Proposal of Advance Care Planning Support System

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Abstract. In terminal care, patients may not receive the treatment they want because they cannot express their will. We found that the "Advance Directive" and the "Living Will" are useful for determining the treatment in terminal care. However, patients being unable to respond to changes due to self-choices and share these self-choices when using a conventional format are some problems that remain. We propose an advance care planning support system that enhances the possibility of performing self-choices, collecting data about end-of-life care, confirming self-choices, and sharing the information with others using social networks.

Keywords: Terminal care · Advance care planning · Quality of death

1 Introduction

In step with the aging of the Japanese society, Ministry of Health, Labour and Welfare announced an "Integrated Community Care System [1]", a policy that regards elderly care at home. Meanwhile, a book about "Calm Death" became a best seller. In this way, the "Quality of Death" is becoming increasingly important. Recently, we found that an "Advance Directive" and a "Living Will" play an important role for patients in improving the "Quality of Death" in elderly medical practice. These previous reports contain directions about medical practice when a patient begins to face difficulties in making his own decisions and intentions clear. The documents can help the family and doctors to determine the treatment for the patient. However, even if elderly people wrote a living will, "it is only possible for heirs to know the result of the choice but unable to understand the reason for the choice" when using a conventional format [2]. Furthermore, a guideline announced by the Ministry of Health, Labour and Welfare warns that patients' will may vary and this must be taken into account [3].

We propose an advance care planning system that not only records the result of the patients' decision, but also the reasons behind their decision.

2 Related Work

Several studies on decision support in medical care are underway. Advance care planning is one of the methods of decision support [4,5].

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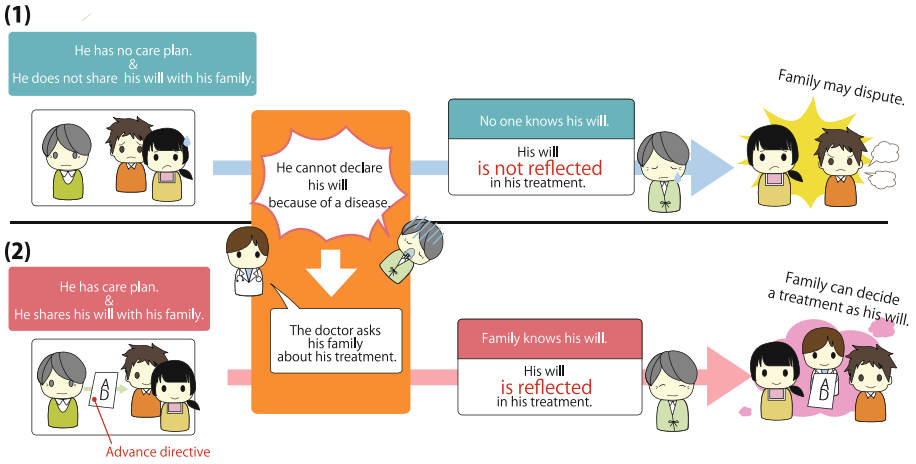

Fig. 1. Difference between presence and absence of advance directive.

The necessity for and the approach to advance care planning has been discussed recently. Many decision support systems for medical workers have been studied [6,7]. However, there are few decision support systems for common people. Thus, it was important to develop a "Patient's Decision-making Support System: PDSS", which is useful for advance care planning of common people [8].

Benjamin et al. developed "Making Your Wishes Known" [9] as an advance care planning support system for common people, which works on Adobe Flash Player[1]. Users can decide their advance directive by answering questions about terminal care. This system has numerous questions about terminal care. Because most questions are of objective type, it is easy for the users to answer these questions. However, this system does not collect the reasons behind the users' choices. Therefore, users' answers may not be used in an actual terminal care scenario. Our purpose is to enhance users' "Quality of Death" by supporting their self-choice in such a way that their family and doctor can select the treatment they want in case they cannot declare their will; this is illustrated in Fig. 1(2). Our system supports the users' self-choice and shares it with family and acquaintances. Furthermore, it records not only users' self-choice but also the reason behind their choice. Consequently, even if a patient is unable to declare his will, his or her family and the doctor could guess his or her will using this system and he or she could be treated accordingly in terminal care. One of the possible reasons for changes in a patient's self-choice could be a change in situation. Our system shows an example of self-choice and treatment presented to a user. If a family and doctor can know the patient's will in each situation, they could decide what treatment the patient wants.

[1] http://get.adobe.com/flashplayer/.

3 Design Policy

The design policy of our system is summarized in this section. In this system, there are two roles: the "user" and the "information provider". The "user" makes self-choices, and the "Information provider" records the questions about terminal care in the system.

Design policy 1 Encouraging user to make self-choices. We set this policy to collect enough data to help the user's family and doctor to decide his or her treatment in terminal care.

Design policy 2 Collecting enough useful data on self-choice and perception regarding terminal care. We set this policy to solve the problem in a conventional format as described in reference [2].
This system collects enough useful data of self-choice and general perception regarding terminal care to help decide the patient's treatment by recording the user's self-choice and the result of the choice.

