



Short Communication

Himotoki as a decision-making empowerment tool to live well with dementia

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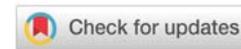
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Abstract

Shared decision-making is indispensable among people with dementia, their families, and healthcare professionals to ensure that people with dementia live well. Since living with dementia involves the process of losing one's independence and requiring support from others in all aspects of life, everyday life becomes a series of shared decision-making and collaborative efforts. Dementia care includes the process of rebuilding relationships through shared decision-making and collaboration. In particular, it is of paramount importance to make decisions on how to live well with dementia. Owing to a decline in independence, it may become difficult for people with dementia to live well or achieve happiness on their own. Hence, they are expected to cooperate with people close to them, including family members, to lead happy and fulfilling lives. While making a shared decision, conversations with a person with dementia may result in miscommunication due to a decline in their ability to communicate. If it is difficult to understand certain words or actions of the person with dementia, rather than dismissing them as incomprehensible, caregivers are recommended to analyze the factors underlying those words and actions (background factors), such as the person's current cognitive state and functioning, human and physical environments, and relationships with other people.

Aims of dementia care

Dementia is a profoundly life-changing condition for those who have it, as well as their families and others close to them. All the parties involved are forced to find ways to cope with the various changes and challenges that continuously occur in daily life due to this condition. Currently, there is no cure for the progressive causative disease for dementia including Alzheimer's disease, and people with dementia inevitably suffer from a gradual decline in cognitive functioning. Moreover, it is unlikely that cognitive functioning will improve with treatment. Therefore, dementia care, rather than treatment, is all the more important to empower people with dementia and their caregivers to grasp the meaning of life, regardless of the cognitive decline. Indeed, an individual's cognitive functioning should not and does not determine their entire identity. Collaborative care is desirable to help people with

dementia, their families, those close to them, and healthcare professionals explore the meaning of life. There are ways to make their lives more meaningful and delineate their hopes of living with dementia, both in the present and the future during the advanced stages of the disease. Even if their cognitive functioning declines, people with dementia can live well if they receive proper support and understanding from others.

Living well with dementia

Physical and cognitive independence may affect an individual's objective Quality of Life (QOL), although it possibly does not affect their subjective sense of well-being. There has been a lengthy discussion on the discrepancy between the subjective sense of well-being or QOL of people with dementia and the observations of their caregivers. Some studies affirmed that self-reported QOL was less reliable than caregivers' reports due to cognitive decline and lack of insight [1,2]. However,

caregiver observation cannot be objective as the relationship between the people with dementia and their caregivers may modulate caregivers' responses [3]. Furthermore, caregivers' burden and depression were associated with a more negative QOL assessment for the people with dementia they cared for [4]. In addition, caregiver observations contain essential contradictions since QOL should be a subjective feeling that others cannot know. Trigg, et al. (2007) reported that self-reported QOL assessments were feasible and appropriate for people with mild to moderate dementia and showed consistency in responses over a 2-week period [5]. Hence, it is worth developing communication skills and methods to assess the subjective QOL of people with dementia.

For people with dementia, interactions with others are important to identify themselves. Autobiographical memories shape a sense of self and identity, including self-consciousness, self-knowledge, and self-image; people with dementia, especially those with Alzheimer's Disease (AD), suffer from a decline in such memories [6]. As living with dementia includes the process of losing independence, interaction with others becomes indispensable and all the more important. Hence, collaborative efforts to find the meaning of life may mean much for people with dementia and their families and enhance their subjective sense of well-being.

Shared decision making

Autonomy and decision empowerment: To live well with dementia, shared decision-making is essential for people with dementia as well as their families and caregivers. The involvement of people with dementia in decision-making should be respected as self-decision, which contributes to maintaining their identity and promoting well-being and dignity [7-9]. Their treatment and care should be based on their values and beliefs, which are personal matters, and should ultimately be related to how they wish to live and die with dementia. Personal relationships are also critical, as dementia essentially deprives people of their independence, and their care depends on their personal relationships.

