



Research on Persons with Early Onset Dementia and Their Employment Maintenance 2

—Current Status of Reaction at Facilities and Study on Support—

(Research Report No.111) Summary

【Key Words】

early onset dementia, support for employment maintenance, higher brain dysfunction

【Usage of This Report】

It reveals current status of support for persons with early onset dementia and their employment. Based on opinions and cases of maintaining employment which were collected from vocational counselors, human resources personnel and specialists, the report provides directions as to how support for employment maintenance should be. Personnel at supporting facilities may make use of this report for coordinated support.

April 2012

Japan Organization for Employment of the Elderly, Persons with Disabilities and Job Seekers

National Institute of Vocational Rehabilitation

1 .Authors (in the order of chapters that they wrote)

Katsuo Taya(Senior Researcher, National Institute of Vocational Rehabilitation)

Nobuko Ito(Research Cooperator, National Institute of Vocational Rehabilitation)

2. Research Period

2010 to 2011

3 .Composition of the research report

Chapter 1 Preface

Chapter 2 Survey on utilization of Local Vocational Centers for persons with disabilities

Chapter 3 Medical specialist survey

Chapter 4 Companies survey

Chapter 5 Survey on cases of maintaining employment

Chapter 6 Conclusion

Appendix

4. Background and purpose of Research

Early Onset Dementia (EOD) strikes persons in their labor age, which leads to high demand in employment support. Recent research on EOD revealed the actual conditions of employment. All the statistics show that more than 80% of persons who have diagnosis of EOD left their work, which clearly shows the difficulty of maintaining employment. For this reason, this study explores an ideal position of the support system including the one that helps maintain employment, by collecting actual cases of employment and conducting surveys on professionals such as employment support organizations, physicians and offices.

5. Method

- (1) Research on reference materials
- (2) Hearing survey of specialists
- (3) Survey targeting local vocational rehabilitation centers for persons with disabilities, physicians specialized with dementia, and major companies
- (4) Collect cases of employment and hearing survey of relevant personnel

6. Summarized results of the study

(1) Current state of support system for persons with EOD

In the middle of 1980, Alzheimer's Association Japan brought up an issue about supporting persons with dementia under the age of 65. In 1991, this family association began researching current state and

exploring ways of support. In the late 1990, a family association that focuses on EOD was established, followed by some other associations in the late 2000. Funded by National Treasury, Project for early onset dementia is established in 2009 and municipal support system for EOD expanded throughout Japan. In 2010, “National Family and Supporter Council for Young-onset Dementia” was established and support system from private sectors has also becoming nationwide.

(2) Survey of Local Vocational Centers for Persons with Disabilities

a. Current status of service use 23 Local Vocational Centers served persons with EOD in the past 12 years (Fiscal year 1999-2010), which account for 44.2% of all centers in Japan.

The number of persons with EOD was 50 and it is likely to increase (figure1.) Local Vocational Centers have following tendencies in their clients:

