

Activities of the Trisomy 18 Support Group Mental Care for the Parents of Infants with Trisomy 18

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Mental care is indispensable for disabled infants and their parents, who exist in mentally and physically difficult situations. Peer support groups are highly effective in providing mental care for the parents of disabled infants. This report introduces the activities of one such patient association, the “Trisomy 18 Support Group.” Patient association in this paper means groups that supports parents who have infants with Trisomy 18. (The words of survey respondents are italicized.)

□ What is Trisomy 18? □

Let us explain the current condition of infants with Trisomy 18 by citing Kosho (2007).

“Trisomy 18, first introduced by Edwards et al. (1960) is a chromosomal abnormality. It is said to occur in one of 3600 to 8500 persons. Patients with Trisomy 18 can have growth retardation, significant psychomotor and mental retardation, characteristic bodily features (overlapping fingers, a short sternum, rocker bottom feet), congenital heart disease, high blood pressure of the lungs, problems of the respiratory system (diaphragmatic relaxation, upper respiratory tract obstruction, apnea attack, etc.), digestive system (esophageal atresia, anal atresia, gastroesophageal reflux, etc.), urinary system (horseshoe kidney, hydronephrosis, inguinal hernia, etc.), skeletal systems (stiff knee, scoliosis, etc.), hypacusia, or malignant tumors (Wilm’s tumor, hepatoblastoma). According to Carey et al. (2005), about 50% of newborns with Trisomy 18 can survive for a week and about 5 to 10% of them can survive for one year. The main cause of their death is apneic attack.”

□ Problems over medical treatment of infants with Trisomy 18 in Japan □

Although information about issues like coexisting illness and prognosis severity have been reported by medical professional concerning infants with Trisomy 18, there is not enough information about treatments and healthcare for infants with Trisomy 18, about quality of life for both the infants and their parents or about the type of care that parents hope for their infants. In addition, the expectations of medical staffs can be quite low. For example, according to the classification of medical decisions at Tokyo Women’s Medical University, infants with Trisomy 18 are kept under their current treatment and thus belong to the class C (Nishida 1985), in which only temperature control, internal nutrition, skin care, and love are provided. Therefore, when medical staff members inform parents of the

condition of their child's illness, they often state treatment choices such as "We do not provide active treatment" or comment on the baby's "short life." Actually, in Japan, there is no uniform treatment protocol, so some hospitals provide no active treatment but only concentrate on palliative care, while other hospitals provide active treatment in consideration of parents' hopes and requests. As a result, when parents with infants with Trisomy 18 go to the former type of hospital, they feel depressed and lonely, and they feel sad and angry because the human rights of infants with Trisomy 18 are not respected.

□ Activities of Trisomy 18 Support Group (see Table 1) □

The Trisomy 18 Support Group was established in order to support parents who are lonely and confused. It consists of 250 families and 20 supporting members, as of June 2008. As for the state of infants with Trisomy 18 within the group, 100 infants continue to live and 150 have died. Supporting members consist of neonatologists, pediatricians, genetic doctors, gynecologists, nurses and counselors. The group's expenses are covered by the membership fee (the admission fee is free and the annual membership fee is 2,000 Japanese yen) and contributions. 20 volunteer family members manage the group and the organization consists of 1) the group representative, 2) an accountant, 3) an auditor, 4) a person in charge of managing the member's list, 5) a person in charge of distributing a circular bulletin among members, 6) a person in charge of managing the mailing list, 7) a person in charge of distributing information, 8) a person in charge of accepting new members, 9) an editor of the newsletters, 10) a person in charge of making inquiries, and 11) a person in charge of managing the homepage. The group's main activities are helping parents access the medical information they need, conducting peer counseling, distributing pamphlets and handbooks to hospitals, and publicly releasing investigations of actual conditions faced by infants with Trisomy 18 and their parents.

□ The necessity of information about peer support groups □

(Investigation about actual conditions of infants with Trisomy 18 and their parents, conducted in fiscal year 2003)

In 2003, we conducted a survey of group members to grasp the current condition of infants and their parents. The following is an outline of the investigation.

The response rate was 70% (88 of 125 members). The main survey items were 1) emotional care: the situation and existence or non-existence of emotional care at the time of the doctor's explanation and/or the parents' first meeting with their child, as well as the type of emotional care the parents would like to receive from medical staff members and 2) medical data: the history of the pregnancy / delivery (pregnancy complications, mode of delivery, measurement at birth and rebirth), postnatal management (complications, treatments, including surgery and the hospitalization period), history of rearing (situation at home, respiratory management, growth, developmental situation and immunization), the cause of death, and so on.

We would like to describe the support that parents received from medical staff members based on the result of the survey here.