Previous reports have shown a broad spectrum of involvement in decision-making in dementia [10]. McGlade, et al. (2016) reported that people with dementia in advanced stages could reveal their will with structured end-of-life care planning support and that the benefits of shared decision-making enhanced the peace of mind for both the individual and medical professionals [11]. This report suggests that people in the advanced stages of dementia could express their will when healthcare professionals used their elaborate communication skills. Furthermore, such communication would bring benefits for people with dementia as well as healthcare professionals. Therefore, it is worth developing a method of communication to empower decision-making in people with dementia. Furthermore, such a role should lie in the realm of care, rather than medicine.

Shared decision making for interdependent LIFE: SMILE

The author proposed intervention for dementia, titled, Shared Decision Making for Interdependent Life: SMILE [12-

14]. In this intervention, first, people with dementia were requested to identify what made them happy. Next, they were asked to discuss how they would build lifestyles to make themselves happy in collaboration with those close to them, including family members. Through this discussion, they were expected to realize that everyday life consisted of reciprocal interpersonal relationships.

However, from clinical experiences, it is sometimes difficult for people with dementia and their family members to discuss their future lives together. Since dementia is progressive in nature, both the individual and their family members may be frightened by the progression of the disease, making it difficult for them to imagine what the future holds. In these cases, professional healthcare support can be useful for providing evidence- and practice-based perspectives on the vague concerns regarding the future. Furthermore, when providing information, emotional support and trustworthy relationships are prerequisites for providing negative information.

Another concern is the discrepancy in thoughts between people with dementia and their family members [15]. When an individual with dementia faces cognitive impairment and a decline in cognitive functions, family members often encourage the individual to recover from these difficulties. Since people with dementia may be aware of this decline and know that they will not recover, the families' expectations lay heavy on them and such encouragement may be taken as reprimands. Thus, although trustful relationships at home are desirable, these could become strained. Rather than facing dementia together, the trusting relationship is often damaged by differences in the approach toward the disease. Furthermore, the words and behaviors of people with dementia do not always express what they really intend. In some cases, it is difficult for persons with dementia to organize and verbalize their true feelings, and sometimes it may be difficult for them to manage their words and actions, often manifested as Behavioral and Psychological Symptoms of Dementia (BPSD). As miscommunication between people with dementia and their family grows, mutual understanding becomes increasingly less.

Himotoki as a tool to develop a framework for their hopes and desires

As mentioned above, even in the early stages, it is difficult for people with dementia to express what they want and what they are willing to do. In such cases, caregiver support is required to help them delineate their thoughts and provide a structure for their vague feelings. Himotoki (a Japanese word meaning "to unravel tangled threads") can be used as a tool to unravel the tangled, vague thoughts of people with dementia. To make a shared decision while also confirming the thoughts of the person with dementia, it is necessary to unravel their hidden intentions from various aspects.

Himotoki was originally developed for professional caregivers; a family version is currently under development. Professional caregivers are expected to have knowledge and care experiences about dementia and its comorbidities, while caregivers within the family usually do not have much

knowledge; therefore, the contents of the family version of Himotoki should be understandable even for those without knowledge of dementia. In addition, experts have experience in caring for multiple persons with dementia and can predict the prognosis and view the symptoms objectively, whereas, family members are often new to dementia care, find it difficult to make predictions, and are easily overwhelmed by the symptoms they encounter. It is also difficult for family members to be objective because they have known the person since before the onset of the disease and have struggled to care for him/her, whereas, professionals are expected to have an objective point of view because their relationship begins to post the onset of dementia and is impersonal. Therefore, in the family version, the feelings of family members should be also taken into consideration. In the following text, “caregivers” is used to refer to professionals.