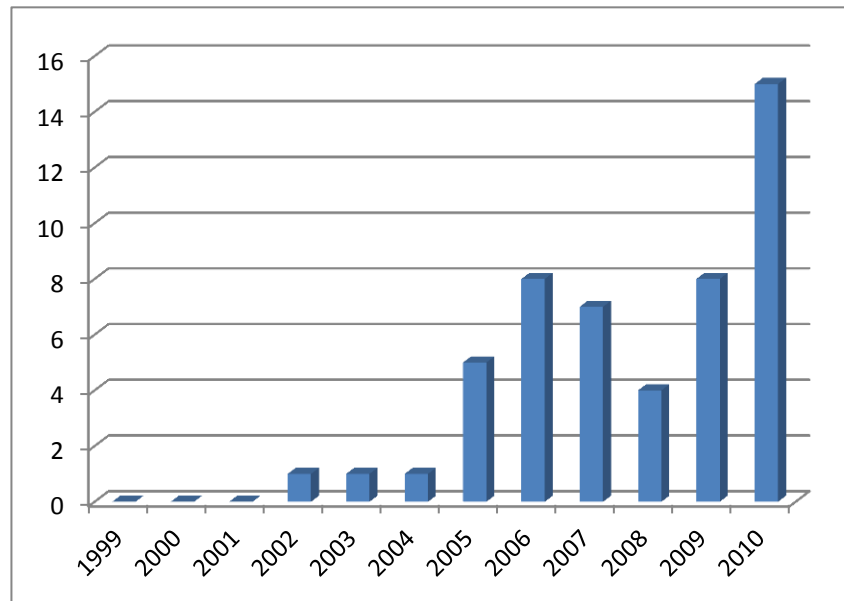


Figure 1 number of people who used services by year

1. Mostly male (97.8%)
2. Relatively young (53.2 in average and 73.4% are in their 50s)
3. Half or less have Mental or Physical Disability Certificates (42.2%)
4. Many (62.2%) have progressive diseases including Alzheimer and front temporal dementia as the root cause
5. Relatively young when their symptoms emerged (49.9 in average)
6. Consulted with medical institutes at the early stage and the period between onset of symptoms and diagnosis is relatively short (0.9 years in average)
7. Services include only counseling or vocational- assessment and do not reach practical supports such as job preparation, case discussions, "Support Offered by Job Coaches" (In order to assist persons with intellectual disabilities and persons with mental disabilities in smoothly adjusting to the workplace, the centers dispatch job coaches to workplaces to provide direct and professional support to such persons and their employers based on individual disability traits.) and workplace readiness.
8. Only 24.4% of them (1 maintained employment and 5 returned to employment) actually found employment after the service, which means much lower job returning and finding rate, compared to persons with other kind of disabilities such as higher brain dysfunction, developmental disabilities, and

mental disabilities.

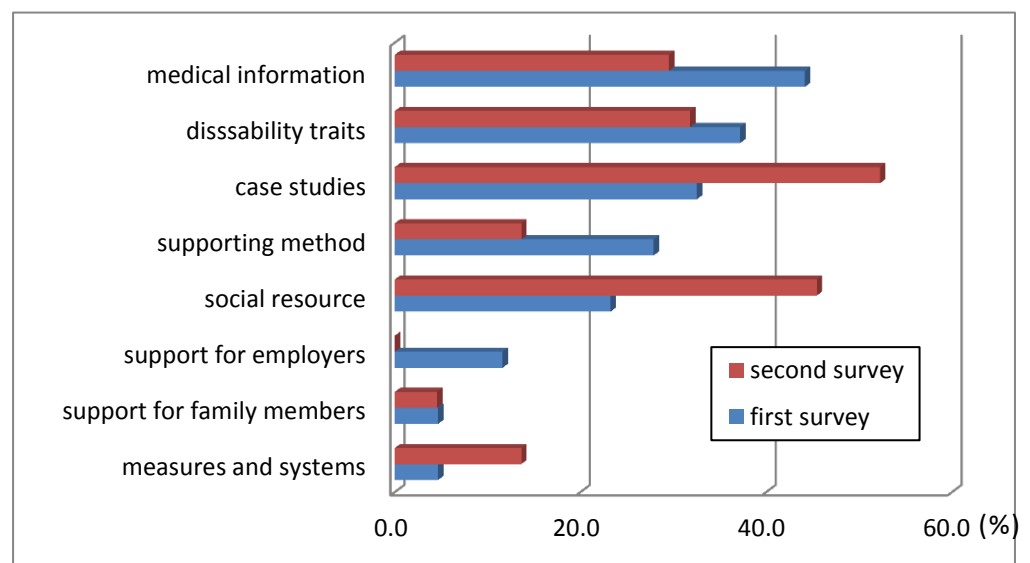
The group of persons with EOD who were able to maintain their employment has the following tendencies:

1. Younger in age
2. Have Mental or Physical Disability Certificates
3. The root cause is non-progressive
4. Developed symptoms and were diagnosed at younger age
5. Shorter period between onset of symptom and diagnosis
6. Received services such as “Support Offered by Job Coaches” and workplace readiness

b. Results of vocational counselors for persons with disabilities survey

Surveys of senior vocational counselors who take care of disabled clients and their family were conducted, and the results of the first (July 2009: only a few counselors had done their support) and second (December 2010: more counselors had done their support) surveys are shown below.

