



Original Article

Caregivers' roles in preventing patients with severe Alzheimer's disease from becoming distracted during mealtimes: two case reports

KETU RI, MA¹⁾, TERUO YOKOI, RPT, PhD^{1)*}, YAYOI MIYOSHI, RN, PhD¹⁾, HIROYUKI WATANABE, PhD²⁾, TOSHIHIDE FUKUDA, PhD¹⁾

¹⁾ Faculty of Social Welfare, University of Kochi: 2751-1 Ike, Kochi-city, Kochi 781-8515, Japan

²⁾ Faculty of Nutrition, University of Kochi, Japan

Abstract. [Purpose] The purpose of this study was to identify the roles of caregivers in preventing patients with severe Alzheimer's disease with loss of language skills from becoming distracted while eating their meals. [Participants and Methods] The study was conducted on two residents of a nursing home with severe Alzheimer's disease who had lost their language skills. In this study, by comparing the scenes in which the two participants were distracted and not distracted from eating, we analyzed the factors associated with patients with severe Alzheimer's disease who had lost their language skills becoming distracted and factors that prevented them from becoming distracted from eating at mealtimes and considered the roles of caregivers. [Results] The participants became distracted from eating where they were in a lively environment. On the other hand, they were not distracted when they were made to sit and eat in quiet environments. [Conclusion] Patients with severe Alzheimer's disease who have lost their language skills cannot filter out a range of other information around them and focus on the information necessary to oneself. The role of caregivers is to serve as filters for patients with severe Alzheimer's disease who have lost their language skills and whose selective attention abilities have become impaired.

Key words: Alzheimer's disease, Care, Environment

(This article was submitted Apr. 28, 2021, and was accepted Jul. 1, 2021)

INTRODUCTION

Rehabilitation personnel have an important role to play in preventing individuals with chronic progressive diseases, such as Alzheimer's dementia, from requiring long-term care (hereinafter referred to as "care prevention"). According to the Ministry of Health, Labour and Welfare (MHLW) of Japan, "care prevention" is defined as "preventing (delaying) progression to a state that would necessitate long-term care for as long as possible, and preventing, as much as possible, further deterioration even in patients already in a state that necessitates long-term care, and also mitigating the state that necessitates long-term care¹⁾". In addition, reflecting on the measures adopted for care prevention in the past, the MHLW emphasizes the importance of a well-balanced approach for future care prevention, including not only measures to deal with the patient's mental and physical functions, but also measures to handle the environment surrounding the person²⁾. In Japan, the leading indication for long-term care is dementia at present, and not cerebrovascular disease³⁾. The most common cause of dementia is Alzheimer's disease (AD), which is a progressive disease. It is difficult to improve the mental and physical functions of patients with severe AD. However, by focusing on the environment surrounding severe AD patients, it is possible to improve the care needs of severe AD patients. Rehabilitation professionals not only need to have a thorough knowledge of the mental and physical conditions of the patients, but also a clear understanding of the influences of the environment on their patients. In this paper, we take up eating behavior, one of the activities of daily living (ADLs), as an example to present the influence

*Corresponding author. Teruo Yokoi (E-mail: joy_yokoi@yahoo.co.jp)

©2021 The Society of Physical Therapy Science. Published by IPEC Inc.



This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial No Derivatives (by-nc-nd) License. (CC-BY-NC-ND 4.0: <https://creativecommons.org/licenses/by-nc-nd/4.0/>)

of the environment on the behaviors of AD patients, and discuss the roles of caregivers.

