Investigation into the factors relating to the intention of workplaces to retain employees diagnosed with Young Onset Dementia.

Shizuko Omote*, Satomi Ikeuchi¹**, Tomoko Ishiwata², Rie Okamoto³, Yutaro Takahashi³, Yoshiko Koyama⁴

Abstract

Objective: The purpose of the present study was to clarify and identify the factors related to the intentions of workplaces to retain employees diagnosed with young onset dementia (YOD).

Methods: An anonymous self-administrated questionnaire survey was sent by mail to all 1,293 workplaces with 50 or more employees in A Prefecture. In addition to providing demographic data for the workplace, employers were asked to answer freely about their intention of continuing to employ employees in the case of their being diagnosed with young onset dementia. Intention regarding continuous employment was analyzed qualitatively using encoded descriptive data.

Results: Responses were received from 357 workplaces, and 292 valid responses were used for analysis. Workplaces intended to consider continuing employment for employees diagnosed with young onset dementia, with a view to offering continued non-discriminatory employment and staying legally compliant. In addition, while considering offering job accommodations and keeping their employees safe according to their abilities, there was also an intention on the part of the business establishment to demand meeting their obligations to customers such as assuring customer safety and satisfaction. In addition, they stated the need for a offering systematic support for workplace personnel and company departments, and wrote that they would consult with their attending physician / industrial physician to identifying dementia-related symptoms and to make decisions with regard to employment continuation and placement.

Discussion: Workplaces should understand YOD at an Young stage. It is necessary to provide training and information to businesses so that they can consider continuation of employment.

KEY WORDS
young onset dementia, workplace intention, continuing employment, corporate social responsibility, support system

Introduction

Dementia is a general term for diseases and conditions characterized by a decline in cognitive functions such as memory, language, and problem-solving¹. Young-onset dementia (YOD) is defined as dementia that occurs before the age of 65². In Japan,
the number of individuals diagnosed with YOD between the ages of 20 and 64 has been estimated to be 37,800 (0.05% of the population between 18 and 64), and the mean age of onset is 51.3±9.8 years\(^3\). Because YOD occurs in the prime of a person's working life, it has a significant impact on their ability to continue in their occupation and on their working life\(^4\). Only about 10% of employees diagnosed with YOD during their working lives, including those on leave, stay employed\(^5\), due to a general lack of understanding among Japanese companies regarding YOD\(^6\).

A survey by the authors regarding the possibility of continued employment for employees living with YOD found that workplaces were ill-prepared to cope\(^7\). Only 2.7% of the workplaces responding to the survey indicated that they had experience with employees developing YOD. In addition, only around 5% provided internal training on the subject for both managers and staff. In a study of Alzheimer's disease or related disorders (ADRD) in the workplace, Cox and Pardasani (2013) found that even when workplaces had a policy in place for employees who were caregivers of a person with dementia, very few (only 2%) had a policy for employees that had symptoms of dementia themselves\(^8\). Given that workplaces place a priority on addressing employment issues for which a legal framework is in place, such as mental health, insufficient effort has been made to address employee dementia.

In 2019, Japan adopted requirements to address YOD as one of the pillars of the “New Orange Plan,” the government’s comprehensive strategy to promote measures to address dementia\(^9\). Although the plan states that “A guide to support services for young-onset dementia should be distributed to people diagnosed with YOD and their families via medical providers and municipal offices,” so that people living with YOD can begin obtaining the appropriate support in the early stages of the disease, it remains unclear what specific support is available to ordinary workers or how workplaces currently support them.

Three studies have been conducted regarding the employment situation for employees living with YOD: a study of physicians certified in occupational medicine\(^10\), a study of workplaces to identify cases of continued employment\(^11\), and a fact-finding survey of workplaces in one Japanese prefecture\(^12\). Although these studies reported on subjects such as how workplaces responded when an employee was diagnosed with YOD and employee reasons for resigning, they did not report on what workplaces thought about continued employment for these employees. Research conducted by the authors into the perceptions relating to the retention of employees with YOD found that 48.3% of workplaces stated that retention was a high possibility, and this possibility was related to the number of employees and their experience employing people with disabilities\(^7\).

