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| Author(s) | Iguchi, Takashi |
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How Has the New Image of People with Dementia Emerged in Japan? : An Analysis of TV Documentary Programs in the NHK Data Archives

IGUCHI Takashi

Introduction

This paper is a progress report of our research¹⁾ about dementia care and conceptions of people with dementia (PWD) using the NHK (Japan Broadcasting Corporation) TV program data archives²⁾. In this paper, I will present a trial analysis of two types of data. The first type is a list of TV programs that we made by searching through the NHK TV programs database. The second type is text data that we recorded by watching some typical samples of NHK TV documentaries about dementia sufferers.

This paper will be divided into three parts. In the first section, I will clarify what we can see in past TV documentary programs about dementia care that relates to the 21st century context of the culture of dementia care. I will attempt to specify why visual data recorded as TV documentary programs is important in understanding the new culture in dementia care. In the second section, I will analyze transcription of some scenes in which the will and feelings of PWD were represented and referred to, focusing on conflict between PWD and caregivers. In the third section, I will rethink the importance of taking a historical approach using TV program archives for sociological criticism of the practical field of dementia care.

1 Background

Since the second half of the 1990s, the social concept of “dementia” and “people with Dementia (PWD)” has been dramatically changing. The British researcher Tom Kitwood, a psychologist who was one of the leaders of this movement, argued for person-centered care as a basic paradigm for understanding PWD (Kitwood 1997). He criticized the ordinary approach toward PWD as outdated, based on “old culture”. In this old culture, many people assumed that PWD inevitably lost their sense of self; moreover, their behavioral and psychological symptoms were often considered as the inevitable outcomes of brain diseases such as Alzheimer’s by laypeople and health care professionals.

Based on their research and their caring practice for PWD, Kitwood urged us to leave behind the old culture of dementia care and to adopt a new person-centered culture. He and his research team presented an important concept, *malignant social psychology*, which was a central component of the old culture (Kitwood 1997: 45-49). This term refers to a social environment in which interactions and communications reduce the personhood of PWD. Malignant social psychology is fueled by a

lack of insight into or knowledge of the negative effects brought about by these interactions. It is true that PWD gradually lose cognitive ability in the biological sense; however, they remain self-aware and respond to their surroundings. On the other hand, caregivers living with PWD have understood such individuals' behavior as problematic from a medical standpoint. In that view, the actions of PWD become an obstacle for caregivers doing their work and are seen as merely the irreversible outcome of a biological illness. Against this prejudice, Kitwood claimed that these phenomena, seen as symptoms in PWD, were created by such malignant social psychology. Some kinds of caregiving can create these quasi-symptoms in PWD; caregivers should take precautions to avoid this. This is a summary of the deterioration process of PWD under the malignant social psychology. The purpose of the new culture in dementia care is to cut off that malignant social psychological process.

In Japan, the public began noticing signs of the new culture around 2000. At the dawn of the 21st century, some English books about person-centered care theory were translated into Japanese, and many general kinds of books about the new view of dementia and PWD were published. However, in the context of Japanese society, it is significant to note that approaches to caring for PWDs incorporating elements of person-centered care were already practiced without its name in some institutions, day care centers, and informal group homes by a few pioneering practitioners. Those who were already trying such revolutionary approaches to PWD care published many books around 2000.

Research institutions and law dedicated to dementia care developed following the practices previously mentioned. Centers for Dementia Care Research and Practices (CDCRPs) was launched in 2000. The new concept began to appear in social care policy for elderly care. Published by private research committee organized in Ministry of Health, Labor and Welfare in 2003, “Long-term Care for Older Persons in 2015³⁾” was a document that tried to give blueprint for the next reform of long-term care insurance systems. This document presented the idea that PWD exhibited both feeling and self-consciousness and urged caregivers and the general public to care for the dignity of PWD.

Simply, the changing process of dementia care has been understood as a mainly linear developmental process, moving from a dark age to new, enlightened era in Japan. Some researchers, who are mostly practitioners too, described the history of dementia care as a development from a caregiver-centered culture to a “person-centered” culture (Ueda 1999; Miyazaki 2011; Nagata 2007). We are able to read such tendencies in some books written by practitioners engaging in this revolutionary approach for dementia care (Ozawa 1998; Sasaki 1994). On the basis of such historical recognition, it can be said that we are standing at the dawn of a new era of dementia care in the 21st century.

