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## **Special Feature Article**

### **Overview of the Development of Guidelines of Treatment and Support Network and Non-Specialist Treatment Programs for Eating Disorders**

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#### **Abstract**

The study, "The development of guidelines of treatment and support network and non-specialist treatment programs for eating disorders" was conducted between 2017 and 2019 with the aim of promoting cooperation among medical institutions and local governments to enable patients to receive appropriate treatment for eating disorders at an early stage. The goals of the project were: 1) to clarify the problems of prefectural governments and municipalities in establishing a regional network system of treatment and support for eating disorder patients; 2) to develop tools, such as guidelines, manuals, and materials, for collaboration of multiple psychiatric and medical facilities relevant to eating disorders; 3) to develop early treatments for eating disorders that are feasible to non-specialist doctors; and 4) to establish a model of regional multi-facility cooperation for treatment and support of eating disorders. The organization of the study group consisted of researchers and collaborators with expertise in mental health, psychiatry, and psychosomatic medicine. In this paper, we report on the background and outline of the development of: (1) guidelines for collaboration in the field of psychiatry and in the

field of physical medicine, respectively; and (2) early treatment programs for anorexia nervosa and online guided self-help. In the future, it will be necessary to disseminate the deliverables of this research and to verify their effectiveness. The development of more specialized treatment guidelines and materials is also an issue for the future.

**Keywords:** guideline, treatment program, medical collaboration, eating disorders

### Introduction

The number of out- and inpatients with eating disorders (ED) in Japan is reportedly around 220,000 per year.<sup>18)</sup> It is known that it takes a long time from the onset of ED to receiving treatment. The average duration of untreated anorexia nervosa (AN) is reportedly 30 months, bulimia nervosa (BN) is 53 months, and binge eating disorder (BED) is 67 months.<sup>8)</sup>

In Japan, too, it has been reported that the proportion of patients who have not yet received or discontinued treatment is close to half of all ED patients, based on consultation cases at public health and health centers,<sup>3)</sup> and consultation cases through the Project for the Establishment and Operation of Eating Disorder Treatment Support Centers.<sup>19)</sup> Many cases of ED become long-term. In a survey in the United States, it was reported that the duration of illness was prolonged, with approximately half of AN patients having a condition persisting for more than 5 years, and approximately half of BN patients

having that for more than 8 years.<sup>27)</sup>

Many cases involve adolescents and early young adults in their teens and 20s,<sup>16)</sup> the impact on subsequent mental and physical health and psychosocial functioning is significant, and it is not uncommon for the condition to be life-threatening.<sup>7)</sup> Early diagnosis and intervention for ED are considered to be cornerstones of ED countermeasures, along with evidence-based treatment.<sup>21)</sup> To this end, it is necessary to build a treatment support network for ED patients.

In this paper, we will discuss the background of the study “Guidelines for Treatment Support Networks and Development of Brief Treatment Programs for Eating Disorders” supported by the Japan Agency for Medical Research and Development (AMED) (AMED Eating Disorders Research Group) from FY2017 to FY2019, as well as provide an overview of the development of collaboration guidelines and treatment programs that can be implemented by non-specialists.<sup>5)</sup>

## I. Research Structure and Objectives of the AMED Eating Disorders Research Group

The objectives of the AMED Eating Disorders Research Group's research and development were to: (i) investigate the current situation, awareness, and issues regarding consultations at mental health and welfare centers and local governments, (ii) create a model for collaboration between local governments and medical institutions in Chiba Prefecture, (iii) create guidelines and materials for collaboration between psychiatric and physical medicine departments, and (iv) develop a simple treatment program that non-specialists can implement.<sup>5)</sup>

The research organization consists of the principal investigator, Tetsuya Ando (National Center of Neurology and Psychiatry), joint researchers, Hisateru Tachimori (National Center of Neurology and Psychiatry), Koki Inoue (Osaka City University), Hisato Matsunaga (Hyogo Medical University), Kazuhiro Yoshiuchi (University of Tokyo), Nobuyuki Sudo (Kyushu University), Michiko Nakazato (Chiba University/International University of Health and Welfare), Keisuke Kawai (International Medical Center of Japan), and research collaborators. The research structure is shown in the figure.

