

**The Free-Rider Problem in Self-Help Groups for Parents of Children
with Rare Diseases: How “Selfishness” is dealt with in Mutual Help
Organizations in the Japanese Cultural Context**

Key words: self-help groups, parent groups, patient groups,
peer counseling, mutual help, Japanese culture,
free-rider problem.

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Abstract

After ten years' fieldwork on self-help groups for parents of ill children, including conducting thirty-one qualitative, individual and group interviews with forty-two leaders of twenty-one parent groups, I have found that one of the most serious problems confronting such groups is how to treat the numerous "free-riders" using their telephone counseling service. I have since conducted six focus group interviews with twenty-four leaders of seventeen parent groups, and asked questions about the problems associated with their peer counseling service. Because the leaders seldom consider their counseling service' problems from an organizational development viewpoint, "free-riders" have not been intensively examined. However, some tactics were discussed for changing individual-based, unilateral, counselor-counselee relationships into group-based, reciprocal, self-helper relationships. This paper discusses these findings, together with Japanese cultural factors that might aggravate the free-rider problem.

The voluntary service that self-help group members provide one another has been recognized by researchers as being uniquely important (Gartner & Riessman, 1977). The "Helper-therapy principle" (Riessman, 1965; Riessman & Carroll, 1995) is often quoted as a theory that emphasizes the benefits that self-help group members can gain through the process of being engaged in voluntary services: "While it may be uncertain that people *receiving* help are always benefited, it seems more likely that the people *giving* help are profiting from their role" (Riessman, 1965, p. 27).

Even though this theory has proven to be correct, it is clear that most people believe the opposite: that the helped are benefited more than the helpers. Consequently it has been reported that most people tend to avoid taking on helping roles even in self-help groups, the basic principle of which should be mutual help. According to a report by Meissen, Gleason and Embree (1991), "members not sharing enough of the work of the group . . . and overworked and tired leaders" (p. 435) are considered by group leaders to be significant issues. Furthermore, Revenson and Cassel's study (1991) have described leadership problems of self-help groups for families coping with scoliosis as follows:

The most rewarding aspect of leadership involved bidirectional support provision, the essence of mutual help. . . Unfortunately, such activities occupied only a small portion of leaders' time. . . Much of what mutual help leaders do, as one leader bluntly stated, is "grunt work"; another presented us with an itemized activity list "I xerox, label, fold, staple, sort and mail 200 monthly newsletters." For some, the chores that needed to be done on a regular basis overshadowed the pleasure of helping, but as one leader stated, "someone's gotta do it." (pp. 695-696)

My previous research projects with self-help groups for parents of children with intractable diseases have shown similar results: the leaders suffer from an overburden of management tasks that are necessary for maintaining their parent groups (Oka, 1999, 2000, 2002, 2003). However, there is a difference: in Revenson and Cassel's study on medical self-help groups, the leadership activities categorized as "Help

Provision” were considered “highly enjoyable and challenging, and affording a good deal of progress and a likely successful outcome” (p. 691). On the other hand, my qualitative interview research has shown that peer counseling is not always seen as “highly enjoyable and challenging” by Japanese group leaders. Instead, some leaders have criticized some counsees as “free-riders” who take advantage of, or abuse their parent groups’ voluntary service without contributing anything to their groups in return (Oka, 2003, pp. 243-246). My research questions have therefore been about the tactics group leaders can use to avoid the problems caused by free-riders in their counseling service, and the cultural factors that might influence these problems.

Method

A loosely organized association, which comprises over twenty self-help groups for parents of children with intractable diseases, was inaugurated in Tokyo in 1990. In this paper, I will call this association by the pseudonym: “Conference of Parent Groups” or “the Conference”. As a researcher, I have been associated with the Conference since 1993. I began my research by conducting thirty-one qualitative, individual or group interviews with forty-two leaders who came from twenty-one different parent groups. During the interviews, I found that one of the most serious difficulties the groups face is the problem of leadership, and in particular the excessive workload associated with the role. A major cause of the leaders’ overload is related to their peer counseling service (Oka, 1999, 2000, 2002, 2003).