1. Results of the first survey show that the counselors need relatively practical information about medical disability traits, case studies, and support method. The second survey says that more counselors need social resources in order to deal with cases which have difficulties maintaining employment as well as case studies in order to use as references.



(figure 2)

Figure 2 Types of information necessary

2. The results show that there are some local social resources that are available to persons with EOD who have difficulties maintaining employment, such as:

A) employment support facilities for persons with disabilities including community activities supporting centers, Support program for continuation of work (Type B). (Work and production activities are provided at the support providers' place to persons with disabilities who have experience to work but have found it difficult to be employed due to age or lack of physical strength.) , supporting authorities, employment and life support centers for persons with disabilities, and work providing facilities and workshops in the old form.

- B) nursing facilities including day services and local integrated supporting centers
- C) medical institutions including medical centers or clinic for dementia, day care for persons with psychiatric disorders, and institutions for persons with higher brain dysfunction and their subsidiaries
- D) Associations of patients and their family members and private supporting organizations
- E) Welfare facilities including Life Support centers for Persons with disabilities
- F) Public sectors including welfare offices and departments, and health center and offices.

However, their coordinated supporting system has not been established yet and counselors have the following comments about social resources: no history in coordination projects, uncertain whether they accept persons with EOD or not, they need a better understanding to accept persons with EOD is unknown, some possibility of acceptance, high possibility of acceptance, upfront confirmation is necessary, they have no helpful information, no research is actually conducted, more social resources need to be discovered, their practicality is unknown.

Even if these social facilities accept persons with EOD, those clients need to meet the requirements including possess of mental or physical disability certificates and nursing care authorization , so that these facilities are only available to limited number of persons with EOD .

3. The first and second surveys shown difference in the number of positive answers for the presence of medical institutions that can coordinate with them, which was less than of total answers. The number that they answer nothing in request for medical institution was 17(39.5%) in the first and 5 (11.4%) in the second survey. The number of abstract (indirect) requests (coordinative information exchange) decreased and tangible (direct)(symptom progress and medical assessment)increased in the second survey compared to the first. (figure 3)