However, when considering employment continuity, it is unknown why workplaces choose specific responses. As few workplaces have experience of YOD, there is a need to identify factors, such as the nature of workplace intentions relating to continued YOD employment, to investigate the support for retaining people living with YOD.

The study’s results should enable further, more detailed, investigation into issues and remedial measures that can be taken to support continued employment for these employees, which should help in the development of systems to support them. Thus, the purpose of the current research is to identify the factors relating to workplace intentions regarding continued employment for YOD-diagnosed employees, such as how workplaces view employment and continuation.

**Methods**

1. **Sampling and survey methodologies**

The current research utilizes some of the data collected in the research, ‘Workplace preparedness and recognition of the continued employment of employees with early onset dementia’\(^1\), conducted in Prefecture A. Here, we analyzed the free text format of participant data of workplace intentions regarding employment support for workers with YOD. Prefecture A is located in the Chubu Region of Japan and is a regional city wedged between the ocean and the mountains. The method of the survey data collection is outlined below.

An anonymous survey was conducted by 2017, self-administered, with the cooperation of Prefecture A’s occupational health promotion center, a letter requesting participation in the study, and a survey questionnaire were sent to owners of all 1,293 businesses in the view with 50 or more employees. We asked the owners to
have the survey completed by someone familiar with employment support services at the company.

2. Survey items

Survey demographic information included respondent’s occupation, workplace industry type, number of employees, and whether the workplace employed people with disabilities. In addition, there was an open-ended question about continued employment for employees diagnosed with YOD.

The question was an open-ended question as follows: “Please tell us your thoughts about the continued employment of YOD diagnosed employees.” Selections for occupation type were categorized as “white collar” (education/research, finance, commerce, public health & hygiene) or “blue-collar” (transportation, cargo handling, construction, fisheries, agriculture, manufacturing, cleaning/meatpacking, hospitality/entertainment, communications, other). Selection categories for the number of employees were fewer than 100, 100-299, or 300 or more.

3. Analysis

Qualitative description was used for the analysis. The current research utilized a qualitative analysis to analyze intention factors to retain the focus on the described context. In general, apart from interviews, qualitative research employs literature and free text format responses from questionnaires. In addition, given that free-text format responses were gathered from more than 80% of respondent workplaces, it is thought that the data can be considered to reflect the intent of the respondents reliably, and the analysis is also considered valid. Study data consisted of the open-ended responses copied into Excel. To understand the contexts for the workplaces’ views regarding providing continued employment to employees with YOD, comments in the data were grouped by meaning and qualitatively and descriptively analyzed. Focusing on considerations contributing to workplace intentions about continued employment, codes were assigned to similar comments, and then subcategories and categories of codes were identified. In addition, the total numbers of comments used for the codes and each subcategory and category were tabulated. Work related to data categorization continued until consensus was reached among the researchers. Furthermore, two experts in YOD research iteratively reviewed the overall results of the categorization process to ensure validity.

4. Ethical considerations

This study was conducted with the approval of the Kanazawa University Medical Research Ethics Review Committee (approval no. 749-1). Care was taken to be considerate of subjects’ rights in the use of YOD-related terminology in the study’s documentation.

Results

1. Survey response

Of the 1,293 surveys mailed, 357 were returned (a response rate of 27.6%). Of these, 292 workplaces answered the open-ended question (a valid response rate of 22.6%).

