

# Professional support of self-help groups: a support group project for Chronic Fatigue Syndrome patients

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**ABSTRACT** *Professionals are involved in self-help groups in a variety of roles as advising experts, facilitators and even as group leaders. A few studies focus on attitudes toward professional involvement, but very little is known about the nature of this collaboration. The study follows a collaborative support group project between a team of health professionals at a regional hospital in Norway and a Chronic Fatigue Syndrome patients' group. It is arguably an advantage for professionals to decide upon the aim of a joint intervention in dialogue with the participants, but simply asking the participants what their aims are does not guarantee actual agreement. As this case study demonstrates, participants may have reason to conceal their objectives.*

The aim of this study was to learn more about the practical experience of collaboration between professionals and self-help groups (SHGs) and in particular how group participants experience and assess this collaboration. The relationship between health care professionals and SHGs has become a central issue in research (Kurtz, 1990; Levy, 2000; Wituk *et al.*, 2000), but the studies are largely limited to surveys of the level of professional involvement in SHGs and of the attitudes the two parties have towards each other and of collaboration.

Self-help groups (i.e. groups of peers with a common problem supporting each other) are a well-known and continuously growing phenomenon in the western world (for figures, see Hjemdal *et al.*, 1998; Kessler *et al.*, 1997, 1999; Kurtz, 1997). In the SHGs literature it is common to distinguish between SHGs and support groups. Support groups have many of the same attributes as SHGs and are also based on mutual assistance between peers, but the group leaders are professionals. This difference has been emphasised because it has been observed that the dynamics and the empowering quality of the group may change when professional group leaders are introduced (Humphreys & Rappaport, 1994; Jacobs & Goodman, 1989; Rosenberg, 1984). While the literature on SHGs in Scandinavia is limited, a substantial part of Scandinavian SHGs appears to be integrated into the welfare state and in general the

links between professionals and SHGs appear to be closer than in other countries (Hjemdal *et al.*, 1998, Karlsson, 1997, Nylund, 2000).

Many authors differentiate between SHGs with an external focus on social change and those with an internal focus on personal change (Katz, 1993; Kurtz, 1990, 1997; Nylund, 2000). Various SHGs define their problem as both external and internal. In such cases a core group of members takes care of the external side, working as a pressure group, while smaller groups provide meeting places where members talk about their common problem.

Recent literature has focused on the question of the effectiveness of the groups. Some of the well-documented positive aspects in SHGs include: giving and receiving support; sharing information; conveying a sense of belonging and normalisation; sharing experiential knowledge; and sharing and developing coping methods (Adamsen, 2002; Cheung & Sun, 2001; Kurtz, 1997; Mok & Martinson, 2000).

### **The relationship between professional health care and self-help groups**

In studies of the relationship between professionals and self-helpers the discussion is centred around both the empirical questions of factual involvement of professionals in SHGs and the attitudes of self-helpers and professionals towards each other, as well as the normative question of how the relationships should be to enhance effectiveness (e.g. Adamsen & Rasmussen, 2001; Ben, 2002; Fitch *et al.*, 2001; Powell *et al.*, 2000; Salzer *et al.*, 1999; Wituk *et al.*, 2000).

The debate about whether collaboration between SHGs and health experts is desirable is taking place in both camps. Some SHGs were established in opposition to professional health care in an effort to avoid the passive patient role one tends to fall into when confronting the 'expertism' of professional health systems (Moeller, 1999). There have been warnings that professionals' meddling with SHGs negatively influences mutual aid processes (Gartner & Riessman, 1984; Penney, 1997; Toro *et al.*, 1988). The alternative these groups represent is empowerment grounded in experience-based knowledge. However, other SHGs see the advantage of keeping a link to relevant health professionals as this might promote acceptance of and focus on their ailment (Kurtz, 1997). A US survey found that 62% of the SHGs accepted support from professionals and 21% had professional leaders, while 16% rejected involvement of professionals in the groups (Emerick, 1990). Gottlieb (1982) suggests that SHG participants' views of professionals' possible and actual contribution to the groups differ according to the problem area of the SHG. In a Californian survey Lotery and Jacobs (1995) found that medical groups had the closest ties with professionals.

