

REHABILITATION AND SOCIAL PARTICIPATION
AMONG LARYNGECTOMEES*

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I am very pleased to be here for the opening of this International Conference of the Laryngectomees' Organization: General Meeting of the Asian Federation of Laryngectomees' Association, Tokyo. Let me congratulate everyone present for helping to make this event happen. I also feel very honored to be given the opportunity to share my comments with you now.

First of all, let us take Japan as an example. According to an estimate based on the number of participants in the Japanese Federation of Laryngectomees, as well as the 1981 investigation undertaken by Dr. Umataki and his colleagues¹⁾, there were 6,800 laryngectomees in Japan at that time. Especially recently, added to simple laryngectomies, there has been a huge increase in the number of operations which involve tumors of the hypopharynx as well as pharyngo-laryngo-esophagectomies and every variety of plastic surgery. In fact, operations of every sort are increasing substantially, so that there is every likelihood that the total number of both laryngectomies and related operations will continue to increase noticeably. The estimated number of laryngectomees at present in Japan is over 10,000.

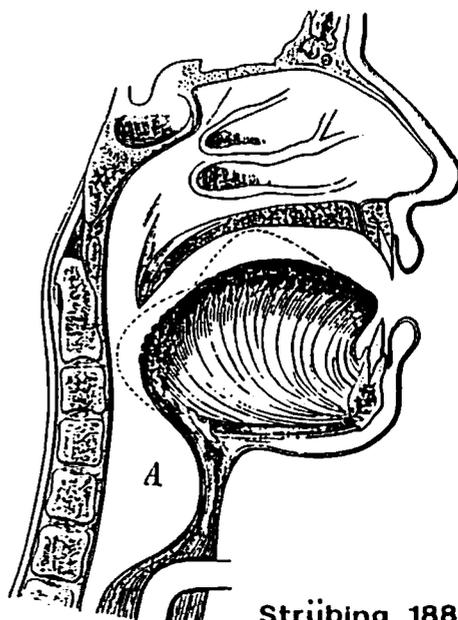
After having a total laryngectomy, various problems arise from a medical standpoint. Among these, the rehabilitation of the voice-producing function is especially important in terms of the patient's social life. In our "information society", this problem has great significance I believe.

Now, let us take a moment to look back into history. Laryngectomies were first performed in the latter half of the nineteenth century. According to the records, the first laryngectomy was performed in 1866 by Watson. The operation was carried out because the patient was having difficulty in breathing due to laryngeal syphilis. The first certified laryngectomy was carried out on a laryngeal tumor, as announced in 1873 by Billroth. He had already become famous as a surgeon who had formulated a new way of operating on the stomach. At that time, surgical laryngectomies had not yet been perfected, though. It was not until 1912 that two Germans, Gluck and Sorensen, perfected the operation which we use today.

On the other hand, as for the first alaryngeal speech, Czermak reported in 1859 that speech could be produced in the form of a buccal whisper even when the larynx was completely blocked due to severe inflammation. Following a total

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laryngectomy due to laryngeal tumor, the possibility of making utterances by breathing air into the esophagus was first reported in 1888 by the German Strübing. Looking at the diagram of his paper (Fig. 1), it seems that air was basically held in the hypopharynx, and that it was also possible to use air in the upper esophagus for voice production. In the 1890s, there are other reports by scholars of voice production using air in the esophagus. It is clear that after Billroth's report, it was only a matter of a few decades before this subject of esophageal speech attracted wide attention.



Strübing 1888

Fig.1 Original figure from Strübing's paper. "A" indicates an air-holding space for voice production.

The key to the rehabilitation of today's laryngectomee is undoubtedly the promotion of esophageal speech. But here it must be emphasized that this success depends on, in the case of Japan, laryngectomees participating in the social activities of the local chapter of the Japan Federation of Laryngectomees. Of course, to facilitate the acquisition of alaryngeal speech following the operation, special techniques may also be used during the operation. For example, the provision of a tracheo-esophageal shunt; every kind of plastic surgery as well as voice prosthesis; and all kinds of artificial larynges are available. However, considering the convenience of vicarious voice and the quality of the voice sound, there is no doubt that esophageal speech has a great advantage over all other methods. According to Takahashi's recent investigation²⁾, the most frequently used alaryngeal speech is esophageal speech.

