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Special Feature Article

Decision-Making Support of Medical Choice for People with Dementia

Jin NARUMOTO

Department of Psychiatry, Graduate School of Medical Science, Kyoto Prefectural University of Medicine

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Abstract

The number of households with only older people and older couples who have no relatives is increasing, and how to decide the treatment for patients with dementia is an issue. Psychiatrists face these challenges as an attending physician in admission wards for dementia, a consultation liaison psychiatrist and a clinical ethics committee member. As it becomes difficult to understand and judge treatment due to the influence of dementia, decision-making support is required to decide the treatment according to the intentions of the person. When performing medical treatment based on consent, it is necessary to evaluate the medical consent capacity, and if there is a decline in this capacity, the multidisciplinary team and family members should estimate the intention of the patient and support decision making. If there is an advance directive or advanced care planning, it should be reflected in the decision. Moreover, attention should be paid to nonverbal reactions. A four-element model of "understanding", "appreciation", "reasoning", and "expressing a choice" is generally used for medical consent assessment, and a semi-structured interview, such as MacArthur Competence Assessment Tool-Treatment (MacCAT-T), is used for detailed assessment. Consent capacity is affected by behavioral and psychological symptoms of dementia, such as depression and delirium, and patterns of cognitive decline. The capacity required also depends on the risks, complexity, and needs of the treatment. In decision-making

support, communication skills and support for family members are also required, in which specialty as a psychiatrist is needed. The active involvement of psychiatrists in the treatment decision process is required to ensure that people with dementia retain their right to receive satisfactory medical care.

Keywords : dementia, medical choice, consent capacity, decision-making support

Introduction

As dementia progresses, it becomes more and more difficult for patients to express their wishes. When a patient with severe dementia develops a physical illness such as cancer or pneumonia that requires treatment, the question arises as to how to determine a treatment plan that reflects the patient's wishes. Psychiatrists face this issue as attending physicians in dementia treatment wards and commissioned physicians in nursing homes, and recently, psychiatrists also have the opportunity to be involved as members of hospital clinical ethics committees. Medical treatment is invasive to a patient's body, so it is legally stipulated that it must be performed based on the patient's consent. For this reason, it is recommended that even if the patient has difficulty in verbally expressing their intention, advance directives and advance care planning should be referred if available, and even in the absence of such directives, the

presumed intention should be reflected by listening to the opinions of those who know the patient well and paying attention to non-verbal responses.

This paper describes points to keep in mind in order to achieve the best interests of the patient while respecting their will, regarding the assessment of medical consent capacity necessary for obtaining consent when verbal communication is possible, and the decision-making support process when decision-making capacity has deteriorated due to serious illness.

I. Assessment of medical consent capacity

When obtaining informed consent, physicians tend to assume that patients with a diagnosis of dementia do not have the capacity to consent, and explain the diagnosis and treatment option only to family members. In Japan, there is a culture that says "Be guided by your children when you are old", and patients and their families have accepted this practice without any

particular sense of unease. However, as the number of older people living alone or in older people-only households increase, the number of older patients who do not have family members to give consent on their behalf is increasing in acute care hospitals, and it has become necessary to obtain consent from the patients themselves. Thus, the assessment of the ability of patients with dementia to consent to medical care has been attracting much attention in recent years. Although this change is driven by necessity, it is certainly a desirable direction from the viewpoint of respect for self-determination, and we believe that this is a good opportunity for physicians in other medical departments to learn about the concept of decision-making support.

The first step in obtaining consent from the patient is to assess the patient's capacity to give consent. The physician tends to proceed with the treatment without concern for the patient's capacity to consent as far as the patient agrees to the medical treatment proposed by the physician, whereas if the patient refuses, the physician tends to consider that the patient lack the capacity to consent without sufficient examination. In addition, objective evaluation is necessary because the physician's evaluation is influenced by the diagnosis, appearance, and manner of

speaking. We have experience with a case in which a patient with idiopathic normal pressure hydrocephalus who was admitted to a psychiatric hospital for mental retardation and psychiatric symptoms was evaluated for the capacity to consent using the semi-structured interview method described below, and was judged to have the capacity to consent by devising an explanation that matched his intellectual ability 4). It is important to note that the subjective evaluation may be influenced by the patient's diagnosis and impression. The following table summarizing such common mistakes in clinical practice was published in the Journal of the American Academy of Family Physicians (Table 11). As shown in the table, many physicians believe that only a specialist can evaluate medical consent capacity, but most medical procedures do not require such strict evaluation due to the high necessity of medical care, so it is sufficient for the treating physician to be a little aware of it and check it in their practice. On the other hand, if the medical treatment is invasive or has a significant impact on the patient's life, it is necessary to evaluate whether the patient's consent is valid if the medical treatment is performed only with the patient's consent.