## II. Background to Research and Development - Importance of Early Diagnosis and Treatment

The ED duration is associated with various favorable and unfavorable outcomes. For example, in those with AN, a long baseline duration is associated with a high mortality rate,<sup>11)13)14)</sup> while a short duration is associated with favorable weight outcomes.<sup>1)10)28)</sup> In addition, the longer the duration of illness, the more significant the decrease in bone mineral density.<sup>26)</sup> In those with BN, it has been reported that the shorter the duration of illness at the baseline, the better the ED symptoms,<sup>17)23)</sup> and the longer the duration of illness, the higher the suicide-attempt rate.<sup>2)</sup>

So, does shortening the untreated period really improve outcomes? Schmidt, U. et al. from King's College London developed a First Episode Rapid Early Intervention for Eating Disorders (FREED) service to facilitate early diagnosis and intervention for young adults (aged 18-25) within three years of onset, and are currently testing its effectiveness. The FREED service has significantly reduced the duration of untreated illness, time to specialist assessment, and waiting time for treatment compared with conventional services, and has also led to a higher rate of treatment uptake (97.8 vs. 75.4%,

respectively). Furthermore, when comparing the outcomes of AN patients who received treatment through the FREED service (n=22) and those who received treatment through the usual service (n=35) at two years, it was reported that the FREED service group required intensive treatment less frequently (23 vs. 32%, respectively) and had a higher average BMI (19.2 vs. 18.0 kg/m<sup>2</sup>, respectively).<sup>12)</sup> As such, it has been suggested that early intervention and treatment for ED can actually lead to improved outcomes.

In Japan, there have been no reports on the length of time that people with ED go without seeking treatment, but according to a survey of public health and health centers nationwide, it was reported that about half of the patients who were consulted had not sought or discontinued treatment.<sup>3)</sup> In a report on consultation cases at ED treatment support centers, which will be discussed later, only around 40% of consultation cases were actually being treated for ED at the time of consultation.<sup>19)</sup>

### III. Background to Research and Development - Need for Collaboration

ED patients often initially complain of physical discomfort or irregular menstruation, and visit departments such as pediatrics, internal medicine, gynecology, or emergency medicine. According to a survey of the time and

route from onset to treatment of 140 AN patients in Germany, more than half of the information provided on initial diagnosis and treatment facilities came from general practitioners, pediatricians, and other physical medicine departments, while information on mental health diagnosis and treatment facilities accounted for one third.<sup>22)</sup> According to a nationwide hospital survey in Japan in 2014-2015, 64.7% of estimated ED patients were psychiatric, 9.3% were psychosomatic medicine, 8.2% were pediatric, 3.6% were obstetrics and gynecology, and 19.2% were internal medicine patients.<sup>3)</sup> It is important to respond appropriately when ED patients visit a department of general practice and refer them for specialized treatment.

In addition, when looking at the number of patients by facility, 50% of the total number of psychiatric patients were reported by the top 5% of facilities. In psychosomatic medicine and pediatrics, the top 5% of facilities treated 60% of the total number of reported patients. Thus, ED patients were concentrated in a small number of facilities, with more than 100 ED patients per year visiting a limited number, centered on psychiatric and psychosomatic departments at general hospitals<sup>3)</sup> It was considered that it would be necessary to prevent the concentration of patients in some

general hospitals by having more medical institutions that are able to treat ED, and also by having psychiatric treatment facilities, such as general hospital psychiatry departments with inpatient facilities, single-specialty psychiatric hospitals, general hospital psychiatry departments without inpatient facilities, and clinics, work together to share the burden of ED treatment.

#### **IV. The Project for the Establishment and Operation of Treatment Support Centers for Eating Disorders as Model for Treatment Support Networks for Eating Disorders**

In order to contribute to countermeasures against ED, the “Project for the Establishment and Operation of Eating Disorder Treatment Support Centers” was started by the Ministry of Health, Labour and Welfare in 2014.<sup>4)</sup> First, the national core center for ED, which is the controlling organization, was established in 2014, in 2015, ED treatment support centers were established in Miyagi, Shizuoka, and Fukuoka Prefectures, and in 2017, one was established in Chiba Prefecture.<sup>19)</sup> From 2021, the National Eating Disorders Core Center was renamed the National Eating Disorders Support Center (National Support Center), and the Eating Disorders Treatment

Support Center was renamed the Eating Disorders Support Base Hospital (Support Base Hospital).

