SELF-HELP GROUPS
FOR PARENTS OF CHILDREN
WITH INTRACTABLE DISEASES

A Qualitative Study of Their Organisational Problems

Tomofumi Oka


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Tomofumi Oka

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the regulations for the degree of
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Finally, I would like to say how much I appreciate the help of Sumiko, my wife, who worked as assistant moderator of my focus group interviews in this research, and gave me many suggestions based on her experience as a researcher of paediatric nursing. While I was engaged in this dissertation, my first child, Ryōchi, was born. His existence has provided an alternative, and more personal perspective to my data analysis. Thank you, Ryōchi.
ABSTRACT

The purpose of this dissertation is to examine the organisational problems, and in particular the leadership problems, of self-help groups in Japan for parents whose children have intractable diseases. Since 1993, I have been involved with these parent groups, and have conducted three sorts of qualitative interview: thirteen informal conversational interviews, four focus group interviews, and fourteen guided interviews, involving the members of twenty-one parent groups. Part of the research was carried out as participatory action research in which a research team was formed and authorised by the parent groups.

My findings have shown that the groups’ most serious problems lay not outside their groups but within, with the shortage of suitable leaders who volunteered in the activities. Three different sorts of account were given concerning the leadership shortage. They included justification, accusation and exposure: the participants claimed that taking care of ill children caused the leadership shortage; selfish members created it; or the determination of older leaders to remain at the helm prevented new members from becoming leaders. Cognitive maps have been drawn of these situations.

I have explained the theories behind the free-rider and social loafing problems, and the leadership traps confronting the parent groups, and have applied attribution theory to the results. I have discussed the practicality of consultation for group leaders, and argued that organisational socialisation should be activated in the parent groups while propounding the island-within-a-lake model of parent groups. Methodologically, I have discussed social research within Japanese culture and the ethical issues pertain to participatory action research.
INTRODUCTION

My introduction has two parts. First, I describe my research questions, and second, I explained why I chose them.

THE PROBLEMS: HOW THEY EMERGED

This section discusses three sorts of the research problems: theoretical problems, practical problems, and methodological problems.

Theoretical problems

The theoretical problems emerging in this research were organisational ones concerning the self-help groups for parents whose children had intractable diseases. These problems emerged during my interview research. As Rubin and Rubin (1995) have so aptly stated:

In a qualitative interviewing study, . . . concerns that appear important at the beginning of the research may seem less vital later, and points that seemed unimportant when the study began may turn out to be valuable. (p. 43)

In the beginning of this research, when I started to conduct informal conversational interviews (Table 1.1 on p. 4), my original purpose was to explore how these self-help groups were started by parents who probably felt isolated and devastated. However, the interviewees looked bored when I asked about how they started their groups, simply because they were not the founders and had had no direct experiences on the subject, or probably because their present problems occupied their thoughts. So, after completing some interviews, I changed the problem areas to include their present activities and problems, because
Table 1.1  
Conducted interviews and client reports

<table>
<thead>
<tr>
<th>Date</th>
<th>Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997.02. – 1997.03.</td>
<td>4 Focus Group Interviews with 15 groups</td>
</tr>
<tr>
<td>1997.07. – 1997.12.</td>
<td>5 Discussions with the Research Team</td>
</tr>
<tr>
<td>1998.01.</td>
<td>Client Report I published</td>
</tr>
<tr>
<td>1998.05. – 1999.04.</td>
<td>Guided interviews with 15 groups</td>
</tr>
<tr>
<td>1999.09. – 1999.12.</td>
<td>3 Discussions with the Research Team</td>
</tr>
<tr>
<td>2000.02. – 2000.03.</td>
<td>* 6 Focus group interviews with 17 groups</td>
</tr>
</tbody>
</table>

Note. (*) The research findings of these two projects are not included in this dissertation.
the literature review on self-help groups showed, as I will mention in
Chapter 2, that much research had been made about self-help groups
who had weekly or monthly meetings, especially addicts’ groups such
as Alcoholics Anonymous. I had little knowledge of the activities of
these parent groups.