A four-factor model of the ability to consent to medical treatment is

generally used, which consists of understanding, appreciation, reasoning, and expressing a choice (Table 2) 11). It is said that the ability required differs depending on the complexity, risk, and necessity of the medical treatment. For medical treatments with clear benefits and low risk, such as influenza vaccination, it is possible to obtain valid consent even with low ability, while for treatments with high risk and a significant impact on life after treatment, such as cancer surgery, high ability is required to obtain valid consent (Figure 1).

Evaluation should be done at the best condition and if the patient's understanding and judgment are temporarily impaired due to delirium or depression, it is important to evaluate the patient after improvement of the patient's condition through treatment if there is time to make a decision 5). In addition, it is necessary to prepare an environment in which the patient can concentrate on conversation and to devise explanations that are easy to understand. Psychiatrists routinely explain medical conditions and treatment to patients with impaired understanding due to cognitive decline or psychiatric symptoms, and are accustomed to providing easy-to-understand explanations. However, physicians in other departments, where the majority of patients have no

understanding problems, find it surprisingly difficult to change the way of explanation while taking patients' understanding into consideration.

One simple method to assess the ability to consent is to ask the patient to tell in their own words what they have been told about the diagnosis and treatment. Dementia, especially Alzheimer's disease, patients tend to be highly attuned and compliant to what others say, and tend to answer "yes" to everything, so it is important to check in a way that they explain spontaneously. This kind of simple capacity assessment can be performed not only by specialists in dementia care, but also by other healthcare professionals.

When careful consideration is needed, semi-structured interviews are used. There are several methods, the MacArthur Competence Assessment Tool-Treatment (MacCAT-T) being the most common 2). The MacCAT-T is designed to evaluate individual medical procedures, their contents, and treatment options by dividing them into four components: understanding, appreciation, reasoning, and expressing a choice, as described above (Table 2). The time required is 20 to 30 minutes, and each of the sub-item questions is scored, but there is no cutoff score, such as judging capable if the score is higher than a certain number. Instead, assessor judge according to the general

impression based on the scores. By scoring, the objectivity of the evaluation is enhanced, and it is possible to identify which areas of the patient's ability have declined, which is useful for promoting understanding by compensating for the decline, and supporting decision-making. The explanations and scoring criteria need to be modified according to the individual disease and treatment. The MacCAT-T recording form and scoring rubric for anti-dementia medications that we developed for research purposes are available for download for your reference 8)9).

The following is an explanation of the evaluation method for each element. In the evaluation of understanding, we ask the patient to explain in his/her own words the diagnosis, characteristics of the disease, course, good points and bad points of the treatment, and good points and bad points if the patient does not receive treatment. Regarding the appreciation, we ask questions such as whether the patient has any questions about the explanations given by us and whether the treatment is beneficial to him/her, and assess whether the patient recognizes the currently needed treatment as his/her own. Regarding reasoning, the logic behind the choice is assessed by asking the reason for the choice and the future prospects of how it will affect their life and work. In the depressed state, reasoning may be

affected by feelings of guilt and delusion of poverty. In such cases, the evaluation should be done again after the improvement of depression by treatment. The expressing a choice is evaluated to see if the patient is able to express their opinions consistently. If verbal expression is difficult, it is necessary to consider whether there are other ways of expressing one's opinions.

II. Decision-making support process

When deciding on a treatment plan, if the patient's capacity to consent to the medical treatment is judged to be maintained based on the above-mentioned medical consent capacity assessment, the patient's intention, whether it is consent or refusal, should be respected. On the other hand, if the patient's capacity to consent is judged to be impaired, the medical staffs, caregivers, family members, friends, guardians, and other related parties will be involved in presuming the patient's intention. If the patient does not refuse the treatment, the appropriateness of the treatment is verified. If the patient does refuse the treatment, repeated explanations are given in consideration of the person's best interests, and promoting understanding by building relationships and reducing the anxiety.