2. Respondent characteristics

A total of 156 (53.4%) of respondents belonged to the human resources department, and 106 (36.3%) were health officers, which accounted for about 90% of the data. The remaining respondents included 8 (2.8%), who were occupational nurses, and 22 (7.5%) who were the general affairs or facility manager or another manager. Of the respondents, 184 (63.0%) had white-collar occupations and 108 (37.0%) had blue occupations. As to industry type, in order of frequency, 94 (32.2%) of the businesses were in manufacturing, followed by 53 (18.2%) in public health & hygiene, and 31 (10.6%) in commerce. Of all the companies, 159 (54.5%) had less than 100 employees, 129 (44.2%) had

Table 1: Respondent characteristics

<table>
<thead>
<tr>
<th>Affiliation of respondent</th>
<th>N=292</th>
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<tbody>
<tr>
<td>human resources department</td>
<td>156</td>
</tr>
<tr>
<td>health officers</td>
<td>106</td>
</tr>
<tr>
<td>occupational nurse</td>
<td>8</td>
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<tr>
<td>others</td>
<td>22</td>
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<td>manufacturing</td>
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<td>public health &amp; hygiene</td>
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<td>commerce</td>
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<td>Transportation Industry</td>
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<td>Construction industry</td>
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<td>Hospitality and Entertainment Industry</td>
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<td>Cleaning / and Livestock Industries</td>
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<td>Communication Industry</td>
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<td>Education and Research Industry</td>
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<td>Financial Services Industry</td>
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<td>Cargo Handling Industry</td>
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<td>Agricultural and Fishery Industries</td>
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<tr>
<td>Others</td>
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<tr>
<td>number of employees</td>
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<td>between 100-299</td>
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<td>no response</td>
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between 100–299, and 3 (1.0%) gave no response. Of all respondents, 192 (65.8%) were workplaces that employed people with disabilities (Table 1).

3. Factors relating to the intentions of workplace

Twenty subcategories and seven categories were identified from 60 codes related to workplace considerations related to intentions to continue employment for employees should they be diagnosed with YOD (Table 2). Except for industrial work experience, the identified subcategories were generally not biased by the number of employees or experience of employing people with disabilities. The seven categories and the number of comments in the data underlying each, in order, were: keeping their employees safe (48), meeting their obligations to customers (43), staying legally compliant (41), offering job accommodations (40), offering systematic support (33), identifying dementia-related symptoms (27), and offering continued non-discriminatory employment (26). Six respondents answered that, because it had never happened, they did not know what they would do.

In the explanations for each category that follows, the categories are highlighted in **bold italics**, the subcategories in **bold**, and comments from the data are in *italics*.

**Keeping their employees safe**

Workplaces indicated they had apprehensions about on-the-job accidents, saying that depending on the extent of the employee’s dementia, they may not be able to take responsibility for their safety and that working at job sites entails risk. The reason these particular workplaces were apprehensive about on-the-job accidents, was that they were in blue-collar industries, such as construction and manufacturing. In addition, out of safety considerations, they said they would monitor the employee’s condition by meeting regularly with them to assess changes in their health.

**Meeting their obligations to customers**

Workplaces said they thought that continued employment for employees developing YOD would be difficult, for reasons to do with prioritizing customer safety and responsibilities regarding client

<table>
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<th>Table 2: Factors relating to the intentions of workplaces to retain employees who are diagnosed with young onset dementia</th>
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<tbody>
<tr>
<td>Category</td>
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<tr>
<td>Keeping their employees safe</td>
</tr>
<tr>
<td>Monitoring the employee’s condition</td>
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<tr>
<td>Meeting their obligations to customers</td>
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### Offering systemic support

- **Offering systemic support (48)**

*Offering systemic support (48), meeting their obligations to customers (43), staying legally compliant (41), offering job accommodations (40), offering systematic support (33), identifying dementia-related symptoms (27), and offering continued non-discriminatory employment (26).*
satisfaction and profits. For example, depending on the characteristics of the business, their job was to deal with customers, there could be food safety problems, or a mistake could cause life-threatening problems. In addition, in general, workplaces thought that achieving high-maintaining productivity and operating efficiency by getting a limited number of staff to produce as much as possible with speed and proficiency, was part of meeting their obligations to customers.