My next step was to focus on this peer counseling service, and so with the authority of the Conference of Parent Groups, I organized a research team that was comprised of six members: the leaders of three parent groups, a social worker employed by a parent group, a social worker from a child welfare agency that sponsored the Conference of Parent Groups, and myself. This group discussed the question route, and did a pilot testing.

As the head of the research team, I then asked leaders of the twenty-two parent groups who belonged to the Conference of Parent Groups to participate in focus group interviews. One of the groups did not respond to my request, and four others declined for various reasons: a contact person from one group said that they had no suitable participants, two groups referred to their scant experience as counselors, and one group explained how they believed that they were not “counselors”, but “friends.” The remaining seventeen groups (see Appendix A) sent a total of twenty-four leaders to my focus group interviews.

The aims of my questioning route (see Appendix B) included: 1) enumerating problems that the leaders face in providing their peer counseling service; 2) enumerating mediums that are used for their peer counseling service, and clarifying the perceived strength and weakness of these mediums; 3) collecting a list of the groups’ self-imposed principles or rules for providing peer counseling; 4) clarifying what they perceive to be the differences between their peer counseling service and professional counseling service; and 5) finding out what they believe is needed if their peer counseling service is to improve.

To make it more convenient for the twenty-four participants, I then organized them into six focus groups: four groups with four participants, one with three, and another with five. Each focus group lasted two hours. I was the moderator of each focus group, and I had as an assistant moderator, a graduate student whose MA thesis on hospital social work I had supervised. After each of the interviews, the assistant

moderator and I had a 10-minute debriefing to capture our “first impressions” (Krueger, 1994, p. 128) and document non-verbal communications that the audiotapes were unable to capture. All of the interviews and the debriefings were transcribed verbatim, and the transcripts were analyzed using qualitative data analysis software (QSR Nud*ist 6).

Findings

Research participants

The twenty-four participants — twenty-one women and three men — were selected by their parent groups because they were the members responsible for their peer counseling service. In my previous focus group interviews, the participants were likewise selected by their groups, because they were seen as the ones who best knew their groups’ organizational problems. In that case, the ratio of women to men was sixteen to nine. Thus, more female leaders were involved in this series of focus group interviews, which might mean that more female leaders than male leaders are responsible for the groups’ counseling service. This is a reasonable assumption, because most of counselees are mothers, and one could suppose that the mothers of ill children would prefer to talk with other mothers than with fathers. Besides, one of the three men was responding to his groups’ members by e-mail only; another man came because his wife had to stay at home and take care of their child; and the third, a self-employed professional, appeared because his wife had to go out to work, and his child meanwhile was a long-term patient in hospital. The average age of the participants was 46.0: one was in his 20s, three were in their 30s, thirteen in their 40s, six in their 50s, and one was over 60.

Types of problems

The problems that the participants described have been classified into three types according to the participants’ perceived roles: parents, counselors, and group organizers; however the participants seldom discussed each type of the problem separately.

Firstly, they discussed the problems that parents usually face. During this time, they did not distinguish clearly between their own problems and those of their counselees, which had evoked their sympathy. An example is shown below:

[Extract 1]

T: When parents and their ill children go to hospital, their brothers and sisters are neglected. For example, while a parent and her ill child see a doctor, their brother and sister have to wait alone for a long time. When the ill child enters hospital, their brother and sister are left in the care of their grandparents [because their mother has so much to do for the ill child in the hospital]. These days, the number of nuclear families is increasing, and more and more families are unable to receive medical treatment without the use of public social services or childcare services.

TO: Is this the counselors’ problem?