However, I think it is most important to emphasize here that regaining speech ability depends entirely on the will power of the laryngectomees themselves. If we investigate actual conditions, for which we find further support in Takahashi's research, it is clear that it is almost always members of the local laryngectomee groups who most often provide instruction in esophageal speech. Here I would like you to appreciate the terrific power that cooperation makes available to members of the laryngectomee groups.

Now I would like to return to my original point. Let us reconsider the ideal of rehabilitation. Rehabilitation essentially means the restoration of rights, honor and, generally speaking, the restoration of something to its original form. In the America of the 1920s, the vocational training of the disabled

was connected with medical problems. Then in the 1940s, rehabilitation was defined as the restoration of their physical and emotional, as well as social and financial, power or independence. Especially following World War II, the ideal of people having a right to live in a human way was established. And, from a medical standpoint, what had formerly been "medical treatment in terms of illness" became treatment of the patient as a person and became a "medicine for the restoration of rights". In this way, the definition of rehabilitation medicine was changed.

If we summarize the meaning of "handicap", we can draw a relationship between various levels of symptoms and impairment as shown in Fig. 2.

In the case of a disease, the primary disability is the functional or organic impairment. Next, because of this, the person is not able to participate in normal activities. This is disability, the second form of impairment. As a result, there is social disadvantage. That is the order I suggest. In short, first the patient suffers a laryngeal tumor. Through a laryngectomy, s/he loses her/his larynx. This is the first stage of impairment. Secondly, because s/he is unable to speak, various other impairments occur.

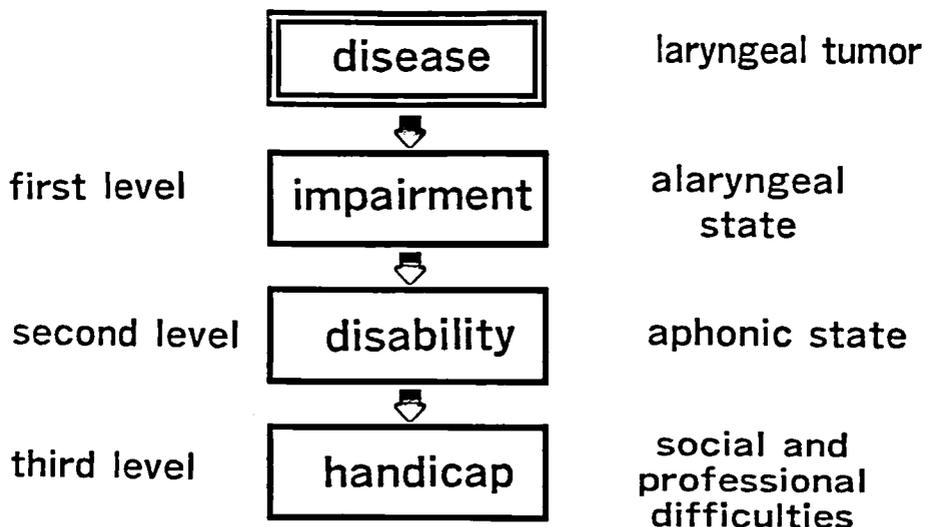


Fig. 2 Three levels of impairment.

If we divide these levels in this way, we notice that there are three separate and independent forms of disability. For example, even if the primary impairment does not change in nature, a change in meaning can make a significant difference in the way it is perceived. I think that it is easy to understand that solving problems of social disadvantage (the third form of impairment) depends on the patient exploiting his/her compensatory abilities even without attaining the full recovery of the secondary impairment to its former state of operation.

However, if we think of the rehabilitation of these conditions in broad medical terms, we find that it must be quite a comprehensive education composed of training based on functional re-education, learning new patterns of sports, developing compensatory abilities, building up physical strength, and, furthermore, establishing a stable mentality based on a good psychological and spiritual attitude so that the patient is determined to achieve rehabilitation. It is not enough for the patient to be a passive receptor. Rather, the patients must take the initiative and assume the responsibility for their own rehabilitation. In short, each patient must reclaim his/her rights. This must be the final goal.