Support base hospitals have set up consultation services and co-ordinators who handle consultations from patients and their families, medical institutions, etc., as well as conduct business activities such as providing lectures and training for medical institutions in the prefecture, and provide lectures and training for those involved in education, such as school nurses, and those involved in health and welfare, e.g., public health nurses, nurses, mental health and welfare workers, and dietitians. In addition, they have set up a website and are working to raise awareness through holding lectures, printed materials, and the media.<sup>4)19)</sup>

#### **V. Need for a Network from the Perspective of Consultation Cases at Support Base Hospitals**

From April to November 2020, there were a total of 1,388 consultation cases at support base hospitals in the four prefectures (monthly average of 173.5 cases), including 766 new cases. The breakdown of people who sought counseling was as follows: 50.7% were family members of patients, 30.7% were patients themselves, and 13.6% were staff from medical, administrative, educational, or other organizations. The average age of patients who consulted

us was 23.7 years old, and age groups were most common in the teens, 20s, and 30s in that order. The consultation status was as follows: 40.6% were being treated for ED, 12.1% were being treated for a condition other than ED, 10.0% had discontinued treatment, 27.6% had not yet been treated, and 9.8% were in other/unknown categories. Nearly 40% of patients had not yet been treated or had discontinued treatment. The most common consultation topic was about visiting a hospital (748 cases), followed by consultations about diseases and symptoms (522 cases), and consultations about how to deal with and interact with patients from family members and others (305 cases). The most common response from the coordinators to consultations was to introduce hospitals (646 cases), followed by providing information (590 cases), and giving advice (539 cases).<sup>19)</sup> As you can see, there are many ED patients who are not receiving treatment, and there is a marked need for referrals to medical institutions that actually provide treatment. The support base hospitals have been working on regional medical cooperation, and as a result, the number of medical institutions treating ED patients has increased, and a network has been established.<sup>6)</sup>

The consultation support provided by support base hospitals may lead to early treatment. According to the business

report of the Fukuoka Prefecture eating disorders support base hospital: (i) the proportion of young patients among consultation cases has been increasing annually, and (ii) the proportion of young people among patients who were referred to and received treatment at support base hospitals after consultation has also been increasing annually. Although being young does not necessarily mean that the disease is in the early stages after onset, it is considered that the possibility is high, and consultation and support are thought to contribute to early treatment.<sup>19)</sup>

## **VI. Development of Guidelines of Treatment and Support Network and Non-specialist Treatment Programs for Eating Disorders**

Finally, we will outline the guidelines and programs developed by the AMED Eating Disorders Research Group. Of the guidelines and programs developed, the “Guidelines for Collaboration for Eating Disorders in the Psychiatric Field,” “Guidelines for Collaboration for Eating Disorders in the Physical Field,” “Guide to Consultation for Those Suffering from Eating Disorders and Those Who Support Them,” and “Guide to initial treatment of anorexia nervosa (AN)” have been published in booklet forms and are available for free download from the website of the Japan

Eating Disorders Society, eating disorders information portal site of the National eating disorders support center. Regarding the Guide to initial treatment of anorexia nervosa (AN), as a method of promotion in the future, it is planned that the text and materials will be used and distributed in training sessions.

The Guidelines for Collaboration for Eating Disorders in the Psychiatric Field were created with the aim of helping more medical institutions to collaborate smoothly by providing a model and written materials for collaboration between psychiatric institutions involved in the treatment of ED patients, and are intended for use by medical professionals at psychiatric institutions. The key issues were set as: “Cooperation with appropriate medical institutions in outpatient treatment of eating disorder patients,” “Cooperation with appropriate medical institutions in inpatient treatment for eating disorder patients,” and “Cooperation with appropriate medical institutions in treatment for eating disorders involving children and adolescents,” and it is based on the “expert consensus” that was compiled by surveying and consolidating the opinions of psychiatrists involved in ED treatment (general hospital psychiatry, psychiatric hospitals, psychiatric clinics), and it sets out a policy for ED treatment

collaboration. As appendices, there is a “Flowchart for Collaboration in the Treatment of Eating Disorder Patients” that can be edited as necessary based on the local healthcare system, a “Communication Form for Eating Disorder Patients” that can be used in conjunction with the standard medical information provision form, and a “List of Eating Disorder-treating Medical Institutions” that can be used to enter the situations at local medical institutions.<sup>15)</sup>

In the “Guidelines for Collaboration for Eating Disorders in the Physical Field,” the guideline-creation team, led by the sub-researcher, set two important clinical issues: “Guidelines for when the physical department is asked by the psychiatric department to manage the physical condition of an eating disorder patient” and “Guidelines for when an eating disorder patient directly visits a department other than a specialist medical institution (internal medicine, pediatrics, emergency department, obstetrics and gynecology).” We invited proposals for clinical questions (CQs) from primary care providers, general practitioners, pediatricians, obstetricians/gynecologists, and emergency physicians. A total of 14 clinical questions were selected, seven for each of the important issues. The guideline development team prepared the recommendations and commentary

based on a systematic review of the evidence and expert consensus, in accordance with the Minds Guideline Development Manual.<sup>25)</sup>