Design policy 3 Providing information as a useful reference for self-choice. Sometimes, people may not make self-choices because of a lack of knowledge. We set this policy to help the user answer questions about terminal care.

Design policy 4 Considering variable self-choice. We set this policy to address the issue that the "patient's decision may vary," as stated in the guideline [3] announced by Ministry of Health, Labour and Welfare.

Design policy 5 Easy to share self-choice with others. In case a conventional format is used, the way to share the advance directive with family and acquaintances has been uncertain. Therefore, family and acquaintances may not be aware of the patient's will and the patient may not receive the treatment he or she wants. We set this policy to solve such a problem.

4 System Overview

4.1 Measures to Follow the Design Policies

The following measures apply to our design policies in Sect. 3.

- **Encouraging user to make self-choices.** We encourage users to make self-choices in our system by easily answering questions about terminal care. We developed our system as a web application. The user can answer the questions about terminal care anytime, anywhere, if they have a device which can access the web. Our system shows the question as a graphic image instead of a table. The image is that of a flower, where the color of its petals varies for every category.
- **Collecting enough useful data on self-choice and perception regarding terminal care.** The reason behind the self-choice is important to decide the treatment for a patient in terminal care using advance directive and living will. When answering a question about terminal care using this system, a user records a self-choice as well as a comment such as the reason for the self-choice and a request. Both the self-choice and the comment are mandatory fields.

- **Providing information as a useful reference for self-choice.** People may not make a self-choice because of a lack of knowledge if they are shown only the name of the symptoms and the treatments. When determining the treatment of a patient, their condition and situation that they're in is considered. Our system shows examples of true incidents to patients in terminal care. Thus, users may read understandable information. Users may refer to examples of actual self-choices and treatments during terminal care; these are introduced through books or news web sites, which an information provider experienced.
- **Considering variable self-choice.** Users can change their answers anytime in our system. However, people may not be aware of these changes when confirming the latest answer. Our system accumulates all the data answered by users. Users and their family and acquaintances can then comprehend the evolution of answers.
- **Easy to share self-choice with others.** Our system uses the function of sharing link in Facebook[2]. A message personalized by the user and the URL of the shared page is posted in their timeline when they click the share button.

4.2 System Configuration

Figure 2 shows the system configuration. Our system consists of the server that stores the data and the terminal used by each user. The server stores the following data: user data, question data, and users' answers. The information provider creates the questions data, while users can answer the questions about terminal care and view their self-choices and statistical data. Users can share their self-choice with others using SNS. We use Facebook as SNS to create the sharing function.

5 Function for Users

5.1 Screen for Users

A user can access the system using his or her Facebook account. The system acquires the information of the user within Facebook, and then the system can use the user's basic information.

Figure 3 is the screen shown after the registration or login. A flower shown on a screen shows one category. The number of petals is the number of questions present in the category [10]. One petal shows one question. A question is shown when the user chooses a petal. The colored area of the petal corresponds to the number of answers of the user. A user knows at a glance the number of times the answer has been changed. A user can appreciate an answer with several changes and another with very little changes. An answer with several changes may be the answer that will tend to change more for a user.

[2] https://www.facebook.com/.

