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Participatory Research on Sensitive Topics of Self-Help Groups

in Focus Group Interviews

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Abstract

This article examines the combined use of focus group interviews and participatory action research on self-help groups, and the psychological effects on co-researchers when dealing with sensitive topics. The research was in conjunction with a parent group conference, which involved 21 self-help groups for parents of severely ill children; its purpose was to identify group problems and find feasible solutions. The research team conducted 4 focus group interviews with 24 participants. Five research team members became interview participants and, as co-researchers, checked quotes from the interview transcripts. The co-researchers functioned well on data analysis by weighting data and formatting the data display, but were subject to psychological stress when handling a sensitive topic: the management roles of bereaved parents. As a result, the research team proved to be an effective safety device preventing possible psychological damage being inflicted on research consumers.

Before the 1960s there were few studies on self-help groups. The front-runners of the researchers into self-help groups used the case study or ideographic approach as their research (Katz, 1961; Drakeford, 1969; Sagarin, 1969). However, in the 1970s many papers published demonstrated that researchers had begun to use the nomothetic approach (Borman & Lieberman, 1976; Lieberman & Borman, 1979). Two of these researchers, Lieberman & Borman (1976), have made the following appraisal of self-help groups:

With a few exceptions, self-help groups owe little to the professional; . . . have frequently been resistant to professional intervention into their activities. At times, their ideology actively precludes such individuals from entering their system; . . . As social scientists, we have too frequently been naive about the potentials for collaboration, and it seems that few have really explored the possibilities of collaborative inquiry. We believe that models of meaningful collaboration can be developed and executed, but that they will involve the researcher in activities that do not entirely fit with an archetypal view of what research is and how one conducts it. (p. 461)

Obviously then, a third approach was needed to follow the ideographic and nomothetic approaches, and so in the 1990s, after Lavoie (1984) discussed the possibilities of using action research, researchers on self-help groups began using participatory action research (Chesler, 1991; Borkman & Schubert, 1994; Schubert & Borkman, 1994, Kurtz, 1997, pp. 127-128). This third approach would be welcomed by the Japanese self-help groups which often have a negative attitude towards the research of human service professionals even though Japanese culture tends to respect authority (Oka, 1994).

Participatory action research, under a variety of names (Elden & Chisholm, 1993), has been intensively studied by three groups of researchers (Reason, 1988b, 1994). The first group is interested in people in developing countries (Fals-Borda & Rahman, 1991; Smith, Willms, & Johnson, 1997). Their findings presuppose "the differences between bourgeois intellectuals and grassroots communities, between elite vanguards and base groups, between experts (technocrats) and direct producers, between bureaucracies and their clients, between mental and manual labor" (Fals-Borda, 1991a, p. 5). This case study, however, was free of these differences. The participants were leaders of self-help groups for parents of sick children. They worked as volunteers and they spent their own money on their groups although they were financially burdened with caring for sick children. Therefore, because of the financial burden, the leaders of the self-help groups are unlikely to be people with low socioeconomic status.

The second group of researchers was led by J. Heron and P. Reason (Reason & Rowan, 1981; Reason, 1988a, 1994; Heron, 1996; Reason & Lincoln, 1996). Their approach was different from that of the first group because "while participatory research was developed for work within existing social settings such as Third World villages, in experiential inquiry we have often chosen to establish groups entirely for the purpose of research" (Reason, 1988b, p. 2). This approach drew criticism from an author from the first group who believed that Heron, Reason, et al. would experiment "in order to 'make sense' of data, without giving enough attention to action in real contexts" (Fals-Borda, 1991b, p. 161).

Third group of researchers on participatory action research may have the position most similar position to ours, because they show a strong interest in organisational development (Reason, 1988b, p. 2; Fals-Borda, 1991b, p. 160; Greenwood, Whyte, & Harkavy, 1993) and they relate participatory action research with

action research (Bryman, 1992, pp. 178-187; Hart & Bond, 1995; Stringer, 1996). One of their definitions of participatory action research is as follows:

In participatory action research (PAR), some of the people in the organization or community under study participate actively with the professional researcher throughout the research process from the initial design to the final presentation of results and discussion of their action implications. PAR thus contrasts sharply with the conventional model of pure research, in which members of organizations and communities are treated as passive subjects, with some of them participating only to the extent of authorizing the projects, being its subjects, and receiving the results. (Whyte, Greenwood, & Lazes, 1991, p. 20)

Although this group of researchers may share more interest in organisational development with researchers on self-help groups than the other two groups, it is not productive for us to exclude the findings of those groups (Fals-Borda, 1996) because some users of self-help groups are socially oppressed; for example in Japan, people with schizophrenia or mental retardation.

Case Description

The purpose of this article is to explore the possibilities of participatory action research with self-help groups, using a case description: focus group interviews with self-help groups for parents of seriously ill children.

