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Special Feature Article

Inappropriate Responses from Others Can Worsen Prognosis in Patients with Bipolar Disorder: Opinions of Support Group Participants

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Abstract

At meetings conducted by the Japanese alliance of bipolar disorder, a non-profit organization that specializes in bipolar disorder, patients express their honest opinions in a safe and supportive environment. Among them, the responses from those around them that worsen the course of bipolar disorder often become a topic of discussion. For instance, many people comment that their family members and employers/supervisors do not make an effort to understand the illness, that they do not understand the pain caused by the illness, or that they even try to prevent treatment. This draws attention to the fact that the patient is being hurt by their environment, and that their efforts to recover from bipolar disorder are undermined through such responses. Increased awareness of this situation is necessary is to provide optimal treatment and support for each patient.

Keywords：self-help group, bipolar disorder, mutual assistance activities, inappropriate response

Introduction.

The term “party association” refers to a group of people who voluntarily come together to conduct activities designed to raise awareness and provide mutual aid, existing independently of

other groups in principle. Originally, self-help groups (SHGs) were intended to engage in mutual aid activities only. However, as they have recently begun to partake in social activities as well, the term is often used synonymously with the Japanese term "party association". However, some organizations do not register with local governments, gathering only a few people on a voluntary basis or conducting activities on social network services (SNS) only. Therefore, their actual status remains unclear. The United States is estimated to include more than 500,000 SHGs with a total of more than 10 million menbers[15]. In Japan, associations including people with mental disorders have been active since the 1960s, and the National Federation of Mental Disability Organizations—a non-profit organization run by people with mental disorders—was established in 1993[14].

The Depression and Bipolar Support Alliance (DBSA), headquartered in Chicago,[8] is likely the best known SHG for bipolar disorder. Other prominent organizations include Bipolar UK (UK)[2], the Black Dog Institute (Australia)[3], the Mood Disorders Society of Canada[24], and Argos (2001) (France)[1].

Although there are many associations specializing in bipolar disorder in Japan, the only one registered as a non-profit organization (approved in 2010) is the Japan Bipolar Disorder Association (commonly known as Nautilus-kai[28]), which is also regarded as the most stable[33]. The Nautilus Association is headquartered in Shinagawa-ku, Tokyo, and currently has 20 chapters throughout Japan, from Morioka in the north to Kagoshima in the south. The organization conducts meetings in various locations; publishes a monthly magazine; and provides free telephone counseling by volunteer professionals and peer counselors, lectures, and training sessions. The author, as president of the Nautilus Society, participates in meetings twice a month.

I. Effectiveness of SHGs and peer support

The effects of SHGs have been most well-studied among those attending Alcoholics Anonymous (AA), with numerous meta-analyses demonstrating that participation in AA increases sobriety[9,17,25,30,35]. Further studies of addiction groups have revealed that attending more meetings is associated with a greater benefit from peer support[11,26,36].

SHGs are known to affect various factors associated with the course of mental disorders[6,7,16,19,32]. Previous studies have reported that groups focusing on depression are associated with both symptom reduction and functional recovery[4,5,10,18,20,21,22,31]. Despite several studies showing that

SHG can decrease symptom severity and improve coping skills in patients with mental illness[19,29,32], to the best of my knowledge, no studies have specifically examined the effects of SHGs on bipolar disorder.

II. Discussion of inappropriate responses at SHG meeting

The Nautilus Society holds meetings almost every month at regional facilities and at its headquarters. Upon attending meetings, participants provide blanket consent that their statements will be recorded anonymously, although those who refuse to participate are not recorded. The meeting notes are published monthly in the "Journal of the Japanese Alliance of Bipolar Disorder." The following remarks are based on past records (Vol. 1, No. 1 to the latest Vol. 7, No. 8), mainly focusing on meetings in which the author participated. Some details presented herein overlap with those published in previous reports.

1. Inappropriate responses from family members

The three types of inappropriate responses by family members may be summarized as follows: (1) not understanding or trying to understand the disease, (2) not understanding the pain caused by the disease, and (3) not cooperating with treatment (Table 1). Family members who fail to understand the disease may deny the presence of illness, deeming the patient as lazy or suggesting that they are imagining their symptoms. Indeed, one male patient in his 30s reported that his sister often remarked that patients diagnosed with bipolar disorder imagine their symptoms. In addition, many family members may lack a deeper awareness of the pain caused by the disease despite knowing its name. For example, misunderstandings can occur when parents were requesting that the patient allow them to feel relief, rather than the patient feeling relief (male, 30s), or when the attending physician tells the patient to take a break, but the family tells the patient to work (female, 50s). In some cases, individuals are made to feel uncomfortable when talking about their illness and stop talking to their parents (male, 30s). One woman in her 40s reported that she is often compared to her younger, healthier sister because her sister is employed. Another woman in her 30s mentioned that she had cried and begged her mother to understand her illness, only to be told that she was the one who did not understand her hardships, while one man in his 30s verbally and physically abused his mother during an argument.