**Staying legally compliant**

The workplaces thought that firing an employee with YOD if the employer determined they could not tolerate the work would be a decision based on employment regulations and that, based on their responsibility toward hires, once a company hired someone, the company was responsible for providing that person with ongoing employment. In addition, they thought that people with disabilities and with YOD need a wide variety of opportunities for employment, and awareness regarding the hiring of people with disabilities made it difficult to imagine terminating a person’s employment contract for illness-related reasons, such as having a disability. Both points indicated that compliance with labor laws influenced workplace intentions regarding providing continued employment.

**Offering job accommodations**

Workplaces thought, if an employee was diagnosed with YOD, they would lighten their workload by redeploying them into jobs where the work was simpler, for example by shifting them from customer service to office work; and, depending on the person’s symptoms, adjust the employee’s job functions to match their abilities. At the same time, they thought about redeployment for safety concerns. For example, because worksites were dangerous, accommodations would be made by placing them in jobs judged appropriate for them.

**Offering systematic support**

Workplaces in small- and mid-sized companies indicated that greater sufficiency of human resources (support staff) would be essential for them to be able to support the continued employment of employees diagnosed with YOD because they employed the bare minimum number of employees needed. There was no extra capacity. Organizationally, a support system that extends beyond the department would be required, because the person’s department would not be able to cover the extra work if the person’s job functions were altered. The person would need to be transferred to a department that would be able to spread the functions the person was unable to perform over the entire department. Some workplaces also said that, because the progression of YOD symptoms differs by person, they would seek advice using outside support organizations and systems.

**Identifying dementia-related symptoms**

Workplaces indicated that, regarding the continued employment of an employee with YOD, they would consult with the employee’s primary care doctor and with an occupational physician. For example, there were comments such as It would be essential to obtain information from a specialist regarding the person’s ability to work and their suitability for the workplace. Respondents thought that if the employee’s physician judged them as employable, then they would look into accommodations, such as a change in job functions or a transfer, at which time they would work with an occupational physician. In addition, they would hold investigative work reviews involving the employee and their family. They indicated that they would consider continuing to employ the person after identifying their dementia-related symptoms. However, they also imagined the consideration of the possibility of retirement if it became unavoidable because the employee’s inability to perform their job functions made it too difficult for them to continue working.

**Offering continued non-discriminatory employment**

A factor influencing their intentions should an employee be diagnosed with YOD, was that workplaces had a reliance on their employees, with every employee being important, so they did not want to make an employee who had contributed to the company over many years retired. Workplaces thought they would respect the person’s wishes: that is, if the person wanted to work, they would respect that and try to do what they could to make that possible. In addition, they
showed an understanding that there were different ways employees could work and that they wanted to avoid discriminating against employees with YOD. The example was raised of a company having changed how it responded to employee maladjustment disorders and to employees developing cancer. YOD was viewed as a similar issue related to mental health and work-life balance. In relation to understanding that there were different ways employees could work and staying legally compliant, the subcategory employing people with disabilities included workplaces that actually employed people with disabilities.

Discussion

In this study, we investigated the factors influencing workplace intentions regarding the provision of continued employment to employees diagnosed with YOD. Workplace intentions regarding the continued employment of YOD diagnosed employees are considered to have been identified by the current research. The study identified and described the context behind three factors related to company responsibilities to society (keeping employees safe, meeting their obligations to customers, and staying legally compliant) and four factors related to company responsibilities to the employee (offering continued discriminatory employment, offering job accommodations, the offering of systematic support, and identifying dementia-related symptoms).

1. Factors related to company responsibilities to society

The categories based on the largest numbers of comments in the underlying data related to company responsibilities to society: keeping employees safe, fulfilling duties to customers, and staying legally compliant. These categories identified the most important factors influencing workplace intentions regarding the continued employment of a person diagnosed with YOD.