In recent years, some autobiographies of PWD, most of which were written with the support of their caregivers, have been published (Bryden 1998; Ota 2005). Some of these people even began to give lectures and talk for the general public. Narratives of PWD had a great impact on Japanese

society and supported the credibility of the new culture of dementia care. In 2004, the Conference of Alzheimer’s Disease International (ADI) was held in Kyoto. Thanks to the conference, some people who were diagnosed with Alzheimer’s began to speak publicly about their experience. Their voices and narratives were broadcast by the mass media, especially by NHK (*Nihon Hoso Kyokai*), a public television network in Japan. As a result, the reality of the lives of PWD, including their desires and feelings, was made available to the public, and so caregivers were able to change their practices accordingly.

2 Overview of TV programs

2.1 The number of programs about dementia care

As mentioned above, the appearance of the voices and narratives of PWD since the turn of the last century has made a strong impression on the public, and NHK has played an important role in this through interviewing for PWD and their caregiver, producing many programs and broadcasting them. The stories of PWD make it easier for the general public to understand their will and feelings, and make it easier for researchers to investigate historical changes in dementia care.

The number of programs⁴⁾ on dementia increased in the 2000s. Fig. 1 shows that whereas 54 programs aired between the 1960s and 1990, the number of such programs that aired between 2000 and 2008 is 182. The number of programs on dementia dramatically increased after 2004 (Fig. 2).

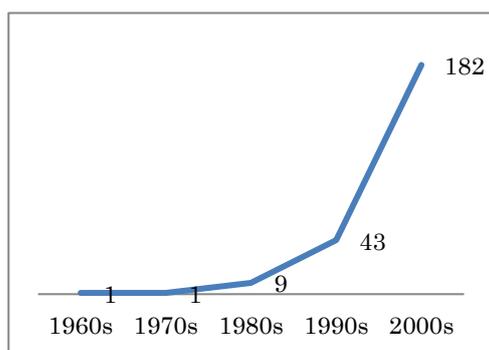


Figure 1. number of programs from 1960s to 2000s (total of 236)

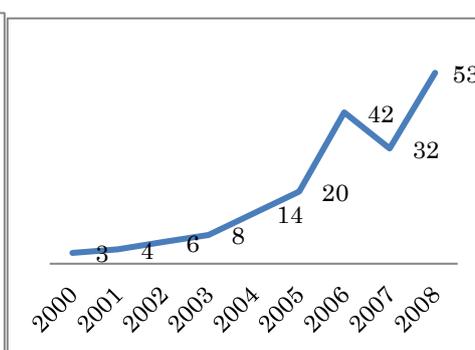


Figure 2. number of programs in 2000s (total of 182)

The reason that this number of programs increased after 2004 is that in that year, two important events pertaining to public perceptions of PWD occurred. One event was the ADI Kyoto international conference held in October 2004. That conference was a momentous opportunity for many PWDs to speak out their

voices. The previous year, in preparation for the 2004 ADI conference, a person diagnosed with Alzheimer's named Cristine Bryden came to Japan to give a lecture to the general public. Bryden became a spokesperson for PWD at the following year's conference. After her speech, some Japanese PWD began to make public appearances.

The other event was a national campaign to inform to the general public about dementia. One symbolic event of that campaign was successfully changing the official Japanese term signifying dementia from *chiho* to *ninchisho*. Both terms mean "dementia." *Chiho* includes a stigmatized nuance, whereas *ninchisho* was meant to have a more medical diagnostic meaning that indicated symptoms.

2.2 The appearance of PWD voices and narratives

Programs focusing on the PWD themselves, which stressed the importance of their individual needs and lifestyle choices, began increasing after 2004. If we take the appearance of these kinds of programs as an indicator of the segue into the new era of dementia care, there should be able to find significant changes around 2000, and especially after 2004. Thus, it may be easy to conclude that years around 2004 together indicate the historical pivot for the paradigm shift.