It is important to note that there is still a possibility that the individual refuses

treatment even though they fully understand the risks and consequences of doing so. If the patient's values and decision-making tendencies are consistent with their previous values, it may be necessary to respect the patient's will, even if it differs from the recommendation of the medical staff. It is important for the physicians in charge to listen to the patient's thoughts, putting aside the values of them, but they may be motivated by a desire to aggressively treat the patient, or they may be inclined to withhold necessary treatment because the patient has dementia. From this perspective, psychiatrists, who are relatively independent in terms of treatment, play an important role.

Next, the importance of decision-making support for family members is taken up. First, it is necessary to interview the family members, focusing on their relationship with the patient and their concerns, and to create an environment in which they can express their opinions at ease through supportive involvement. When the dementia is advanced and consent cannot be obtained from the patient, medical professionals tend to find a key person in the family and put the decision into the hands of that person, but as a result, the family member who is considered the key person is often troubled by the decision and regrets

whether the decision was the right one even after it was made. It is desirable to provide more in-depth information to help families make decisions, such as what options are recommended as a professional. It is also helpful to reduce the psychological burden on family members by informing them that their role is to provide the information necessary for presuming the patient's will, and not to make decisions on their behalf. Sometimes, family members may insist on a treatment plan that is not in the best interest of the patient from the medical point of view, and it is difficult to adjust the treatment plan, but in such cases, a solution may be found by exploring the psychosocial factors behind the family's claims. The skills of a psychiatrist, such as supportive psychotherapy techniques and a perspective on the family as a system, may be useful. The authors have published a guide that summarizes these points to keep in mind, which we hope will be useful at conferences and training sessions 3)10).

Next, we would like to consider medical consent and support systems for patients with dementia without relatives, which have been increasing recently. Currently, guardians in the adult guardianship system are not granted the right to consent to medical care and cannot consent on behalf of the patient. However, from the viewpoint of

protecting the rights of patients, they can listen to explanations of treatment plans and express their opinions. It is also important to involve them in the discussion as much as possible, as they can provide input from an economic perspective that is essential to the patient's treatment and subsequent life. In fact, bar associations and judicial scrivener associations provide training on decision-making support for medical treatment. In the psychiatric department, there are patients who have no relatives and are hospitalized for medical care with the consent of the mayor of the municipality. Notice from the Minister of Health and Medical Care and Ministry of Health and Welfare (regarding consent for hospitalization by the mayor of a municipality for admission for medical care based on Article 33, Paragraph 3 of the Act on Mental Health and Welfare of Persons with Mental Disabilities; June 22, 1988) states that "efforts should be made to understand the condition and trends of the patient by visiting them after consent is given". However, since there are many municipalities that only send a letter of consent and do not even visit the patient, it is not expected that the government will be involved in decision-making support for treatment of physical illnesses. The Ministry of Health, Labour and Welfare (MHLW) has

published "Guidelines for Hospitalization of Persons without Relatives and Support for Persons with Difficulty in Decision-Making Regarding Medical Treatment" 7), which explains process from the preparation of necessary supplies to what to do in the event of death and the decision-making process regarding medical treatment.

Finally, I would like to introduce an overview of the "Guidelines for Decision-Making Support in Daily Life and Social Life of People with Dementia" 6). These guidelines were developed in response to the importance of decision-making support pointed out in the Basic Plan for the Promotion of the Use of the Adult Guardianship System. They cover not only decision-making related to medical treatment, but also decisions related to daily life, such as shopping and use of services, as well as decisions on where to live and management of assets. The decision support process is divided into the following four categories: (1) improvement of personal and physical environment, (2) decision-formation support, (3) decision-expression support, and (4) decision-realization support (Figure 2). In addition to these processes of support for the patient, the importance of the family's role and support, and how to hold a meeting (decision support meeting) when

difficulties or questions are felt in assessing decision-making ability or support methods are also discussed.

