Brief Report

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The effects of mindfulness-based cognitive behavioral group program for patients with intractable disease and high depression

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SUMMARY: This study examined the efficacy of a Mindfulness-Based Cognitive Behavioral Group Program (MCBGP) designed to improve the mental health of patients with intractable diseases. Adults (n = 35) with such diseases participated in the study. They were categorized into a high- or low-depression group based on the Profile of Mood States (POMS) depression subscale score of 60 as the cutoff score. MCBGP was conducted monthly over three sessions, each session lasting 120 minutes. Each session consisted of psychoeducation, self-disclosure, and mindfulness meditation. The program outcomes were evaluated using the Stanford University Chronic Disease Self-Management Questionnaire, the POMS, and the World Health Organization Quality of Life instruments. The results showed that in the high-depression group (n = 11), health distress (p = 0.013), activity limitations (p = 0.022), depression ($p <$ 0.001), anxiety/tension (p = 0.002), anger/irritability (p = 0.004), fatigue (p = 0.023), and confusion (p = 0.033) were significantly reduced. The total quality of life scores were significantly improved (p = 0.028) after the program, whereas no significant improvements were observed in the low-depression group (n = 24). It was concluded that the MCBGP was effective in improving mental health outcomes and enhanced the quality of life in patients with intractable diseases and comorbid depression.

Keywords: intractable disease, mindfulness meditation, depression, QOL, cognitive behavioral group therapy

1. Introduction

Unclear pathophysiological mechanisms and a lack of established treatments are characteristics of intractable diseases. Patients with such diseases typically require lifelong medical care. Intractable diseases, which are chronic illnesses, cause persistent physical pain, emotional distress, and burdens, including reduced income and increased medical expenses (*1,2*). These conditions also disrupt family relationships and roles (*3*), reduce social functioning, and diminish overall well-being (*4*). People with chronic physical illnesses also have a high prevalence of comorbid depression, which aggravates their mental health decline (*5*). Optimal healthcare maintenance becomes increasingly complex because of these numerous stressors. Stress responses also negatively affect patients' quality of life (QOL) (*6*). Therefore, effective stress management interventions are crucial for improving the mental health of patients with intractable diseases.

Psychosocial interventions for improving the mental health of this population have focused on specific diseases. Luo *et al*. (*7*) performed a meta-analysis of 14 studies involving 507 patients with Parkinson's disease and reported that Cognitive Behavioral Therapy (CBT) was effective in improving symptoms of depression, anxiety, and sleep disturbances but not fatigue or QOL. The CBT provided in these research included relaxation training, thought restructuring, sleep hygiene, and worry control, and others. Sessions lasted 60–120 minutes once a week for 6–12 weeks. The CBT was delivered by group or by telephone.

Similarly, Shi *et al*. (*8*) conducted a systematic review of CBT interventions for individuals living with HIV and reported that CBT led to short-term improvements in depression and long-term reductions in viral load. The CBT included psychoeducation about HIV and depression, motivational interview, behavioral activation, cognitive restructuring, problem-solving, and relaxation. The CBT was delivered individually, once a week for 45–60 minutes, for 9 to 14 weeks, and were conducted by clinical psychologists with a master's or doctoral degree.

On the contrary, a review of psychosocial interventions' impact on adults with muscular dystrophy by Walklet *et al*. (*9*) reported that only 7 of the 10 studies meeting the inclusion criteria demonstrated short-term effects of the interventions. Moreover, the evidence

supporting improvements in QOL and well-being was limited. The psychosocial interventions carried out here included expressive disclosure, CBT to fatigue, Hypnosis, and others. These interventions were delivered by psychologists, social workers, or occupational therapists.

The current study implemented a cognitive behavioral group therapy program incorporating mindfulness meditation named the Mindfulness-Based Cognitive Behavioral Group Program (MCBGP). The MCBGP was designed to reduce psychological stress and improve QOL in individuals with various intractable diseases. This study evaluated the MCBGP to determine its efficacy in enhancing mental health outcomes and the overall well-being of this population.