Himotoki was conceptualized based on the Theory of Mind (ToM) reasoning, the ability to infer what is going on in the minds of others [16]. It is impossible to actually *understand* others' thoughts and feelings; it is only possible to infer them. ToM reasoning refers to the mental function of making inferences about others' minds based on their words and actions. The following hypothesis explains the process of inferring others' thoughts: 1) First, a representation of the external stimuli is made corresponding to the subject's own belief from a first-person perspective. 2) Next, the subject infers someone else's belief and interprets the representation from the other's perspective. If there is a discrepancy between the subject's own belief and the inferred belief of the other person, the subject is expected to choose one or the other. 3) If the subject adopts the other person's perspective, they are required to inhibit their own perspective [17-25].

The process of thinking using Himotoki is as follows

1) First, the caregiver is expected to explicitly face what they think about the words and behaviors of the individual with dementia. The caregiver is expected to honestly verbalize their feelings regarding the words and/or behaviors of the individual with dementia (external stimuli), and also verbalize their demands of that person. The caregiver is asked to verbalize complex emotions, such as the burden of caregiving, the desire to manage the behavior and anger at the incomprehensible behavior of the person with dementia, and even feelings of disgust and apology. The caregiver is also requested to be honest about their expectations of the person with dementia. As mentioned above, it is important for caregivers to face their own feelings regarding the individual they care for.

2) To infer the thoughts and feelings of the individual with dementia, the caregiver is asked to analyze the factors underlying their words and actions objectively. Once a miscommunication occurs, it is difficult for an individual with dementia to recover through dialogue, due to a decline in their ability to communicate. In addition, when the burden of care increases due to their words and behaviors, the caregivers tend to react emotionally. Therefore, it may be effective for caregivers to objectively analyze the background of the words and actions of the person with dementia, as well as objectively consider their own thoughts.

While focusing on the words and behaviors of people with dementia, the caregiver is required to organize any information that may be relevant as background and/or supporting factors. The analysis is conducted using the framework of the International Classification of Functioning, Disability, and Health (ICF) [26]. Examples of factors to consider are as follows:

Body Functions and Structures: the influence of the effects/ side effects of medication, pain, insomnia, and hunger;

Activities (at individual and societal levels): incompatibility of current activities with the person's wishes and level of functioning (including cognitive function);

Participation (at societal levels): relationships with family members and caregivers;

Personal factors (at a contextual level): a gap between life history, familiar life, current situation, and feelings such as sadness, anger, and anxiety;

Environmental factors (at a contextual level): stimuli, such as sound, light, smell, coldness, warmth, and the environment of the living space. Human environments are also considered.

3) In the last step, the caregiver is expected to try and inhibit their own perspective, which has been realized in the first step, and imagine the true intentions, hidden behind the apparent words and actions, of the person with dementia. The caregiver is then expected to *put themselves in the shoes of the individual with dementia* and think of what they can do for that person. Here, it is important to note that even if the caregiver thinks that they can empathize with the individual with dementia through this process, these feelings are still subjective on the caregiver's part. Only individual with dementia knows what they are really thinking or feeling. Therefore, it is always necessary to confirm what a person with dementia is thinking, by communicating with them. If the person with dementia has difficulty giving an answer in exact words, the caregiver is required to observe their reaction and repeat the analysis. In this way, dementia care can be an accumulation of empathetic communication between the caregiver and the care receiver (Figure 1a).

One example of using Himotoki has been described here (female case of Alzheimer's disease; intervention for this case was approved by the Ethical Committee of Tokyo Center for Dementia Care Research and Practices #5-2016).

1) The person with dementia attended day service, and at the service, she said that her belongings had been stolen, as though asking the people around her to agree. The caregiver wanted her to quit saying such things since it made the other participants of the day service feel anxious, and wanted her to spend her time at the day service happily. Then, the caregiver looked for a role that the person with dementia might prefer to do at the day service, without consulting her.