As Alzheimer's disease (AD) progresses, eating behavior disorders occur, such as eating with the hands, grabbing others' food, inability to start eating, distraction from eating, taking a long time to eat, and having a poor appetite⁴⁻⁸). Eating is an activity that humans indulge in at least three times daily, or 4 times, if we were to also include a snack. Therefore, eating behavior disorders impose a huge burden of nursing care on the caregiver. AD patients themselves often become undernourished and lose weight, necessitating artificial nutrition and hydration (ANH)^{9, 10}). Therefore, eating behavior disorders are a serious problem for both caregivers and the AD patients themselves. Eating behavior disorders are also included in the diagnostic criteria for the behavioral variant of frontotemporal dementia (bvFTD)¹¹). There have been several reports of eating behavior disorders in patients with AD in comparison with those in patients with bvFTD^{4, 7}). Similarly, some studies have also reported eating behavior disorders in AD patients in comparison with those in patients with Lewy body dementia and cerebrovascular dementia^{5, 6}). Recently, the relationship between the severity of AD and eating behavior disorders was reported⁸). Thus, systematic research on eating behavior disorders in AD patients has only just begun. In addition, an empirical interventional study of changes in the patients' eating behaviors was reported by Melin & Götestam¹²) in 1981. However, the diagnostic reliability is low in light of the current diagnostic criteria, and the interventional method is inappropriate in the context of the current institutional environment. A search of the literature to the best of our ability revealed no reports of reliable empirical studies, even after this study.

Therefore, in order to identify appropriate caregiving methods for eating behavior disorders in patients with severe AD, we observed the mealtime behaviors of five participants with severe AD who had lost their language skills, and extracted the scenes associated with self-feeding and non-self-feeding behaviors. We found that the patients exhibited self-feeding behaviors when preparations were made for them to become ready to eat, by getting them to hold a spoon or chopsticks in the right hand and a bowl, plate, or cup in the left hand. However, when the participants' consciousness turned toward the voices and sounds of the people around, the crisscrossing movements of people, aprons, etc., they became distracted from the food and started a different activity. For example, when a staff member at the nurse station picked up a phone that rang and started talking, the participant became distracted and started mixing the rice porridge or soup in the bowl with the spoon. When two staff members near the participant began talking to each other, the participant was distracted from eating and started a disruptive speech with repeated hand clapping. When a resident sitting in front of the participant pulled the participant's apron, the participant became distracted, pulled off her apron, and wrapped the plate and spoon with the apron. When two residents walked by near the participant while hurriedly being guided to take their seats in the dining room by their caregivers, the participant became distracted and wrapped the pasta served as the day's dinner in the hand towel.

During our observations of mealtimes, we also happened to encounter scenes in which the two participants finished their meals without being distracted from eating. The purpose of this study was to identify the roles of caregivers in preventing severe AD patients with loss of language skills from becoming distracted while eating their meals, by analyzing the factors associated and not associated with such distraction.

PARTICIPANTS AND METHODS

As the study representative and a nursing care worker, the author recorded the daily behavior of 5 patients with severe AD who had lost their language skills. The author observed them twice a week from 9 am to 7 pm for 5 months, while assisting them with eating, dressing, oral hygiene, toileting, bathing, transfer, etc. All of them were residents of a nursing home, and their family members had given informed consent for their participation in this study. Two of the 5 patients could finish their meals without being distracted from eating in certain environments, and therefore were selected as the participants in this study. To study the eating behaviors of the participants, the author recorded eating scenes by focusing on self-feeding and non-self-feeding behaviors.

In patients with severe AD, the sense of self, which is the subject of consciousness and action, is steadily lost. Due to this, these patients repeat almost the same behaviors daily, especially when they are in a facility where their living space is limited. The same is true for their eating behavior. In the Results section, the author had described situations in which the participants were distracted and not distracted from eating. Situations in which the participants were distracted were the daily routine eating scenes, whereas the situations in which they were not distracted were encountered by chance by the author.

Their daily living conditions, ability to perform activities of daily living (ADLs), and language skills of two of the participants are shown in [Table 1](#).

The study plan was explained orally and in writing to the family members of the two study participants and the facility director, and their written consent was obtained. This study was conducted with the approval of the Research Ethics Committee of University of Kochi and also by the Social Welfare Research Ethics Committee of University of Kochi (Approval No.: 19-50).

RESULTS

The results are shown in [Tables 2 and 3](#).

[Figure 1](#) illustrates the floor plan of the dining room, seats of Ms. X, Ms. XX and other residents, as well as the movements of the caregivers, Ms. X and Ms. XX.

