Why is the Early Detection of Dementia Failed?

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Abstract

To prevent dementia, the early detection is important. However, it's often failed because it's difficult to articulate "dementia" as "dementia" verbally. In this paper, I analyzed semi-structured interview data stored in DIPEx-Japan, a database of personal experiences of health and illness, and discussed the difficulty of early detection of dementia.

Keywords: early detection of dementia, analysis of semi-structured interview data, illness narrative.

1. Introduction

It is said that early detection of dementia is important. For example, Honma[1] pointed out the importance of the early detection as follows.

- In case of Alzheimer's dementia, its progress will be delayed by Donepezil hydrochloride, which is a type of medicine. Therefore, a period of in-home care will be able to be extended.
- The right of self-determination will be respected. For example, the elderly people will be able to communicate with their family in regard to wealth management or nursing before they will suffer from several symptoms of dementia.
- QOL (Quality of Life) will be preserved. If caregivers (including family members) recognize the state of dementia in advance, they will be able to keep communicating with a person with dementia.

To detect dementia, several tools have been recommended. For example, fundamental check list is shown in Manual for preventing nursing[2]. According to this list, if an elderly person is often pointed out that he/she is forgetful, his/her cognitive functions will be suspected to decline. However, it is difficult to determine whether an elderly person is dementia or not. Generally, dementia is defined as ``the sustainable decline of intelligent abilities and the state which interfere with daily life and social life due to several types of cognitive disorders. We think ``early detection of dementia is difficult due to the ``sustainable" decline of intelligent abilities. In this paper, we will discuss the difficulty of early detection of dementia based on narrative data.

2. Dementia problem

Alzheimer's disease, Lewy body disease or cerebrovascular disease are known as the factor of dementia. However, an appearance of these disease is not always equal to the beginning of dementia. Deguchi[3] interpreted dementia ``not just as physical and somatic problem for the elderly people but as interactive problem due to communicative disorder between the elderly people and people concerned. So we regard dementia as communicative problem which is gradually articulated through communication with people concerned. Through an interview data, Deguchi illustrated the phases of dementia troubles as follows: Zero point of an unspecialized trouble, Variation of an interpretation or definition about the trouble, Confusing how to deal with the trouble, Regarding the trouble as a claim, Discussing how to deal with the trouble among people concerned, Determining how to deal with the trouble among people concerned.

To discover the beginning point of dementia trouble (``Zero point of an unspecialized trouble"), Deguchi interviewed the elderly people with dementia and their

family. However, there were not so many samples so we'll analyze the other type of interview data in the next chapter.

Furthermore, in articulation and cognitive anomie hypothesis, Nakagawa[4] examined the process of dementia. According to his hypothesis, ``a claim on unspecialized trouble will refuse a process of normalization. Then the claim will gradually be articulated and be classified into deviation, social problem or the other type of problems. Finally, the factor and solution for the claim will also be articulated. In the following chapter, we will analyze communicative aspect of dementia and examine the difficulties of early detection of dementia.

3. Analysis

3.1. *Method*

We have analyzed semi-structured interview data stored in DIPEx-Japan[5]. DIPEx is a database of personal experiences of health and illness. It contains patient interviews data and the database is opened to public through the Internet. So patients, their family members and medical professionals can access the narrative. DIPEx-Japan has various theme of narrative. In each section, there are voice data (some interviewees hide their face) and text data like Fig. 1. In this chapter, we will focus on narrative about ``beginning of dementia".

3.2. *Results*

We examined how caregivers (including family members) noticed the beginning of dementia before some type of troubles are clearly classified into dementia. In the following analysis, characteristic phrases will be shown in several categories.

The first type of narrative is the narrative in which people didn't regard as dementia. There are some examples as follows (with Japanese translations).

- I didn't imagine the possibility of disease. (病気の予想なんかしてなかった。)
- I think our family had never considered the possibility of dementia. (認知症かどうかっていうような風にはみんな捉えてなかったんじゃないかと思う。)

In several cases, we observed the reason why people had not regarded as dementia.

- My mother had depression and saw her doctor regularly. So I was not sure whether she was dementia or not. (うつになって以来神経科とかにかかってて、それでずーっと来たので、その異変ていうのが、どこから異変ていうのがわからなくて。)
- I thought she looked strange due to her age. (年をとって、そういうふうになっているみたいな。)
- On that day, he might be not feeling very well. (その日は、体調が悪いのかなとか思って。)

Secondly, there are the narrative in which people pointed out some specific events they felt wrong or strange as follows (with Japanese translations).

インタビュー内容テキスト

実は、異変に気付いたときはね、まあ、今から思うとってことなんですよね。そのときは、やっぱり、分からなかったんです。ていうのが、両親も年とっていきますしね、自分自身もね、昔に比べるとだんだんもの忘れが激しくなってね、外出するにも３回も４回もうちを出入りしたりしている自分がいるもんですからね。単純に、両親も、もう年齢的なものかなってそのときは思っていました。

Fig. 1. The construction of interview data. Upper side is voice data and lower side is text data (in Japanese).

- I think she often left her belongings. (置き忘れとかはね、結構あったと思う。)
- It took so long time for my husband to search his belongings. (あれどこいったんだろうって、探す時間が長くなって。)
- He sometimes forgot a password for ATM. (たまに暗証番号忘れてお金が下ろせなかったりとか。)
- He made a phone call to a certain person and did soon again to the same person. (さっき電話をかけたところにまたかけ直す、みたいなことがあって。)

These behaviours are nearly equal to the dementia symptoms which are known as typical ones. In addition, some people focused on the other type of behaviour.

- Her bahaviours, especially in the way of walking, looked wrong for me. (やっぱり挙動ですかねえ。歩き方がおかしいとか。)
- Her sleeping hours gradually increased. (睡眠時間がだんだん長くなってきたようなのを覚えています。)

As we mentioned, the beginning point of dementia is usually not clear. In fact, the following examples shows the aspect of dementia and a type of confusion for family members.

- I'm not sure when is the beginning of dementia. (いつごろ始まったかっていうのは、はっきりしない。)
- In those days, I was not sure whether my husband is dementia or not. (そのときは、やっぱり、分からなかった。)

However, there are the narrative in which people pointed out something wrong or strange as follows (with Japanese translations).

- A few years ago before my husband was diagnosed with dementia two years ago, I think something strange happened around him. (その診断の2, 3年前には、何かいろいろあったような気がする。)
- My mother was mature for her age. However, there were something strange with her. (しっかりした母親やったんですよ。ところが、何か様子がどうも。)
- When I visited my mother, I felt something wrong with her. (訪ねて行ったときに、どうもいつもと様子が違う感じを受けた。)

3.3. *Discussion*

Usually people didn't determine whether their family member was dementia or not because they compared their family with common people. In addition, it may be difficult for them to detect the differences between normal state and wrong state.

In the second type of narrative, people pointed out some specific events they felt wrong or strange. However, these behaviours are nearly equal to the dementia symptoms which are known as typical ones. So it is not so suitable for early detection of dementia. On the other hand, in the last type of narrative, people told they felt something wrong or strange. These narrative seem not to have significant meanings, but feelings which family members as caregiver may feel are important. We think these narrative are less influenced by cognitive bias.

4. Conclusion

For early detection of dementia, we regarded dementia as a type of communicative problem which was gradually articulated through communication with people concerned. From the viewpoint of that, we examined narrative data stored in DIPEx-Japan and classified characteristic phrases into several categories.

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Authors Introduction

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