Research Context

Twenty-one groups for parents of severely ill children organised a parent group conference [the Conference]; this conference was supported by a child welfare agency, the National Network for Supporting Sick Children, which has an office in Tokyo. As a volunteer, I have participated in the National Network for five years, and I have developed relationships with the leaders of the parent groups who organised the

Conference.

In addition to the self-help groups for parents, Japan has the Japan Patients Council [JPC], whose member-organisations claim to represent a total of 230,000 patients patients (Purimedo-sha, 1996).

Although the Conference shares some groups with the JPC, there are differences between them. While the JPC consists mainly of self-help groups for patients, the Conference is made up of groups for parents. The JPC aims to be the National Centre for all the patients in Japan, but the Conference is not eager to include more parent groups than it currently has. While the JPC has advocacy for patients' human right as its main purpose, the Conference started as a forum where parent groups could exchange information and learn about each other to enable them to improve their groups. Moreover, the Conference has no trustees, no executive committee, nor any article of associations, which could become a burden for the leaders of the parent groups who participate in it (Oya-no-Kai Renrakukai, 1996).

With the co-operation of the Conference, I had previously carried out two research projects using individual interviews to collect data on self-help groups. Then two years ago, as the next step in my research program, I decided to conduct participatory action research using focus group interviews to further my research on self-help groups. My research questions were about the management problems the parent groups have and how they have solved them, and what successful or unsuccessful experiences they have had as a result.

Approval of the Gatekeeper and the Conference

To organise the research, I first consulted with the Director of the National Network. He was the "gatekeeper" in this research project. The first difficulty I encountered was that he was unfamiliar with focus group interviews. While "only a

decade ago, focus groups were almost unknown to social scientists" (Morgan, 1997, p. 2), they are now well-known in North America. However, only a few Japanese social scientists currently use them and it is quite possible that a social worker within a welfare agency would not know much about them. The Director of the National Network had had experience of being interviewed in focus groups conducted by marketing researchers - focus groups are frequently used in this way in Japan, as they are in North America (Templeton, 1994) - and his attitude towards them was not positive.

"Just chatting? It doesn't sound great," he said. He then showed me the research report that he had made in collaboration with a doctor of medicine. It had some graphs and tables; clearly his notions of "genuine" research were quantitative, not qualitative.

He also had doubts about the usefulness of research although he acknowledged the importance of research generally. Many leaders of the parent groups seemed to share this doubt, probably because they had had previous experience of being used for research by human service professionals, and they had found it useless. The research had contributed nothing towards developing a cure for their children's diseases nor had it improved the quality of the care they received.

What made him and some of the leaders take a more positive attitude towards the research was the fact that I suggested that the group leaders could become co-researchers, which would enable them to be in control the research. When I made this suggestion, I did not anticipate that they would gladly agree to it, because I did not think that these sceptics would be so easily converted. However, their strong interest in participatory action research may indicate that they were sceptical of researchers and not of research.

After the Director and I had come to an agreement, he introduced my research plan to the Conference, and put forward his idea of creating a design team for the

research. Because the Conference had no formal committees for decision-making, the participants who occasionally attended a Conference meeting were expected to make such decisions. The meeting during which my research plan was introduced was unusual because a famous paediatrician was a guest speaker and so there was a higher than usual attendance. Many of those present did not know of my previous work with the Conference and although I explained about the research for about a quarter of an hour, many of the 30 or so people neither asked any questions nor expressed their opinions. After a short silence of the attendants, a leader who knew me well summarised what I said, and consequently explained it again on my behalf. Because of his support, the Conference approved my research plan and decided to let me form a research team. After the meeting, I said to the Director that I felt that those present were indifferent to my plan. He replied, "Don't worry. They didn't understand what you said at all. Many of them were people attending the meeting for the first time."

The Conference was such a loose organisation that even after I had got the approval of the Conference, I had to actively persuade some individual parent groups to join the research. Additionally, the Director introduced my research plan to the Conference and so many Conference members thought that he had initiated it. Some members were in conflicts with the Director and so adopted an uncooperative attitude towards the research.

Organising a Design Team and a Research Team

I invited four leaders who had expressed a willingness to join the design team, and on the Director's advice I included the leader who had supported me in the previous meeting. The team consisted of these leaders, the Director, and myself. This team had only one meeting, during which it authorised our research design.

In the next quarterly meeting, the Conference approved the research design. The

Chairperson of this particular meeting - they had a different chairperson at each meeting - asked the design team to function as a research team, and then encouraged two people who were attending for the first time to join the team, saying "This will surely be a good chance for you to learn about the other parent groups." Also, one of two members who belonged to a parent group suddenly withdrew from the research team - the other did not give us any reason although I asked - and the Director also withdrew because of his busy work schedule. Consequently, two old members went out, and two new members came in.