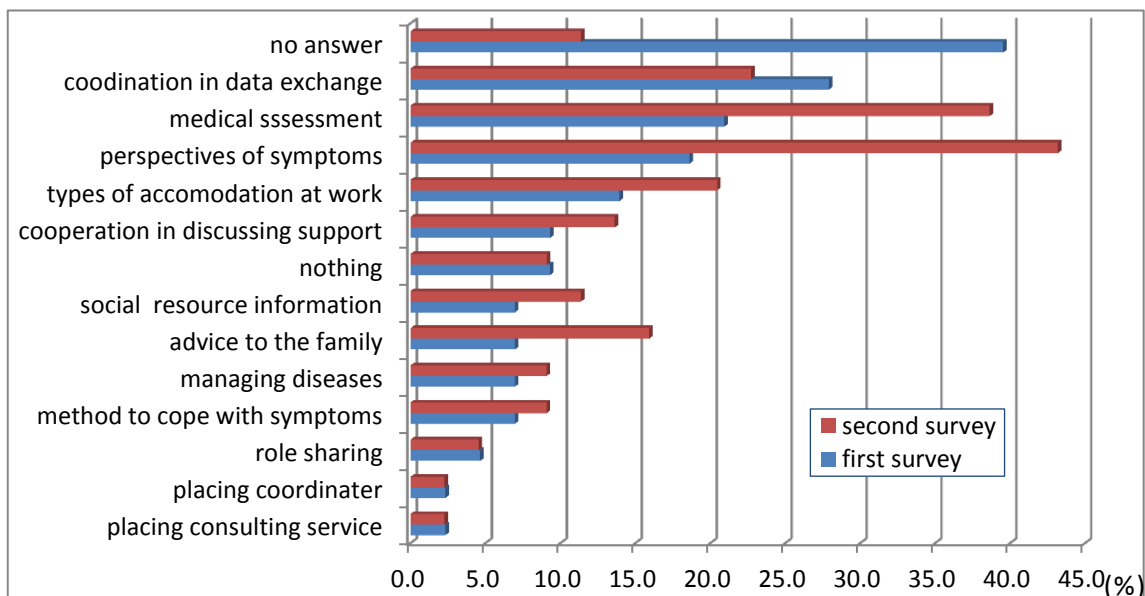


Figure 3 Request to medical facilities

4. The question asking what kind of support local center could (should) provide had 30% of no answer in both surveys. It may suggest that the counselors are still exploring the best way to support persons with EOD to maintain employment. Increasing needs in the second survey for educating society, an understanding of facilities, coordinating with medical institutions and welfare offices and developing life support system reflects the idea that maintaining employment for persons with EOD may depend on how much people understand. High number of “soft landing” answers in both surveys reflects the idea that employment support should turn into life support according to stages of symptoms.

(3) Medical Specialist survey

A survey of medical personnel who give an early treatment to persons with EOD was conducted and some cases of job maintenance and opinions of medical specialists were collected.

Target respondents were 460 medical specialists (members of Japanese Psychogeriatric Society,) who were assumed to have clinical experience in EOD .

45 specialists provided answers (which makes the response rate 9.8%) and 108 cases are collected. 77 of this 108 cases were EOD patients under the age of 65, who was younger than 65 when their symptoms emerged and received salary under employment at the time of the survey (September 1, 2011). These 77 cases were target for the analyzation in this study.

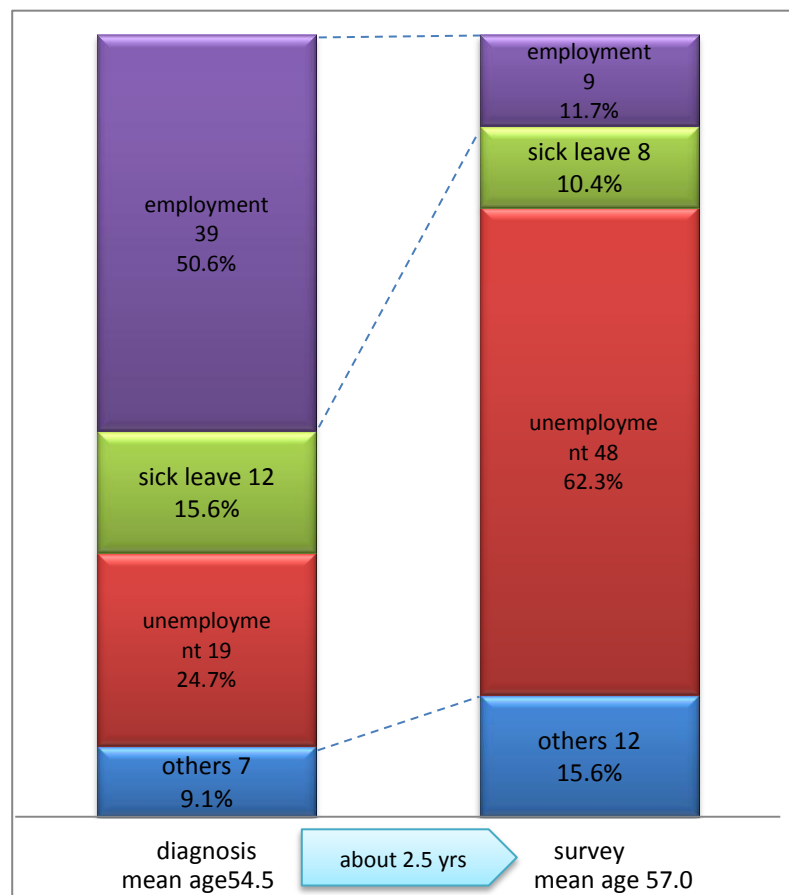


Figure 4 Transition in employment statuses

1. Alzheimer disease (57.1%) and frontotemporal lobar degeneration (27.3%) account for nearly 85% of root causes of the 77 cases which indicates a high percentage of progressive degenerative diseases. 39 patients (50.6%), whose average age was 54.5, were still in employment at the time of diagnosis. However, this number greatly decreased to 9 (11.7%) at the time of survey, with their average age 57.0.
2. Medical specialists' opinion provided good examples of addressing problems at the early stage, such