2) To analyze the background of the word “stolen,” the caregiver considered the following. Regarding activities, the woman with dementia liked singing, but she sang at her own

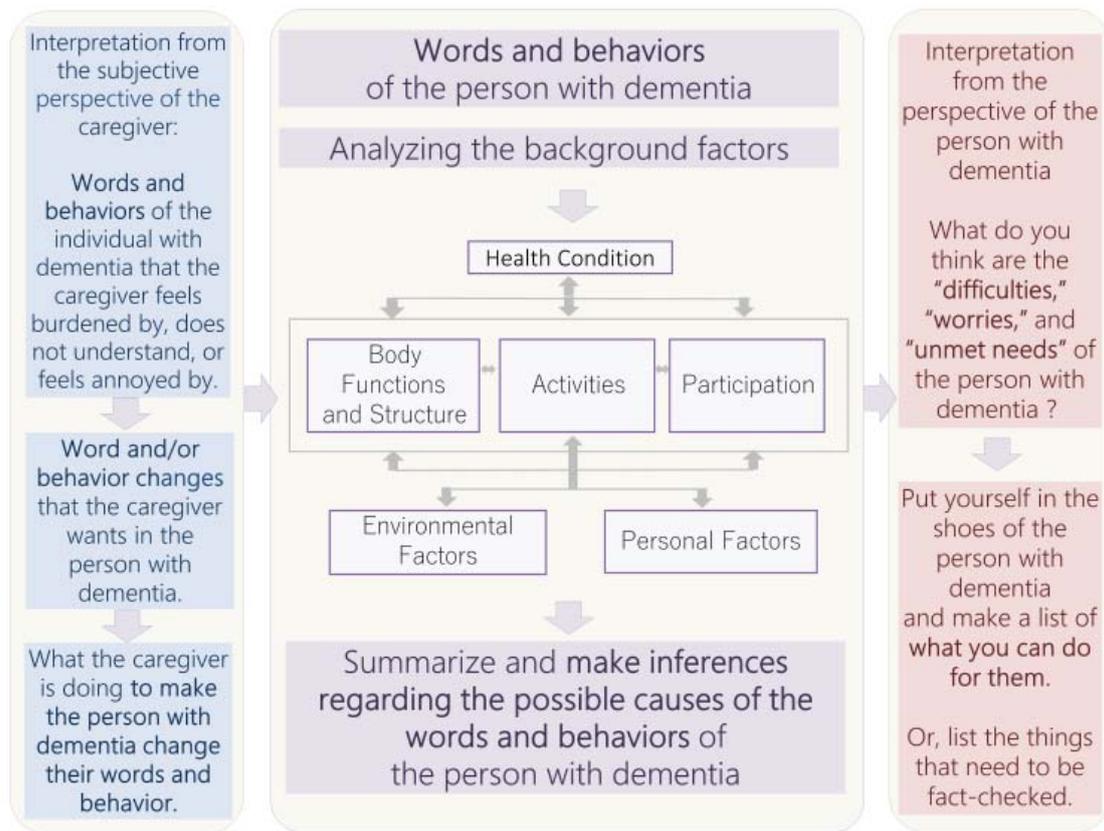


Figure 1a: Concept of Himotoki.

- 1) Left column: first, the caregiver faces their own intentions. They are expected to write down the words and behaviors of the people with dementia that they feel burdened by, do not understand, or feel annoyed by. Next, the caregiver is expected to write down how they want the individual with dementia to change. They are also expected to write down what they are doing to make the individual with dementia change their words and behavior.
- 2) Center column: to infer what an individual with dementia thinks and feels, the caregiver is requested to analyze the background factors of their words and behaviors objectively. The analysis is conducted within the framework of the International Classification of Functioning, Disability, and Health (ICF). [27] Next, the caregiver is expected to summarize and make inferences regarding the possible causes of the words and behaviors.
- 3) Right column: in the last step, the caregiver is expected to interpret the words and actions from the perspective of the person with dementia and think of their "difficulties" "worries," and "unmet needs." Finally, the caregiver is expected to list what they can do. The list of the things to be fact-checked.

pace; therefore, she had difficulty singing harmoniously in the chorus. In terms of participation, since she appealed for consent from other participants about her belongings being "stolen," it appeared she did not share a good relationship with them. Furthermore, regarding relationships with her family members, she said that it would be a help to her family (reduced care burden) if she came to the day service.

