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PRINCIPLES OF FAMILY SUPPORT SERVICES OF MEDICAL SELF-HELP GROUPS

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Abstract

In Japan, medical self-help groups are now receiving greater acknowledgement, and their telephone numbers are more widely distributed as social resources. Nevertheless because many small self-help groups have no offices or paid staff, their volunteers must receive telephone calls at home, which imposes a heavy burden on those in charge. My question was: How do self-help group leaders deal with callers seeking advice and support? Do they follow common principles regarding these calls? If so, what are they? My research involved six focus groups of self-help group leaders who were in charge of support services. These included 24 leaders from 17 groups for parents of ill children. The identified principles for providing support services on the phone included: 1) **Self-determination of callers** - encouraging callers to decide for themselves by suggesting some options; 2) **Networking** - connecting callers to members who are in the same situations; 3) **Non-professionalism** - emphasizing the fact that the volunteers are non-professionals: 4) **Careful optimism** - accentuating the positive side of the callers' situations. In many cases, the groups' leaders taking the "rescue calls" in their own homes had limited resources. I therefore discuss how their principles work as "fail-safe devises".

Introduction

"A central distinguishing feature of the self-help group is the reliance on information and wisdom gained from working through one' s personal experience of the problem in a network of experientially similar peers" (Borkman, 1999, p. 15). Because of this feature and the desperate shortage of relevant information, in the case of parents of children with rare diseases, self-help groups are often their only reliable source of information and insight. Additionally, because of the geographic distances separating these parents and the difficulties they have to overcome whenever they want to leave their homes, much of the support they receive from the groups is provided by telephone. Hence, this study aims to explore how self-help groups for parents of children with rare diseases provide information and advisory support to their people via the phone.

Unavailability of counseling and social work services

One of the reasons why Japanese self-help groups are called upon to help people is because there are far fewer medical counseling or social work services in Japan than in the US. Psychotherapeutic and family counseling services are simply nonexistent or unknown to people in many localities, consequently those who would otherwise use professional services have no alternative but to use the support services of self-help groups.

Social stigma of having ill children

Social stigma and prejudice against children with rare diseases and/or disabilities in Japanese society is also a factor we should consider when discussing the social backgrounds of callers. This stigma isolates parents and makes it far more difficult for them to share their problems with people in their community. In the case of hereditary diseases, parents tend to conceal their problems for fear that their other children might be affected by the inevitable prejudice.

Research questions

My research questions were: How do self-help group leaders deal with callers seeking advice and support? Although they have "experiential knowledge" (Borkman, 1999) as parents of ill children, these supporters work under several limitations to provide support services on behalf of their groups: (1) They are usually unpaid volunteers, which means that they have limited time available; (2) Many of them receive the calls in their private homes, which means that they cannot choose when they will receive them. They have to be ready to respond to calls from early in the morning to late at night. (3) They are invariably alone when taking calls, and have few colleagues to share their problems with. Professional or peer supervision is not provided, although some of the information they are required to give deals with matters of life and death. (4) Because they provide their support free of charge, nothing but the callers' sense of decency controls abuse of the service. (5) Some groups' "high-flown names" suggest large, national organizations, and this can mislead callers into thinking that they are being answered by well-resourced professionals. In other words, very few callers know about the actual state of the organization before telephoning (Oka, 2003a).

Because these limitations are common to many parents' groups, my next question was whether there are principles that are common to the support services of the various groups. If so, making these principles known would help newly formed parents' groups for ill children, whose numbers are growing in accordance with new medical developments.

Method: focus groups

This was a PAR (participatory action research) project that I conducted with a collective of self-help groups for parents of children with rare and intractable diseases (pseudonym: the Conference). I organized a research team comprised of group leaders from different self-help groups. This research team requested that the leaders of the Conference's twenty-two parent groups participate in focus group interviews about their family support services. This involved twenty-four members from seventeen groups who were responsible for their family support services (in most cases, information-providing and advisory services). All the groups are run entirely by parents, and in some cases their children. Only three of the groups have offices that are not in their members' houses.

I organized the participants into six focus groups: four groups with four participants, one with three, and another with five. Each group interview lasted two hours, with myself as the moderator. The participants included twenty-one women and three men, which might reflect the fact that more female members than males are responsible for family support services. The average age of the participants was 46.0.

All the interviews were transcribed verbatim, and by perusing the transcripts, I was able to make a list of themes related to the groups' principles governing the provision of information and advisory support via the phone. While revising this list, I coded the transcripts, developed the themes while comparing coded passages, and classified these themes into four types: self-determination of the callers, networking, non-professionalism, and careful optimism.

Results (1): Three principles

The following three principles are applied to improve the independence of the callers or prevent their over-dependence on the group's services (Oka, 2003b).

Self-determination of callers

This principle maintains that supporters should encourage callers to make decisions by themselves. This is necessary, because the supporters cannot fully ascertain each caller's situation, and medical conditions can vary greatly from one case to another. To realize this principle, the following two strategies are applied: multiple options and avoiding conclusions.

