

Do members of self-help groups in Japan consider the medicalisation of their problems and conditions to have liberated them or pathologised them? Three case studies

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This paper aims to examine how self-help groups' "liberating meaning perspectives" (Borkman, 1999) are influenced by medicalisation (Conrad, 1992); it also discusses the benefits and pitfalls of medicalisation for self-help groups and the possible role of social workers in supporting these groups.

Many self-help groups have been established to help members overcome their perceived stigma and self-stigma. These groups have developed beliefs that Borkman (1999) calls "liberating meaning perspectives." These beliefs enable members to view their conditions from a new and alternative perspective and "can free them of self-hate, a negative self-identity, and assumptions that they are inadequate" (Borkman, 1999, p. 115). The worldview of self-help groups (Kennedy & Humphreys, 1994) is penetrated by the liberating meaning perspectives; from these perspectives, self-help group members understand how they should interact with others, the society, and themselves.

In the case of self-help groups for alcoholics, to consider their alcoholism as a disease is the core of their liberating meaning perspective because this disease concept of alcoholism will help the alcoholics escape the sense of sin. According to this concept of alcoholism (White, Boyle & Loveland, 2002), they are not corrupted by alcohol but are merely patients of the disease. This is an example of medicalisation. "Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat' it" (Conrad, 1992, p. 211). This medicalisation is double-edged against the self-help groups for alcoholics; while it can reduce their moral responsibility for their problems, it may accept the professional authority as superior to what Borkman (1999) calls "experiential authority" that self-help group members establish by sharing their experiences. This may invite the professional dominance of self-help groups.

Apart from alcoholism, medicalisation also influences the concepts of depression or sadness; as psychiatric professionals often treat even "normal sadness" with antidepressant medication, the distinction between normal sadness and depressive disorders is being ignored (Horwitz & Wakefield, 2007; see also Szasz, 2007, pp. 23–24). This disease concept of sadness seems to have an impact on self-help groups for grief-stricken individuals including the bereaved. Further, since the disease concept of sadness justifies professional intervention, some self-help groups that loathe professional attendance in their groups have to oppose the medicalisation of their sadness.

On the other hand, medicalisation has been advocated by some self-help groups (Broom & Woodward, 1996; Conrad, 2005). Therefore, we observe that self-help groups can have various attitudes towards the medicalisation of their concerned problems and life situations. Also, since one of the roles of social workers who assist in self-help groups is to mediate between the groups and medical professionals, it is imperative for social workers to understand how the concept of medicalisation influences the liberating meaning perspectives of various self-help groups positively or negatively.

Method

To clarify the relationship between self-help groups' liberating meaning perspectives and medicalisation, we used a theory-based sampling strategy (Patton, 2002, p. 238) and selected three self-help groups, each with positive, negative, or ambivalent attitudes towards medicalisation.

As a sample of a positive attitude towards medicalisation, self-help groups for patients with type 1 diabetes were researched. These groups are currently taking social action in order to change pertinent social policies and medical treatments while emphasising how they have suffered in medical terms. Since several years, the second author (Hayashi) has been involved with these patient movements as a patient leader and researcher. Although his involvement focused on a particular group of which he was the leader, he was also working with other groups, which have also been considered in this research.

The alcoholic groups were used as a sample with an ambivalent attitude towards medicalisation. Our sample group was *Danshukai*, which was started in the 1950s and was inspired by Alcoholics Anonymous, although they operate quite differently from the latter. *Danshukai* is completely independent of medical professionals, and while alcoholics are their main members, their families also contribute to the group as complementary members. The first author (Oka) collected data from his fieldwork with *Danshukai* (Chenhall & Oka, 2009).

The third sample was self-help groups for family survivors of suicide. They showed a strong negative attitude towards medicalisation; they loath psychiatrists and psychologists who treat the family survivors as patients with mental illnesses or manic depression. The first author (Oka) has been involved with these groups since 2008 as a supporting researcher. In order to cope with psychiatrists and psychologists who try to "medicalise" their grief in the name of "grief care," they asked the first author (Oka) for help because they knew that he was an expert in self-help groups (Oka, 2009).