T: Yes. The counselees ask me about available child care services. I answer, “Ask the welfare office or the child care office in your community,” or

*“Why don’t you ask a public health center?” These are the only suggestions we can give.
(Focus group #2, Section 2)*

The second type of problems that they mentioned involved those that they feel as peer counselors. In a sub-category of this type is the problem of scarce personal resources, especially time. Of the seventeen parent groups that participated in my focus group interviews, only three had their offices in public spaces. The other groups received telephone calls at their leaders’ private homes, and the nature of telephone calls — the fact that they are time-consuming and continue around-the-clock — exhausted those in charge. A mother, who was responsible for her group’s hot line and received calls at home, described her problem of lack of time as follows:

[Extract 2]

N: We don’t announce the operation time of the hot line, and so some people believe we are operating around the clock, from very early to very late. And, people seem to think that I don’t work because I am the president of the parent group. In fact I am working at home, and when I receive a call for help while working, [I am much troubled.] Even so, I can’t hang up, because if I hang up, saying, “I’m working now,” many first-time callers would not call me again.

(Focus group #3, Section 2)

[Extract 3]

A: Our parent group’s telephone shared the line with my private one. However, after seeing this telephone number in various sources of information, people thought that the line was used only for the group. They did not care what time they telephoned; say, at suppertime, lunch, or early in the morning. It seemed that whenever I was very busy, the telephone rang. Not only the time, but also the length of the calls was a problem. They talked for hours. I had difficulty stopping them. They just knew one thing: that their child had the disease, and they were terribly confused. So, how could I hang up? I had no choice but to listen to them, saying, “Yes, Yes, I know what you mean.” Meanwhile time was passing. That was a very serious problem for me; it destroyed my private life. Oh, some called me at midnight, just to have a moan. I know there are times when everyone wants to moan, but some called me for nothing more than that. They had no intention of joining us, and after they had said what they wanted to say, they suddenly hung up. This happened often.

(Focus group #4, Section 2)

Another interesting sub-category of this second type of the problem involves the psychological burden; some leaders felt that the responsibility that went with maintaining the hot line was far too great:

[Extract 4]

W: Callers always ask me, “Which hospital is the best?” I felt like saying, “What do you mean by ‘the best’?”(laughing) It all depends on their personalities, the time they have available, or the place where they live. All I can do is introduce them to other members who live nearby, and let them

listen to their opinions. Why do they ask me which is the best so often? It might be because they want help, but also because they want somebody to blame if they find they have made the wrong choice.

(Focus group #3, Section 2)

Although the psychological burden felt by leaders who are responsible for their counseling service is very interesting, it is beyond the scope of this paper.

The third type of problem involves organizational matters that can lead to the exhaustion of the parent group leaders. This type of problem is most relevant to this paper, because it focuses on free riders.

The free-rider problem and “nominalism” of self-help groups

A free rider can be defined as “a member of a group who obtains benefits from group membership but does not bear a proportional share of the costs of providing the benefits” (Albanese & Van Fleet, 1985, p. 244). In the case of self-help group counseling service, free riders are people who use the groups’ services but make no contribution to the groups’ activity. Although this definition is clear and simple, practical application of this concept is difficult due to “nominalism” within self-help groups. Indeed, many aspects in some self-help groups are only nominal. My previous fieldwork (Oka, 2003) revealed that in some groups, many people, whose names are on the long list of group leaders, are often only nominal leaders; they don’t actually do anything. I also found that apparently sophisticated organizations often included nominal departments or branches, as a consequence of the delegation of nominal leaders; and many people who are counted among the membership are nominal members only. Many no longer paid membership fees, if they have ever paid them at all. This “nominalism” is probably tolerated by everyone involved in self-help groups, partly because they realize that the groups need to pretend that they are sophisticated, successful organizations with numerous active leaders and a large body of members in order to attract support from various sections of society.

This “nominalism” influenced the interview transcripts causing contradictions and discrepancies. For example, while some participants said that after taking counseling most counsees join their groups, other participants stated the very opposite: that very few joined the groups. Although these two statements appear to be contradictory, the truth is that both claims could be correct if we take into consideration that most of those who join the groups are nominal members only. They do nothing more than pay a membership fee. Because the cost in terms of time and energy are not recouped by the leaders providing the counseling service, the members who do nothing but pay membership fees should be considered “free riders.” In this context, free riders can be divided into two groups: non-members and nominal members. However, in this paper, I will not discuss them separately because some nominal members do not even pay a membership fee, whereas others pay very little, hence it is not necessary to distinguish between non-members and nominal members.