However, the fact that PWD began to appear on TV is merely a superficial indicator of an already existing cultural change toward respecting the autonomy of PWD in some institutions and care situations. When looking at programs produced between 1980s and 2003, we found some outstanding caregiving practices in which the autonomy of PWD was identified and constructed within the limitations of each era and place, though the voices and narratives of PWD, strictly speaking, did not appear. Therefore, it is essential to inquire how this gradual change arose in the context of each care situations between 1980s and 2003.

2.3 What is the nature of TV programs as data?

What is the significance of TV programs as historical data compared to more textual and discursive forms of data? After considering the data and conducting an interview with a TV producer, the lead researcher found that it is better for us to take TV programs not as data that represent the nationwide spread of practices but rather as data reflecting a production team's agenda in progressive practices.

I will take the situation of TV production after 2004 as an example. TV programs about dementia were produced by teams representing subdivisions at NHK, for example, the science section and the life and welfare section (Niwa 2013). Concerning the popularity of programs featuring the narratives of PWD after 2004, a production team in the life and welfare section, led by the famous documentary director Yuji Kawamura, made many representative programs. They first made a program about Christine Bryden in 2003 and followed that up by producing more programs on the new culture of dementia care. Co-researcher and I interviewed Kawamura and discussed "validation therapy," which became something of fad in the field of dementia care at the time. He said as follows.

I: Why didn't you produce part II of the program about "Validation therapy"?

K: We are basically people engaged in the information industry, so responding to new topics and broadcasting them is our work.

(“On describing people with dementia: interview with Yuji Kawamura,” *shien*, vol.2: 99).

Considering that Kawamura was a typical director of an engaging main series of programs on this theme at NHK at the time, we can assume that other producers at NHK shared a policy of focusing on exciting and revolutionary practices in each era. If many TV documentaries were produced on this kind of policy, that assumption may be applied to programs produced before 2004.

Table 1. TV Documentary Program list

| No. | Date | Title | Subtitle | Care practice |
|-----|-----------|--------------------------|---|---|
| 1 | 1982/9/13 | NHK Special | <i>Nidowarashi-no-yakata</i> “The house of people who go back to [being] babies.” | First nursing home established in Japan specializing in providing care to the elderly with dementia. |
| 2 | 1983/5/30 | Close-up | <i>Boke-wa dokomade naoseruka</i> “To what extent can dementia be cured? A trial of music therapy.” | Music therapy provided at an institution. |
| 3 | 1986/6/13 | The Future Welfare | <i>Boke-no-Rojin-sansyukan-home</i> “A 3-week stay of elderly people with dementia at nursing home: A documentary on a support program for family caregivers.” | Short stays for PWD at institutions, observation of PWD, and advice given to families of PWD on how to provide dementia care. |
| 4 | 1989/2/27 | NHK Special | <i>Kokoro-wa kessite shindoran</i> “The mind is definitely not dying: A documentary on elderly people with dementia spending 5 years in the hospital.” | First established hospital specializing in providing care for the elderly with dementia in Japan. |
| 5 | 1990/7/19 | The Japanese Island | <i>Ojii-chan waratte</i> “Please laugh, grandparents: A documentary on arranging caregiving for a 10-day stay at home.” | Practical training for family caregivers at sheltered housing. |
| 6 | 1991/9/11 | The NHK Midnight Journal | <i>Kokoro-wo hiraku rojinkaigo</i> “Elderly care focused on opening their minds: A documentary on the elderly with dementia going around the city.” | Helping PWD go outside of their homes. |
| 7 | 1993/3/11 | The Journal of Living | <i>Chiho-wo kuitomero</i> “A trial to stop the deterioration of memory function in people with mild dementia: Practices of an informal institution.” | Rehabilitation and cohabitation for several months at the institution. |
| 8 | 1995/1/7 | The Prime 11 | <i>Kokoro-wo hiraite egao-wo misete</i> “Open your mind and smile: Living with dementia.” | Group psychotherapy at a day care center. |