Collecting Data

In accordance with the research design, I conducted four focus group interviews. Each group had six participants. I was a moderator, and I had for my assistant moderator, a graduate student of nursing who had previously conducted interviewing research with the Conference.

I asked all the 21 groups of the Conference to send me one or two participants for the interviews. This was not a good way of sampling, but the group leaders were so busy caring for their sick children and working for the parent groups that I had no choice. Consequently, from 16 of the groups came a total of nine men and fifteen women. For various reasons, the five remaining groups did not send me any participants. One group had negative feelings about the research team. One had too few members who lived near our interview room, and could not afford to send a member to Tokyo. One said that there were serious conflicts occurring amongst their members and they did not think it would be appropriate to allow members to take part in discussions about their group. One said that their contact person was too busy and that the remainder were too inactive to enable them to find another member who could participate in the interview. The last group's application to participate was declined

because all places had already been taken on the days its members were able to attend. Also, this group was different from the others because it was for parents of children with a variety of diseases and it shared a common interest in community care while the others were organised around specific diseases or symptoms.

I organised the focus groups so that they were made up of participants who belonged to different parent groups. I did this so that they could speak out freely about their group's problems.

My requirements of the participants were that they should have experience in leading groups, and that they should be parents. Consequently, two members of the research team, a patient and a social worker employed by a parent group, were excluded from the list of the interviewees. Instead, I asked them to contribute to testing a pilot interview (Krueger, 1994, pp. 68-69).

During and after interviews, I found that parent groups had various reasons for selecting their participants, some of which were ulterior. I restricted the interview participants to parents, however some group leaders thought that this was a good chance to educate their new leaders, because in the focus groups they would have opportunities to learn about the other parent groups which would give them a new perspective of their own group. Consequently, one participant was found to be a patient, not a parent, and another had just started to work as a leader. Also, a pair of participants from one group severely criticised their leader in the focus group interviews. The person who chose them was not the leader and therefore the choice of participants might have had a political purpose.

Analysing Data and Making a Client Report

While the research team contributed almost nothing to correcting the data except for testing a pilot interview, it played an active part in data analysis. I was the only one

dealing with the data in the beginning of the analysing process, because I had promised the participants that the transcripts of all interviews would be strictly confidential and therefore I could not show the raw data file to the research team. I analysed the interview transcripts with QSR NUD*IST, and made a draft which contained many anonymous direct quotes. The research team then discussed the report during the course of five meetings held over a six month period.

Although I originally submitted to the team a draft that was a simplified version of my academic report, they required me to produce a "client report" (Hall & Hall, 1996, chap 10) that would be in a style that was quite different from my academic report. The draft was rewritten seven times over, incorporating their feedback, until it became less formal and had more graphics and illustrations, including humorous cartoons.

This collaborative method of analysis contributed to the development of the client report in three significant ways.

First, the team helped me to weight the data, that is, to differentiate between the important data and the unimportant. Second, the team helped me to format the data more effectively. The team gave me a great deal of advice, from the choice of fonts and figures to the design of the layouts. Third, the team worked as a safety device. The report included many "sensitive topics" (Lee & Renzetti, 1993) and my drafts had comments that could hurt group leaders if they read them. The team checked confusing statements, and often asked me to tone down some of the harsher comments.

Dealing with Sensitive Topics

In the process of analysing data, the co-researchers of the research team read and discussed the comments made by the participants in the focus group interview transcripts, and recognised that some of the quotes were their own words. In this

situation, some of the co-researchers felt emotionally threatened and under psychological stress during discussions on sensitive topics.

One of the most sensitive topics was the management role of the parents of dead children. Among the group leaders, there were bereaved parents, that is, parents whose children had died. Because bereaved parents are free from having to care for sick children, they have more time to be able to volunteer and to take an active role in the management of their parent groups. Also, according to Japanese Buddhist teachings, living people can work for the happiness of the dead; these good deeds are called kuyo in Japanese. Therefore, some bereaved parents are spiritually motivated and eagerly work for their parent groups to do kuyo.

On the other hand, during focus group interviews some parents caring for sick children said that bereaved parents could not be good leaders. They pointed out the following three main reasons: first, bereaved parents are not living in the same situations as care-giving parents. To be caring for sick children in the present is quite different from having once cared for them in the past. Bereaved parents can not share the same feelings as parents who are in the process of caring for sick children. Second, bereaved parents often have out-of-date perceptions about the current environment around sick children. The medical and educational environment around sick children is rapidly changing, but for the bereaved parents, time stopped when their children died. The third point is psychological; parents with sick children are not ready to deal with the likelihood of their dying and they are not happy to be advised by parents whose children are dead.