In other cases, family members may not be willing to cooperate with treatment, as indicated by one woman

in her 40s who was told not to see her doctor despite the doctor's instructions to take her medicine as prescribed[4]. In another case, a man in his 30s indicated that his father threw away his medicine, commenting that he could not work when taking such a medicine[5]. Some of the participants also nodded their heads in agreement when a woman in her 20s said that she did not tell their parents that she was going to the hospital.

2. Inappropriate responses from friends

Serious problems with inappropriate responses from friends are rarely mentioned, perhaps because friends are not as close to patients as family members. However, it is not uncommon for a lack of understanding concerning the disease to result in a separation that leaves the patient feeling even more alone. One man in his 30s noted the following comment from his female friend in her 40s: "You are not the only one who is having a hard time." He mentioned that he kept calling her when he was in a manic state, and that she had stopped talking to him after that (male, 30s). Other group members reported feeling disliked after saying too much in a manic state (male, 30s), losing relationships with friends after becoming ill (female, 40s), and repeatedly cancelling appointments and becoming estranged from others (female, 50s). Some individuals also reported feeling lonely when depressed because they have no one to contact (female, 40s) and not wanting their old friends to know about their illness (male, 40s).

3. Inappropriate responses in the workplace

Table 2 and 3 summarizes the stress experienced by the concerned parties and inappropriate responses in the workplace, respectively. In one case, a woman in her 20s stated that she felt like she was being "thrown into hell" and had thought about hanging herself in the toilet many times. A man in his 30s reported difficulty finding new employment. Despite feeling the need to do something, he also stated that he feels pathetic when he cannot learn a new task, often hitting himself with a hammer as a result.

Several patients also reported an inability to meet deadlines. A woman in her 30s indicated that, when a deadline arrives, she experiences such tension that it sends her into a manic state. One woman in her 50s indicated that she has trouble concentrating and following instructions when she is depressed, and that others have noticed her lack of understanding.

"Hounsou" (a term used to describe reporting, communication, and consultation, and generally considered to be a form of business etiquette) was mentioned as a common fear. One group

member mentioned having particular difficulty with this aspect of work when feeling rushed (male, 30s), while another stated that she is not good at meeting new people and prefers not to do so (female, 30s). A woman in her 40s commented that the feelings of self-loathing she has experienced since becoming ill make it difficult for her to appear in front of other people (female, 40s). Another woman (40s) said that she cannot think clearly in meetings, and that she is afraid of slurring her words or being called out later.

A female group member (40s) indicated that she does not feel half as guilty when she cannot take of work or go an appointment when sick, stating that she would even crawl but that she sometimes cannot move her. One man in his 30s said that he feels stressed when thinking and making decisions, noting that he cannot even decide what to wear at times. Participants also reported feeling that others had been avoiding them since their diagnosis, and that they have negative thoughts when feeling alone or like they have too much time on their hands. Other issues mentioned included an inability to come up with ideas when depressed even when prompted (male, 50s), feeling unworthy when receiving evaluations at work (male, 60s), and being told to "take another day off" when having difficulty with tasks such as making phone calls (female, 30s). One man in his 30s commented that inadequate understanding of the disease by employers may lead individuals to lie and return to work before they have recovered (male, 30s).

During further group discussions, a woman in her 50s reported being reprimanded at work for dozing off due to the side effects of her medication (female, 50s). One man said that his supervisor assumed he was not depressed because he had taken a training course on depression (male, 50s), while others said they they were told to "keep their mouths shut" if they were sick (male, 30s) and not to use their illness as an excuse (male, 40s). Even when nothing was said to him directly, one group member said that he heard co-workers talking negatively about others who had quit due to mental illness (male, 30s).

On several occasions, group members reported being lectured in such a way as to make them feel trapped. Some indicated that it is not uncommon for a boss to brand you as a person who lacks patience (male, 40s) or to frequently ask you if you have any intention of quitting (male, 30s).

It is difficult to continue working with mental illness, and the reality is harsh for those who have left the job. Some indicated that they had withdrawn due to self-loathing (male,

30s), or that they experienced no stimulation at home and could not establish a rhythm in life (male, 40s). One man in his 40s said that he became depressed when he found out that he could not return to his old job. Other group members reported that staying at home was also stressful (male, 20s), and that they had no motivation when staying at home (male, 40s). One person stated that he feels afraid to go out in the daytime when unemployed, even if he does not know anyone, and that he sneaks out at night instead (male, 30s).