Through this first series of qualitative interviews, I realised that
these groups developed special forms of activities, such as “summer
camps”, which were different from those of groups whose members
can easily attend regular meetings. Also, I found that the problems the
parents faced were characterised by the rarity of their children’s
related diseases and the rapidly changing medical information that was
becoming available to them.

During the second series of interviews, I conducted focus groups to
identify the parent groups’ major problems. These problems included
not only organisational ones but also service-related ones, especially
involving telephone counselling. However, through these interviews,
intraorganisational conflicts emerged as the major problem. Because it
would be natural for any social groups to hide their own
intraorganisational conflicts from outsiders, especially outsiders who
aim to write about them publicly as all researchers would do, it took
me some years to build up enough trust with the leaders that they
would talk frankly to me about their groups’ problems.

With the third series of interviews, I succeeded in eliciting
accounts of their intraorganisational problems in greater detail. This
series of interviews was individual-based, and so was quite different
from the focus group interviews where participants were aware that
relative strangers were listening in. Because I chose interviewees who
trusted me enough and had already talked about their serious
intraorganisational problems, their narratives were much more critical
of group leaders than I expected.

Practical problems

The theoretical problems mentioned above are also practical ones,
because knowledge of the intraorganisational problems of self-help
groups is useful for group leaders and professional supporters to
understand the serious problems the groups face. In fact, according to
the newsletters of the National Supporting Network for Children with
Intractable Diseases (pseudonym), which helped me with my research,
more and more new self-help groups involving sufferers of rare diseases were being organised in Japan. These groups had to start their activities without any explicit guidelines. If they could use consulting services that deal with the organisational problems of such self-help groups, they would have a better chance of understanding how to develop their groups. Accordingly, the knowledge that I have attempted to produce is designed to assist such consultation.

**Methodological problems**

Our methodological problems are divided into three groups. First, I used three sorts of qualitative interviews: informal conversational interviews, focus group interviews, and guided individual interviews. Comparing the results of these interviews, especially the group interviews and the guided individual interviews, gives us an insight into possibilities and limitations of focus group and individual interviews.

The second problem was centred around participatory action research, especially the ethical issues involved. I formed a research team whose members I recruited from group leaders, and with this team’s assistance I compiled the client reports (Appendix A and B on pp. 403-426). Because this research dealt with intraorganisational problems, some quotes that I originally planned to use sounded offensive to the team members and had to be omitted.

The third problem is a minor one. I attempted to use counting as a means of analysing the processes used in the focus group interviews. As this dissertation shows, by simply counting coded lines of transcripts, the results of group interviews can be clarified. Also, I will discuss the problem of commensurability between qualitative and quantitative research findings.

**WHY I HAVE CHOSEN THIS TOPIC**

My reasons are twofold. One is related to the “natural history” (Silverman, 2000) of my research; the other is theoretical. Because I narrate the natural history of my research at length in Chapter 6, I will state it only briefly here, and then discuss the theoretical reasons,
though some reasons for choosing this topic were related to both natural history and theoretical considerations.

**Natural history**

As Taylor and Bogdan (1998) have stated, in qualitative research “getting into a setting is often hard work. . . . You cannot always determine beforehand whether you will be able to get into a setting and pursue your interests” (p. 27). This is particularly true, given that some self-help groups sometimes refuse to be researched. As a matter of fact, Paul (pseudonym), my gatekeeper, who was a bureau chief of the National Supporting Network for Children with Intractable Diseases (pseudonym) and ex-leader of a parent group, had consistently refused the research proposals of almost all researchers other than me. He often used the phrase: “We are not working for researchers!”