Table 1. Daily living condition, ability to perform ADLs and language skills of the participants

Ms. X Female in her early 90's
Severity of dementia: Clinical Dementia Rating 3 (severe)
Daily living condition and ADLs: She usually spent a large part of her days sitting on a chair in the dining room. Whenever she got up to start walking, her caregiver stopped her, because of the risk of fall. She walked to the toilet with assistance. The Bathel Index (ability to perform ADLs) was 0, and she was completely dependent on assistance for her ADLs.
Language skills: In response to being greeted with "Good morning", she usually replied "Yes, I'm okay (followed by laughter)". To the same greeting spoken in Chinese ("zao shang hao"), she often replied with something that did not make any sense, such as "(with laughter) Yes, thank you, go over there".
Ms. XX Female in her late 80's
Severity of dementia: Clinical Dementia Rating 3 (severe)
Daily living condition and ADLs: She often wandered, apparently aimlessly. While wandering, she touched other residents' heads, entered other residents' rooms, and pulled out bed sheets. When sitting on a chair in the dining room, she repeatedly tried to pick up the image of the light reflected on the shiny surface of the table with her right hand and transfer it to the palm of her left hand. She also often tried to scoop a scratch on the wood grain of the table with a spoon and putting it in a bowl. The Bathel Index (ability to perform ADLs) was 15; she was independent in respect of her mobility, but was completely dependent on assistance for her ADLs.
Language skills: She did not turn her head when she was called by name (XX) from behind. She never responded to her caregiver's request/instruction for any action, such as "Please brush your teeth".

Table 2. Situations in which Ms. X was distracted and not distracted from eating

Common situations that led to distraction from eating
Ms. X was sitting at her usual seat, together with residents A and B, at the same table. The caregiver placed a tray with a set of dishes in front of each of the three of them. Ms. X began to move the dishes from her tray to the front of the tray for Ms. A, who was sitting right next to Ms. X. Then, Ms. X began to move the dishes from the tray for Ms. A to near the center of the table. The caregiver stopped this activity and returned each dish to the respective trays. Thereafter, the caregiver was moving between residents A and B, while assisting them both with eating; she was calling out to resident A in a loud voice, as she was falling asleep. While assisting them, the caregiver also repeatedly cautioned Ms. X, asking her "not to take someone else's things". However, Ms. X did not stop her behavior of taking resident A's dishes. At this point, the author got Ms. X to hold a spoon with the right hand and a bowl in her left hand, and she started to eat with the spoon. After eating two or three spoonfuls, however, Ms. X again started the behavior of taking Resident A's dishes as before. Such a scene occurred three times. Then, the other three caregivers began in a hurry to guide the residents who had finished eating to their oral care routine and toileting activities, in a loud voice. Again at this time, the author tried to get Ms. X to hold the spoon and a plate in her hands, but she did not accept the spoon/plate, and instead began to repeatedly say something that did not make sense, while looking around.
Situations that did not lead to distraction from eating
Immediately before the start of dinner, Ms. X stood up from her usual seat and started to walk. The author, present at the scene, guided her across the aisle to a seat between residents C and D, for no particular purpose. After a while, a caregiver served meal sets on a tray to residents C, D, E and F, and also to Ms. X. After residents C, D, E and F started eating quietly, the author got Ms. X to hold a spoon in her right hand and she took a bowl with her left hand herself and ate quietly for about 15 minutes. When residents C and F, who finished eating earlier than Ms. X, started to stack their dishes, Ms. X also began to place her bowl, that still contained some rice, and side dishes on top of the stacked dishes. The caregiver stopped this behavior of Ms. X and Residents C and F, and offered a cup of tea to residents C and F. During that period, the caregiver took the dishes of residents C and F away from the table. At this time point, the author again got Ms. X to hold a spoon in her right hand and bowl in her left hand, and Ms. X resumed eating and finished all her food within about 5 minutes.

DISCUSSION

In lively environments, with loud voices and noises, and people crisscrossing around them, the two participants with severe AD who had lost their language skills often became distracted from eating and started some different activity. On the other hand, in quiet environments free of the loud voices and noises, and of people crisscrossing around them, they were able to finish their meals smoothly without becoming distracted from eating.

