

ACTIVITIES OF THE CLEFT LIP AND PALATE ASSOCIATION IN THE KANSAI AREA OF JAPAN

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ABSTRACT

This article describes the activities and history of The Cleft Lip and Palate Association in the Kansai Area of Japan, a self help/mutual aid association consisting of children born with cleft lip and/or palate and their parents. After describing how the association was formed, this article details how it began to come under the control of a professionally-operated medical institution before ultimately managing to win independence. The meaning and significance of independence to the association will also be discussed.

The Cleft Lip and Palate Association in Kansai Area is a mutual aid association for children born with cleft lip and/or palate and their parents (hitherto referred to as "the association"). The association started in 1977 in Kansai Area and currently has about 330 members, next in size only to that of Tokyo Area which has approximately 1000 members. The association is headed by an executive director and supported by eighteen regional contact persons. The association has an office in a private home of a member and a small annual membership fee of ¥ 3600 (US\$28).

The association engages in a number of activities including publication of a quarterly newsletter, consultation and support with members over the telephone, fostering comradeship among members, and arranging lectures on medical treatments. The goals of such activities are as follows. (1) Parents, ashamed of their children born with a cleft, tend to conceal the fact from their relatives and community. The association strives to relieve these parents from a sense of isolation by offering them a chance to meet people in a similar situation. The association hopes that mutual support will help free parents from their own inner prejudice. (2) To share various experiences as well as necessary information that

will allow parents to make their own decisions on cleft management. This is accomplished through medical lectures and through the efforts of senior members, who are expected to educate new members. (3) To widely and constantly raise a voice of protest to prejudice of society against the cleft population. (4) To create social services in a cooperative way with the similar associations all over Japan.

I joined the association in 1980, became a regional contact person in 1991, and was executive director from 1995 to 1997. My initial goal was to obtain easy access to medical information. (Some information about medical treatment of clefts in Japan is necessary context for understanding the experience of parents and children in the association.) For a cleft, continuous medical care is necessary from birth to adulthood. Treatment on a cleft is usually practiced either in an oral surgery unit or in a plastic surgery unit.

In Japan, oral surgery is conducted by professionals trained in dentistry, a field which is less difficult to enter than is plastic surgery (a medical specialty). Historically, oral surgeons preceded plastic surgeons in cleft treatment, and there is a subtle sense of rivalry between these two associations of professionals over whose approach is best, and who “owns” cleft treatment. Because of this context, the information provided by professionals to parents, children, and to the association itself can be colored by guild-related interests.

At the birth of a cleft baby, parents are often overwhelmed and often feel obliged to take their child to a medical center recommended by their obstetrician. During this period, accurate medical information on all available options is often scarce, making it difficult for parents to make an informed decision. Availability of unbiased information from multiple sources is a key to establishment of one’s own medical care. Therefore, the association strives to provide members with the latest and unbiased information from multiple sources. To fulfill this role, the association must be free and independent of any medical professionals. To develop this point further, I will now turn to the story of the relationship between the cleft population and medical professionals. Particularly, I will focus on how the association was slowly drawn under the powerful influence of the medical professionals of one institution, but eventually freed itself and became independent.

THREE STAGES IN THE HISTORY OF THE “CLEFT LIP AND PALATE ASSOCIATION IN KANSAI AREA”

Stage #1

Stage #1 consisted of the first seventeen months (March 1977-August 1978). In March 1977 several parents of children with a cleft who underwent surgery at the oral surgery unit at O University Hospital (OUH) wished to keep contact with each other for mutual support. They formed a small association and started circulating a notebook. In one of the earliest bulletins one parent wrote, “I alone could not get

through all these sufferings, but together with all these friends I thought I could bear up. Fortunately a surgery on my son was successful and he has been enjoying his life. The association is still young but I hope our support and effort will help the association grow in size and activity” (first issue, January 1978). Another expressed, “Reminded of experience of other parents I like to grow with my child believing in my child’s potential. I am certain there will be more difficulties ahead of us. But if the parents are determined to live positively, I suppose the child will follow the parents’ path” (second issue, August 1978). Apparently, these parents were happy to meet parents with a similar plight to expand their comradeship and to keep their life going by mutual support.

At this stage, members of the association were in desperate need of information as to treatment of cleft, selection of a medical institution, aspects of surgery, its follow-up, emotional and psychological care, and so on. Their initial efforts to find accurate information were not successful. However, on one occasion the association planned a workshop on medical care and a lecturer from OUH kindly volunteered. There followed more support from OUH, such as providing the association with the latest information, responding kindly to requests for consultation, and even giving some financial assistance. The positive support by this particular medical institution was a great encouragement to the members. The members who were emotionally vulnerable appreciated the open friendliness of the staff from the treatment unit and expected more support from them. In this way the link between the two parties became more firmly set.