Justification accounts of free riders and the acceptance of their child’s illness

My previous interview research identified three sorts of accounts of free riders on the voluntary services of self-help groups: justification, accusation and exposure accounts. The justification accounts expressed the belief that parents who act as free riders often cannot contribute to the group because they have to take care of their ill children, or

because they live so far from their leaders. The accusation accounts, on the other hand, emphasized the selfishness or the egoism of the free riders. Meanwhile, the exposure accounts revealed a very different slant: those who are to blame are not the free riders, but the leaders who diminish newcomers' enthusiasm for leadership (Oka, 2003).

In this series of focus group interviews, a more psychological type of justification account was given: for some parents, joining a parent group means admitting that their child has a disease. Hence their reluctance to join can therefore be seen as a form of denial and a defense mechanism. The following quotes describe the feelings of such parents:

[Extract 5]

S: [The caller said,] "If I could, I wouldn't be involved with such a group as yours, because if my child recovers, I will immediately be quite 'normal' again. I really feel I would like to keep away from your group." I talk carefully with such people. (laughing)
(Focus group #1, Section 2)

[Extract 6]

H: Some parents don't want to see their future because the disease is progressive. They want information, but they don't want to join the group. I say to such people, "You are free to join us or not. However, you are welcome whenever you are in trouble. You can call me anytime. We are open to everyone."

TO: Could you talk a little bit more about why they don't want to join you? Is it because your disease is progressive?

H: Yes, but they surely believe their children will be the exceptions. They won't accept the fact.

S: Yes, Yes, Yes!

W: They want to believe that their child will be the first case [to recover].

H: They know it, but they won't believe it, because [they think] "My child [looks] quite normal!" [because the disease is at the beginning stage.] So, they don't want to see the future. They are in a state of fear.

(Focus group #3, Section 7)

Thus, by inviting parents to their parent groups, leaders can help parents accept the fact that their children are very ill. In the next section, I will discuss how the leaders go about asking counselees, especially telephone callers, to join their group.

Tactics against free riders

To resolve the problem of free riders, different tactics have been suggested or implied by the participants in the focus groups. These include: using information as an incentive to join the groups; changing counselor-counselee, one-to-one relationships into between-members network relationships; and stressing the leaders' parenthood.

1. Using information as an incentive to join the group

Some participants have said that their groups prefer to keep a certain amount of information about the children's diseases and their treatment from non-members, so they can use the information as an incentive to join the group.

[Extract 7]

K: I often find that messages are left on the phone. They say, "Please phone me," and give their telephone numbers and a convenient time. Because I am given some amount of correspondence expense by the group, which comes from the membership fees, so this isn't a big issue if the callers are members. However, when non-members ask me to telephone, I wonder how long I am allowed to telephone them, using our membership fees. I am not sure. So, when I started to be responsible for this hot line, other leaders said to me, "Ms. K, you are too generous. Many people want to get nothing but information, and once they get it, they leave. So, you should say decisively, 'Pay a membership fee. Then, we will tell you about various things.'" (laughing)

T: It's difficult!

K: Nevertheless our experienced leaders said that's what I need to do. They say, "Nowadays, people will leave once they get information. They are really selfish. Unless you point it out, such people won't notice what they are doing.

T: We also receive similar calls. They ask us to send books. We jot down all their particulars [names and addresses], and send our newsletter to them all. And some people continue to read the newsletters. (laughing)

K: Without paying any membership fees?

T: Without paying. Though we have sent them a package of membership application forms, they won't reply. The other day we felt this was too much, and stopped [sending the newsletters to them].

(Focus group #5, Section 7)

Some leaders, in accordance with their group's policy, have decided to limit an amount of information that is put on their websites to prevent free riders from using it.

