

The process of establishing support for Learning disabilities with symptoms of dementia who reside in support facilities

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INTRODUCTION

•In recent years, the population of people with learning disabilities or Down syndrome has been aging.

•The aging of the population has brought about a variety of support issues. For example, 82% of the facilities reported that the aging of their users was a problem, yet 48% of the facilities reported that they had no programs for the aging population¹. And the problems are caused by aging, the most common response, at 84%, was "assistance and care in daily activities," indicating that there is confusion about the changes that accompany aging, or in other words, that it is difficult to respond to changes in the person's past state of mind. What are the possible changes that may occur as a result of aging? There are two major types: the first is the decline in ADLs, and the second is dementia. The first is simply a sense of bewilderment at the increase in physical assistance that did not exist before, and the second is the difficulty in dealing with core symptoms and Behavioral and Psychological Symptoms in Dementia (BPSD) due to dementia that did not exist before.

•In Japan, however, appropriate support for people with intellectual disabilities or Down syndrome who develop dementia has not been established.

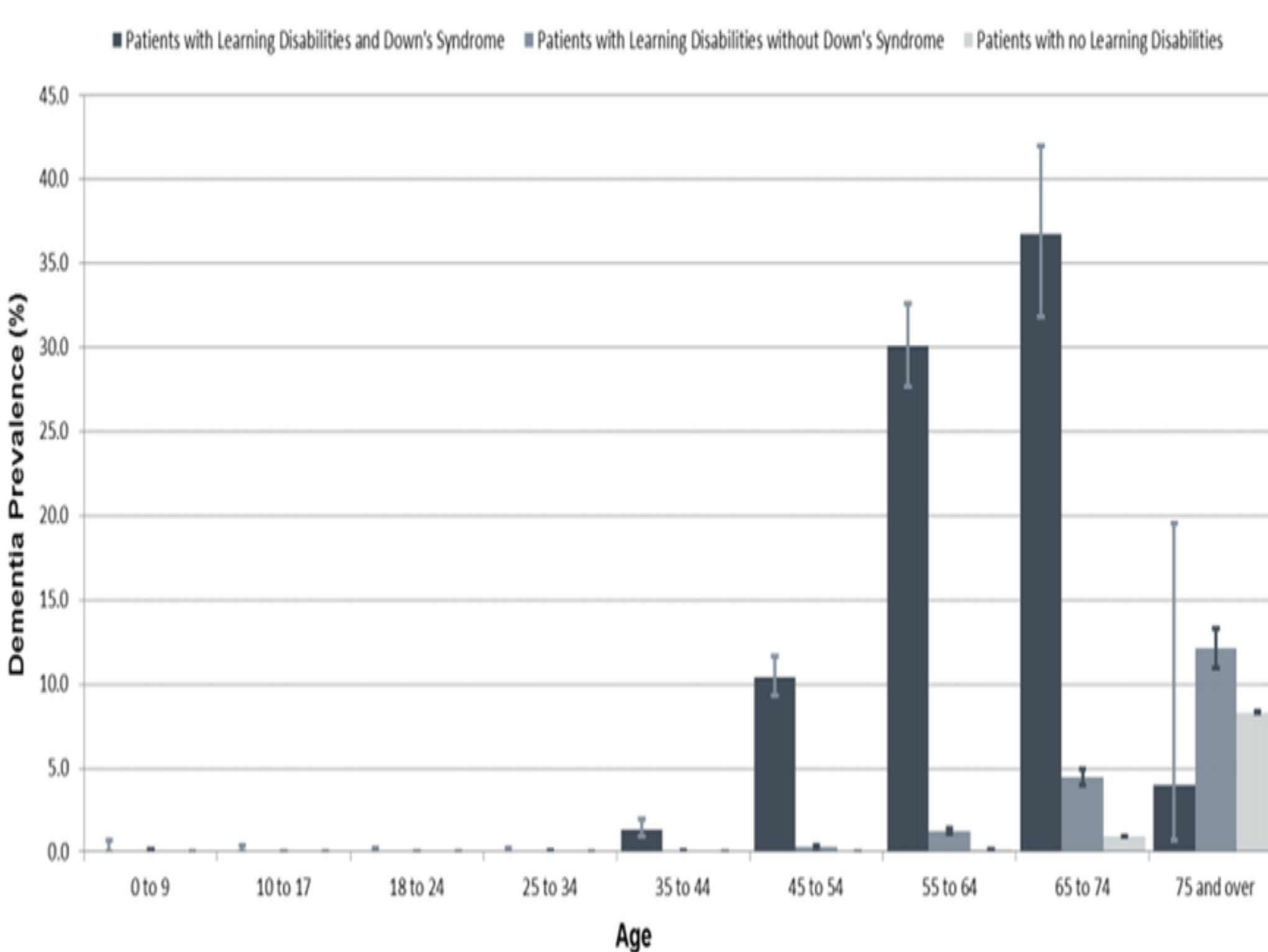


Figure 1. Dementia prevalence (per cent) by age and co-morbidity of Down's syndrome and/or learning disabilities, England, 2014 to 2015²⁾

METHODS

•We interviewed 12 support staff at seven facilities who had developed ways to support people with learning disabilities who had symptoms of dementia in their facilities for people with disabilities.

•The duration of the interviews ranged from 60 to 120 minutes. The interviews were recorded with the consent of the research participants, and a verbatim transcript was made after the survey was completed. The survey period was from June to July 2016. Semi-structured interviews were conducted around these questions.

•The interview data was analyzed using the Modified Grounded Theory Approach ("M-GTA")³⁾

No	Sex	Years of experience	Facility Remarks
1	F	10y	Manager
2	F	23y	Senior Nurse
3	M	33y	Director
4	F	34y	Support section chief and service manager
5	M	30y	Chief inspector and service manager
6	M	25y	Director
7	M	12y	Deputy chief support staff
8	F	22y	Director
9	F	28y	Senior Manager
10	M	28y	Section chief
11	M	43y	Manager
12	M	32y	Consultation support specialist

RESULTS

In this interview survey, 11 core categories and 44 subcategories were extracted as a result of M-GTA analysis of the process of building support for people with learning disabilities who have dementia symptoms at the support facility.

•Storyline.

While no dementia symptoms had ever appeared in the residents before, and the support staff did not have information that dementia symptoms appeared in persons with learning disabilities, the residents showed behaviors of dementia symptoms that had never been seen before, and their awareness of these behaviors led them to suspect **(1) [people with learning disabilities suffer from dementia]**. Then, based on the doctor's diagnosis and the collection of information on dementia in people with learning disabilities, the support staff became **(2) [convinced that the person with learning disabilities had dementia]**.