Group members also faced obstacles when attempting to find a new job, with one young man reporting that he attended 30 job interviews in a row without success (male, 20s). Another man (40s) stated that he was scolded when he appeared at an interview for the disabled category (male, 40s). There also appeared to be a vast difference in understanding of the level of support required from employers depending on the workplace (male, 50s), which can lead to feelings of despair or futility (female, 30s).

III. Desired responses

Although the previous section focused on responses considered inappropriate, it is also important to reflect on the types of responses desired by those with mental illness. Examples discussed at Nautilus meetings are presented in Table 4. Members expressed the need for others to understand their medical conditions (male, 30s) and to validate their feelings regarding the burden placed upon them (male, 50s). Two men in their 40s and 50s, respectively, highlighted the importance of being able to tell their wives that they are not feeling well or are depressed without hesitation. One man (30s) indicated that he wants his wife to change the way she treats him depending on whether he is depressed or manic (male, 30s), while a woman in her 30s stated that she wants to be allowed to live at her own pace.

Group members also expressed many opinions that touched on a deeper level, such as the desire for others not to run away when discussing their mental illness (male, 30s). Others specified the desire for others to treat them like human beings (male, 60s), and to accept their illness without prejudice (male, 40s). One woman (30s) expressed that she wanted to be with people who treated her illness lightly. Similarly, two male group members in their 30s and 40s, respectively, wished for a society that does not speak harshly of those with mental illness. Another group member (female, 30s) stated her desire for an atmosphere in which people are not required to exert themselves beyond their means in terms of effort or cognitive/emotional resources (female,

30s).

Medical professionals provide psychoeducation and inform patients of the need to maintain their physical health as well as awareness of their condition. However, perhaps those around them should be more concerned about their physical condition and aware of the difficulties they face. Research highlights the need for peer supporters to be sensitive to the emotional states of and learn from those they support[23,27]. This may also apply to medical professionals.

According to Chamberlin, who is credited with popularizing the concept of recovery, what people with mental illness want is "not medical-centered treatment, but the ability to live with pride"[23,27]. They want to live a "normal life"[13] and " achieve their potential "[12] as they see fit. The author believes that non-participants should respond by encouraging the recovery of the person concerned, rather than imposing their beliefs regarding the concerned individual's convenience or contribution to society.

Conclusion.

In the context of mental health care and awareness, the parties concerned are in the minority, and their voices are often drowned out by those of family members, friends, employers, and medical professionals. Even when individuals with bipolar disorder discuss their opinions among themselves, they are rarely conveyed to the broader community. Although I was given the opportunity to write this paper, I once again realized how difficult it was to put real voices into writing. The author encourages psychiatrists to directly participate in group meetings for patients as much as possible, and to listen to their true feelings. Further, as the opinions of those with mental illness are often suppressed as minor ones both at home and in society, it is important to convey these opinions, and to observe when patients are being hurt by the people around them and when their efforts for recovery are being discouraged.

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1. 病気を理解していない・しようとしない
（例）病気の否定（怠け，気のせい）
特に躁状態に関しての無理解
得体の知れない病気だなどと言う
2. 病気によるつらさを理解してくれない
（例）そのくらいできるでしょう
いい加減働きなさい
3. 治療に非協力的
（例）薬のせいで働けないのだと言う
怖い薬だと言う

Table 1: Inappropriate responses from family (summary)

(1) Not understanding or trying to understand the disease.

(Example) Denial of illness (laziness and imagination).

Condemning behavior in manic state

(Fear of illness).

(2) Not understanding the pain caused by the illness.

(Examples) “Don't be lazy.”

“You can do more.”

“Just work.”

(3) Not cooperating with treatment.

(Example) “You can't work because of the medicine.”

Family emphasizes the fear of medicine.

・締め切り，約束
・報告・連絡・相談
・会議
・きつい言葉
・うつのときに
—考えなければならない
—決めなければならない
—休まなければならない
・仕事の内容
—変更
—難しい
—やさしすぎる

Table 2: Stress in the workplace (summary)

Deadlines, commitments
Reporting, communication, and consultation
Meetings
Harsh words
Difficulty thinking, making decisions, and needing to take leave during an episode of depression
Work that is too difficult or too easy
Changes in the type of work

・何がつらいのか理解してもらえない ・退職してほしいと迫る（態度で示す） ・再就職が厳しいのでしがみついているのをわかってもらえない

Table 3: Inappropriate workplace responses (summary)
Inability of employers to understand what is painful for employees.
Pressuring employees to resign (showing attitude)
Inability of employers to understand that the employee is holding on because it is difficult to find another job.

・病気を理解する，受け止める ・病状にあわせて対応する ・同じ人間として自然につきあう ・双極性障害を寛容に受け入れる社会をめざす

Table 4: Responses desired by the participants (summary)
Understanding and acceptance of the disease
Responding according to the state of the disease (mania vs. depression)
To be treated naturally as a human being by others
Establishing a society that tolerates and accepts bipolar disorder