2. Patients and Methods

2.1. Participants

Patients diagnosed with 27 intractable diseases (n = 35, mean age = 48 years, SD = 17.1; mean illness duration = 13.9 years, range = 1–45 years) voluntarily participated in the stress reduction program organized by the Okinawa Intractable Diseases Support Center (OIDSC) between 2017 and 2023. Eligibility criteria for this study required participants to have a medically diagnosed intractable disease and the ability to attend all the program sessions. Table 1 summarizes the patient characteristics. Their diagnoses included Behcet's disease, Castleman Disease, Collagen disease, Congenital adrenal enzyme deficiency, Crohn's disease, Dermatomyositis, Eosinophilic chronic rhinosinusitis, Eosinophilic polyangiitis granulomatosis, Generalized dystonia, Hypoparathyroidism, Ichthyosis, Idiopathic osteonecrosis of the femoral head, Juvenile Idiopathic Arthritis, Mixed connective tissue disease, Multiple sclerosis, Multiple system atrophy, Neurofibromatosis type 1, Neuromyelitis optica, Parkinson's disease, Primary biliary cholangitis, Retinitis Pigmentosa, Scleroderma, Sjogren syndrome, Systemic lupus erythematosus, Takayasu arteritis, and Ulcerative colitis. Participation in the program was free of charge.

Table 1. Demographics and characteristics of participants

Characteristics	Data
Participants (n = 35, adults)	
Sex	
Men	7 (20.0%)
Women	28 (80.0%)
Age (years)	Mean = 48.0 (SD = 17.1) Range = 20–82
Duration of illness (years)	Mean = 13.9 (SD = 13.1) Range = 1–45
Disease	n (%)
Behcet's disease	1 (2.9%)
Castleman Disease	1 (2.9%)
Collagen disease	1 (2.9%)
Congenital adrenal enzyme deficiency	1 (2.9%)
Crohn's disease	1 (2.9%)
Dermatomyositis	1 (2.9%)
Eosinophilic chronic rhinosinusitis	1 (2.9%)
Eosinophilic polyangiitis granulomatosis	1 (2.9%)
Generalized dystonia	1 (2.9%)
Hypoparathyroidism	1 (2.9%)
Ichthyosis	1 (2.9%)
Idiopathic osteonecrosis of the femoral head	1 (2.9%)
Juvenile Idiopathic Arthritis	1 (2.9%)
Mixed connective tissue disease	1 (2.9%)
Multiple sclerosis	3 (8.6%)
Multiple system atrophy	2 (5.7%)
Neurofibromatosis type 1	1 (2.9%)
Neuromyelitis optica	1 (2.9%)
Parkinson's disease	3 (8.6%)
Primary biliary cholangitis	2 (5.7%)
Retinitis Pigmentosa	3 (8.6%)
Scleroderma	1 (2.9%)
Sjogren syndrome	2 (5.7%)
Systemic lupus erythematosus	1 (2.9%)
Takayasu arteritis	1 (2.9%)
Ulcerative colitis	1 (2.9%)

2.2. The MCBGP

The program was conducted monthly for three sessions (3 months), each lasting 120 minutes. It was supervised by a clinical psychologist (CP) with a doctoral degree who had completed a 7-day professional training in Mindfulness-Based Stress Reduction in 1999 and had maintained a regular mindfulness meditation practice for 27 years. Figure 1 illustrates the program's structure and content. The fundamental elements of each session consisted of psychoeducation, self-disclosure, and stress reduction strategies.

The psychoeducation module of the intervention taught participants about stress mechanisms and coping methods, the association between cognition, emotions, and behavior, automatic thought identification, problem-solving therapy, interpersonal relationships, the effects of the illness on interpersonal relationships, and communication with healthcare providers. During psychoeducation, participants were informed that mindfulness would not eliminate all suffering related to their illness but could serve as a tool for managing stress, which is one of the many challenges encountered in daily life.