[Extract 8]

S: It might appear unethical, but I am neglecting to answer questions in BBS and e-mails. . . . This is our group's policy. We don't allow people [to ask questions] without joining us. We feel we have a responsibility to those who have joined us, [not to those who won't]. . . . If we opened up [the information] to the public, joining us would be meaningless. So we have no web pages for answering questions [from the public].

(Focus group #1, Section 5)

[Extract 9]

Y: If you thought of the benefits you could get from joining our group, and if you could find out whatever you wanted to know on [our website on] the Internet, you would feel that there was no need to join us. So, this is not the point. [What is important is] the spirituality or human relations [among us]. So far I have seen parents and children completely changing [and developing] themselves after joining us. From experience, I know that there are a lot of things that the Internet can never achieve.

(Focus group #6, Section 3)

Ms. Y thought that free riders would miss out on the great power that her parent group

has. While the Internet is a powerful tool that allows parent groups to distribute their information easily, it does not let the recipients form any close relationships, which might limit their opportunities for developing friendships.

2. *Changing one-to-one relationships into network relationships*

Some leaders attempted to avoid one-to-one relationships with counsees because they were reminiscent of professional counseling. Although the interview participants had no clear idea of how to change one-to-one relationships into network relationships, they pointed out two possibilities: using newsletters, and introducing counsees to other members with the same circumstances.

When I asked about factors that could improve the groups' counseling service, Ms. O talked about the benefits of using newsletters for counseling, because it enable other members to participate in the discussion.

[Extract 10]

O: If I were a counsee, though it would be fine if only one person answered (my questions), I would be happy to receive answers from people with different ideas.

TO: Counsee?

O: If I said, "I have this problem," I would be glad to receive [answers] that were given from various viewpoints, because I could compare them.

TO: I see. You mean, for example, you need an opportunity for group counseling.

O: Yes. And, our newsletters

K: You mean, for a question of "What should I do in this case?" the newsletter can publicize different answers from Ms. A and Ms. B.

O: I believe this will lead to the development of the group. In fact, after reading this, I decided to join the leadership. In the past, our newsletter was not very good, and there was very little interaction among members. Then I thought of leaving [the group]. In the meantime, the newsletters have changed. I wished it had always been as it is now, because I couldn't ask questions before. So, I telephoned a leader and said "This is great!" Then I joined the leadership.

(Focus group #1, Section 9)

Answering the same question, another leader recalled the early days of his group:

[Extract 11]

N: In those days when our group first started, we had twelve issues a year: a letter appeared in an issue, and then replies to this were given next month. This was like so-called "group correspondence". [For example,] a question of "Why [is my child] choking?" was asked, then next month, an answer was given, like "My child's choking was healed in this way." [Through this process] our group had a great deal of unity.

(Focus group #2, Section 9)

Although the newsletter is a "slow" medium, in the sense that people have to wait for at least a month to get answers, it is nevertheless a useful way of expanding one-to-one relationships into network relationships.

Another way of changing one-to-one relationships is to introduce other parents who are in similar situations to the counselees. When I asked what was needed to develop their counseling service, some leaders pointed out the importance of introducing members to one another.

[Extract 12]

T: Our chapter president's role is getting members together. When a new mother joins, we feel she might become a good friend of a certain mother, don't we? In fact, in the case of such a big group, after joining, members will be confused and isolated. But this president is great: she always gets [a new member and other members] together, saying, "You are with this mother." After this, all members have a feeling of being part of the group.

Y: I am doing this, too. When a new person joins us, I say, "You would like to have some friends [in your neighborhood], wouldn't you?" If she says yes, I tell this to another member, and if that member also says yes, they usually get to know each other. As you know, if you have parents [of children] with the same disease in your neighborhood, you feel empowered.

(Focus group #6, Section 9)

Most of the parent groups in this research have no regular group meetings for members, partly because the parents have difficulty leaving their homes, and partly because the rarity of the disease means that the members are dispersed over a wide geographical area. Consequently, it is difficult for new members to make friends without the leaders' intervention, as described above.