If we take this as our ideal of rehabilitation, patients or disabled people are no longer just those who require care. They become independent individuals who must be seen as having great value to society and who are able to participate in society alongside normal people. The year 1981 was made the International Year of Disabled Persons and its slogan, "Total participation and equality" still has a new ring to our ears. The idea of the patient's rehabilitation is clearly the fundamental principle supporting this slogan. As I have mentioned above, the Japan Federation of Laryngectomees strives for a spirit of self-rehabilitation, as one's own restoration of his/her individual rights.

Of course, we cannot deny the existence of the third form of disability -- social disadvantage -- which the laryngectomee suffers. On this point, even when we look at the survey conducted by Hirano et al.³⁾ through a questionnaire given to the 1,000 members of the Japan Federation of Laryngectomees, we find that almost 90 % report some inconvenience in daily life following their laryngectomy. The same investigation shows that many members had to change jobs following their operation, or that there was a significant drop in income. This disadvantage is due to a communication handicap based on the inability to speak. This situation is especially prevalent among those who used their voices extensively before the operation. It is no surprise, therefore when we look at the rates of successful vicarious voice production to find that these same people felt more compelled to restore their voices to pre-operation functionality, and that their rates of success were the highest.

We clearly want to include a return to family life for housewives as part of "going back to work", but today let us

limit our discussion to the problems which men in Ginreikai, the Tokyo branch of the Japan Federation of Laryngectomees, have faced.

One survey investigated the amount of social interaction of men who completed esophageal speech training. In the case of those such as salaried workers and public officials who had ample opportunity to speak while at work, and also, because they were in intermediate or higher esophageal speech training classes and had the ability to participate in social activities, the results of this survey show that more than 51 % of Ginreikai members were able to practically participate in society. If we consider that more than half of the male members of Ginreikai are over 60 years of age, the rate of social participation is comparatively high. Furthermore, to give a good example of self-reliance and cooperation, more than half of the 40 members of Ginreikai who enthusiastically volunteer as instructors of esophageal speech also hold down their own jobs.

There should be no need to repeat that the primary goal of rehabilitation is for the patient to return to active participation in society in various ways.

Because the alaryngeal condition is based on the illness of laryngeal tumors, the premise of rehabilitation is to completely recover from the illness. Before attempting to cultivate the vicarious voice, the disease itself should have been cured by medical attention. However, it is as important that the patient maintain his/her attitude of a fighting spirit against the disease.

We have a proverb that illness is created in the mind. This might seem to be merely a form of wishful thinking. However, modern research and also biological studies support the accuracy of this expression.

In biological terms, the mental attitude is dependent on the condition or activity in the central nervous system. It is clear that neurotransmitters are transmitted according to the activity of the limbic system of the cerebrum and the hypothalamus. These transmitters increase the activity of the lymphocytes flowing in the blood, thus increasing resistance to disease. In short, it increases the immune function. This means, for example, that we can expect the body to have a greater power to rid itself of cancer cells when we are in good mental condition.

Let us consider a piece of research that relates to this mechanism. In a study of women with breast cancer, among those who had a fighting spirit regarding their disease and wanted to survive, 80 % were still alive ten years later. This means that eight out of ten patients were still alive ten years later. However, of those in the other group who felt overwhelmed by the disease, only 20 % had survived ten years later. It is clear that a desire to fight against illness and the will to overcome a handicap are closely related to the preservation of health.

I recommend the following points as important aspects of maintaining that attitude of fighting against illness which I have been talking about above.

- 1) Try to live as your own medical consultant.
- 2) Put your health and soul into achieving your goal day by day.
- 3) Do everything you can for other people.
- 4) Train yourself to live with the worry and fear of illness.

One might say that what the Japan Federation of Laryngectomees should do is just to put these measures into action. For example, Ginreikai has many times accepted students for training from various countries of Asia; the results of their hard practice and leadership show results. I believe that ideas like these should be capitalized upon by members of the Asian Federation of Laryngectomees.

I would like to close by mentioning one last time the spirit of the slogan of the International Year of Disabled Persons "Total participation and equality". Let us stand by the basic ideal of rehabilitation for the restoration of disabled people's rights, and wish wholeheartedly that the Asian Federation of Laryngectomees' Association will continue to develop and prosper.

References

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