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|----|-----------|-------------------------------------|--|---|
| 9 | 1996/3/31 | The Document of the Japanese Island | <i>Boketemo egao-wo wasurenaide</i> "Don't forget your smile even if you become demented: A documentary of a group living home in Okayama." | Caregiving for each rhythm of life. |
| 10 | 1996/5/2 | Living Together Tomorrow | <i>Kagi-wo hazusou issho-ni kurasou</i> "Let's unlock the physical restraints and live together: A practice trial of a special nursing home for elderly with dementia." | Open care space for PWD. |
| 11 | 1997/1/26 | A Sketch of Japan | <i>Boke-nanka kowakunai</i> "No need to be afraid of suffering dementia A trial of a new approach toward care for the elderly with dementia." | Livelihood support for the elderly with dementia. |
| 12 | 1998/7/16 | Living Together Tomorrow | <i>Minna hitotsu yane-no shita</i> "Let's live together in the same house." | Support for the elderly with dementia through cohabitation. |
| 13 | 2002/1/19 | Island Special | <i>Tooki-michi ima-kagayaite</i> "The long road, now shining: A documentary on reminiscence/life review." | Reminiscence/life review at a hospital. |
| 14 | 2003/12/2 | Every Day Life Morning Show | <i>Chiho-kea honnin-ga kataru kokoro-no sekai</i> "Dementia care: a sense of reality as narrated by people with dementia." | A documentary on a person with dementia. |

Table. 1 is a list of the titles and summaries of TV documentaries that aired between 1983 and 2003 and were produced by filming care practices in institutions specializing in dementia care. No. 1 shows the first-ever nursing home to specialize in dementia care for the elderly. Since that program, new approaches have become main topics in programs. For example, No. 4 shows specialized hospital for elderly dementia sufferers. No. 9 and No. 12 shows group living for elderly with dementia in mid of 1990s. No. 8 shows group psychotherapy, and No. 14 shows reminiscence and life review of PWD. Almost all of the institutions and professionals, who appeared in these programs, are now famous. Their discourse represents a written history of dementia itself.

The practices we can see in NHK documentary programs tend to be high level of practices that the production team would like to show to the public. Conversely, we can assume that institutions with average standard of caregiving did not appear. Based on the current standard of dementia care, we may see these practices as somewhat poor; however, it is necessary to remember that dementia care is constantly changing and that these practices constituted the most pioneering efforts at the time. As such, we should not use this data as representative of the general care situation of the time throughout Japan, but as representing the very best techniques of their respective eras. What this article must focus on is the pioneering aspect of these practices in programs. Using this type of data, we can also study various difficulties that arise when practicing these pioneering dementia cares, to avoid repeating them in the future.

If we consider the pioneering practices meant to enhance quality of life (QOL) for PWD in TV programs before the mid-2000s, we can see that drawing the conclusion that the mid-2000s was the main turning point in dementia care would in fact be quite naïve. Before the mid-2000s, there were already revolutionary practices being attempted. Therefore, it is important to inquire into the history of how these practices were put in place and the conflicts and difficulties that appeared as a result. By studying such conflicts and difficulties, it is possible to predict problems that current pioneering practices may face.

From the viewpoint mentioned above, this paper provides a brief overview and analysis of how the history of pioneering caregiving practices for PWD are portrayed in TV documentaries. By conducting such an analysis, we can study issues that practices based on the current person-centered ideology will face in the future. In the next section, I will analyze three TV programs on dementia care in institutions, with especial focus on how and in what context the thoughts and desires of PWD have been situated. For fulfilling the idea of new culture of dementia care, it is most important to comprehend the will of PWD and giving care to them based on their needs. Though attention to voices and narratives of PWD is more noticeable beginning around 2004 than earlier, there were already some trial-and-error processes for discovering the will of PWD and providing care based on these in TV programs in the 1990s.