3) Analyzing her own true feelings about the word "stolen," the caregiver supposed that the woman might be saying such things to get people's attention because she was lonely. In other words, in the first step, the caregiver thought from the subjective perspective of the caregiver, that the woman *should* stop saying such things since it made other participants feel uneasy and annoyed. Therefore, the caregiver tried to seek some roles at the day service to keep the person with dementia occupied in order to prevent her from saying such things, without consulting her; however, the caregiver failed to find an appropriate role. At this stage, the caregiver was looking for a role to *distract* the woman, without considering why she was saying such things. Distraction does not lead to an actual

solution. Thus, instead of trying to distract her, the caregiver imagined the background of the word "stolen." Consequently, the caregiver realized that the woman's loneliness might be behind this word. If she had said "stolen" to get other people's attention, the caregiver decided it would be more effective to hold a conversation that she and the others would enjoy. Therefore, the caregiver tried to mediate between the woman and the people around her by offering topics that they were all interested in so that she and those around her could relax and enjoy the conversation. Similarly, in the chorus, the caregiver tried to find songs that this woman could sing in harmony with others (Figure 1b).

In this way, Himotoki is a prerequisite tool for communicating with persons with dementia. Here, what is important is try to understand the feelings behind their words and behaviors, rather than *making them "stop"* the annoying words and actions. It is not a question of whether what is understood or imagined is true; to build relationships, it is important that the person with dementia feels that they were given consideration.



Figure 1b: A case of delusion of theft of a female with Alzheimer disease at a day service.

- 1) Left column: the caregiver wanted to make the person with dementia stop saying the words "stolen," and tried to offer her a role at the day service to keep her occupied.
- 2) Center column: the caregiver tried to determine the reason for the words "stolen," and imagined that the feeling of loneliness might be the cause.
- 3) Right column: instead of trying to make her stop saying "stolen," the caregiver tried to find a topic that she and other participants might enjoy and to mediate the conversation.

As a result, it can be expected that the undesirable words and actions (as in this case, "stolen") may be eliminated, but the goal is not to eliminate these words; the aim is to build a good relationship with the person with dementia through communication. In this way, dementia care can be an accumulation of reciprocal empathetic communication between the caregiver and the care receiver.

Behavioral and psychological symptoms of dementia

Using Himotoki is especially recommended when families and caregivers experience difficulties in understanding the words and behaviors of people with dementia, for example, the BPSD. The BPSD has been assessed using tools such as standardized questionnaires, and a medical approach has been applied to identify the symptoms and conduct the appropriate treatment to manage them.

However, this approach is not always effective, for two reasons. First, even if the symptoms are similar, each person's background is different. For example, when a person tends to be withdrawn, it may be related to a failure at a gathering of friends, self-awareness of one's declining abilities, or a loss of cognitive function to understand the activities that used to interest them. Since each person has a unique background, it is not logical to name the symptom "withdrawal tendency" and

think of ways to deal with this abstract symptom. Second, a psychological aspect can be manifested as a variety of symptoms. In other words, different symptoms may have the same cause. For example, it may be possible that a sense of abandonment is the background for the manifestation of delusions of theft and/or verbal abuse; in such cases, it is effective to address the common background, rather than separately approach the symptoms.

The approach using Himotoki is completely different. Himotoki is a tool that analyzes the background of the actual words and behaviors and does not easily label the symptoms. If the actual words or behaviors of people with dementia are difficult for caregivers to understand, they can try to analyze the background or underlying factors and guess why the person says or does something and what their true intentions are.

Here, it is recommended that caregivers analyze the background of incomprehensible words and actions, such as the BPSD; however, it is not recommended to use Himotoki as a tool to alleviate the BPSD. Himotoki is not a tool for coping strategies, but is used to explore a person's true intentions; although one cannot know the other person's true intentions, one can guess at them. Setting goals in order to control people's behavior is not an appropriate or effective approach.