The self-disclosure component requested the participants to share their experiences related to the illness, sources of stress, coping strategies, emotional reactions, current problems, and changes in interpersonal relationships after the illness diagnosis. The participants were free to choose whether they wanted to participate in self-disclosure activities and retained the right to avoid discussing any information they felt uncomfortable sharing. Each session included two 10-minute mindfulness meditation practices as a stress reduction strategy.

The homework component assigned participants daily

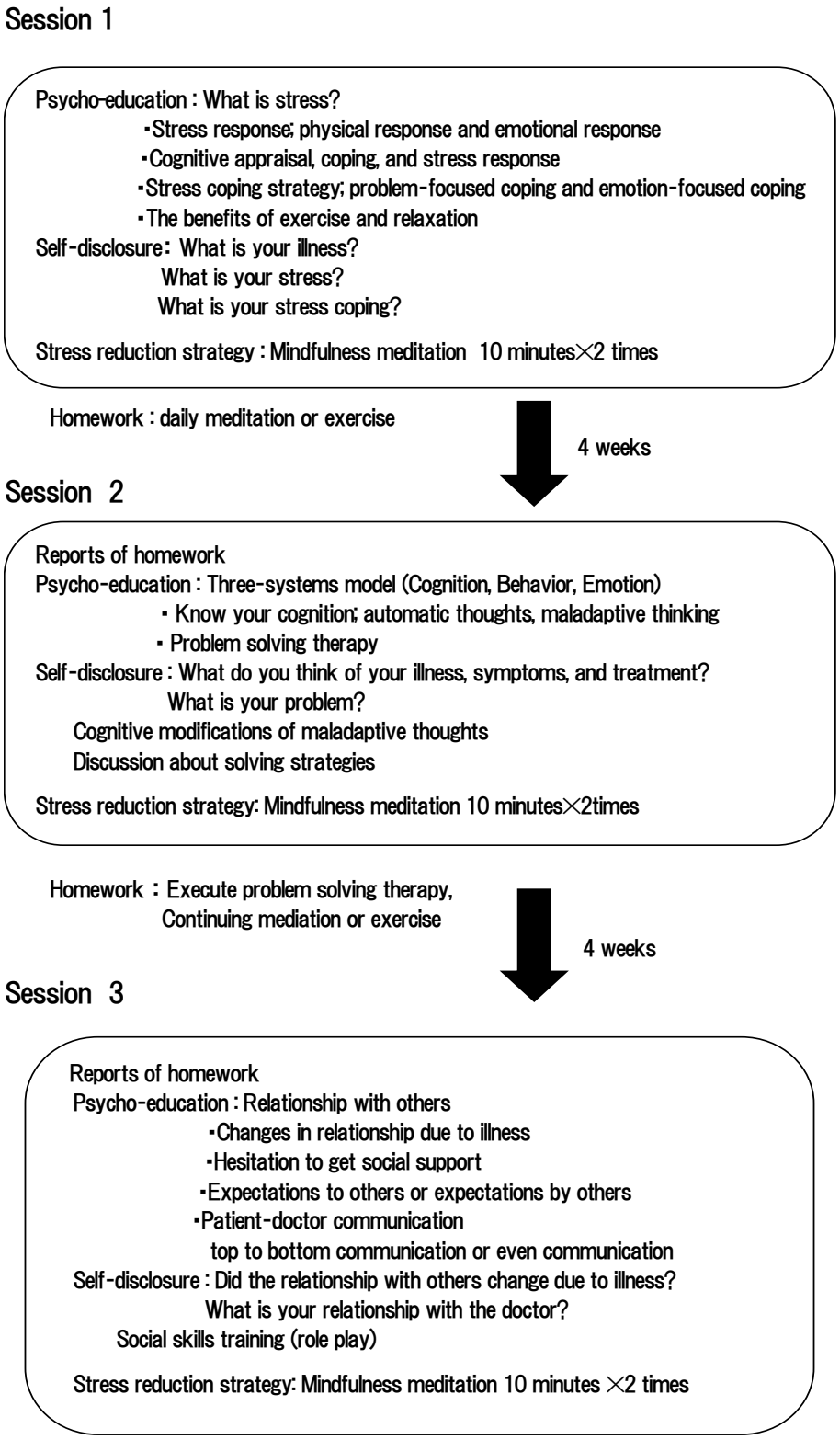

Figure 1. Contents of the Mindfulness-Based Cognitive Behavioral Group Program (MCBGP).

homework between sessions, which included practicing and recording stress management activities, such as mindfulness meditation, or physical exercise, such as walking. The CP made phone calls between sessions to follow up on the participant's adherence to homework. If the participants were not completing their assigned tasks, the CP helped identify barriers and explored solutions to improve compliance.

To ensure fidelity of the intervention and prevent therapist bias, three staff of OIDSC attended each group as observers and, with participants' permission, recorded each session verbatim and on videotape.

2.3. Instruments for evaluating the program's efficacy

2.3.1. Symptoms evaluation

The Stanford University Chronic Disease Self-Management Questionnaire assesses five symptom-related domains (*10*). These domains include Health Distress (0–5), Fatigue (0–10), Pain (0–10), Shortness of Breath (0–10), Limitations in Social/Role Activities (0–4), and Self-Efficacy for Managing Chronic Disease (0–10). Higher scores for all items except for self-efficacy indicate more disease symptoms.

2.3.2. Stress response evaluation