3 Analysis: Conflict and dilemma in previous practices

3.1 The will behind problematic behavior

In many TV programs, the will of PWD has been perceived and interpreted in the context of caregivers coping with the problematic behavior of PWD. Program No. 1 was produced in 1982 and is the oldest program that we watched. This program can be seen as representative of other programs around that time. This program was produced through researching “*Daini-oyamada-tokubetsuyougo-roujin-home (oyamada special nursing home No.2)*,” which was the first nursing home specializing in care for the elderly with dementia, for several months. The structure of the program consisted of a repetition of two kinds of scenes. The first type of scene portrayed the everyday routine in the institution, and the second type portrayed discussion between a psychiatrist and a neurologist in the TV studio, watching the scene of the institution’s everyday routine.

This program contains many visuals on how PWD caused some trouble in the institution. For example, quarrels between residents are shown and some PWD are portrayed as not obeying the rules of the institution and many such problems are shown during the 50-minute documentary. One of the most impressive scenes was when a man was walking around in that institution urinating into garbage bins. The following scene recounts the conversation between three staff members regarding that incident.

S1 : He often walks around, maybe obsessed with the notion of delivering newspapers to each house. I think there may be a special meaning when he urinates into garbage bins too. He seems like he’s working. He may be obsessed with a strange notion. For example, the behavior of urinating into garbage bins may be like pouring water into fire pomp?

Doctor : Has he done this before?

S1 : Yes, he has.

S2 : I think this behavior is becoming less frequent.

S1 : How will we cope with this problem? Don't we have a good method for solving this problem?

Doctor : Um, No we don't. So we have to think and find the best way possible.

.....

Doctor : We have to observe whether he eats anything or not. But, as I always suggest, you had better observe his tongue to see whether he is dehydrated or not. This observation is easy, because you can find something changing on the basis of the drying of his tongue.

In this scene, one staff member first suggests that the resident's urination had a particular meaning for the man. In response, the doctor in charge of the institution assumes that there must have been a biological cause behind his problematic behavior. After watching the meeting scene at the institution, the psychiatrist Kazuo Hasegawa, famous for the Revised Hasegawa's Dementia Scale, commented as follows.

I think strange behavior, which may be not easy for us to understand, must have some meaning for the individual. There must be a reason that the elderly man appearing in that video urinated into garbage bins.

I think it is most important for us to try to understand and respect that reason. At the very least, we should try not to scold them, for this would result in confusing the elderly and aggravating their symptoms of dementia.

As you can see from this typical example, some programs imply that there were *reasonable* causes behind the problematic behavior of PWD. In this context, the concept of "reasonable" means *understandable*. If we in the audience were in the same situation, the implication goes, we would behave like that. This program thereby implies that PWD have the same psychology as "us," the rational individuals who do not suffer from dementia, and it insists that we have to treat them as such.

What must be stressed here is that the TV commentator first focuses on the problematic behavior of PWD and then insists that the audience focus on the will of PWD only for reducing this problematic behavior. Focusing on the will in this portrayal is simply a means of dealing with problematic behavior; this focus was becoming a typical motif of TV programs around this period⁵⁾.

3.2 Reducing problematic behavior to increase QOL of PWD

In many programs, we can see some caregiving approaches aiming to increase the non-medical QOL among PWD. Since there is no cure for dementia⁶⁾, the primary goal and meaning of dementia care as represented in the programs was to reduce patients' problematic behavior for the sake of caregivers. While it is largely agreed that respecting the will of PWD is a core element of their QOL, it is troubling that their will was primarily considered in the context of reducing problems for caregivers rather than for the PWD themselves.

I will take Program No.2, produced in 1983, as an example. The aim of this program is to observe a trial music therapy conducted by Dr. Tabun Tanaka. He was a pioneer of this kind of therapy in Japan, and we can see him practicing it in his special nursing home, *Yuseien*, and observe its effects on the resident PWD. This program consists of two types of scenes. The first type shows everyday life in the institution, including music therapy sessions and residents' everyday routines. The visuals on music therapy are the main component of this first type. Here, elderly residents with dementia are shown moving their hands, marching, and singing while clapping their hands in time with music. In the second type of scene, we can see the results of research about the brain compensates for signaling deficiency caused by cranial nerve disease. "Rehabilitation of mind," the practice performed at Tanaka's institution, intended to improve the function. Music was regarded as effective for this purpose and used in the therapy at this institution.