3. Stressing the leaders' parenthood

The third way of resolving the free-rider problem is to emphasize that the counselors are also parents, not professionals nor employees of public agencies. This tactic has several different aims. First, by stressing their non-professionalism, leaders avoid having to provide medical advice. Second, by saying that they have children with the same disease, they are better able to develop a feeling of empathy and equality with their counselees. Third, by stating that their work is done voluntarily and they are employed by no agencies, they remove their counselees' "consumers' right" because they are using a voluntary service. However, the participants in the focus groups never distinguished between these aims, as the following example shows:

[Extract 13]

W: Mothers who have gotten over [the shock of the disease], are often asked for advice. They say: "I was asked for advice, but I had no ideas what to say." Those who are asked advice, seek advice. Anyway, we should make them all know that everyone is an ordinary parent. No one is especially great. . . . The principle is that every member is an ordinary parent. On this principle, we can exchange information with one another. We have no prominent figures. We never use somebody's life as the model.

(Focus group #3, Section 3)

By emphasizing the equality between those who ask advice and those who give it, the leaders might be attempting to reduce the imbalance between counselors and counselees.

Discussion

As mentioned above, the helper-therapy principle (Riessman, 1965) tells us that helping others is a fashionable opportunity for people to grow psychologically, and that being a leader and playing a helping role in a self-help group contributes to one's personal development. Although Revenson and Cassel (1991) in their Western-based research have reported on the burnout of leaders of self-help groups, they have also found that leaders were satisfied with roles in which directly helped others, but were dissatisfied with their other chores. In this Japanese-based research, however, there is still the question of why the leaders had so many problems with their counseling service. Perhaps it is due to cultural differences between the United States and Japan, in which case two explanations are plausible: Japan's shortage of professional and familial support, and the new phenomenon of mutual help without mutual monitoring.

Professional and familial support

Reading the following quote of Medvene, Volk and Meissen (1997) might help us identify the cultural differences that exist between the US and Japan:

It is common that new members of self-help groups express strong and emotional appreciation for having others who really understand things – things that even the most empathic nurses and spouses cannot understand. Further, self-help group members do not expect to be “cared for” by leaders, nor do leaders spend nearly as much time with members as do nurses or spouses. (p. 273)

Unfortunately, in my ten-years of fieldwork with parent groups, I have almost never heard of nurses who “cared for” parents. The participants in my qualitative interviews, who are forty-seven in number, have never talked about helpful nurses. Additionally, some participants have asserted that more medical social workers are needed in hospitals, which reflects the fact that only a small number of hospitals in Japan employ medical social workers. Those professionals that the participants referred to as being helpful were exclusively medical doctors. However, doctors are usually very busy, and they cannot afford to care for parents for a long time. Also, in Japan, psychological counselors are not well recognized as professionals. They are few in number, and people are not accustomed to paying high fees for their services. Moreover, mental health services are not greatly used in Japan, probably because there is a strong prejudice against the mentally ill, or also because the Japanese government's budget for mental health services is very limited.

In a word, the shortage of professional support systems might lead parents to use the voluntary counseling service of the parent groups, in the expectation that the groups' leaders will do the work of various professionals, including social workers, nurses, doctors, and psychological counselors.

Concerning familial support, my interview participants repeatedly told stories of isolated mothers who cared for their children entirely by themselves. Because the

children's diseases caused such complicated problems, the fathers often had little knowledge of what was involved. Even when they obtained a lot of information through the Internet, there was a great gap between their theoretical knowledge that had been given in writing, and the mothers' practical knowledge that they had acquired through their practical experience with their sick children. This gap in understanding has destroyed relationships between many parents. In the case of a genetic disease, the problem is more complicated. Often the mothers won't tell anything about the disease to their parents-in-law. They may not be able to talk about the disease even with their other children, because they fear that when the children know of the hereditary aspects of their siblings' problems, they will become fearful and depressed.