Multiple options : Supporters give callers multiple options or answers, and allow them to decide which to take. *"I will say, 'You can ask this doctor,' and, 'You may want to use this method,' and 'Somebody did this.' I will give many examples, and I carefully let (the callers) make their own decisions."*

Avoiding conclusions: To prevent callers from thinking that the supporter has decided which course should be taken, evasive answers are given. *"I will say, 'I am doing this, but your case might be different from mine.' Although I will say, 'Can I put you in touch with somebody who is doing this." I won't say that this is a better option for them."*

Networking

This principle states that supporters should establish networks of parents, rather than become involved in closed one-to-one relationships. This is very important because the provision of support services should be linked with increasing the group's membership. However, the groups' leaders acknowledge that they have to be very careful to protect their callers' privacy. This principle includes the rule: pairing and matching.

Pairing and matching: Supporters encourage callers to meet other parents in their communities who have children of the same age, with the same symptoms. *"If the callers are willing to join our group, we will introduce them to (members) in their communities with children of the same age, who have the same (symptoms) and are using the same hospitals."*

Non-professionalism

This principle emphasizes that although they have considerable "experiential knowledge," supporters are not professionals. This principle is crucial because many callers tend to assume that they are talking to medical professionals. This principle includes the following rules: no medical advice to be given, and the emphasis must be on parenthood.

No medical advice: Supporters should not give medical advice because they are not medical professionals. However, they can give advice on how to deal with doctors. *"Our parents' group should have nothing to do with (callers') medical problems, because these can be a matter of life and death."*

Emphasis on parenthood: Supporters should stress that they are not professionals but parents with the same experiences, and that they are ready to share their experiences of childcare. This leads to egalitarianism among group members. *"We want to keep it clear that everybody is just a parent. There are no giants here."*

Results (2): Careful optimism

The remaining principle, "careful optimism", is about protecting callers and preventing supporters from inadvertently hurting their feelings. This principle means that supporters should accentuate the positive aspects of the callers' situations, and avoid causing anxiety and fear. This is partly caused by the self-help groups' "liberating meaning perspectives" with which group members can "find a truly positive and self-respecting way of viewing themselves in relation to their problem" (Borkman, 1999, p. 43).

This "careful optimism" can create a painful dilemma for the supporters who know that the callers' situation will never get better, or will inevitably become worse due to the intractable, progressive and/or lethal nature of the disease. Careful optimism is necessary, however, because in many cases the callers are not yet committed members of the group, and the supporters will be unable to follow them up if they become too depressed to maintain contact. This principle includes the following rules: finding positive aspects in the situation, remaining silent about negative aspects, and not talking about the future.

Finding positive aspects

To prevent callers from becoming depressed and to encourage them to maintain contact, supporters should help them look for the positive aspects in their situation. *"To parents of children who are seriously ill, we say that this situation will not last forever. To those whose children have left the hospital, we say that they are so lucky that they can return home. To those whose children are at home, but are a great worry, we say that their children's smiles should help relieve their anxieties. This way we try to find positive aspects in their otherwise grim lives."*

Remaining silent about negative aspects

When supporters share their own experiences, they only share the positive aspects and keep silent about their bad and sad experiences. This means that the supporters cannot share their own negative experiences with their callers, so the telephone conversations offer support in one direction only. Those providing telephone support have to get help from other members of their group, and not from their callers. *"I won't tell (the callers) some parts of our live. What I talk about is nothing but good. I say that my girl is very glad to go to day center. I say, 'When she was born, our doctor said that she would never talk, but it was not the case at all. Far from being unable to speak, she can tell lies!' However, I cannot talk further. I won't talk anymore. What can I say? I restrict my talks to my happy stories."*

Not talking about the future

Supporters refrain from talking about the callers' future lives, in which they will inevitably have additional or sometimes more serious problems because of the intractable and/or progressive nature of their children's diseases. In other words, supporters want to help callers face their present situations without being worried by their uncertain future. *"I ask them, 'What do you want to know?' and I won't talk about anything unless they mention it directly. For example, to parents whose children are in their early teens, I won't talk about the problems of late-teenage children. In their late teens, they might develop learning disabilities and become school dropouts. On the other hand, it is possible that they won't have any such disabilities. Nobody knows. So I don't say anything that will worry the parents.*

Conclusions: Fail-safe devices

Although family support services of these self-help groups are not litigated against in Japanese society, their supporters have developed principles that include "fail-safe devices" to ensure the safety of the callers and those who support them. When we consider the situations in which the supporters work, it is clear that these are necessary. Supporters are helping callers without any supervision or peer support, they are unpaid, they are constantly on call, and they have no proper offices. Moreover, their callers often assume that they are talking to paid professionals who work in well-equipped offices.

When considering the results of this research, we must remember the following two facts: firstly, the groups' guiding principles are not written in any formal documents. Instead they are an amorphous part of the groups' culture or values that are shared among those who are responsible for receiving calls. Secondly, these groups had almost no chance to share or talking about their principles before my group interviews. It is therefore impressive that they have so many rules in common.

As medical science develops, increasing numbers of (genetic) diseases are being discovered and diagnosed, all of which require the formation of new medical self-help groups. Accumulating the wisdom of the supporters of longstanding groups will help leaders of these newly formed groups provide support services with fewer risks. On the other hand, for existing groups to develop further, it is important that they link their support services with their organizational growth. Many groups have failed to do this, because callers often use their services without becoming members or without contributing to the groups (Oka, 2003a, 2003b). These groups might therefore need to apply additional principles or devices to overcome this problem.

References

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