Mr. A's treatment with music therapy is the main case of this program. During a music therapy scene, in which the elderly patients clap their hands to a baseball song, Mr. A who has speech difficulty, does not reveal any response. This session is a turning point that prompts Dr. Tanaka to take another approach toward Mr. A's treatment. Dr. Tanaka takes Mr. A on a short trip to visit a port that is familiar to Mr. A, who used to be a commercial fisherman. In the wake of this, Mr. A's facial expressions and speech become lively, and he begins singing his familiar song to a recorded music at the hotel. Mr. A's story occupies approximately one-third of this program and is given as a successful case of the care practice led by the music therapy. In the treatment process that integrates a music therapy as a turning point, PWD become able to express their desires and feelings, and finally communicate with others. In this story, it is considered that QOL of PWD is strongly related to this process.

In addition to that result, as main motif of the program, the high QOL of PWD, led by music therapy as well as other approaches, is shown to overlap with the interests of the caregivers. *Their* first interest is to lessen what *they* perceive as the problematic behavior of PWD. For example, after the scene of the short trip of Mr. A and Dr. Tanaka, there is a scene where residents and care staff members have a dinner party in *Yuseien*. At the party, Mr. A pours alcohol for Dr. Tanaka and expresses his joy at the dishes made by participants. One of the things this scene intends to represent is that Mr. A has recovered his language ability. The other is the fact that almost all his problematic behavior has disappeared. In this scene, in addition to Mr. A's behavior, we can hear the narrator saying "Mr. A's previous bad behavior almost vanished after the drive to his hometown."

In summary, the content analysis of Program No. 2 revealed that the QOL and encouragement of the will of PWD was mainly treated in the context of decreasing caregivers' burdens. The reason for this storyline was that caregiving for PWD was the main issue from the 1980s to the 1990s. Some programs conveyed themes on how to approach PWD and their families for them to continue living together. For example, Program No. 3 demonstrated practices for giving advice to families caring for PWD. This program featured social care staff members had some elderly people with dementia stay at special institutions where the staff could observe their lifestyles and behavior. On the basis of these observations, care staff advised the family caregivers on how to provide care for PWD. In Program No. 5, a male with dementia and his partner stayed in a room in a special institution and were trained on how to live their everyday lives. These practices are intended to motivate the family caregiver to continue to provide care for PWD in the household. During that

decade, family members, as the main caregivers, were generally expected to continue providing care and endure the difficulties of such care. Within such limitations, they had to try to increase the QOL of PWD.

3.3 Conflict between the will of PWD and the interests of caregivers

In contrast to the practices mentioned above, Program No. 13, which was produced in 2003, reveals that increasing PWD QOL by enhancing their ability to exercise their will and meeting their needs often increased the burden of caregivers. This program allows audiences to examine the trade-offs in the relationship between the QOL in PWD and their caregivers.

This TV program presents an approach to caring for PWD using reminiscence and life reviews in the *Oume-keiyu byoin* (Oume-keiyu Hospital for the Elderly). The core of this approach is conversation sessions among male residents, during each participant remembers his life history using photographs from his past. This is termed a reminiscence and life review. The reason that the session is held only for male residents is because elderly male residents often will not communicate with others and tend to be more depressed than female residents.

The TV program has three main parts. The first part is a scene showing a conversation session wherein male residents and staff specializing in reminiscence/life reviews gather for a weekly meeting. In these meetings, they exchange name cards and introduce themselves to each other. The second part is an everyday scene in the ward where participants live. The third part is a life history of Mr. Sato, the main character of this program.

This approach uses the reminiscence and life review as a core component to encourage PWD to express their needs and intentions. One particular scene illustrates the effects of the approach. The scene is about the everyday life of Mr. Sato, the former owner of a bookstore, who is in the ward after having received several sessions of reminiscence/life review in the day care room.