The Profile of Mood States (POMS) Brief Form Japanese Version (*11*) was used to evaluate Stress responses. This scale is a 30-item shortened version of the full 65-item version of the POMS (*12*). Like the full version, it assessed five items: Tension-Anxiety, Depression, Anger-Hostility, Vigor, Fatigue, and Confusion. It also assesses Total Mood Disturbance (TMD), which is the sum of tension-anxiety, depression, anger, fatigue, and confusion then subtracts vigor. In this scale, high scores indicate a more negative mood for all items except for vigor. All subscale scores were converted into T scores (20–85).

2.3.3. QOL evaluation:

The WHO-QOL 26 (*13*) assesses the overall QOL (1–5), as well as satisfaction in Physical (1–5), Psychological (1–5), Social relationship (1–5), and Environmental (1–5) subdomains of QOL. Higher scores in all areas indicate high QOL.

2.4. Procedure

The three scales were administered as a pre-test one week before starting the program and a post-test one week after the program concluded. Participants received written feedback summarizing their test results. The purpose and use of the data for research were explained to the participants in advance, and written informed consent was obtained. The Research Ethics Committee of Okinawa International University approved this study (Approval No.:66). It was conducted following the principles outlined in the Declaration of Helsinki.

2.5. Data analysis

At the pre-test, the participants were divided into high- and low-depression groups based on the Profile of Mood States depression subscale score of 60 as the cutoff score. The high- and low-depression groups' pre- and post-test means (*t*-tests) were compared using R (*14*). Effect sizes were calculated using Cohen's method (*15*).

3. Results and Discussion

Table 2. Demographics and characteristics of high depression participants

Characteristics	Data
High depression participants (n = 11, adults)	
Sex	
Men	3 (27.3%)
Women	8 (71.7%)
Age (years)	Mean = 42.4
	(SD = 20.7)
	Range = 20–76
Duration of illness (years)	Mean = 11.0
	(SD = 10.3)
	Range = 1–32
Disease	*n*
Multiple sclerosis	1
Parkinson's disease	1
Behcet's disease	1
Idiopathic osteonecrosis of the femoral head	1
Eosinophilic polyangiitis granulomatosis	1
Primary biliary cholangitis	1
Juvenile Idiopathic Arthritis	1
Ichthyosis	1
Eosinophilic chronic rhinosinusitis	1
Dermatomyositis	1
Hypoparathyroidism	1