Rather interestingly, Nylund, in a study from Finland, finds that SHG members collaborating closely with professionals think that the special knowledge they have obtained about their problem area could support professionals in their work, a reversal of the usual approach to the professional–SHG relationship (Nylund, 2000).

Current studies of professionals show mainly positive attitudes towards SHGs, though a few recent publications suggest that some scepticism and ignorance prevails

among the professionals (Carroll *et al.*, 2000; Dunne & Fitzpatrick, 1999; Kurtz, 1997; Powell *et al.*, 2000; Salzer *et al.*, 1999). A Canadian survey of 1500 family physicians found that while more than 80% of the respondents believed SHGs to be helpful (Gray *et al.*, 1998), only 12% were used to referring patients to SHGs. Some major differences between SHGs and professionally-led therapy groups regarding group processes, objectives and effects of participation exist; the professional attitude is goal-oriented and cost-conscious while SHGs are primarily process-oriented and often do not aim to restrict time or human resources as long as the participants are happy with the group (Humphreys & Rappaport, 1994; Medvene, 1984; Stewart *et al.*, 1995; Toro *et al.*, 1988). However, surprisingly little is known about how these differences actually affect the practice of collaboration.

Kurtz (1990, 1997) argues for the use of 'balance theory' as a framework for professional involvement in SHGs. According to her study, an effective collaboration includes activities by professionals such as consultation, initiation of groups, speaking to members, sponsoring groups or attending meetings as an observer, but not leading groups. Kurtz argues further that this kind of contact gives the professionals a place to refer clients to fulfil the needs that are inadequately taken care of within the professional sector. The SHGs for their part get the advantage of professional support and credibility. The use of professionals by SHGs as a path to legitimisation through fund-raising, medical approval and research on their illness has also been reported in early research on SHGs (Borman & Lieberman, 1979).

### **The support group project**

The context of this study is a support group project that was initiated in co-operation between an SHG for Chronic Fatigue Syndrome (CFS) patients and a group of professionals from a department of neurology at a large regional hospital in Norway.

In the following I will refer to the self-help patient organisation as the *CFS group* while I refer to the groups monitored by the professional team as *support groups* according to the generally accepted distinction between self-help groups and support groups referred to above. The group leaders were social workers employed at the hospital. Other health professionals were invited as speakers to the groups.

### **Chronic Fatigue Syndrome (CFS)**

CFS is a controversial diagnosis and the definition of the disease as well as its cause is much disputed. In most contexts CFS patients are categorised as sufferers of diffuse ailments and it was not until 1988 that a working CFS case definition was presented by the *International Chronic Fatigue Syndrome Study Group* (Holmes *et al.*, 1988). In Norway the diagnosis was partly accepted as basis for disability pension by the National Insurance Administration in 1999. As no biological aetiology has been found diagnosis is based on the subjective symptoms presented by the patient and the

elimination of other diagnoses by clinical evaluation. The symptoms are severe disabling fatigue as well as musculoskeletal pain, sleep disturbance, impaired concentration, and headaches (Reid *et al.*, 2000). For many of the patients the condition becomes permanent and there is no explanation or cure (Söderlund *et al.*, 2000). CFS has also been explained as a psychosomatic disorder, and an association with psychiatric disorders has been confirmed in several studies, although the causality is unclear. Patients may suffer from depression as an effect of the disabling condition (Söderlund *et al.*, 2000; Wessely, 1999).

### **Starting up of the support groups**

The regional CFS group has existed for 11 years, has about 40 members and is an active SHG based in a middle-sized town but welcoming members from all of Norway. Its members are predominantly women, the majority between 30 and 50 years of age. At the time of the project the CFS group was striving to make the National Insurance Service accept the CFS diagnosis as a valid cause for disability pension.