The “Guide to Consultation for Those Suffering from Eating Disorders and Those Who Support Them” aims to provide patients and their families with information on where to seek appropriate medical care. It was created based on a survey of the needs and current situation of ED patients and their families, existing guidelines, and expert consensus obtained from a questionnaire conducted by the Research Group for the Development of a Treatment System for Eating Disorder Patients, which was part of the Research on Policies for Persons with Disabilities (Psychiatric Disorders) project funded by the Ministry of Health, Labour and Welfare from 2014 to 2016.<sup>20)</sup>

The “Guide to initial treatment of anorexia nervosa (AN)” is a simple treatment program for AN patients that can be used in psychosomatic medicine and psychiatry departments that do not specialize in general internal medicine or ED treatment. It was created by collecting information from domestic and international guidelines and literature in the four fields of: physical management, nutritional management, psychoeducation, and psychotherapy, with an emphasis on evidence.<sup>24)</sup>

Guided self-help for BN and BED is recommended as first-line treatment in NICE guidelines.<sup>21)</sup> Online-guided self-help is easy to access, low-cost, and can be scaled up, so it is expected to contribute to early recovery, prevention of severe illness, and reduction of the burden on medical institutions as first-line treatment for relatively mild ED without low body weight and early-stage ED.<sup>5)</sup> In this study, we created a Japanese version of the online-guided self-help program for BED that was developed overseas. We plan to investigate its feasibility in the future.

### Conclusion

This report has described the background and given an overview of the development of the AN simple treatment program and online-guide self-help program, as well as the development of guidelines for collaboration in the psychiatric field, the referral guide and roadmap, guidelines for collaboration in the physical medicine field, and the simple treatment program, as materials for collaboration in ED patient treatment based on the AMED “the Development of Guidelines of Treatment and Support Network and Non-Specialist Treatment Programs for Eating Disorders” research. In the future, it will be necessary to disseminate the results of this research and development and

verify their effectiveness. In addition, the development of more specialized treatment guidelines and materials is a future issue. We hope that the results of this research will encourage more physicians and medical institutions to participate in the ED treatment support network.

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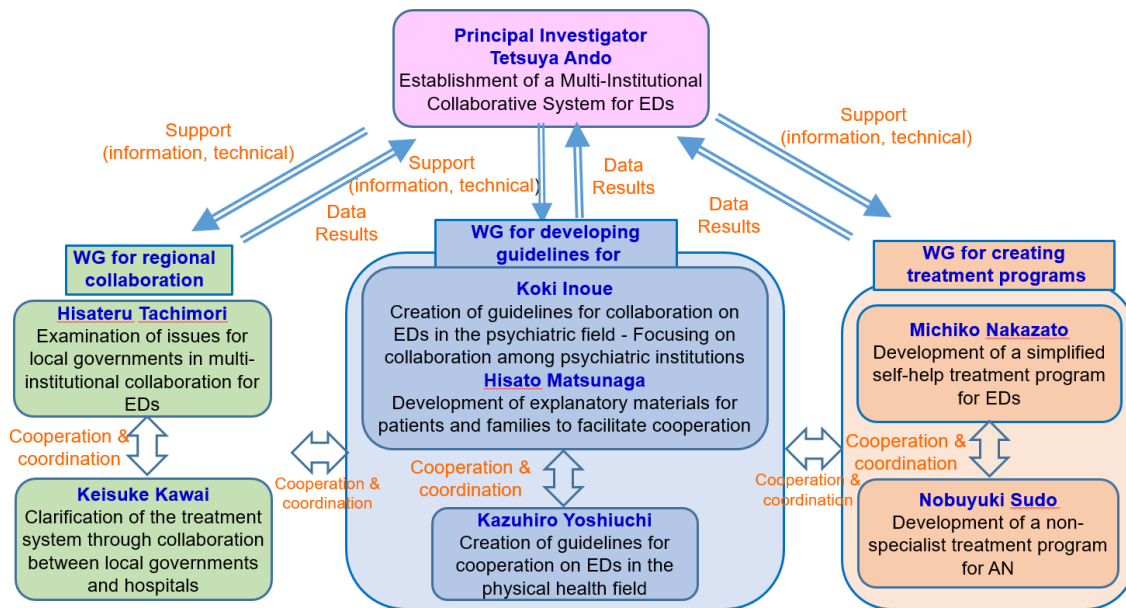


Figure: Research structure for the AMED “Development of Guidelines of Treatment and Support Networks and Non-Specialist Treatment Programs for Eating Disorders” project for 2017-2019