The high-depression group (n = 11, mean age = 42.4 years, SD = 20.7; mean illness duration = 11.0 years, SD = 10.3) and the low-depression group (n = 24, mean age = 50.6 years, SD = 15.0; mean illness duration =15.3 years, SD = 14.3) consisted of patients with Multiple sclerosis, Parkinson's disease, Behcet's disease, Idiopathic osteonecrosis of the femoral head, Eosinophilic polyangiitis granulomatosis, Primary biliary cholangitis, Juvenile Idiopathic Arthritis, Ichthyosis, Eosinophilic chronic rhinosinusitis, Dermatomyositis, and Hypoparathyroidism (Table 2). There were neither statistically significant differences between the two groups in their age distribution (T = 3.33, df = 14.97, p = 0.255) nor illness duration (T = 0.988, df = 26.54, p = 0.331). Moreover, there were no significant group differences in the types of illness in each group.

Table 3 shows that the post-intervention results of the high-depression group indicated a significant reduction in health distress (T = 3.00, df = 10, p = 0.013, d = 0.75) and a significant improvement in activity limitations (T = 2.70, df = 10, p = 0.022, d = 0.43). Moreover, significant reductions were observed in tension-anxiety (T = 4.26, df = 10, p = 0.002, d = 1.04), depression (T = 7.31, df = 10, p < 0.001, d = 2.30), anger-hostility (T = 3.70, df = 10, p = 0.004, d = 0.96), fatigue (T = 2.68, df = 10, p = 0.023, d = 0.73), and confusion (T = 2.48, df = 10, p = 0.033, d = 0.66), indicating a reduced stress responses. Furthermore, the TMD scores decreased significantly at post-test (T = 6.87, df = 10, p < 0.001, d = 1.59). Furthermore, significant QOL improvements were observed in the physical (T = 2.47, df = 10, p = 0.033, d = 0.59) and psychological (T = 2.68, df = 10, p = 0.023, d = 0.58) domains. The overall QOL score also showed a statistically significant increase (T = 2.56, df = 10, p =

Table 3. The effects of MCBGP in the high depression participants (*n* = 11)

Items	Pre		Post		*t*	*df*	*p*-value	*d*
	Mean	SD	Mean	SD				
Health Distress	3.1	0.89	2.4	0.98	3.00	10	0.013	0.75
Fatigue	6.5	2.34	6.0	2.45	1.05	10	0.320	0.21
Shortness of Breath	2.5	1.92	2.1	2.21	0.66	10	0.526	0.19
Pain	3.2	3.16	2.5	2.62	1.30	10	0.224	0.24
Activities Limitations	2.0	1.50	1.4	1.29	2.70	10	0.022	0.43
Self-Efficacy	5.7	1.74	6.2	2.00	1.07	10	0.308	0.27
POMS								
Tension-Anxiety	66.4	8.72	57.5	8.45	4.26	10	0.002	1.04
Depression	71.6	5.63	56.5	7.37	7.31	10	0.000	2.30
Anger-Hostility	61.6	13.63	49.7	10.92	3.70	10	0.004	0.96
Vigor	45.3	8.58	48.6	8.43	1.28	10	0.231	0.39
Fatigue	61.1	8.80	53.7	11.33	2.68	10	0.023	0.73
Confusion	69.0	9.77	61.9	11.60	2.48	10	0.033	0.66
TMD	284.5	28.71	230.7	38.33	6.87	10	0.000	1.59
QOL-26								
QOL	2.9	0.32	3.1	0.27	2.56	10	0.028	0.69
Physical	2.9	0.56	3.2	0.45	2.47	10	0.033	0.59
Psychological	2.6	0.57	2.9	0.47	2.68	10	0.023	0.58
Social	2.8	0.86	2.9	0.57	0.50	10	0.629	0.14
Environment	3.1	0.30	3.3	0.42	1.51	10	0.163	0.55

Bold font shows significance in statistical tests ($p < 0.05$). MCBGP, Mindfulness-Based Cognitive Behavioral Group Program (MCBGP).