The initiative to start a support group intervention came from the CFS group who contacted a medical professor at the department of neurology at the regional hospital. The CFS group already had connections with the professor because he was running several research projects involving CFS patients. The professor provided a source of recognition and diagnoses for the CFS group. The professor also aided the group's work towards the government and the National Insurance Administration to get acceptance for their diagnosis. At the time the professor was the only physician in town who was both well informed about CFS and believed in a physiological explanation for it. He claimed that he got involved in the group project because he wanted to do something for the well-being of his patients besides experimenting with them [1].

The professor collaborated with the CFS group in the planning and announcement of a group intervention. He then contacted two social workers at the hospital to plan and lead the groups, and the project was given a small grant from the hospital. The hospital team also contacted me to have the groups evaluated.

An information meeting about the group intervention was advertised in the CFS group's newsletter. At this meeting, the hospital team, the leader of the CFS group and the researcher informed about the objective and organisation of the groups as well as the evaluation project. At the meeting 15 participants signed up for the groups. One person dropped out before the groups started.

The support group participants were divided in two groups of seven participants each. The groups had six meetings during the evaluation period and they met every 3 weeks. Half of the meetings were reserved exclusively for dialogue between the participants. At the other three meetings different experts (a physician, a researcher/nurse and a physiotherapist) were invited to give lectures and advice.

## **Study design**

The main source of data is from 10 in-depth interviews with five of the participants. After the information meeting the social workers selected five support group participants and asked them to participate in the interviews. They were selected according to my criteria, which were variation in age, sex and duration of illness. The informants had all been ill for several years and they were already members of the CFS group before they joined the support group project. The age of the informants varied between 23 and 67.

All group participants were contacted and informed by the social workers about the research project and my presence at the meetings. The participants did not have any objections to this. The participants who were to be interviewed were given additional information about the use of data and were promised anonymity and confidentiality. All informants consented to the interviews.

I interviewed five of the participants, four women and one man, in depth for 1½–2 hours before the first group session and after the last using an open interview guide. These interviews were recorded and I transcribed them for analysis myself. The interview guide included the following topics:

- experience and history of illness;
- experience and history of contact with health care professionals; and
- expectations for (first interview) and assessment of (second interview) the support groups.

The interviews were analysed by combining a strategy of coding and categorisation (Kvale, 1996) with condensation as described by Giorgi (1985). Then relevant categories of ‘meaning units’ (Giorgi, 1985) were identified in the transcripts. The selected meaning units made up a synthesis of the informants’ and my own concepts. Subsequently the meaning units were recomposed into a summary of the informant’s assessment of the groups as I interpreted them.

The main meaning units selected were:

- general situation (family, work, home, disability pension);
- presentation of illness (illness-story, explanations, severity, duration, belief in recovery, daily routines);
- presentation of self (general, identity as CFS patient);
- experience with health services (GP, regional hospital, specialists, others);
- connection to the CFS group (first contact, nature of involvement);
- CFS in society (e.g. CFS in relation to the National Insurance Administration);
- CFS (beliefs about the illness, knowledge of research);
- motives for involvement in the groups (nature of involvement, expectations, hopes, reservations); and
- evaluation of the support groups (positive, negative, suggestions).

In addition to the interviews, I participated in four of the six groups meetings. I did not ask questions or participate in the discussions, but was mainly a passive observer taking notes.

As only those group participants that were interviewed had consented to being cited in connection to the research project, the conversations at the meetings were not recorded and will not be cited in the paper. Nevertheless, the participant observation served as a valuable source of general understanding of the groups, the CFS group environment and as triangulation of the statements from the interviews. It was vital for me to have my own notes and impression of the group meetings when the informants made references to episodes from these meetings.

I conducted open interviews and had three meetings with the social workers and the medical doctor. I also studied the social workers' evaluation report, which was based on a questionnaire that was handed out during the first and last group meetings. The questionnaire contained open-ended and scaled questions (Likert type) about expectations of the support groups, motives for participating, to what degree their expectations were fulfilled, positive and negative comments about the groups and whether they wanted the groups to continue. I do not have access to the raw data of this study. In addition other written material about CFS and the CFS group was collected from the CFS group and the social workers at the hospital.