Normally, people can selectively pay attention to our names and self-related things, even in lively environments; this is called the cocktail party effect. Such ability for selective attention occurs as a result of the ability to filter out a range of other information around and focus on the information necessary to oneself (filter model)¹³. However, severe AD patients who have lost their language skills cannot filter out a range of other information around them by focusing on the information necessary to themselves. Linguistically, this is considered to result from the loss of their sense of self, which is what enables

Table 3. Situations in which Ms. XX was distracted and not distracted from eating

Common situations that led to distraction from eating
At lunch time, Ms. XX was sitting in her usual seat, at the same table as residents G and H. The caregiver placed a tray holding a set of dishes in front of each of them (residents G and H and Ms. XX). Ms. XX grabbed the food on the tray with her hands. The author stopped her behavior, and got her to hold chopsticks in her right hand and a small bowl in her left hand. After this, Ms. XX dexterously picked up the food from the small bowls with her chopsticks and started eating. The caregiver who brought the trays was moving back and forth between residents G and H while assisting them with their eating. Ms. XX then stopped eating, while repeatedly picking up the food with her chopsticks. The author lightly supported her right elbow so as to help her take the chopsticks with the food to her mouth. However, this time, Ms. XX continued to be distracted, stood up holding the chopsticks in her hand, and started to walk.
Situations that did not lead to distraction from eating
(Continuation of the scene described above) The author guided Ms. XX to a seat at another table. The other residents at the table were eating their food by themselves, quietly, without assistance. From the seat to which she was guided, Ms. XX could not see residents G and H or their caregiver moving between them while assisting them. The author got Ms. XX to hold chopsticks in her right hand and a bowl in her left hand. This time, Ms. XX started eating and finished all her food without further distraction.
(Another scene) Before lunch, Ms. XX was moving about aimlessly, and then sat at a seat between residents D and F, by chance, at the table where Ms. X had just finished her meal without being distracted from eating. At lunch time, the caregiver brought a tray of food in dishes to each of residents C, D, F and Ms. XX. After Residents C, D and F started eating quietly, the author got Ms. XX to hold a spoon in her right hand; she then took a dish with her left hand by herself and started eating. All the four residents continued to eat quietly for about 10 minutes. Then, Residents I and J, who were sitting at another table (next to the lounge) across the aisle, started to quarrel. All the other residents stopped eating, and Ms. XX also stopped eating, stood up, and was about to walk. The caregiver stopped the behavior of Residents I and J. When the turmoil subsided, the residents resumed eating. Ms. XX also, who was made by the author to hold a spoon in her right hand and a dish in her left hand, resumed eating and finished eating all her food.

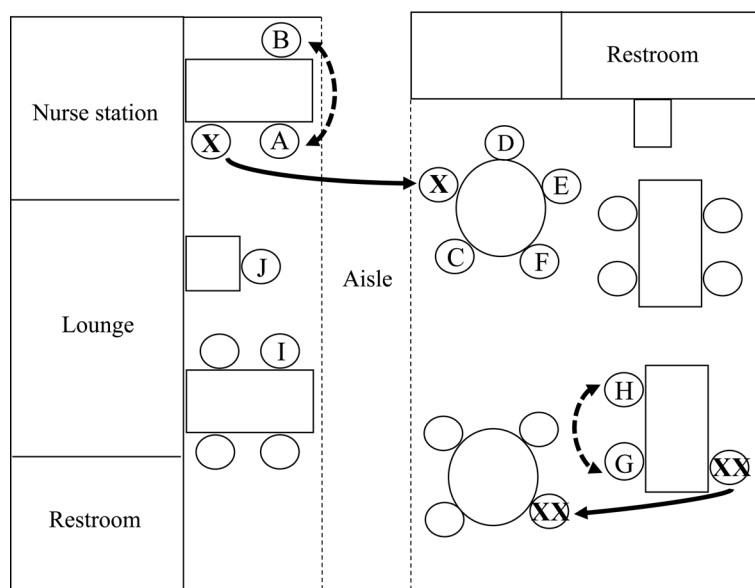


Fig. 1. Floor plan of the dining room and the seats of Ms. X, Ms. XX and other residents in the dining room
 ← - - - → Movements of the respective caregivers; → Movements of Ms. X and Ms. XX