On the other way, the research area of “self-help groups for parents whose children have intractable diseases” was not initially chosen by me. On the contrary, the field, or more precisely Paul, approached me, so I did not choose them but rather they me. Being approached by Paul was not the only reason for my deciding to research this area. I had in fact been approached by several sorts of self-help group: Alcoholics Anonymous, Independent Living Movements for people with physical disabilities, self-help groups for patients with mental illnesses, and so on.

So why did I choose to research groups for parents with ill children? I had three reasons. The first was the timing. When Paul started to make contact with me, I was not intensely involved in any self-help groups, having failed to enter the fields of alcoholics’ or neurotics’ self-help groups with some research purpose. The second was that Paul’s proposal was the one and only “research proposal” I had so far received from supporters of self-help groups. Although I had sometimes been asked by self-help groups and their supporters to help by giving lectures or advice, I had almost never received a proposal to do research on self-help groups until Paul asked me. This stimulated my intellectual interest.

The third reason was theoretical; at that time there had been very little research on self-help groups in this area of Japan. In fact, since I started working with the National Supporting Network for Children with Intractable Diseases (the Network) in 1993, I had been looking
for research papers on self-help groups for these parents, and so far I have found none, except for papers that involve only one or, at most, a handful of groups in case studies. This is not only because very few Japanese researchers had been interested in this area of research, but also because no organisations apart from the Network could help researchers make contact with the many self-help groups in the field. The Network had so far refused to involve any more researchers in the activities of the parent groups, although it had welcomed many medical and child care researchers who were not researching the parent groups as such, but were more interested in the treatment of the children.

**Theoretical considerations**

The theoretical importance of the research might be been clearer if I had compared these parent groups with addicts’ groups or parent groups for children with disabilities. My researched groups seldom had face-to-face meetings, and they were much more likely to recognise the value of having the latest information.

As examined in Chapter 2, present definitions and models of self-help groups are greatly influenced by addicts’ groups, especially Alcoholics Anonymous and other 12-step groups. The greatest difference between these groups and my research target groups is that parents whose children had rare diseases had far more difficulty having regular group meetings, say on a weekly or monthly basis. This is because the rarity of their children’s diseases means that the parents were dispersed over a wide geographical area, and because the parents, particularly the mothers, were forced to stay at home to take care of their ill children.

Compared with parent groups for children with disabilities, parents of children with intractable diseases lived in a more turbulent environment in the sense that medical knowledge was changing both continuously and rapidly. Without the latest information, parents might miss very important opportunities for ensuring their children’s survival. Consequently, many self-help groups for these parents functioned as valuable information providers. This seems to produce a free-rider problem that may not be so serious among other sorts of self-help group.

Research on self-help groups with such a unique set of
characteristics could therefore produce an alternative model or image of self-help groups, thus enriching their definitions and theories.

**SYNOPSIS**

The purpose of this research is to examine organisational problems of self-help groups for parents whose children have intractable diseases. The reasons why I have chosen this topic are partly related to the natural history of my research. A gatekeeper, who was a bureau chief working for a welfare agency that supported self-help groups for parents of ill children, contacted me to ask whether I could do some research on his clientele.

The reasons were also theoretical. Little research had been done on these self-help groups, so researching their unique characteristics would provide an alternative model of self-help groups, particularly as these parent groups were, on at least two points, different from those groups that have been well researched, for example: Alcoholics Anonymous.

First, the rarity of their children’s diseases means that group members were widely dispersed geographically and were often confined indoors to take care of their ill children, or must remain within quick access of the nearest hospital. Therefore, it was difficult for their membership to maintain regular, face-to-face meetings.

Second, their groups were often desperately seeking the latest information on medical progress concerning their children’s diseases. Medical advances were developing so rapidly, and along with them, new knowledge and technology that might help their children survive.

Methodological discussions are also an important part of this dissertation. Three sorts of qualitative interview were conducted, the different results of which will be discussed. Participatory action research, in which some participants played important roles in the research proceedings, was also an important topic, the ethical dilemmas arising from which, will be also discussed at length.
PART I

Literature review