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Social and Cultural Representations of Dementia in Newspaper Articles and Novels

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## Abstract

### 1. Background and Purpose

Illness forms negative metaphors that penetrate people's minds and lead them to be fearful. In recent years, dementia has terrorized many people in Japan. Elderly people were once called "dodders" or "dotards," and were considered "shameful" due to feelings of aversion in reaction to the abnormal behaviors associated with dementia. Further, as knowledge about this illness has increased, so have people's the negative perceptions towards it. There is a widespread image among the general public that "dementia is horrible." Ariyoshi Sawako's "Kokotsu No Hito (Twilight Year)" is one example of the negative image towards dementia. Ariyoshi employed a number of negative expressions and created a drama that projected the darker, more frightening, side of dementia. What has caused dementia to be feared to this extent? Could the negative perceptions of dementia have been created by prejudice and misunderstanding within society?

Based on the awareness of such issues, and taking into consideration the concept of dementia from the medical viewpoint as well as the history of this illness, this study aimed to reveal the current societal representation of dementia. The purpose of this study was to capture the various aspects of dementia within the social and cultural contexts while clarifying how the social awareness of dementia has been formed and changed over time.

### 2. Approach

The first part of this study focused on expressions related to dementia in newspaper articles published from 1868 to 2014. The materials used for this analysis were articles in the Asahi Shimbun newspaper database featuring "dementia" or "Alzheimer's" in their headlines. These articles were analyzed using content and quantitative text analysis approaches. The second part of the study used a context approach to clarify the social aspect of dementia, focusing on the expressions used in novels written between the mid-19<sup>th</sup> century and the present time.

### 3. Results

The term "chiho," which was used for dementia before it was renamed to "ninchi-sho," included meanings such as "fool or idiot," and people mainly intended such meanings during the mid-19<sup>th</sup> century (Meiji Period). As a result, the term "chiho" historically did not carry positive meanings.

Elderly people have been thought to have suffered from dementia since ancient times. During the late 19<sup>th</sup> century (early Meiji Period), they were referred to as “dotards,” and newspapers reported their symptoms, such as wandering and disorientation, as “bizarre incidents.” From the press’s tone, society’s perceptions of elderly people with dementia seemed relatively benevolent at that time.

However, Shimazaki Toson’s “Yoake Mae (Before the Dawn)” illustrated the suffering of those with family members who actually had such an illness. Although the eccentric behavior of the main character, Aoyama Hanzo, could be considered as being due to symptoms of dementia caused by “feelings of loss at old age,” people around him perceived it as representative of “insanity.” Hanzo’s symptoms gradually worsened and caused fear and anxiety not only among his family but also among other villagers. In a remote mountain village where there was no hospital, the only option was to isolate Hanzo in solitary confinement. The novel describes how it was unbearably painful for both Hanzo and his family to accept such an option.

From the late 19<sup>th</sup> century to the early 20<sup>th</sup> century, dementia began to be perceived within the framework of mental illness. There were increasing reports of criminals in various cases being patients suffering from “dementia,” such as dementia praecox and dementia paralytica, leading to the word “chiho-sho (dementia)” to carry such meanings as “maniac” and “insanity,” and these terms soon became associated with images of aversion and fear.

“Kara (Shell)” by Nakamura Kokyo details the symptoms of Tameo, who has dementia praecox. It shows the abnormality of his behavior and how the family reacts to it as being unbearable. As Tameo’s symptoms worsen, the emotions between him and his family shift from love to hatred and fear, thereby presenting dementia as a cause of changes in emotions and relationships among family members. The novel also depicts the strong feelings of the family, “which considers having a dementia patient as ‘an embarrassment.’” This indicates that during the late 19<sup>th</sup> century and the early 20<sup>th</sup> century, dementia patients were considered to be the “family’s victims,” as well as “society’s victims.”

During the post-war period, elderly people who were physically weak and suffering from mental illnesses, such as dementia, were categorized as unproductive and incompetent. They were thus treated as “burdens.” A dementia patient depicted in Niwa Fumio’s “Iyagarase No Nenrei (The Hateful Age)” was called the family’s “cancer” and was passed among granddaughters who were unwilling to look after him. Longevity became something that was “embarrassing” and “troublesome,” rather than representing health or happiness. In such social circumstances, the negative aspects of dementia are

thought to be highlighted.

The publishing of Ariyoshi Sawako's "Kokotsu No Hito (The Twilight Years)" in 1972 spread awareness of dementia; however, due to the images of the ugliness of old age and fear produced in this novel, many of the readers became hateful or anxious about aging. This novel created a misunderstanding about dementia, as it only depicted the actions and not the inner world of the patient, leading the media conclude people who suffer from dementia are unable to understand anything. In the 1970s, when the welfare system was not yet well established, people who were affected by dementia had no choice but to live in despair.

Studies and educational materials published by experts contributed to a gradual increase in media reports about dementia in the 1980s. However, a large number of people still considered having a dementia patient in their family to be "embarrassing," and discussion about dementia remained limited.

Until the first half of the 1990s, which overlapped with Japan's bubble economy period, the aging of the population was not treated as a serious issue, and society's awareness of dementia was still lacking. However, the suffering and feelings of isolation borne by families caring for elderly dementia patients reached a breaking point in the late 1990s, and the reality of nursing dementia patients was revealed through newspaper serials and letters from caregivers. Simultaneously, alternative forms of caregiving, such as Scandinavian-style group homes that provided a sense of being at home, were introduced. In addition, more attention was paid not only to the burden that was borne by caregivers but also the minds of the patients themselves. Novels started to appear that depicted issues of "elderly care provided by the elderly," in which both the patient and the caregiver both begin to age.

With the enforcement of the Long-Term Care Insurance System in 2000, dementia began to change from a family problem to a social issue. The number of murder and suicide cases triggered by the aging of the caregivers and their suffering increased, finally leading to a wider recognition of dementia as a serious illness. By the mid-2000s, there was a growing concern about early-onset dementia. Dementia could now be seen not only through the caregivers' viewpoints but also through the patients' own narratives for the first time, and the illness that both the patients and their families used to find difficult to accept slowly started to be perceived positively.

Novels and movies that focused on early-onset dementia appeared, spreading awareness about the patients' suffering, and presenting dementia as an illness that does not only affect elderly people but one that could happen to anybody. The novels featuring early-onset dementia depicted the recognition that the patients' worst fear

was to losing their memories and experiencing a mental breakdown. Memories are deeply associated with an individual's identity; hence, they play a crucial role in his or her relationships with others, as well as his or her life.

Society's awareness and understanding of dementia improved after 2010, and there was a shift in people's consciousness that involved working to create a community in which those affected by dementia could feel safe without prejudice through invigorating activities and interactions. People from a wide range of age groups started to responsibly and actively involve themselves in tackling the issue of dementia.

#### 4. Conclusion

Rather than being irrelevant, dementia is a familiar illness to many people living in modern society. With a prediction that the number of dementia cases will continue to increase, it is necessary to more actively discuss the illness, with the media, such as newspapers and novels, acting as intermediaries in order to establish a society in which many of those affected by dementia are able to live safely.

Dementia is still considered a serious, as opposed to a curable, illness. However, we have been seeing more positive representations of dementia in recent years. "Dementia is inconvenient, but not it is not unhappiness," and "I can work despite having dementia" are some of the phrases found in magazines, but as the number of dementia patients is about to reach 7 million, we may need to be creative about dementia representations and change the associated images of fear and aversion.