Conclusion

This paper has described the process of medical consent capacity assessment and decision-making support. The assessment of the patient's ability to consent requires, as a prerequisite, the treatment of psychiatric symptoms that affect the patient's ability to consent and an understanding of the pattern with cognitive decline in order to explain in an easy-to-understand manner. In addition, decision-making support requires the establishment of a relationship with the patient, an accurate understanding of symptoms, and treatment, as well as communication skills and support for family members. Therefore, active participation of psychiatrists in this field is expected.

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表 1 臨床現場でよく起きる間違い

1. 臨床的な能力低下と法的な能力低下を同じと考える
2. 患者がこちらの指示に従わなければ同意能力がないと考える
3. 患者が治療に従っているうちは同意能力を評価する必要はない
4. 同意能力はあるかないかの2つに1つである
5. 認知機能障害があれば同意能力が欠けている
6. 同意能力の低下は永続的である
7. 十分な情報を提供せずに同意能力がないと決めつける
8. 認知症など精神疾患の患者はすべて同意能力を欠いている
9. 非自発的入院の対象となっている患者は同意能力を欠いている
10. 専門家でないと同意能力は評価できない

(文献1より著者翻訳のうえ引用)

Table 1: Ten myths about decision-making capacity

表 2 医療同意能力を構成する 4 要素

理解	<ul style="list-style-type: none"> ・ 医師から受けた説明の内容をどの程度理解しているか ・ 本人自らの言葉で開示された情報を説明してもらう
認識	<ul style="list-style-type: none"> ・ 医師から受けた説明の内容を、患者本人が自分のこととして認識しているか ・ 宗教的信念や文化的背景など個人の価値観も含めて検討する必要がある、最も複雑なプロセス
論理的思考	<ul style="list-style-type: none"> ・ 医療行為の結果を推測したうえで論理的に考えられるか
選択の表明	<ul style="list-style-type: none"> ・ 一貫性をもって自分の意見をはっきり表明できているか ・ 言葉で伝える以外に、文章にして書く、うなづくなどの手段で伝えられる場合も含む

(文献 11 より引用)

Table 2: Four Components of Medical Consent Competence

Understanding

- ・How much the patient understands the content of the explanation received from the physician
- ・Have the patient explain the disclosed information in their own words

Appreciation

- ・Whether the patient themselves perceives the explanation received from the physician as their own.
- ・This complex process requires consideration of personal values such as religious beliefs and cultural backgrounds.

Reasoning

- ・Whether the patient is able to think logically after inferring the consequences of medical treatment.

Expressing a choice

- ・Whether the patient express their opinions clearly and consistently.

In addition to verbal communication, this also includes cases in which the person is able to communicate in writing, nodding, and other means.

(Adapted from Ref. 11)

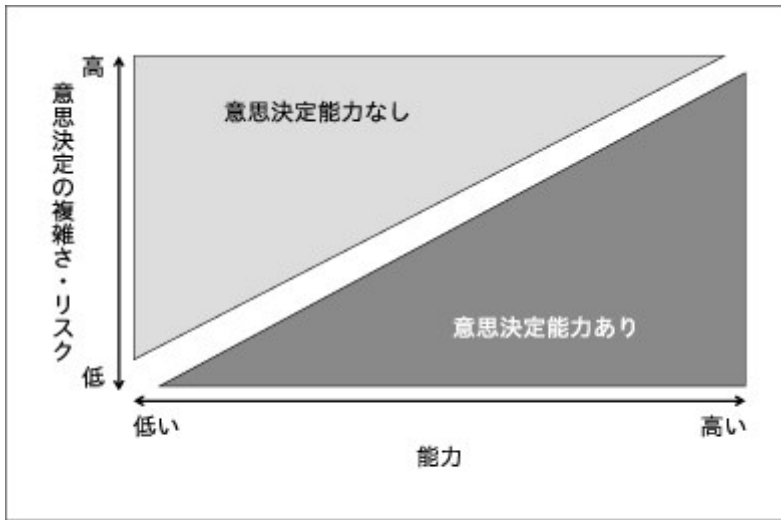


図1 意思決定に必要とされる能力と意思決定の内容の関係
(文献11より引用)

Figure 1: Relationship between competencies required for decision-making and the content of the decision (Adapted from Ref. 11)