as: bosses visited medical institutions with patients, bosses and coworkers showed an understanding of the issue, family physicians, family, and bosses addressed to the issue in coordination, and occupational physicians provided appropriate directions. This suggests that people concerned in companies made practical efforts to support the employees’ work. Because most offices had never had patients who left their job before, their comments include; they had come to be too late address problems. They pointed out understanding of EOD patients and addressing a financial problem was important. EOD patients often face financial difficulty as maintaining employment is not easy for them. Medical specialists do not have enough chances to talk about this problem with relevant companies and are not certain yet how they should deal with it.

(4) Company survey

Since support for relevant personnel and companies for maintaining employment of persons with EOD seemed essential, company survey was conducted to correct cases of maintaining employment, current effort at companies, opinions about possibilities of effort ideas and requests for support.

The first survey targeted major domestic companies and had questions such as the presence of persons with EOD, their employment status, and their will for the response to the detailed survey. The second survey consisted of 2 types of questions: if answered they had any persons with EOD in the first survey, we asked what kind of assistance they provided; if they did not have persons with EOD or the answer was unknown, we asked actual cases that persons with other disabilities returned to their work after sick leave.

a. The first survey

The questionnaire was mailed to human resource department at 3,100 major domestic listed companies. 964 companies provided answers, which makes the response rate 31.2%. 958 was effective answers and 35 of them (3.7%) had persons with EOD and 720 (75.2%) did not.203 of them (21.2%) had no answer. Out of 35 companies, 12 (34.3%) were employed, 15 (42.9%) were on sick leave, 8 (22.9%) were unemployed. There was no case with discharge.

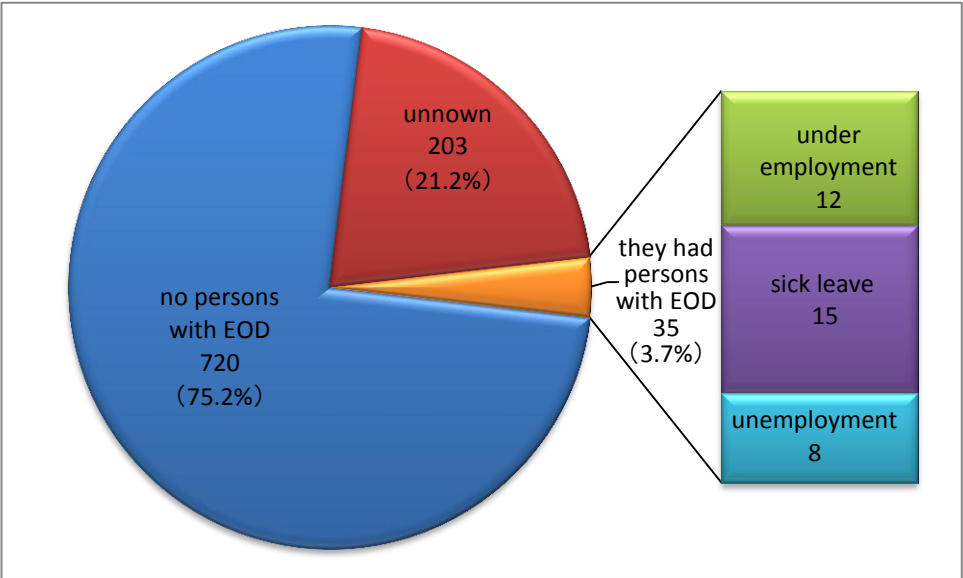


Figure 5 Employment statuses in the first facilities survey

b. the second survey

The questionnaire was mailed to 400 companies. 13 of them had persons with EOD, 303 did not, and 84 answered unknown.

1. Companies that had persons with EOD

9 companies provided practical answers, which makes response rate 69.2%. The mean number of employees was 2,121. All 9 companies had only 1 person with EOD each and thus the analysis was carried out on these 9 persons with EOD, 3 of them were employed, 1 was on sick leave and 5 were unemployed. After diagnosis, 6 of 22 answers (multiple answers) made persons with EOD consult with medical institutions and 5 made them report to family members.