one to focus on the information necessary to oneself and filter out irrelevant information. A philosopher, Heidegger¹⁴⁾, stated that “language is the house of being”. The fundamental function of language is to articulate the world, and the world was not clearly articulated before the introduction of language¹⁵⁾. More specifically, before the world was articulated by language, it was a continuum¹⁶⁾, and there were no such things or ideas that we are seeing now, including the existence of the self. Therefore, for an individual who develops AD and loses her language skills, the articulation between self and others disappears, and the sense of self fades away. As a result, the individual becomes unable to select the information necessary for oneself from the assault of information from around.

Behaviors depend on the mutual relationship between the environment and the sense of self, which is the subject of conscious action. Therefore, loss of a sense of self leads to more dependence on the environment. Therefore, when the sense of self fades away, the individual is more easily overwhelmed by her environment, and as a result, responds sensitively to lively and quiet environments. Also, because words are responsible for controlling one's behaviors and emotions¹⁷⁾, an individual who has lost her language skills becomes unable to control her behaviors and emotions. Therefore, in a lively environment, Ms. X failed to continue with her eating behavior. She was unable to control the behavior of taking Resident A's dish and saying something that did not make sense. Similarly, in a lively environment, Ms. XX also failed to continue with her eating behavior and also to control her behavior of repeatedly picking up food with chopsticks and of standing up while keeping the chopsticks in her hand and starting to walk. However, these patients can be made to exhibit smooth eating behaviors when they are helped into holding a spoon or chopsticks in the right hand and a bowl, plate or cup in the left hand. Severe AD patients who have lost their language skills, the subjects of this study, have no language representation skills. The habitualized eating behavior of Ms. X and Ms. XX took place without using language representation of the concepts of right hand, spoon, chopsticks, left hand, bowl, plate, cup, eating, etc. More specifically, the eating behavior of Ms. X and Ms. XX used procedural memory, which is nondeclarative memory and does not use language representation. Procedural memory is the memory system where behavioral procedures are remembered by the body. Therefore, when preparations are made for an action to start, the person can start the action. In AD, episodic memory, which involves conscious recollection using words, is impaired from an early stage. However, a recent systematic meta-analysis has suggested that procedural memory, which does not involve the use of language representation skills, is maintained even in AD patients¹⁸⁾.

Although the caregiver repeatedly cautioned Ms. X "not to take someone else's thing" in a loud voice, Ms. X did not stop the behavior of taking Resident A's dishes. This stemmed not only from her incapability of understanding what the caregiver told her, but also from the loss of the sense of self, which leads to the loss of the articulation between self and others. Therefore, Ms. X was not even aware that she was taking someone else's things. Severe AD patients who have lost their language skills cannot filter out a range of other information around them and focus on the information necessary to oneself. The roles of caregivers in preventing severe AD patients with loss of language skills from becoming distracted while eating their meals: 1) to act as a filter for the environmental influences of severe AD patients who have lost their language skills, as these patients have impaired selective attention abilities; 2) to ensure that they themselves desist from providing information that is likely to distract their patients from eating.

Of course, the results in these two cases cannot be generalized. However, caregivers who take care of severe AD patients who have lost their language skills in clinical settings every day will be satisfied with these results and this discussion. In this paper, we have shown the impact and mechanisms of lively and quiet environments, more specifically, the sounds/voices and movements of people around the patient that can distract them from eating. Other environmental factors possibly leading to distraction from eating include the interval from the previous meal, presentation of food that the patient craves, the taste and temperature of the food, hardness and other textures of the food, the number of people who eat together, and indoor factors, including the size and temperature of the room and color of the walls. In addition, the physical conditions of the patient, such as presence/absence of constipation, sleeping pattern and presence/absence of fever, are also considered to have influence. We need to further investigate how precisely each of these environmental factors surrounding the patient and the patient's physical conditions influence the eating behaviors of the patients.

Funding

This work was funded by JSPS KAKENHI (Grant Number JP16K12284).