At the end of the intervention I had a meeting with the social workers to discuss the impressions from the groups. Finally, I delivered a report to the hospital team with recommendations for further group sessions.

### *Validity and reliability*

The CFS group in this study represents a common type of SHGs in Norway, according to the only national survey of SHGs (Hjemdal *et al.*, 1998); the participants are mainly women, the problem area is health-related, and it is linked to the professional health sector.

The informants in the interviews may not be representative of the participants in the CFS group because they were selected among the participants who showed interest in the support groups and later agreed to be interviewed. The participants in an SHG may have different motives for joining the group and the informants in this study may represent the most active or externalising in terms of seeking solutions of their problem in society. However, this situation does not represent a problem in relation to external validity because the study describes and aims to explain a naturally occurring social phenomenon, i.e. if it is the most engaged SHG participants who take care of the links with professionals and other external work for the groups' benefit, then I was in fact observing a characteristic situation for professionals' and relations with SHGs.

At group meetings I was warmly welcomed by the participants who seemed to view my presence as a sign of my commitment to their cause. During group discussion the participants seemed too engaged in the discussion to mind my presence. However, one of the visiting experts referred to me in her presentation. I

suspect my presence there influenced the presentation in an academic direction, but the informants did not complain afterwards that the presentation had been too complicated, although a couple of them thought she had a tiring voice and should have made room for more breaks in her speech.

In the advertisement for the support groups the hospital team and the initiators from the CFS group formulated the aim that they had agreed upon; the objective of the groups was to improve coping with CFS through shared information and mutual support between the participants:

‘The aim of the group is to provide participants with support and help in coping with daily life in a better way. In the group participants will be able to support each other by sharing knowledge of and experiences with CFS. It’s all about getting help to cope through information and mutual exchange of knowledge’ (from the advertisement in the local newspaper).

## **Results and discussion**

### *The participants’ view*

‘I had just recovered from a bad throat, when I woke up one morning and felt terrible. My whole body was aching and it felt like my head was going to explode, like my brain was growing inside my skull. Eventually I had to get up to go to the bathroom, and I almost didn’t make it—had to lean on the walls of the corridor and my daughter had to help me reach the toilet’ (woman, 45 years old, CFS for 6 years).

The above is a characteristic opening of the illness-story. All five informants started by describing in detail the sudden onset of CFS [2]. The informants continued to present the illness-stories in a chronological and detailed manner. The stories were quite similar in the two interviews. Words and phrases were sometimes identical and bore evidence of being told many times. The informants described how they had been forced to repeat their story in numerous encounters with different health experts on their journey through the health care system.

The stories of the different informants were very similar, all informants describing how they had suddenly fallen very ill after recovering from a period of either influenza or throat infection, how they were initially scared and thought they might be mortally ill. This also applies to parts of stories I heard during group meetings. In addition, informants sometimes used identical, but unusual metaphors; like ‘charging their batteries’ for describing the frequent rests they had to take to get through the day. These similarities suggested that the informants had exchanged their stories frequently enough in the same setting for a common story-telling style to be established. As all of the informants were active members in the CFS group, I assumed that this was the setting in which this style had been established, an

assumption that was confirmed by some of them during the last interview. They also described some other characteristic features of SHGs mentioned above; how discovering and joining the CFS group had at first surprised them because they had thought their condition was unique.

‘I looked in the paper, and there it was; my illness! It was an advertisement for the CFS group and they had a list of symptoms. When I read through it, it was like reading a description of myself. So I went to that meeting and for the first time in all these years, I met people who understood what it is like. I didn’t even have to explain anything’ (woman, 67 years, CFS for 24 years).

The group gave them a sense of normalisation and of confirmation of diagnosis. Patients sometimes presented this diagnosis to their GPs who would often accept it. The group also provided practical advice on how to live with the illness including advice on diet, on how to organise their daily life and portion out scarce energy, and on how to relate to the medical profession, to welfare institutions, etc. In the absence of medical authority the CFS group served as an expert institution for CFS-sufferers based on a mix of experience-based and scientific knowledge. The interesting aspect of these observations is that what the informants apparently already had got out of the CFS group was very close to the hospital team’s intention of the support group intervention.