In the conversation session, Mr. Sato begins to speak eagerly about running his bookstore. He is proud of his work. After the session in the ward, Mr. Sato reveals that when he owned the bookstore, he called every day to check if everything was OK. After remembering this, Mr. Sato started to want to call his shop again, even though it was no longer in business. Such a significant change in his condition made it difficult for him to keep a routine in the ward. Though some staff members in the ward walk around with Mr. Sato and even take an interest in Mr. Sato's situation by pretending to call his shop, Mr. Sato cannot be calmed down. After a change in the social order in the ward, the program shows a meeting between Dr. Saito, who is in charge of Mr. Sato's therapy, and Ms. Shimura, who is in charge of the ward.

Dr. Saito: Although he forgets many things, I think that remembering various things happened in his life is important for him. The remembrance will allow him to reconsider his life as a good one and to adapt to the current situation, as a result.

Shimura: After the therapy session started, he remembered who he was in the past and started to cause trouble. I think he may be complaining about our usual approach. He may think that the ward staff are always giving the same responses and lying about his situation to him. We, the staff, have to change our approach to him in response to the changes in his actions. Mr. Sato seems to feel stressed because our usual deceptive responses to him are not enough for him.

Dr. Saito: I understand that it may be difficult for you and the other staff members in the ward, however I think that the treatment we are engaging in with Mr. Sato is working well.

Shimura: Our staff members may understand that.

Dr. Saito: I will try to work harder to help the staff deal with this new situation.

In this scene, Dr. Saito and Ms. Shimura reach a consensus about how Mr. Sato's so-called "troublemaking" was actually more beneficial for him than what the ward staff members thought. To fulfill such goals, the therapy staff created a file on Mr. Sato's personality, including information revealed in the conversation sessions, and took it to the ward staff. The staff then gradually began to understand his personality. For example, they asked him about his lively fishing story and even went fishing with him during the holidays.

This program resulted in the conclusion that focusing on what benefits PWD leads to positive outcomes for care staff. However, as we saw, there was also conflict between the needs of the PWD and the interests of the staff in this practice. What was most important for staff members in the ward was reducing problematic behavior. On the other hand, the will of PWD, encouraged through recalling their life, brought about some new tasks for staff members and disrupted the typical coping strategies used with PWD. In the context of the approaches seen in the first and second TV programs, when PWD become more active and outspoken, it could be interpreted as aggression, which is a problematic behavior. However, as Dr. Saito suggested, this increase in activity can actually be beneficial for PWD.

4 Discussion and Conclusions

4.1 Difficulties in some pioneering practices

In the previous section, I investigated how the will of PWD is relevant and referred to in each of the approaches documented in the three TV programs. In the first program, their will was addressed

in the context of how their caregivers cope with problematic behavior of PWD. In that context, the difficulties described in the programs were only the difficulties of the caregivers. In TV Program No. 2, the practitioner tried to stimulate the will of PWD through music therapy and enhance their QOL. Although stimulating the will of PWD was related to that individual's QOL, reducing their problematic behavior was the main purpose, an extension of the paradigm seen in No. 1. The QOL of PWD was considered only so long as it harmonized with the QOL of their caregivers. Indeed, there was no assumption of the possibility of conflict occurring between the two parties.

In contrast to the first two programs, Program No. 13, produced in 2003, described the nature of the conflict between the will of PWD and the burden of staff members. In this program, enhancing and revealing the will of PWD led to additional work by staff members in the ward. At first, this change in their work brought confusion in staff members, and the changes in the will of PWD changed staff members' notions about dementia care and the norms of the workplace. We can see the context in which the will of PWD was discovered and focused on, as well as the power relationship between the will of PWD and the caregivers' interests, by analyzing TV programs produced before 2004. We do not have to judge the arrival of the new culture of dementia care just because the narratives and voices of PWD appear. It is necessary to survey historical caregiving practices and clarify how the will relates to the norms and orders in caregiving situations. The appearance of the voices and narratives of PWD has likely resulted in considerably more conflict and difficulty for caregivers. Thus, we have to survey such aspects of dementia care after 2004.

4.2 Significance of historical analysis and TV documentary programs as data

Until recently, the history of dementia care, based on texts written mainly by caregiving practitioners or scholars, stressed the developmental transition from simple physical care to supporting the personalities that PWD constructed throughout their lives (Iguchi 2011). The appearance of the voices and narratives of PWD was seen as an important indicator of such transition.