Even though these points are valid, it was not easy to include them in the report, because bereaved parents account for a portion of the audience. Initially, this topic caused psychological stress for the research team in the following way: during a

meeting, I asked the team members to examine the interviewees' comments that would be quoted in the research report. One of the team members was a bereaved mother. She pointed out, with much hesitation, that the comments criticising bereaved parents were too cruel. Meanwhile, another member, a mother caring for a sick child, found that some of these comments were her own. She knew the context in which these words were originally said, but she could not explain why and how the comments were made, because she did not want the bereaved mother to know that these were her words. During the discussion, the bereaved mother said that she herself had lost her daughter, which shocked the team member who had made the comments. She said to me later in private that she felt very badly about what she had said, and so during the research team meeting, the mother whose comments were being discussed did an about-face and said that she agreed with the bereaved mother. She did not want to admit that the comments were hers, so she could not justify them. We can see that this was a defence mechanism of a person under psychological stress. I also found that another research team member, who had criticised bereaved parents in private conversations, changed her opinion in front of the bereaved mother.

Discussion

This study used focus group interviews and participatory action research in combination, and so it is not be easy to identify which aspect is more related to the difficulties I encountered. However, I was able to identify three points I learnt from this case study.

Weighting Data in Participatory Analysis on Focus Groups

Qualitative research produces a tremendous amount of data, and so data reduction is an important step (Wolcott, 1990; Miles & Huberman, 1994). Also the data from the focus group interviews were complex, and so far no definitive analysis

methods have been established (Knodel, 1993; Carey & Smith, 1994; Carey, 1995; Frankland & Bloor, in press). Therefore, involving the research consumers may be helpful. In my case study, having the participants weight the data made it easier to reduce the data and identify the data that was going to be important to the research consumers.

Researcher's Control on Co-researcher Team and Sampling

First, in my participatory action research it was difficult for me to control the selection of the research team members and the interviewees.

How could I choose the members of the research team? What are the criteria of "good" team members? Willingness to join the team? Interest in the research? Personal relationships with me? Intelligence and abilities? Influence over the Conference? Resources available to them, including free time? Positions within parent groups? Should the team as a whole provide for representative sampling? I found that I could not establish the criteria. Nor did I had any idea of the proper procedure to use for choosing the research team that would be readily accepted by the group leaders. Consequently, I could not be actively involved in choosing the members of the team although Krueger (1994, pp. 200-201; 1995, p. 526) emphasised the importance of this process.

Reason (1988c), on the other hand, states the following about co-operative inquiry groups: "It is ... helpful to regard co-operative inquiry as an essentially emergent process. You can't just set up a co-operative inquiry group, because co-operative processes have to be negotiated and re-learned by every group in every new instance" (p. 19). When this theory is applied to my case study, it becomes obvious why I did not have control over the choice of members making up the research team.

Also, I could not control the sampling process well enough. This was because the

group leaders were busy involved in caring for sick children, and it was hard for them to leave home just to participate in interviews. On the other hand, some parent groups seemed to have selected the interviewees for ulterior reasons: educating new leaders, criticising old leaders, and so on.

It is useful to distinguish between the two sorts of control a professional researcher has: control on the research team and on sampling procedures. It would be impossible to control a research team in participatory action research, because professional researchers and co-researchers have equal control of the team. Professional researchers are not allowed to dominate it. On the other hand, problems on sampling procedures can be solved by making research more understandable to the group leaders and by building mutual trust with them, although this takes a long time and requires considerable energy from people on both sides.

Group Dynamics and Safe Device against Sensitive Topics

In my study, the group dynamics of the research team influenced the participatory analysis on sensitive topics; if there had been not bereaved parents in the research team, the report might have been different. Although member checking is sometimes done through a "review panel" (Lincoln & Guba, 1985, pp. 373-378), individual interviews with the research team members were needed to validate the discussion of the research team.

The comments I originally quoted in the report might have inflicted psychological damage on bereaved parents who worked for parent groups. However, the research team censored these comments, and consequently functioned as a safety device. This is related to ethical issues of "self-censorship" (Adler & Adler, 1993).

Smith (1995) points out a special ethical issue: "the overdisclosure of sensitive information" (Morgan & Krueger, 1993, p. 7) that is caused by focus group interviews.

What should be remembered in my study that the focus group interviewees, as self-help group leaders, are used to sharing their feelings and personal information among people in the same situations, and so in focus groups, they seemed to speak as if they had been in their own self-help groups. In one of the focus groups all the participants were parents caring for children and one said that she was severely troubled by a leader who was a bereaved parent. The other participants showed emotional resonance. These "psychological factors" (Carey, 1994, pp. 234-240) consequently left harsh criticism of bereaved parents in the interview quotes.

One lesson learned from this case is that psychological stress on the research team members might have been prevented if they had not been included in focus groups. This, however, might have caused different problems, because the research team members had keen interest in participating in focus group interviews.

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