My general impression from the group sessions was that the informants presented their stories in much the same way here as they did in the interviews. They explained their condition in much detail as one does when talking to somebody who is not a fellow sufferer. I wondered if this would have been different if the social workers had not been present, because their stories and much of the impression management seemed to be directed towards them. At the time I interpreted this as a sign of failure of the project. According to the aim of the groups, the participants were supposed to share information and support among themselves and the leaders should not be the focus of attention. Without the external leaders in the groups much of the time spent on explaining what it is like to live with CFS would perhaps have been avoidable. Later I realised that the aim of the participants was primarily to develop contact with the health professionals, and not so much to share stories and support each other. It was therefore rational for the participants to prioritise describing their situation to the group leaders.

In the pre-group interviews the participants expressed moderate expectations that they would be able to help new sufferers by sharing their own experiences, but none of the informants mentioned expectations of receiving information or support from the others.

‘What I expect from the group? Well, I’m not sure. I know I could be of help to somebody who is struggling to understand how to live with this, somebody who doesn’t understand what has hit her ...’ (woman, 36 years old, CFS for 5 years).



'I'm looking forward to learn the latest results from CFS-research. I know they are doing some interesting experiments in the UK' (woman, 43 years old, CFS for 8 years).

All five expected to learn something from the invited professionals, but varied in how useful they thought this information could be to them. Two of the informants had been involved in planning the project and they both revealed long-term hopes that the project would be the start of increased and systematic research incorporating their experiences in solving the CFS-puzzle.

'It is vital to lead an extremely structured life when living with CFS. I have to rest, for an hour, and sometimes two, before making any effort. If I'm going to town, I need at least 2 hours, and when I get back I have to lie down again immediately. If I don't do this, I get it back. Then I get really sick and have to stay in bed for several days. Earlier I used to give in for the temptation, I could sit down by the PC to write and I'd feel fine. You don't notice anything there and then. After half an hour I'd think "this is no problem", so I'd go on for half an hour more, and then I'd be set back for a week and would have to start all over again, staying up for a little while at the time. Think about it! Those doctors believe it is simply a matter of getting up and getting at it, ignoring the illness. I have all this experience, we all have, that could be of use in understanding more about CFS' (woman, 36 years old, CFS for 5 years).

The hope that the experienced-based knowledge of the sufferers could be of use to the professionals replicates the above-mentioned findings of Nylund (2000). This could be part of the motivation for presenting the illness-stories in detail.

The second interview was mainly about the informants' assessment of the support groups:

'Well, to be honest the groups haven't yet become exactly what we wanted. But we must not give up. I think we had too high expectations of involving people from the hospital. We can't expect too much to start with, the professor is extremely busy, and he hardly gets any resources for his CFS-research. I still think there is potential for this and later on we might even have our own centre, like the one [in the USA] I told you about' (woman, 36 years old, CFS for 5 years).

In the second interview, the informants expressed that they were rather dissatisfied with the experience. When discussing the group experience compared to their expectations, they expressed insecurity on how to respond to my question. Summing up they did not feel that the groups had fulfilled their expectations to a high degree and they had quite a few negative comments about the intervention. The meetings

were too long and too tiresome, some of the invited speakers did not demonstrate understanding for the participants' need for breaks and rest during the meetings, there was no elevator in the building and they did not find the information from the invited speakers particularly relevant or new. To my question about the benefits of the intervention in relation to coping with their condition, I was told that they already knew how to live with CFS, as so did the others. Consequently, they did not get the satisfaction of sharing support. Several informants regretted that there were no new sufferers in the groups, although they found this understandable:

'It's a pity that the ones that really are in need for such groups are home in bed, too sick to join the groups, or to even know about them' (woman, 45 years old, CFS for 6 years).