0.028, $d = 0.69$).

The significant improvement in depressive symptoms among high-depression participants may be attributed to the effects of mindfulness meditation. Mindfulness meditation has demonstrated efficacy as a component of mindfulness-based cognitive therapy for depression (*16,17*). The effective mechanism of mindfulness meditation involves interrupting negative thought cycles by promoting cognitive decentering, thereby preventing the worsening of depression (*18*). The observed reduction in health distress among participants further suggests that mindfulness meditation may have helped patients disengage from persistent illness-related rumination, contributing to improving depressive symptoms.

Crucially, the current study introduced mindfulness meditation within the framework of stress management. It is possible that presenting mindfulness in such a context enhanced participants' motivation and engagement. This framing is consistent with previous findings that mindfulness-based cognitive therapy effectively reduces various stress responses, including anxiety, tension, anger, fatigue, and confusion (*16,17*).

The group-based delivery of the program may have further contributed to psychological improvements and enhanced QOL (*19*). Yalom emphasized the therapeutic role of group settings' universality, in which individuals benefit from recognizing shared struggles among peers (*20*). The participants in this program listened to self-disclosures of others who did not necessarily have the same illness but were affected by similar, rare diseases. Sharing their experience may have helped reduce feelings of isolation and promoted a sense of relief and solidarity (*20*), which may have reduced feelings of anxiety, anger, and confusion and supported improvements in their overall well-being.

Table 4 shows the pre and post-intervention results of the low depression groups. The results of pre-intervention in the POMS showed that, compared to the average values of the normative population (*11*), there were no significant differences in tension-anxiety ($T = 1.85$, $df = 5659$, $p = 0.063$), fatigue ($T = 0.309$, $df = 5659$, $p = 0.757$), and confusion ($T = 0.773$, $df = 5659$, $p = 0.439$). Depression ($T = 4.332$, $df = 5659$, $p < 0.0001$), anger-hostility ($T = 7.734$, $df = 5659$, $p < 0.0001$), and vigor ($T = 6.952$, $df = 5659$, $p < 0.0001$) were significantly lower. In terms of QOL, there were no significant differences in overall QOL ($T = 0.761$, $df = 1421$, $p = 0.473$), psychological ($T = 1.183$, $df = 273$, $p = 0.238$), social ($T = 0.542$, $df = 273$, $p = 0.592$), and environment ($T = 0.614$, $df = 273$, $p = 0.539$), but physical ($T = 3.165$, $df = 273$, $p = 0.002$) was significantly lower than the value of normative population (*13*).

At post intervention, activity limitations shows an improving trend ($T = 2.06$, $df = 23$, $p = 0.051$, $d = 0.25$). The mean of depression was increased, but this change is not statistically significant ($T = 1.93$, $df = 23$, $p = 0.662$). There were no statistically significant changes in any other symptom domain, stress responses, or QOL measures, in the low depression group.

Low depression patients did not demonstrate significant psychological or QOL improvements. However, these patients exhibited low stress responses at pre-intervention, and their baseline QOL except physical, was similar to normative average in Japan (Mean = 3.29) (*13*). Therefore, the lack of change in this subgroup may be due to the floor effect rather than the inefficacy of the program. The lack of improvement in physical domain is likely due to that the MCBGP did not result in

Table 4. The effects of MCBGP in the low depression participants (*n* = 24)