In each of the three case studies, we conducted ethnographic fieldwork, making participatory observations, asking conversational questions, and examining their publications including newsletters. Given that these self-help groups do not easily accept outsiders, we did not introduce each other to our respective groups and recognised that such reckless introduction might adversely affect the trusted relationships each of us has established over the years. However, in order to enhance the trustworthiness of our research, we used "researcher triangulation" (Snow & Trom, 2002) in analysing the data and building theories by sharing our field experiences.

Findings

The three self-help groups had different attitudes towards the medicalisation of their conditions for complicated reasons under different circumstances.

Patients with type 1 diabetes

Patients with type 1 diabetes are taking action to improve the government's social policy on healthcare, by emphasising the suffering from their disease. Moreover, they have to cope with the prejudice or misconceptions of the public about the disease since the public can hardly distinguish between type 1 and type 2 diabetes. Since a majority of diabetic patients have type 2 diabetes and the public believes that diabetes is a natural consequence of the patients' neglected health, patients with type 1 diabetes have to emphasise that their disease has nothing to do with their lifestyle. The notion of medicalisation is used to express the fact that these patients are not to blame for the disease.

However, these self-help groups have a liberating meaning perspective with which any patient can enjoy a normal and healthy life despite the illness; the lives of these individuals must not be conquered by diabetes. This liberating meaning perspective opposes the "medicalisation perspective" from which their suffering is described in medical terms, and their medical perspective is a useful tool for taking social action against the local government. Consequently, they have difficulties in using their liberating meaning perspective to penetrate their worldview.

Alcoholics

Our alcoholic group, Danshukai, has several "pledges" for abstinence instead of the Twelve Steps as given by Alcoholics Anonymous. Danshukai has three sets of pledges—the first and main pledge is the "Abstinence Pledge"; the second, "Pledge-at-heart," is only for alcoholics; and the third, "Family Pledge," is for the families (Chenhall & Oka, 2009). Only the Family Pledge includes a phrase that refers to alcoholism as a disease. The first and second pledges define their problem not as a disease but as "the harmful effects of drinking" (*Shugai*). This might reflect the ambiguous attitude of the self-help groups towards medicalisation.

While Danshukai operates independently of medical professionals, it very often invites medical professionals to public meetings and asks them to speak about alcoholism. Since they are medical professionals, they describe alcoholism as a disease. It seems that most members take it for granted that alcoholism is a disease, and they have accepted it as exempting them from a sense of moral failure. The discourse that alcoholism is a disease is thus used as a liberating meaning perspective.

However, as a result, when they mention "recovery," it implies that this recovery is no different from a medical recovery. While the recovery of Alcoholics Anonymous includes spiritual connotations (Kurtz, 2002), Danshukai's recovery has very few such implications, probably due to the lack of Christian traditions in Japan (Oka & Chenhall, 2010). Moreover, since their recovery is almost the same as a medical one, Danshukai may be losing its charm. In fact, Danshukai membership (9455 in 2009) has gradually decreased after it peaked at 12,012 members in 1994 (Zendanren, 2010).

A veteran leader of Danshukai recalls that when Danshukai was started in the 1950s, they had never used the term “recovery”; instead, they referred to this phase as a “new birth.” According to him, the term “recovery,” was introduced to Danshukai by doctors in the mid-1970s, implying medical and bodily recovery (Kobayashi, 2010). Unlike “medical recovery,” “new birth” had more social implications; after their “new birth,” the members were expected to help other alcoholics and their families. As the medicalised recovery replaced “new birth,” Danshukai may have lost its standing of social power and voluntary action (Oka, 2010a).

Family survivors of suicide

The family survivors of suicide strongly opposed the medicalisation of their grief. These individuals constitute a new self-help group (Feigelman & Feigelman, 2009). Many of these groups were started within a few years, especially after the enforcement of the Basic Act on Suicide Prevention in 2006. By 2010, twenty-seven self-help groups for family survivors of suicide have started to work and are affiliated to their loosely organised national association. According to the Basic Act on Suicide Prevention, many public health or mental health centres have started to provide family survivors of suicide with support group services (Takeshima et al., 2008), and the family survivors who were not satisfied with these professional-led support groups decided to organise their own peer-led self-help groups exclusively for survivors at various locations in Japan (Oka, Tanaka & Ake, 2010).