2. Centers that they had no persons with EOD or answers unknown

The number of facilities that they had no patients is 303 and answers unknown are 84, which totals 387. The questionnaire about support to returning to work for persons with other disabilities was mailed to this 387 facilities and 194 of them gave answers, which makes response rate 50.1%. 120 facilities had cases of returning to work and analyzation is shown below:

- The mean number of employees was 2001.1 at 120 companies. 24 of them (20.0%) were manufacturers, 18 (15.0%) were retailers and 17 (14.2%) were service and other business.
- Total 1,082 clients with other disabilities returned to their work. 582 of them (53.8%) had mental disease as their root cause and 500 (46.2%) had other kind of diseases. 345 of them had some kinds of depression, including depressed mood, clinical depression, depression state which account for 59.3% of mental disorder and 31.9% of cases returning to work.
- Actual reactions that the employees at companies took when they noticed changes in patients' mental and physical health were described in 436 answers, including: 91 of them (20.9%) discussed what kind of job the patient could take, 86 of them (19.7%) set up a meeting with specialists, and only 28 (6.4%) reported to their family. At more than half the companies where they had persons with EOD, staff members reported their family. This means that they provide a support for persons with EOD in cooperation with persons around the patients.
- About having persons with EOD in future, 64 of them (53.3%) assumed high possibility in maintaining employment of the patients, persons with EOD, 37 (30.8%) low possibility, 19 (15.8%) gave no answer. Reasons of high possibility include: maintaining employment is an obligation (26.6%) and they are planning to explore best options in accordance with their skills (21.9%). Reasons of low possibility include: maintaining employment is difficult considering types of jobs that they are doing (40.5%) and there is no tasks that they can do (24.3%).

(5) Employment status survey

Problems on assistance of 3 persons with EOD A, B and C who were in the survey were estimated by a hearing survey, which was conducted to patients themselves, their family members, relevant companies,

and personnel in charge of assistance.

Common factor among these 3 persons with EOD was that their spouses (wives) were familiar with the disease, noticed their symptoms at the early stage and shared information actively with relevant companies and personnel in charge of assistance.

Patient A made use of local employment and life support centers for persons with disabilities. Personnel in charge of assistance understood his situation and provided assistance such as visiting vocational rehabilitation centers for persons with disabilities and career information session, and going to their work place with him on the first day of his employment. In patient B's case, his boss and relevant persons were familiar with his work condition and made changes in his job and transformation depending on the situation, which enabled him to maintain employment. Patient C found a job at office where his wife works. His wife became his supervisor and gave directions at work with his conditions in mind.

Common factor among these 3 patients would be high physical ability, which enables them to commute themselves. If the symptoms progress, disorientation or decrease in physical functions disturb their commute and job performance. 3 patients were able to maintain employment because they were still in a stage which accommodations and assistances still had their effects. Their wives noticed the onset of EOD at the early stage, which made early support possible. This reflects knowledge and an understanding of the disease, so educating people about EOD would be essential.

(6) Conclusion

If root causes are non-progressive dementia such as cerebrovascular disease, traumatic brain injury, and encephalitis, applying method that is used for persons with higher brain dysfunction should make supports possible. If root causes are progressive dementia such as Alzheimer's disease and frontotemporal lobar degeneration, discovering symptoms early, consulting with specialized medical institution early and making use of employment support centers early enable patients to maintain employment for a while. Educational activities for companies, creating an understanding between companies and the family, and building supporting networks for patients to make use of employment supporting facilities are essential.

As specialists point out symptoms of EOD progress slowly if patients continue to work, attempting to maintain their employment with best possible assistance is critical. If symptoms progress and patients have difficulty maintaining employment, they need assistance to participate in society including working in social welfare scheme.

Support focused on EOD started 10 years ago. During past 10 years, public assistances have developed, support associations have been established and overall support system for EOD patients have been advancing. The development of total support network covering from employment to community life is being expected.