29 people (38% of the total) answered that they received information about the Trisomy 18 Support Group from a medical staff member, 45 people (59%) answered that they did not receive the information, and 2 people (3%) did not answer the question (see Table 2). When we asked the 29 people about the Trisomy 18 Support Group, 17 of them (59%) answered that the group was very supportive and 10 of them (34%), answered that the group that was supportive. No one answered that the group was not supportive or that the group caused pain. Based on the result, it seems that getting the

information about the support group was helpful for parents who have infants with Trisomy 18. The following are some comments from the parents.

** I wanted to know more about the prognosis of Trisomy 18. I would not have been lonely, if I had had access to stories and information about newborns who have the same illness.*

** We are lucky because we were able to find the homepage of Trisomy 18 Support Group just after our child's birth. Parents who do not receive information must suffer for months.*

** When I asked the doctor to know details about the disease, the handbook of the Trisomy 18 Support Group was shown to me for the first time. I wish I had learned of it when I was notified of my child's condition.*

Parents are requesting medical information that focuses not on the certainty of their infant's death but on the child's chances for life. Information from other members within the peer support group is effective for offering this support. According to Nakamura (2008), doctors cannot explain the functional prognosis and the development prognosis of an infant with Trisomy 18 sufficiently from the doctor's standpoint only. Instead, parents must meet other parents who have similar infants and experiences in order to understand their infant's state. Judging from the above survey results, 1) it is necessary for medical staff members to offer information on the peer support group as an available social resource when parents are notified that their infant has Trisomy 18, and 2) this information works most effectively when parents learn about it at the earliest stage.

□ Peer Counseling □

A special feature of a peer support group is peer counseling. A "peer" is a person at the same level; thus, peer counseling is a way for people with similar experiences to give mutual support to each other in an environment free of hierarchies. Here, we introduce the contents of peer counseling, as we make special efforts in this activity.

1. Real-time consultation and dissemination of information

Private consultation of members is accepted and performed via telephone, fax and, most often, individual email by the group's representative. The consultations usually concern 1) medical treatments for infants with Trisomy 18, 2) medical staff members' consultations with parents about their infants, 3) introductions to supporting members, 4) introductions to hospitals, 5) grief care, and 6) discussions about the next pregnancy and delivery, etc.

If a member wants to request information or advice based on other members' experiences, they often use the bulletin board or mailing list to ask members. For instance, there are a lot of consultations concerning, 7) trachea incisions and operations, 8) mental preparation and equipment set ups for when an infant leaves the hospital and lives at home, 9) information about medical equipment for the home, and 10) social resources for official certification of the disabled child by the government.

2. Matching members

When new members join, they are introduced to members who are similar in their pregnancy and delivery (stillbirth or production), their children's situations (living or dead), their family structures, the region where they live. These introductions are made by supporting members through email or at information exchange meetings.

3. Information exchange meetings

Because the group's members are families that reside throughout Japan, it is difficult to gather everyone. Therefore, information exchange meetings are held in different regions. The meetings are open and members are free to share their experiences. In the exchange meetings, 1) participation is not limited by the child's condition, 2) free discussion is engaged without deciding the theme, 3) members coordinate among themselves so that the participants may make remarks evenly, and 4) parents may have their infants with them.

4. Features of peer counseling by the members of the Trisomy 18 Support Group

- 1) We have 24 hour access to consultations; no reservations are necessary.
- 2) Our advise to each other is based on our similar experiences.
- 3) We offer support to each other through mutual relationships.

Reflections of parents able to experience peer counseling

** Me and my infant are not the only ones who have experienced this.*

** On the surface, I had accepted my infant's illness, but internally, I was not confident about how to deal with the situation. After I talked with other parents in the group, I finally became calm.*

** Although I was explained by the doctor about Trisomy 18, I couldn't really believe the reality. But after I received a letter from a member in the group, I felt strongly that it was not just me who had this situation.*

** A member who I became acquainted with through the Trisomy 18 Support Group supported me by coming to the neonatal intensive care unit (NICU) and talking with me over the phone.*

** A member came to the NICU with her infant. Gradually, I came to understand the reality of infants with Trisomy 18. My anxieties that Trisomy 18 is an incomprehensible and grave illness were relieved gradually.*

** I learned of co-members with the same circumstances through the homepage of the Trisomy 18 Support Group, and this became a support for me. From now on, I will be glad to support other members.*

** When my infant was born, I worried about our everyday life, especially toward the future. However, while watching even the smallest developments in my infant, I was able to laugh more. I am so happy that I joined the Trisomy 18 Support Group. I feel the sympathy of the co-member's feelings, getting power from my infant and spending my days peacefully with my infant.*