The reason psychiatrists, psychologists, and “grief-care professionals and volunteers” met with resistance and anger from the family survivors is that these professionals attempted to treat their grief as “morbid” or “something to be cured.” On the other hand, the members of their self-help groups considered their grief to be deeply connected with their love for the deceased; this perspective makes it possible for them to accept their grief as their normal feelings. Therefore, they regard it to be very difficult or merely impossible to “cure” their grief, as it is impossible to “cure” love; however, the family survivors consider the grief-care professionals as attempting to do this (Oka, 2010b).

The self-help leaders also sensed the professionals’ monetary motivation behind the medicalisation of their survivors’ grief; thanks to the Basic Act on Suicide Prevention, the local government is now generous with the budget for professionals and non-profit organisations that are ready to support family survivors of suicide. Then, according to the family survivor leaders, professionals and non-profit organisations that need a budget start professional-led support groups while claiming that it is professionals/volunteers with professional expertise and skills, and not self-help group leaders, who are eligible to help family survivors. However, many family survivors were disappointed with their support group services and later organised their own self-help groups independently, as mentioned above.

Conclusion

What do we learn from these three case studies on self-help groups and the medicalisation of their concerned problems? In the era of medicalisation, any self-help

group will have to face complicated issues caused by the medicalisation of their concerned problems. We will examine, in terms of the liberating meaning perspectives, the benefits and pitfalls of the self-help groups in the process of medicalising their lives or problems.

The first benefit is that medicalisation reduces or nullifies the moral burden of their lifestyle. If medicalisation is applied to alcoholism, the drinking problem is not caused by their lack of strong will but is a disease, which does not choose its victims. In the case of patients with type 1 diabetes, through medicalisation, they can stress that their life conditions are not a result of the neglect of their health and can claim that they are eligible for public support. Their case presents an interesting fact in that medicalisation does not necessarily deny the momentum of social action.

Secondly, medicalisation might bring about a well-organised framework for self-help group members to understand their problems. As Conrad (1992) states, medicalisation can occur on the conceptual level, where “a medical vocabulary (or model) is used to ‘order’ or define the problem at hand; few medical professionals need be involved, and medical treatments are not necessarily applied” (p. 211). Borkman (1999) points out that self-help group members can develop “the experiential authority” by sharing their experiences directly related to the problem at hand, which makes it less dependent on the professional authority. However, some self-help groups might be slow in establishing their “experiential” frameworks in order to understand their problems; for example, Danshukai has been influenced by the Japanese Buddhist Zen, and therefore, they prefer “practice” to “theories” (Chenhall & Oka, 2009), and they are not very eager to build their own theories. Under such circumstances, uncertain and insecure fresh members may seek the medicalisation on the concept level.

On the other hand, the first pitfall of medicalisation is that medicalisation promotes the self-help groups’ dependence on medical professionals on the conceptual level. As mentioned above, Danshukai seems to be more and more dependent on medical professionals in its concept of alcoholism, although the organisation remains independent from professionals in terms of its initiatives.

Secondly, as the case study of family survivors of suicide indicates, through medicalisation, self-help group members are treated as patients—in many cases, powerless patients to be protected—by medical professionals. This can deprive the members of their social power in changing the society.

Thirdly, medicalisation means understanding problems in existing medical terms, and thus, we cannot expect medicalisation to provide self-help groups with creative or alternative perspectives to their concerned problems. Hence, self-help groups may be gradually degraded to mere supplementary organisations to professional services.

In the era of medicalisation, are social workers not expected to contribute to the development of self-help groups and their members uniquely as “social” professionals? These professionals will not regard the members as “patients” but as “socially-active members” of social voluntary groups. Through social work’s “strengths perspective” (Saleebey, 1997), social workers are able to empower individuals who come together in self-help groups.

Key Words

Self-help groups, medicalisation, liberating meaning perspective, type 1 diabetes, alcoholism, family survivors of suicide

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