Two of the informants explicitly asked me not to present their assessment in too negative a format to the hospital team because this could lead them to discontinue the intervention.

#### *The group leaders' assessment*

The following is a quotation from the group leaders' internal evaluation report for the hospital:

'The group leaders got the impression that the expectations of the group participants were not thoroughly clarified [...] The objectives were formulated in writing, but as group leaders we had the feeling that there were underlying expectations that were not revealed' (from the social workers' evaluation report).

In a post-group meeting, the social workers confirmed that they were puzzled about the results from the evaluation forms. While participants had many negative comments about the organisation of the groups and very few reported any change in the level of coping with CFS, they generally reported that they were satisfied with the groups. All participants answered positively to the question of whether to continue the intervention. Equally ambivalent impressions were given at the group meetings. This led the social workers to speculate that the participants' expectations were not thoroughly clarified and that there might have been underlying expectations that were not made explicit. It was not clear to the professionals why these chronically exhausted people wanted to spend so much of their scarce energy on participation in the support groups.

#### *Underlying motives*

In the interviews, in contrast to the responses in the evaluation forms, the informants were quite explicit about the expectations and hopes they had regarding the support

groups. They also arranged the goals in a hierarchy from short-term and feasible goals to a long-term and more insecure hope.

First of all, they believed that participation in the support groups would strengthen and expand contact with the medical authorities. The organisation already benefited from the connection with the medical professor. He served as their guardian and gate opener towards the medical authorities, even though his theories were partly controversial. The CFS group was very positive to medical science but not neutral about which theories that should be investigated. Theories of psychological explanations for CFS were believed to represent the wrong path and the participants did not support this line of research.

Second, they expected that closer links with the hospital team would lead to increased recognition of CFS among medical specialists and general practitioners in their hometown and eventually on a national level.

Finally, they hoped that increased acceptance in the long run would give them an easier path to diagnosis and disability pension and that it would enhance medical research on CFS, with the ultimate goal of finding a cure. As mentioned before, the participants had hopes that the professor would make use of the experience-based knowledge they had accumulated in his medical research. The professor on his part did not see the use of this kind of information. What he got from the CFS group was access to CFS-diagnosed persons for his medical research experiments as well as a feeling of doing something for the well-being of a group of patients to whom he could not offer medical help.

The participants were caught in a dilemma. They wished to contribute to the evaluation of the groups and thereby have a say in how they were conducted in the future. They wanted the groups to have a format that would enhance contact between the CFS group and the professionals (without being too tiring), but at the same time they realised that the professionals saw the groups as an intervention offering social support as compensation for lack of medical help. They already exchanged social support and knowledge in the CFS group, but they clearly had not given up the thought of grabbing this outstretched hand from the medical world and turning it into a device in their struggle for acceptance. Consequently they reported a moderately positive response in the evaluation forms of the group leaders and were also consulted in the planning of the new round of groups.

In my own evaluation report to the hospital team I stated that I considered the support group participants to be a group difficult to satisfy. Their need for peer support and information was already fulfilled through their participation in the CFS group and they were not typical as support group participants in that their effort came at an unusually high cost due to their chronic lack of strength. I concluded that the intervention was not effective according to the objective agreed upon, but that the participants, in spite of this, wanted the intervention to continue.

After receiving my report the social workers together with the CFS group changed the support group programme. A new 6-month period of support group was carried out and evaluated by the group leaders but this time more responsibility for the content of the meetings was placed with the participants. After this period the

groups have continued as SHGs within the CFS group. The function of the social workers at present is to assist the assessment of the groups, arranging expert lectures and providing research news to the CFS group's newsletter.

### **Concluding remarks**

My aim was to learn about the process of co-operation between professionals and self-helpers through a case study. The study revealed some empirical problems that largely have been treated on a theoretical level in the SHG literature. It supports other studies (Gartner & Riessman, 1984; Humphreys & Rappaport, 1994; Medvene, 1984; Penney, 1997; Stewart *et al.*, 1995; Toro *et al.*, 1988) warning that professionals should be aware that SHG participants and health professionals may have very different, sometimes opposing goals for support groups. In general the explanation given for this is that the goal-oriented, biomedical approach of the professionals is difficult to combine with the experience-based, process-oriented style of the SHG participants. On this background, Kurtz (1990, 1997) argues for limiting the level of involvement by professionals.