Conflict of interest

There are no conflicts of interest.

ACKNOWLEDGMENT

We are grateful to the participants, their families, and the staff of the facility.

REFERENCES

- 1) Ministry of Health, Labour and Welfare. Care prevention manual (revised edition, March 2012). <https://www.mhlw.go.jp/topics/2009/05/tp0501-1.html> (Accessed Apr. 15, 2021)
- 2) Ministry of Health, Labour and Welfare. Future Care Prevention. https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi_kaigo/kaigo_koureisha/yobou/index.html (Accessed Apr. 15, 2021)
- 3) Ministry of Health, Labour and Welfare. Overview of the 2019 comprehensive survey of living conditions. <https://www.mhlw.go.jp/toukei/saikin/hw/k-tyosa/k-tyosa19/index.html> (Accessed Apr. 15, 2021)
- 4) Ikeda M, Brown J, Holland AJ, et al.: Changes in appetite, food preference, and eating habits in frontotemporal dementia and Alzheimer's disease. *J Neuro*

Neurosurg Psychiatry, 2002, 73: 371–376. [[Medline](#)] [[CrossRef](#)]

- 5) Shinagawa S, Adachi H, Toyota Y, et al.: Characteristics of eating and swallowing problems in patients who have dementia with Lewy bodies. *Int Psychogeriatr*, 2009, 21: 520–525. [[Medline](#)] [[CrossRef](#)]
- 6) Edahiro A, Hirano H, Yamada R, et al.: Comparative study of eating behavior in elderly patients with Alzheimer's disease and vascular dementia: a first report—comparison of disturbed eating behavior—. *Nippon Ronen Igakkai Zasshi*, 2013, 50: 651–660 (in Japanese). [[Medline](#)] [[CrossRef](#)]
- 7) Ahmed RM, Irish M, Kam J, et al.: Quantifying the eating abnormalities in frontotemporal dementia. *JAMA Neurol*, 2014, 71: 1540–1546. [[Medline](#)] [[CrossRef](#)]
- 8) Kai K, Hashimoto M, Amano K, et al.: Relationship between eating disturbance and dementia severity in patients with Alzheimer's disease. *PLoS One*, 2015, 10: e0133666. [[Medline](#)] [[CrossRef](#)]
- 9) Eggenberger SK, Nelms TP: Artificial hydration and nutrition in advanced Alzheimer's disease: facilitating family decision-making. *J Clin Nurs*, 2004, 13: 661–667. [[Medline](#)] [[CrossRef](#)]
- 10) Ijaopo EO, Ijaopo RO: Tube feeding in individual with advanced dementia: a review of its burdens and perceived benefits. *J Aging Res*, 2019, 19: 7272067. [[Medline](#)] [[CrossRef](#)]
- 11) American Psychiatric Association: *Diagnosis and statistical manual of mental disorders fifth edition*. Washington, DC: American Psychiatric Association, 2013.
- 12) Melin L, Götestam KG: The effects of rearranging ward routines on communication and eating behaviors of psychogeriatric patients. *J Appl Behav Anal*, 1981, 14: 47–51. [[Medline](#)] [[CrossRef](#)]
- 13) Broadbent DE: *Perception and communication*. New York: Pergamon Press, 1958.
- 14) Heidegger M: Letter on humanism. In: *Basic writings*. London: Routledge, 2011, pp 141–181 (Original work published 1977).
- 15) De Saussure F: *Course in general linguistics*. (Harris R Trans.). London: Bloomsbury Academic; 2016 (Original work published 1983).
- 16) Maruyama K: *Feticism of culture*. Tokyo: Keiso Shobo, 1984 (in Japanese).
- 17) Luria AR: *The role of speech in the regulation of normal and abnormal behavior*. New York: Pergamon Press, 1961.
- 18) De Wit L, Marsiske M, O'Shea D, et al.: Procedural learning in individuals with amnesic mild cognitive impairment and Alzheimer's dementia: a systematic review and meta-analysis. *Neuropsychol Rev*, 2021, 31: 103–114. [[Medline](#)] [[CrossRef](#)]