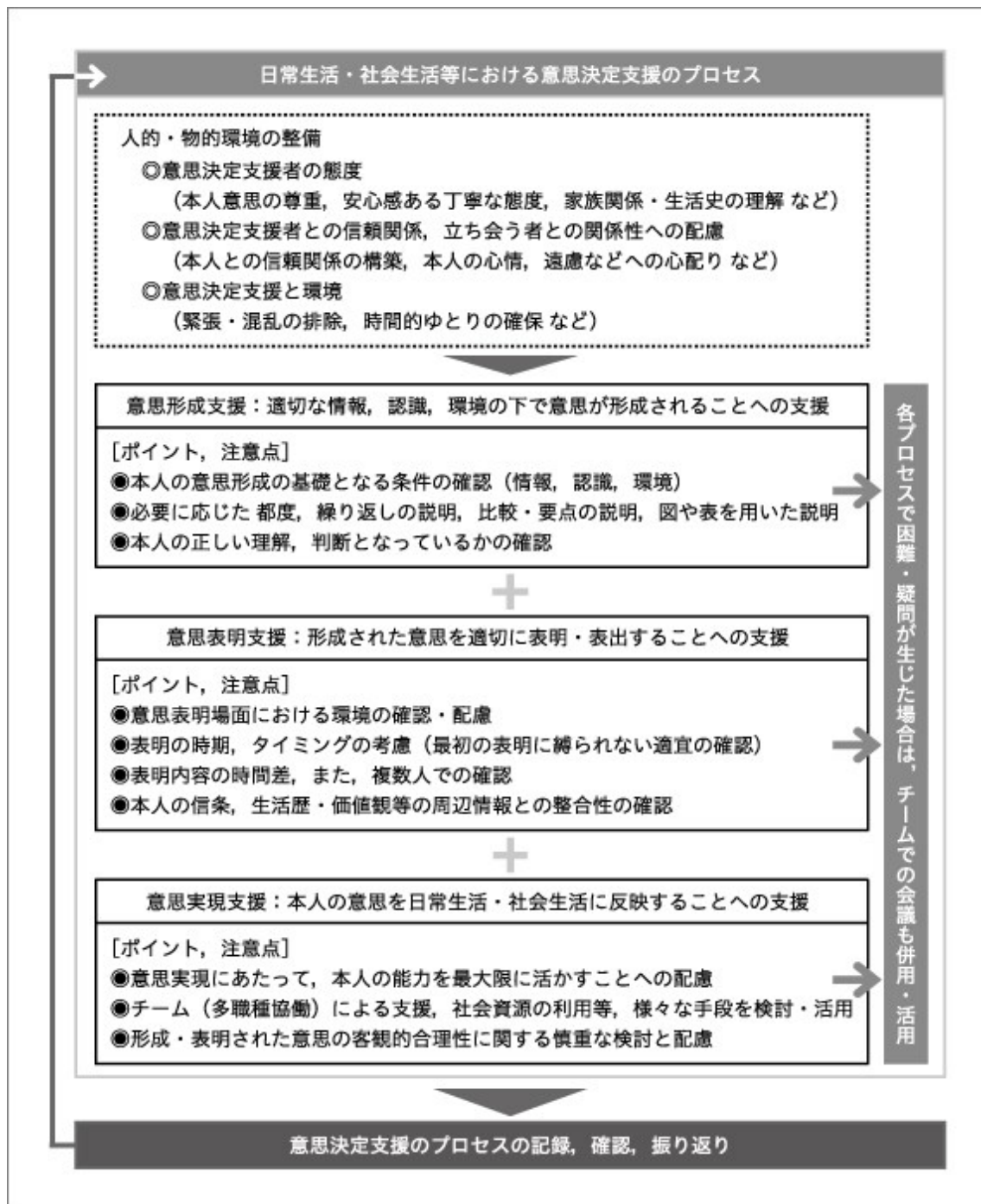


図2 『認知症の人の日常生活・社会生活における意思決定支援ガイドライン』プロセス図 (文献6より引用)

Figure 2: Process diagram of the "Guidelines for Decision-Making Support in Daily Life and Social Life of People with Dementia" (Adapted from Ref. 6)