A medical institution always needs patients. The OUH was extremely eager to recruit patients from the association, and its doctors stood close to the side of the association leader, giving kind encouragement and full attention to alleviate their anxiety. The association leader naturally responded to the doctors with respect and confidence. It must be remembered that the parents of the children born with cleft lips and/or palate often feel weak and vulnerable when confronted with medical authority. The parents in the association were inclined to feel ashamed and consider themselves socially inferior; so they were delighted when they received contact from medical professionals. It was understandable that the parents wished to keep a close relationship with the doctors and thus became more and more dependent on the doctors. The medical institution would willingly offer financial support to the association in organizing the activities or voluntarily participate in lectures and medical consultation.

The above factors explain how the association of parents came increasingly under the powerful influence of medical professionals. The leader of the association was a parent, not a medical specialist; so dependency of this kind, I would say, was “latent” and hence of a different character than the manifest dependency of support groups explicitly formed and operated by medical specialists for their patients. Eventually, the association attempted to become completely independent of the medical specialists. I would name this type of association as a “fully independent” association. In this way self-help organizations could be categorized

into three kinds according to its relationship with the medical specialists, namely manifestly dependent, latently dependent and fully independent.

Stage #2

Stage #2 consisted of the next thirteen years: a period of continuous growth under the influence of a particular medical institution (1978-1990).

During this period an oral surgeon from the oral surgery unit at OUH increasingly offered lectures to the association which inevitably resulted in a closer relationship between the two. In the sixth issue of our journal (March 1980) one reads, "Wonderful news! An oral surgeon from the OUH volunteered to give us counsel on Saturday afternoons. Those interested are advised to make an appointment by telephone." In the tenth issue (May 1981) one reads, "Wonderful news! The oral surgeons at OUH have offered a more cooperative hand than ever. (a) With a letter of introduction by the association anyone can consult with an oral surgeon privately on Wednesdays. Contact the executive director or a regional contact person for the letter. (b) At a workshop for mothers sponsored by OUH, literature on the association will be handed out. (c) A seminar is to be held for the members of the association once every two months at OUH. (d) An available oral surgeon is expected to attend the meeting of the parents, give a lecture there, or give advice." As help and support from a particular association of medical professionals steadily increased, the link between the two associations was more forcibly established and the association came to find itself firmly tied to that particular medical institution.

During this period, the association gave hardly any encouragement to members wishing to learn about and chose different medical treatment options for clefts. The association itself grew steadily thanks to the generous support by the medical professionals at OUH, which used the association to promote itself as the only appropriate treatment option. As a result, the association served inadvertently to publicize that particular medical unit. The association claimed to promote mutual support among the members but it would be more accurate to say that it was actually promoting a single medical unit.

It was around this time when I joined the association. Having consulted with a different medical institution, I was recommended by a member of the association to switch to the oral surgery unit at OUH. Even now I have no doubt about the excellent quality of treatment practiced by that medical unit, but the issue here is why the association recommended only a single institution to its members for treatment.

While the association tightly tied itself up with the professionals of a certain medical institution, one of the primary concerns of the members was an independent development of the association, as demonstrated as early as in the eleventh issue (September 1986) of the newsletter in which the importance of individual experience was stressed: "We find our own experiences more

significant than any advice given by an oral surgeon. Try to offer help to anyone in the Association in return for what you have been given. Speak out your own experience." The members were, in fact, in charge of planning programs such as sharing experience or recreational gathering, while planning of lectures still remained in hands of the medical professionals at OUH.

Significant privileges were given to the executive director of the association by the medical professionals. During this period, some measure of authority came to be attributed to the executive director by that particular medical unit. "A letter of introduction is necessary if one wishes to go to OUH. Contact the executive director for information"(twenty-fourth issue, March 1987)." As clearly shown here, the executive director was privileged to give out a letter of introduction. S/he therefore became a special, quasi-professional figure in the eyes of other members. Regional contact persons could be influential, having ample amount of information originated from the same source. Senior-junior hierarchy appeared among the members, which worked against an awareness of equal comradeship. The executive director who wanted to maintain his/her position catered to the medical professionals and would respond to their requests rather than to those of the members, contradicting the fundamental role of the director.

In good rapport with a particular medical institution, securing confidence between the oral surgeons and the patients, the association continued to grow for thirteen years. Membership rose to 150. Gradually more people who had consulted with the plastic surgeons at other medical institutions came to join the association. Then there arose voice of complaint against exclusive relationship of the association with a particular medical institution.

Stage #3

During Stage #3, there was a transition to an independent association (1991-present).

