to provide care for 170,000 of such sufferers, are an example of vulnerability. Because they look different, they find themselves in a lower social strata. They are more exposed to environmental factors and most die of skin cancer due to the effects of the sun.

Other examples of vulnerability familiar to Dermatologists are the wear and tear in people susceptible to hand dermatitis, and these include the cracks, the abrasions and infections of the skin so common in the legs of patients with lymphedema. Easy blistering, as in epidermolysis bullosa, may also be seen in edema. Perhaps the most well known disease in which there is vulnerability is leprosy. Because of loss of sensation, the hands, the feet and the eyes may be severely affected, but even in this disease, the management has to take into account that leprosy is a prototype for stigmatization and rejection by society. There is no disability worse than to be unwelcome.

The measurement of disability can include assessment of manual dexterity or the distance someone can walk. It should be realized that someone with sore feet can walk less distance than someone with no feet at all who has a good prosthesis. The simple maneuver of cutting toenails may solve a problem of not being able to wear shoes, just as the wearing of glasses may solve the handicap of the short-sighted or those who are aged with failing vision. Other modalities that should be considered are pain and itch, and especially important in the case of lymphedema is the problem of odor, which can be easily remedied in some cases and may be the only problem that the patient wishes to have treated.

In contemporary society, resources for the management of illness are most likely to be provided if mortality has to be prevented. In the case of chronic disablement, as may occur in lymphedema, patients may die from septicemia or malignancy, but this is rare. However, one should also take into account that patients who are disfigured are often poor and their social status falls. This has an effect on themselves, their families and on their community. One consequence is an increase in infant mortality and of reduction in life expectancy within a community in which there are a greater number of the disabled.

If one addresses the problem of handicap by seeking information from the patients themselves, one finds that it is often the treatment provided by the physician or surgeon that creates the greatest handicap. One should not forget that a prosthesis can be a problem for some people. One should not forget that bandaging, which so often badly done, can create many more problems and is always something of a handicap. If one insists that the patient spends much of the day making a career of their skin, even, for instance, simply taking exercise may interfere with their job potential.

In the field of Dermatology, the Dermatologist has now become much more aware of the disfigurement resulting from inadequate surgery and the creation of bad scarring is unacceptable. This, too, needs to be considered in the management of lymphedema by surgical techniques. One has to understand that to look good means that one feels good and has greater achievement. In the management of patients with lymphedema by operative versus non-operative means, one may have to take into account the fact that non-operative therapy is prolonged and that skilled masseurs, intermittent positive pressure pumps, and even bandages, may not be affordable.

When one examines events in life which are important, going for a job may be one, getting married will be another, and in terms of economic potential, being qualified, being available, competing, and even having confidence at an interview has to be taken into account. If one examines the modalities of expressive disability, such as embarass-
ment, anxiety, confidence or depression, each of these are amenable to therapy, but one should also remember that about one-third of all patients if asked about their disability, will not admit to any handicap. Enforcing treatment on such people may handicap lives that otherwise were surprisingly unaffected by their disease.

One of the reasons for insisting on the language of disability is that it is marketable. Concepts such as the Greek ideal of beauty which is “The Confident Nude” or of skin failure, or even recently, the importance of healing and repair emphasized by Wound Healing Societies, creates a language which Dermatologists have found marketable. I have heard three Ministers of Health give excellent talks using the language of wound healing, and so I believe that in managing lymphedema, one should use a language which draws attention to the fact that they may not be able to walk very far, they may not be able to use their hands, they may be unwelcome in society, and they may find that their treatment is a handicap. One needs to make them more welcome in their society, only if their community is isolating them. Nevertheless, “The Confident Nude” is an ideal which should be understood in this competitive world in which the disfigured can lose a great deal. Here in Recife, we are concerned mostly with lymphedema that is a consequence of filariasis. The 5th Report of the WHO Expert Committee on Filariasis (4) ends with several recommendations. The first of these is that there is an urgent need for studies that will help to determine the public health importance of lymphatic filariasis in different endemic countries. These should include investigations of the psychological and social impact of the disease as well as of economic consequences. This recommendation is more-or-less the same as the recommendation made ten years ago for lymphedema in general at the 10th International Congress of Lymphology in Adelaide, 1985.

REFERENCES


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