However, in the meantime, new symptoms of dementia appeared and amplified, and accompanying these symptoms, the participant experienced **(3) [experiences that had not been seen in the past]**, and through the support difficulties that arose from these experiences, the patient lost confidence and **(4) [confusion in support]** began to occur. In the process of trying to cope with the situation, they experienced that **(5) [they are forced to change from the support for people with learning disabilities that has been established up to now]**. In other words, they are forced to change the support method or shift the value of support. On the other hand, **(6) [support for QOL improvement that is common to those without dementia symptoms and those with dementia symptoms is found]**, and **(7) [attempts to promote adaptation of support" are made for those with dementia symptoms through a process of trial and error]**. However, it is not enough to address **(8) [issues arising from unestablished support]**, and **(9) [efforts to improve support for people with dementia symptoms]** were planned and implemented in order to take measures to address these issues.

In addition, through trial and error in direct support for residents in facilities, support issues were identified and sorted out not only from the direct support itself, but also from the lack of systems **(10) [through experience in support practice and information collection]**. The results of this study showed that the following issues were also identified and sorted out through the experience of support practice and the collection of information. Through these experiences, they also thought about **(11) [Suitable living environment]** for learning disabilities with dementia-like symptoms.

CONCLUSIONS

1. When dealing with dementia symptoms for the first time, support staffs may be confused and bewildered, which may lead to loss of confidence in support, but attempts to promote adaptation and support measures are found through support.
2. When supporting residents with dementia symptoms in support facilities for people with disabilities, it may be difficult to change the value of support from conventional directive support to supportive support.
3. The challenges in providing support to facility residents with dementia symptoms may arise from the insufficient accumulation of knowledge about cases and other factors.
4. There are issues arising from the lack of systems in place to support people with dementia symptoms in support facilities, which may be due to the fact that support for people with dementia symptoms in support facilities for residents with disabilities is not expected to be provided.

REFERENCES

- 1) Japan Association for the Welfare of the Mentally Retarded (2014), "Report on the 2012 National Survey of Institutions and Businesses for Children with Mental Disabilities."
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