Companies stay in business by focusing on regular customers that generate revenue and are legal entities established for profit-making. However, when they put their obligations to their customers above all else, it can result in social problems such as employees dying from overwork, which has been a problem in Japan since the latter half of the 1980s. As a result of many reports on precedent-setting court cases against companies for violating their obligation to provide for the safety of their employees, the Labor Contract Act became law in 2008. This law stipulates the provisions for changing the content of an employment contract related to safety considerations for employees and employment regulations. The fact that the workplaces in this study, as well, were concerned about keeping their employees safe and staying legally compliant would have been due to this law. The reason that apprehensions about on-the-job accidents were raised as a concern related to keeping their employees safe could have been that around half of the workplaces responding to the survey were in the manufacturing or healthcare industries.

In addition, these workplaces belonged to for-profit companies and, therefore, would have considered customer service a very important part of their business. Therefore, meeting their obligations to customers would have been an important factor when considering whether to continue the employment of an employee diagnosed with YOD and when making assumptions about what the person’s dementia-related symptoms might be and whether they could perform their jobs.

Regarding the subcategory of awareness about hiring people with disabilities, the Act for Promotion of Employment of Persons with Disabilities mandates that employers hire, at minimum, a set percentage of people with disabilities among the people they usually hire. Workplaces bear responsibility for providing support for sick employees so they can continue working as well as job support for disabled people and for people who develop a disability mid-life to ensure they will be employed. The subcategories understanding there were different ways employees could work, and awareness about hiring people with disabilities were identified in the context of companies having accepted this responsibility. In addition, more than 60% of the workplaces responding to this survey indicated they employed people with disabilities. Only 39.6% of small- and mid-sized companies and 66% of large companies achieved the legally mandated percentages for hiring employees with disabilities. Given that workplaces with less than 100 employees accounted for half of
Investigation into the factors relating to the intention of workplaces to retain employees diagnosed with Young Onset Dementia.

The respondents to this survey, it is possible that the workplaces who responded tended to be more aware of this issue than average.

2. Factors related to company responsibilities to the employee

YOD develops in people in the prime of their working lives, meaning that leaving their job impacts their families in various ways. According to Ohman et al. (2001), while YOD makes it challenging to continue working and has a significant impact on the person’s life overall, with the right understanding and support from their workplace, they can keep working. This has a wide range of benefits that surpasses the monetary compensation the person with YOD receives. If the employer is not sufficiently aware of the employee’s abilities and of the support services that can be used, promoting continued employment for them may not be considered. Currently, in Japan, there are already many measures in place to address problems. For example, measures are already in place to help people with disabilities with employment and to promote mental health. As a result, it is difficult for an employer to have an adequate understanding of all the health-related support services available, including for YOD. For progress to be made in offering systematic support and offering job accommodations for employees with YOD, a legal framework needs to be developed, and employers need to be given examples of how to address this issue. On the other hand, in one study, employers described the challenge they faced to protect the needs of the business when trying to balance support for an employee’s dementia while running a successful business, because “maintaining the employee within the workforce had associated costs.” For mid- and small-sized companies, setting up an internal support system may be difficult. As a result, they would need to enlist help from support organizations and support systems, such as the support agencies that provide job coaching for people with disabilities in Japan, to help these employees improve their work performance.