This is a correct, if oversimplified, understanding of the history of caregiving to PWD; it is a description which include their ideology. During the mid-2000s, the autonomy of PWD in the form of personal narratives appeared. These narratives attracted the attention of the public; however, sociological studies have to pay attention to whether the will of PWD is prevalent in caregiving contexts, or whether they have disrupted the interests of caretakers and the norms based on those. This is what we think of historical studies on past practices. For such purposes, TV documentary programs archived in the NHK, as records of pioneering practices, are important.

Future issues raised by this paper, based on other TV documentary programs that could not be presented in this paper, include a more detailed process on how the will of PWD has changed the norms of the field of dementia care. Such a description may serve as a reference for current and future practitioners in clinical fields.

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Notes

- 1) This research project was conducted with co-researcher Akiko Tajima. I analyzed data that was recorded and edited using the NHK database and library film from October 2010 to November 2011.
- 2) This research project forms part of a research trial using NHK data archives. NHK is now constructing and modifying its broadcast data archives and asking for participants to help catalog the archives; at the same time, they are allowing researchers to further their work regarding specific themes (Retrieved November 30, 2018 from <http://www.nhk.or.jp/archives/academic/>).
- 3) The document was written by the informal study team on LTCI systems in the health and labor administration (Study Meeting on Long-term Care for Older Persons 2003).
- 4) We searched a program database that did not include news programs using the keywords *chiho*, *ninchisho*, Alzheimer's, and others. After omitting some programs not related to medicine or care from the results, we created a basic list. From this, we selected 236 TV programs, excluding science programs, health information programs, etc., as candidates for watching and making transcript of some scenes.
- 5) In some programs produced after No. 1, caring practices focusing on the individual needs of PWD and their lives were used as the material for TV programs, which were about group home living and reminiscence/life reviews. Though such TV programs expressed the will of PWD found through such caring practices, the main theme in narration and comments about these scenes, which play an important role in composing the storyline of the entire program, is for caregivers to solve and cope with PWD's problematic behaviors.
- 6) Programs interested in the mechanisms of curing brain disease have been produced since the 1980s. As such, many programs contain similar parts and storylines. Roughly speaking, these programs introduce and explain the newest results of studies on the mechanisms of the brain, as well as the curing and caring methods that affect cognitive functions.

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*The title in English is a personal translation.

(IGUCHI Takashi The University of Tokyo)

How Has the New Image of People with Dementia Emerged in Japan? : An Analysis of TV Documentary Programs in the NHK Data Archives

IGUCHI Takashi

Abstract

From the late 1990s to the early years of this century, a new representation of people with dementia (PWD) has been promoted in Japan. In this trend the voice of PWD has assumed an important role. Around 2004, some PWD spoke publicly about their views and desires about their environment. Since then, their willingness to publicly reveal their condition and their humanity has become significant in dementia care. The mass media, especially the NHK (Japan Broadcasting Corporation), which produced television documentaries on this subject, has promoted this movement.

The year 2004 was particularly significant in producing new representations of PWD, because an international conference was held in Kyoto, Japan. However, before 2004, the humanity of PWD was revealed in diverse ways in each field of dementia care, and the NHK has reported some outstanding care practices. The empirical exploration of this changing trend is an important issue in sociology. My primary concern is how PWD have been represented in TV documentaries before the 2000s and how previous conceptions of PWD are related to the new conception. This paper explores the emerging patterns of representation of PWD on NHK TV documentary programs produced between 1980 and 2003.

I accessed the video data systems of NHK's broadcast data archives for a year and collected the following three types of data: 1. the title and content lists of TV programs on dementia; 2. documentation of the story, the contexts, and scenes of each program; and 3. image capture of symbolic scenes in these programs.

Two representative descriptive patterns of the humanity of PWD were revealed in our research. The first pattern is that their intention was indicated as the key factor in resolving PWD's problematic behaviors for caregivers. In contrast, the second pattern, independent from the caregiver's concern, the feelings and intentions of PWD were prioritized even when they conflicted with caregivers' convenience.

(Keywords: dementia, TV documentary)