Items	*n*	Pre		Post		*t*	*df*	*p*-value	*d*
		Mean	SD	Mean	SD				
Health Distress	24	2.2	1.19	2.0	1.29	1.17	23	0.253	0.16
Fatigue	24	4.8	2.66	4.6	2.87	0.36	23	0.724	0.07
Shortness of Breath	24	3.1	3.05	2.8	2.73	0.50	23	0.625	0.10
Pain	24	3.5	2.86	3.3	3.20	0.58	23	0.567	0.07
Activities Limitations	24	1.7	1.32	1.4	1.13	2.06	23	0.051	0.25
Self-Efficacy	24	5.4	2.45	5.6	2.06	0.34	23	0.736	0.09
POMS									
Tension-Anxiety	24	48.8	10.86	49.4	11.85	0.32	23	0.753	0.05
Depression	24	47.2	5.64	50.1	9.31	1.93	23	0.662	0.38
Anger-Hostility	24	45.0	6.54	45.8	10.33	0.48	23	0.638	0.09
Vigor	24	45.5	12.65	45.7	9.98	0.05	23	0.961	0.02
Fatigue	24	50.2	8.89	49.5	10.20	0.38	23	0.706	0.07
Confusion	24	50.5	9.11	52.4	11.84	0.93	23	0.365	0.18
TMD	24	196.2	31.97	201.5	47.17	0.68	23	0.503	0.13
QOL-26									
QOL	24	3.2	0.46	3.2	0.48	0.07	23	0.946	0.00
Physical	24	3.1	0.62	3.1	0.64	0.23	23	0.816	0.00
Psychological	24	3.2	0.69	3.3	0.67	0.07	23	0.948	0.15
Social	24	3.4	0.64	3.4	0.60	0.10	23	0.924	0.00
Environment	24	3.3	0.48	3.3	0.44	0.50	23	0.623	0.00

MCBGP, Mindfulness-Based Cognitive Behavioral Group Program (MCBGP).

further improvement in physical symptoms. Similarly, the lack of improvement in vigor, which was lower than normative average, may be due to the fact that the program did not include any energy-boosting content, such as behavioral activation (*8*).

Future studies are expected to address several limitations of this study that constrain the generalizability of its findings. Most notably, the study had no control group, limiting the ability to attribute observed changes to the intervention. However, designing a control group of patients with a comparable mixture of rare, intractable conditions is difficult. Nevertheless, future research could overcome this issue by employing a waiting-list control design (21), allowing researchers to compare data collected before and after a non-intervention period.

This program treated 27 different intractable diseases as one group. This was both a strength and a limitation of the program. One limitation was that the number of patients with each disease was small, and it was not possible to improve symptoms specific to each disease, such as pain and fatigue. A strength was that the program was able to provide to patients with such a wide variety of intractable diseases, which helped participants to learn that there are so many rare intractable diseases. It would be difficult for a hospital to bring together patients with such a wide variety of intractable diseases, and this was made possible by the existence of OIDSC.

Another limitation is the uncertainty regarding the program's long-term effects. Follow-up data are currently being collected, and time and a sufficient sample size are needed to assess the stability and durability of the intervention's long-term outcomes.

According to the transtheoretical behavioral change model, psychotherapy patients move through five stages: pre-contemplation, contemplation, preparation, action, and maintenance (*22*). The intervention used in this study matches the action stage because the participants took direct action to change their behavior. Moreover, people who have chronic and incurable illnesses need to maintain mindfulness practice for an extended period to build psychological resilience. However, people struggle to maintain regular mindfulness practice because they need ongoing support and encouragement (*23*). Therefore, helping patients with intractable diseases integrate mindfulness into their daily lives may require establishing an accessible support system.

4. Conclusion

Despite these limitations, the findings of this study indicate that a cognitive behavioral group program incorporating mindfulness meditation may offer meaningful mental health and QOL for patients with intractable diseases. With access to appropriate and sustainable coping strategies, patients may be better equipped to maintain long-term psychological well-being and life satisfaction.

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