** I think that the sadness and suffering I experienced would not have been experienced unless my infant had Trisomy 18. However meeting with other members provided me with excitement and happiness. I think that the time my infant lived had important meaning. It was a huge, huge meaning this tiny child provided me.*

Hopes of parents never able to experience peer counseling

** I wanted to know that there were other people who experienced similar feelings.*

** I wanted to speak open-mindedly with other parents who had infants with Trisomy 18.*

** I wanted a place where I could discharge my sadness.*

In accessing the Trisomy 18 Support Group, members hear from parents with infants with Trisomy 18, and they have received the encouragement from the other members. According to Weiss & Mackta (1996=1999), when a community of companions meet face to face, by telephone or by a newsletter, despair can change into hope and the value of the infants' and families' lives, which may have seemed

shattered, will be made whole. For those parents who think it is impossible to bring up a disabled infant, when they hear from others who are actually raising such children, they can get an image of what is actually required and come to accept their infant. Thus, it can be said peer counseling through a support group can play a major role in helping parents of disabled children to accept their infants.

□ Peer support group as stake-holder: participation in medical policy □

According to the actual survey conducted by Trisomy 18 Group in 2003, an infant's treatment policy decision is often made by the medical staffs, and parents often feel their opinions are not well valued (Trisomy 18 Support Group, 2005). Moreover, the medical staff members do not understand the parents' desires and occasionally conflicts arise. Reflections of the peer support group's opinions could be a way to improve the communication between medical staffs and parents. From fiscal 2001 through fiscal 2003, our group participated in the creation of "Guidelines for Healthcare Providers and Parents to Follow in Determining the Medical Care of Newborns with Severe Diseases," which was parts of the research activities of sponsored research by Ministry of Health, Labour and Welfare called "Multidisciplinary Studies for the Guideline of Medical Management on Severely Disabilities Infants and the Diagnosis for High Risk Neonate" (Principal Investigator: Masanori Tamura) as a patient group. As a result, while medical staff members and parents speak their mind and discussion together, their made decision making medical treatment of infants. In the planning of medical policy, the peer support group is adopted as the stake-holder that relates to the medical treatment and welfare.

The report, "System of New Disabled Welfare Service" (2006) by the Ministry of Health, Labour and Welfare lists hospitals, rehabilitation centers, homecare support facilities and welfare offices, etc., as places for the support of disabled children, but peer support, unfortunately, receive no mention. Although peer support groups in Japan occupy a small space as a social resource, so far, we believe that, in the future, peer support groups should be allowed to play a significant role in supporting the hearts and minds of parents and their children.

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| Table 1 Trisomy 18 Support Group http://www.18trisomy.com/ (Japanese) | |
|--|---|
| Foundation | 06/03/2001 |
| Membership | Family members: 250 families (20 supporting members) |
| | Support members: 20 persons (Neonatologists, Pediatricians, Genetic Doctors, Gynecologists, Nurses, Counselors) |
| Our Group Activities | Issue and Distribution of Pamphlets to Hospital etc. |
| | Issue of Newsletters (Three Times per Year) |
| | Provision of Medical Information |
| | Peer Counseling |
| | Match with Members |
| | Take Place of Exchange Meeting |
| | Holding of Public Seminars (Once a Year) |
| | Issue and Sale of Handbook |
| | Investigation into the Actual Conditions about Trisomy 18 |
| Outcome Activities | Participation of various study groups mainly held by medical staffs |

| Table 2 Parents experience of care by medical staff (n=76) | Yes (%) | No (%) | NA (%) |
|---|---------|--------|--------|
| Got information of child's symptoms and condition. | 81.6 | 15.8 | 2.6 |
| Got social information such as support groups, etc. | 38.2 | 59.2 | 2.6 |
| Courteous physical care was provided our child. | 92.1 | 6.6 | 1.3 |
| Our child was treated as a responsive, cute baby. | 90.8 | 6.6 | 2.6 |
| We were able to personally bathe child or change child's diapers. | 89.5 | 9.2 | 1.3 |
| We were able to personally give milk to child or perform infusion or suction treatment. | 67.1 | 31.6 | 1.3 |
| Parent was given verbal comfort, encouragement, and advice. | 90.8 | 6.6 | 2.6 |
| Parent's feeling were listened to without interruption. | 76.3 | 21.1 | 2.6 |
| Medical Staff members chatted about things with parent. | 81.6 | 15.8 | 2.6 |
| Consideration was given so that parent could express desires and requests. | 77.6 | 19.7 | 2.6 |
| Medical staffs stayed with parents during difficult times. | 52.6 | 44.7 | 2.6 |