As such, Himotoki is useful only to *try* to understand the person better. One should never assume that it is possible to understand other people completely, including people with dementia. Therefore, it is necessary to communicate directly with people with dementia, and Himotoki is a useful tool for the preparation for such dialogue. Visualizing the thought process can be effective as it is difficult to completely abandon one's own perspective.

Role of professional caregivers

Care is the essence of living together. Regarding care at home, the main characters include individuals with dementia and their family members. In dementia care, the role of healthcare professionals in shared decision-making is to provide health-related information, including the prognosis. Furthermore, if there are any misunderstandings, they can support the restoration of communication. Living with dementia means continuing to rebuild human relationships in response to the changes and challenges of daily living. To live well with dementia, an alliance of the people with dementia, their family members, those close to them, and healthcare professionals is indispensable [27,28].

Communication for shared decision making

Care includes coping with the various challenges of daily living through shared decision-making and rebuilding relationships. The most important thing to share between people with dementia, their family members, those close to them, and healthcare professionals is *what people with dementia think happiness is*. It may be difficult for people with dementia to achieve happiness on their own due to declining independence; hence, they need to cooperate with people close to them to lead happy lives. Therefore, it is important to make shared decisions regarding how to cope with challenges in everyday life and live better with dementia. However, conversations with a person with dementia may result in miscommunication due to a decline in their ability to communicate. In particular, family members and other people who had a close relationship with people with dementia before the onset of the disease tend to hold conversations based on the premise of the relationship before the onset.

If certain words and behaviors of a person with dementia are different from those before the onset of the disease or are difficult to understand, it is recommended to analyze the background factors of these words and behaviors, including current cognitive state and functioning, rather than making judgments based on the standards before the onset of dementia. Himotoki can be a useful tool for this purpose.

Communication with persons with advanced dementia

There is no denying that it is difficult to communicate verbally with persons with advanced dementia. A proper assessment of verbal communication skills is certainly a prerequisite for communication with people with dementia; however, no matter how much the disease progresses or how pronounced the BPSD become, it is important to *believe* that communication is possible since people can understand what

is said to them in their own way even if they do not respond appropriately in language. It is the attitude of *trying to continue communication* with them that is important [29]. As a dementia specialist, Professor Shigeta makes it his rule to provide explanations about the disease even to persons with highly advanced Alzheimer's disease, since he *believes* that no matter how advanced dementia is or how pronounced the BPSD are, each person with dementia has a *healthy self*, which makes it possible for them to interact with others [29]. In particular, it is important to *believe* that emotions and feelings remain in abundance even as the disease progresses. The essential purpose of communication in dementia care is to infer the emotions of the persons with dementia, represent the inner thoughts that they are incapable to organize and verbalize, and provide support to delineate and give form to ambiguous thoughts. Himotoki can be a useful tool for trying to infer the mental state of people with dementia.

Limitations

Himotoki is only a concept of the framework of dementia care and needs to be elaborated in detail. Although this tool was developed for the use of professional caregivers, analysis using Himotoki is time-consuming and it cannot be feasibly implemented for all persons with dementia in care practice. In practice, it is feasible to implement it for specific cases, such as difficult cases.

The main challenge is to work out the details of the implementation methods and to develop methods to easily implement Himotoki. A further challenge is to develop educational methods; Himotoki can be used as teaching material to improve daily clinical practice for learning the concept of dementia care. By acquiring the capacity and skills for analyzing the background factors of the words and behaviors of people with dementia, healthcare professionals can improve communication with these people in daily practice, rather than getting distracted by their actual words and behaviors. Furthermore, developing the family version of Himotoki is another challenge at present.

Conclusion

To live well with dementia, shared decision-making is indispensable; it is recommended that people with dementia and those close to them, including their families, hold intimate discussions on how to live well. As for shared decision-making, people with dementia often have difficulty expressing their thoughts due to a decline in cognitive functions. Therefore, it is of utmost importance for those close to the persons with dementia to analyze the background of their words and actions, try to infer and understand their true intentions, continue communicating with them and rebuild relationships without being restricted or consumed by the superficial words and actions.

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