
SESSION B4 **VANCOUVER ISLAND**

Applying Participatory Methods

Chair: Carol Jillings

B4.1 *Parents' Groups for Children With Rare and Serious Diseases: A Combined Use of Focus Group Interviews and Participatory Action Research*

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Twenty-one self-help groups of parents have an association in Tokyo. All the parents have children with rare and serious diseases. They started a subcommittee to research their groups. Their purpose was to identify group problems and strategies adopted to solve them. I was involved as the research designer and analyst. This was participatory action research. Focus group interviews were chosen as the method. The subcommittee was consulted about the questioning and sampling procedures. Four focus groups were conducted. Each group had six participants. The length of each session was two hours. I acted as moderator. Interviews and debriefings with the assistant moderator were tape-recorded and transcribed. Interviews were also analysed using QSR NUD*IST 4. Cognitive maps were built with Decision Explorer. The groups main problems were intraorganizational. Some moderating techniques were useful to focus on the main problems and also maintain a variety of topics. Member checking and peer debriefing were used as techniques to develop and test the authenticity of the interpretation. Because the participants discussed their groups' faults and the group leaders knew who were sampled, confidentiality was vital.