Consequently, Japanese mothers do not expect to get much support from health professionals, nor from their family members. This might lead to an exceptionally heavy burden being placed on the groups' leaders who are providing volunteer counseling service.

Mutual help without mutual monitoring

It is often pointed out that Japanese mutual help has a unique characteristic: an accompanying mutual monitoring or mutual surveillance (Sugimoto, 1997), which makes Japanese mutual help different from that of the United States. Matsubara and Todoroki (2003) state:

Cooperation in traditional Japanese society had a strong element of monitoring the activities of others, making distinctions between "insiders" and "outsiders," and creating structures through which assistance was offered only to one's relatives or other "in-group" members, to the exclusion of outsiders.

The social psychologist, Yamagishi, (1988) has confirmed this aspect of Japanese mutual help by various experiments, and has pointed out the relationship between mutual monitoring and free riding, describing "the strong . . . role of mutual monitoring and sanctioning in the Japanese society as a deterrent of free riding" (p. 540).

However, it is obviously impossible for leaders of parent groups to conduct mutual monitoring, because they have very little, if any, time together. Likewise, in the case of the non-members, mutual monitoring is not available to deter them from free riding. Because the traditional deterring tool, mutual monitoring, is no longer available in these parent groups, the type of mutual help provided by the groups is something quite new.

Conclusion

In conclusion, voluntary counseling service is essential to parent groups as social movement organizations, because these services provide the main gate through which new members join the groups. Nevertheless this service can also be the groups' downfall because the cost to the members who maintain these services is crippling. On the other hand, this service represents the groups' greatest humane achievement.

At this point, one of the greatest possible contributions that professional supporters can make to the development of self-help groups might be to help them

understand what happens to their counseling service, and to help isolated counselors solve their problems. While this paper has identified and discussed three tactics that can be used against free riding, the research participants themselves have not always clearly acknowledged these tactics, and they seldom think of their counseling service as an important means of recruiting new members. Researchers and helping professionals can emphasize that the mutual help of these parent groups is quite different from Japanese traditional mutual help because the parent groups' mutual help is not accompanied by mutual monitoring. Researchers and helping professionals can also help the leaders develop a new model of counseling service, in which the focus is moved from the traditional, individual-based, counselor-counselee relationship to a new, group-based, member-network relationship.

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Appendix A

A list of diseases and conditions that the groups dealt with, and the numbers of the group members

1. Biliary atresia, 1068
2. Genetic variations, 220
3. Heart disease, 5800
4. Hereditary sensory and autonomic neuropathy, 63
5. Insulin dependent diabetes mellitus, 500
6. Juvenile rheumatoid arthritis, 120
7. Mitochondrial diseases, 70
8. Moya-moya disease, 1000
9. Mucopolysaccharidosis, 120
10. Pituitary dwarfism, 170
11. Prader-Willi syndrome, 320
12. Primary immunodeficiency syndrome, 250
13. Spina bifida, 1820
14. Subacute sclerosing panencephalitis, 90
15. Tuberous sclerosis, 160
16. Use of artificial ventilator, 294
17. Xeroderma pigmentosum, 44

Appendix B

The questioning route of the focus group interviews

1. Tell us your name and your group's name, and briefly describe the disease that you are dealing with.
2. Write down on paper the problems that you face when your group provides peer counseling service, then hold up the paper and explain these problems to us.

3. We'll put the papers up on the wall. After comparing the problems that you have written on your papers, tell me your opinions.
4. This is a list of problems about parent groups' peer counseling service that I collected through my previous research. Tell me your opinions.
5. This is a list of mediums that are used when parent groups provide peer counseling service. Tell me about the strengths and weakness of each of them.
6. What sort of principles or rules do you have in mind when you provide peer counseling service?
7. How does your parent group's counseling service differ from professional counseling service, including medical doctors' and social workers'?
8. What is needed to make your peer counseling service more substantial?
9. What do you feel after these discussions? Have we missed anything?

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