The support group participants in this case clearly had a different set of criteria for success than the professional initiators, but the misconception in some respects appears to be the contrary of what was expected. The professionals wanted to give CFS-sufferers the opportunity to share social support, while the participants had a long-term external objective in mind. Through the assessment of the support groups it became apparent that the SHG members had an agenda of their own and for them the first group intervention was only the first move in a quite ambitious endeavour.

One could argue that the reason for the misconception was that the intervention did not reach the target group, because the patients most in need for peer support were unable to attend. On the other hand, the group leaders knew, before the first meeting, that all participants had been ill for several years as the intervention was announced through the CFS group. It was therefore to be expected that potential participants would have had previous contact with the patient organisation.

It is more likely that the explanation is in the concealed divergence of aims. When planning the groups, the medical professor and group leaders did not discover the participants' aims, even though they collaborated from the beginning. The self-helpers and the professionals were pulling in different directions because the professionals were unaware of the self-helpers' agenda, and as a result neither of the two parties assessed the intervention as successful. The participants chose to keep their agenda hidden from the professional team, trying to reach their goal by changing the course of the intervention step by step. They probably correctly assumed that it would be difficult to release resources from the hospital for an intervention that would focus on the political aims of the CFS group, especially as the diagnosis was controversial.

Because an external researcher studied the intervention, the objectives of the self-helpers in this case were revealed and the professionals had the opportunity to adjust the intervention accordingly.

### *Implications for professional involvement in self-help groups*

Clearly, increased general knowledge among professionals about SHGs and possible pitfalls in co-operation with them is of significance. There also appear to be a couple of practical lessons to be drawn from the study.

First, it is recommended that professionals take some time to familiarise themselves with the SHG before deciding on how to be involved. This could be done as a pilot study for evaluating the intervention, or by the professionals themselves visiting group meetings and having conversations with central persons in the SHG. When the SHG has strong political aims and/or represents a group that lacks general acceptance for its ailment, special attention should be directed to the motives for seeking professional involvement. It would benefit collaboration to clarify whether the self-helpers are more in need of an expert that can advocate their cause or of professional advice on how to cope with the condition. When the former is the case, the professionals could consider acting as external advisers and resource persons while leading groups might be ineffective, as participants probably would direct their attention toward the group leaders instead of talking to their peers [3].

Second, this and other studies (Nylund, 2000) show that SHGs sometimes think that their knowledge and experience could and should be of use to professionals. Professionals involved in an SHG might consider gathering and systematising experience-based knowledge about coping strategies or illness experience. Such information could be presented to new SHG participants, or could possibly be used in medical research on the topic.

The range of SHGs today is great and so is the variety of relationships between professionals and SHGs. Further research is needed to inform us of this variety and to elaborate the above suggestions for practice.

### **Notes**

- [1] This type of reciprocal relationship between a patient organisation and a medical expert has also been pointed out in another Norwegian study (Glenton & Oxman, 1998). Their study discovered that patient organisations in Norway often prefer to rely on medical experts for interpretation of expert knowledge, and typically the organisations depend on a very limited number of such experts. For organisations that represent sufferers of diffuse ailments one criterion for selecting their expert patron is that he shares the group's understanding of the relevant condition.
- [2] This CFS group uses the concept 'post-viral CFS' which indicates that this is a physiological disease set off by a viral infection in contrast to the broader concept of CFS, which they claim includes a range of physiological and psychological conditions, e.g. 'burnt-out syndrome' with the common symptom of tiredness.
- [3] Clearly this problem does not apply to all kinds of SHGs. One would expect it to be more relevant for groups focusing on social change than in groups emphasising personal change. Nylund (2000) registered different patterns of collaboration with other sectors between the two types of SHGs.

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