Because YOD is a progressive disease, it is difficult for people living with it to continue working under the same conditions they were working before onset. However, studies have shown that they can keep working with changes in job content and form of employment (e.g., part-time vs. full-time). Respondents to this study’s survey also reported that they would revise a person’s job according to their symptoms and individual abilities. Therefore, respondents indicated they would identify dementia-related symptoms, by consulting with the employee’s doctor or with an occupational physician and having investigative work reviews involving the employee and their family. According to Chaplin & Davidson (2016), “the most important thing is to encourage the employer to engage in a dialogue which takes into account the employee’s wishes when considering future plans and utilization of residual skills in the workplace.” If it were possible to create this kind of environment, when a person was diagnosed with dementia, they could consider continuing work rather than thinking they had to retire immediately. According to Fujimoto (2015), people who develop YOD are still capable of working; however, until that person retires, the skills of an occupational physician are needed to determine appropriate work. In other words, an occupational physician should play a central role in creating the needed support system.

Workplaces indicated that, even if an employee was diagnosed with YOD, they would want to offer continued non-discriminatory employment, and felt they would like the employee to work as long as possible. There was even a workplace that responded that work might rehabilitate them. However, while continuing to work can keep the brain active, for some people, it is too stressful. Continued employment is not suitable for everyone who develops YOD. Another participant in this study stated, helping the employee adapt to leaving their job by redeploying them and evaluating their performance is also important, rather than focusing only on continued employment.

3. Limitations and further topics

One limitation of this study was the low response rate, which could mean that only workplaces that were very interested in YOD responded. Another was that it is impossible to know what kind of condition the respondents imagined YOD to be when they wrote their responses. In addition, the survey only asked what the respondents thought their workplace would do for an employee diagnosed with YOD, not what they
actually did, which could be different. In the future, the authors would like to conduct interviews in workplaces regarding their experiences with YOD employees to further explore issues and the support these employees need to keep working.

**Conclusion**

Qualitative description was used to explore the factors influencing workplaces’ intentions regarding continued employment for employees receiving a diagnosis of YOD. The workplaces surveyed stated that although they would consider continued employment for such employees, they would keep mind the importance of keeping their employees safe and staying legally compliant. However, they would also take into consideration that, as a business, they needed to meet their obligations to their customers, for example, regarding customer safety and satisfaction. In order to consider offering job accommodations according to the employee’s abilities, they would try to offer continued non-discriminatory employment by consulting with the employee’s doctor and an occupational physician to identify the employee’s dementia-related symptoms and offer the systematic support of other staff and departments. To this end, workplaces need to be provided with the training and information on YOD that will enable them to consider continued employment for these employees.

We would like to express our heartfelt thanks to all the people at the workplaces that responded to our survey for their kind cooperation. We would like to thank Editage (www.editage.com) for English language editing.

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The authors have no conflicts of interest to declare.

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従業員が若年認知症と診断された場合の就労継続に対する事業所の意向

表 志津子*1, 池内 里美*2, 石渡 丈子*2, 岡本 理恵*3, 髙橋 裕太朗*3, 小山 善子*4

要  旨
目的：従業員が若年認知症と診断された場合の就労継続の事業所の意向に係わる要因を明らかにすることを目的とした。
対象と方法：A県内の労働者50人以上のすべての1,293事業所に郵送法による無記名自記式質問紙調査を実施した。調査項目は企業の基本属性のほかに、従業員が若年性認知症と診断された場合の就労継続への意向について、自由記述で回答を求めた。就労継続に関する意向は記述データをコード化し質的記述的に分析した。
結果：357の事業所から回答があり、うち292事業所から就労継続への意向について回答があった。従業員が若年性認知症と診断された場合の就労継続への事業所の意向について、7つのカテゴリが抽出された。事業所は、若年性認知症と診断された従業員に対して“安全配慮”，“法令の遵守”を念頭に雇用の継続を検討するが、事業所として顧客の安全や満足などの“顧客責任”を考える意向があった。また、能力に合わせた“仕事の調整”を考えるためには、事業所の人員や部署などの“サポート体制”，主治医・産業医と相談し“認知症状の見極め”をして、“差別のない雇用”の継続を検討する意向があることが見いだされた。
考察：事業所が若年性認知症について理解し、就労の継続を検討できるように、事業所を対象とした研修や情報提供を行う必要があると考える。