With a subsidy granted by a local government, a survey of the current needs of the members was conducted in 1991. The highest need lay in collecting information on medical care. By this time, the association was divided by two different opinions, one which favored continuous dependency on OUH and the other which was against excessive dependency upon a single institution. I was of the latter opinion. With the subsidy by H local government, in May 1992 I and a few other contact persons succeeded in inviting a lecturer from the plastic surgery unit at H University Hospital rather than from the oral surgery unit at OHU. Our intention was to loosen the close ties with the particular medical institution.

A few members showed concern about our new attempt to invite a lecturer from a different medical institution. So our next step was to obtain subsidy from H local government, so as not to be financed by the association, and to invite a lecturer from a medical institution in the locality away from OUH. The whole program was to be organized by a member who had never consulted with oral surgeons at OUH.

This attempt was successful in avoiding any protest against the association. It was also successful in building confidence in ourselves as we were able to organize programs and put them into practice all by ourselves, not supported by OUH. From this point on, the members themselves began to take initiative in planning programs and carrying them out, even in selecting a lecturer.

In 1996, a booklet was published reporting our activities and running all the lectures of the period of 1990-1995 sponsored by the association. I was actively involved in editing and producing the booklet. Copies of the booklet were distributed to the members, medical institutions, and local health centers and were put for sale to those interested. In this booklet, medical care by both an oral surgery unit and a plastic surgery unit was properly introduced along with the process how the association won independence from influence of a particular medical institution. It also contained lectures given by other physically handicapped people for a deeper understanding of "being handicapped." Thus, the booklet effectively served to advertise the aims and the activities of the association.

At this point, 230 people purchased copies of the booklet, prompting as many as half of them to join the association, which immediately contributed to vitalizing the activities of the association. The current membership, nine years after winning independence, is 330.

SIGNIFICANCE OF BEING INDEPENDENT FROM MEDICAL PROFESSIONALS

Now that the association is tied to no particular institution and is free to obtain information from multiple sources, parents of cleft children are now able to learn about medical care from various perspectives and make their own fully informed decisions. Through this process, parents come to realize that their lives belong to none but to themselves and gradually come to recover confidence and self-esteem.

If by any chance the opinion leaders of the association tend to favor one single medical institution, they increase in power as they are equipped with abundant data and medical knowledge, thus creating the more powerful and the less powerful among the members. One might conclude that only when the association becomes independent of influence of any medical professionals, its members could establish equal relationship among themselves to share painful feelings and bitter experience, and eventually be set free from their own inner prejudice, which quite often leads to self awareness against social injustice and articulate demands for a social change.

What is a fully independent self-help association and how does it function? A fully independent self-help association is an association of people who are financially independent, who organize its programs by their own hands, who exchange information based on their own experience, who share sufferings and sorrows, and who aim to liberate themselves from their own prejudice. Furthermore, if possible, they intend to diminish social prejudice, volunteer social service,

and finally speak up for social reform. For example, in 1984 the association successfully worked to obtain the medical insurance coverage for orthodontic treatment of a child with cleft lip/palate.

Each individual, born as a human being, should live a full life with one's own free will. One should make one's own decisions in every aspect of life not affected by others' way of life. Continuous effort to establish one's identity and to maintain it is of primary value in life. The parents of a handicapped child tend to feel ashamed and consider themselves inferior to those with a child not handicapped and tend to be vulnerable and short of mental strength in selecting what is best for the medical treatment of their child. There is a tradition in Japan that academic schools seldom cooperate in their research and studies. It is particularly so in medical institutions and national universities. There is another tradition in Japan that medical doctors receive a great amount of respect, sometimes excessive, and possess immeasurable authority over a patient who seeks a second opinion or harbors even a slight doubt about a doctor's policy on treatment.

In such a medical environment, the association has aimed to maintain an equal partnership with medical institutions and to advise its members to make their own decisions in any situation. For example, in 1998 the association organized a program in which the doctors of both plastic surgery and oral surgery sat on the same floor and answered questions presented by the members. It was a good example of the association taking an equal partnership with medical institutions. The members became aware of the different approaches each medical institution would make. There dawned on them the importance of collecting information from various sources and making their own decisions based upon information so collected. The specialists of both departments came to show interest in how and where they could cooperate and specialize. An actual plan for cooperation has not been started yet, but it was a memorable step forward.

I have reported on the activities of the association I belong to with a particular interest in how the association became independent of the medical professionals. At present, the association tries to keep an equal distance from the oral surgery unit and the plastic surgery unit. The association invites lecturers from each unit and asks each to give us advice and to contribute an article to the newsletter. I sincerely hope that the association may maintain its independence and the principal of self-support in the years to come.

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