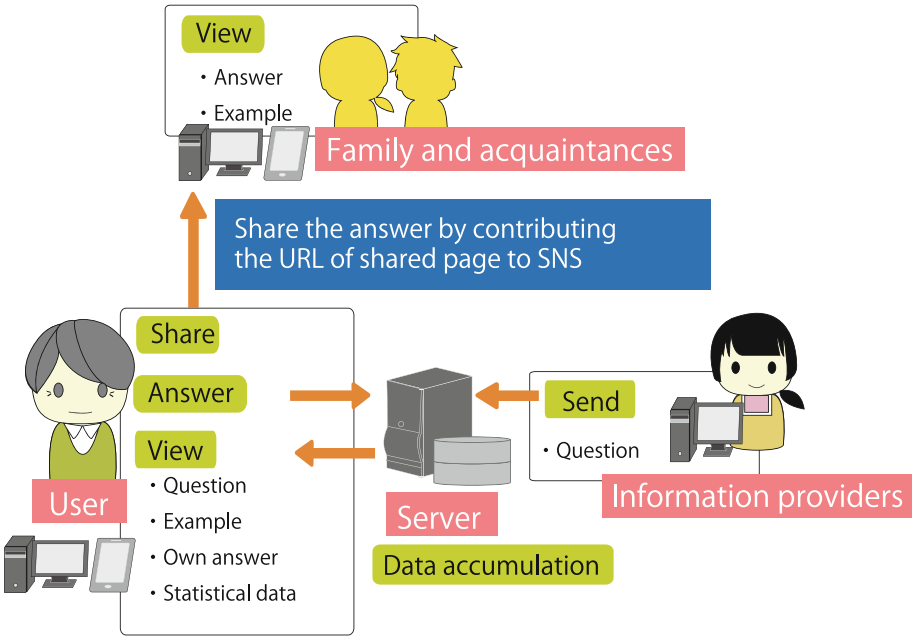

Fig. 2. System configuration

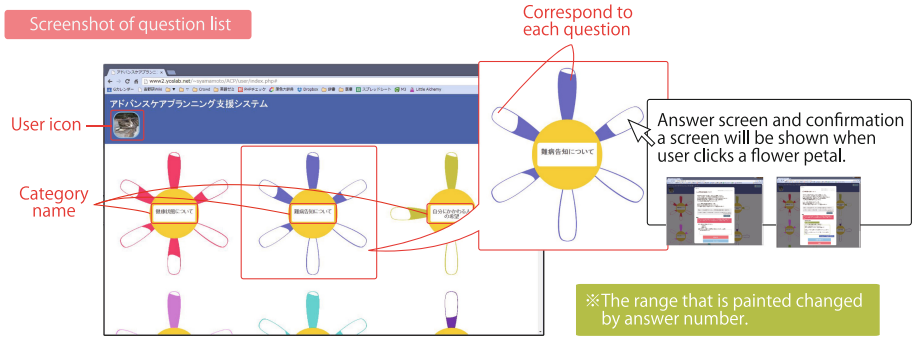

Fig. 3. Screen when logging in (Question list).

5.2 Answer Function to the Question

The top part of Fig. 4 an answer screen for a question.

Figure 5 is the actual case of Fig. 4, and the example of answer is in the bottom part of Fig. 4.

When the user clicks a petal, an answer is shown (Fig. 3). The user reads the case shown and a quoted article, and then answers. The user also gives the reason behind his or her choice and an impression on the quoted article in addition to the answer to the choices. The system requires a description for the reason.

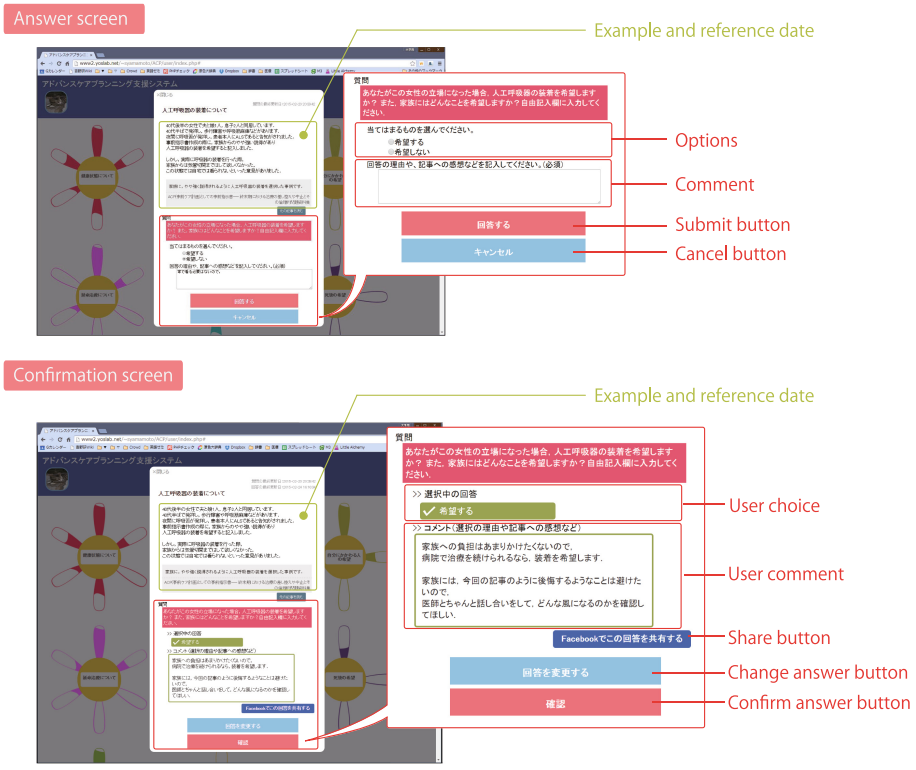

Fig. 4. Screen presented after a question choice (an answer and an answer confirmation).

5.3 Reconfirmation and Revision of an Answer

A user can reconfirm and revise any answer freely. The bottom part of Fig. 4 shows the reconfirmation screen of an answer and the revision screen of an answer. A user can check the contents of the answer and add a description on the confirmation screen.

When the answer was changed, all answers in the past are also stored. The user's family and acquaintance who share an answer can also kwon to answers in the past. In other words, the user's family and acquaintance can know the user's changeable self-selection.

5.4 Sharing an Answer

A user can share his or her answer with others by SNS (Facebook).

6 Function for Information Providers

An information provider shows questions to users. Anyone can prepare a question if they are registered as information providers.

Fig. 5. Case shown in Fig. 4 and an example of an answer.

6.1 Registration Data

An information provider should make up the following items into a question data.

– Basic items of a question
– Actual case
– Cited reference

Basic items of a question are the title of the question, the category of the question, the question itself, the different choices for the answers, and the item of the choices. The categories of a question were extracted from the ending notebooks in the marketplace and the ending notebooks exhibited on the internet.

The form of the answer is one of the following.

- Choice between two
- Choice (one choice)

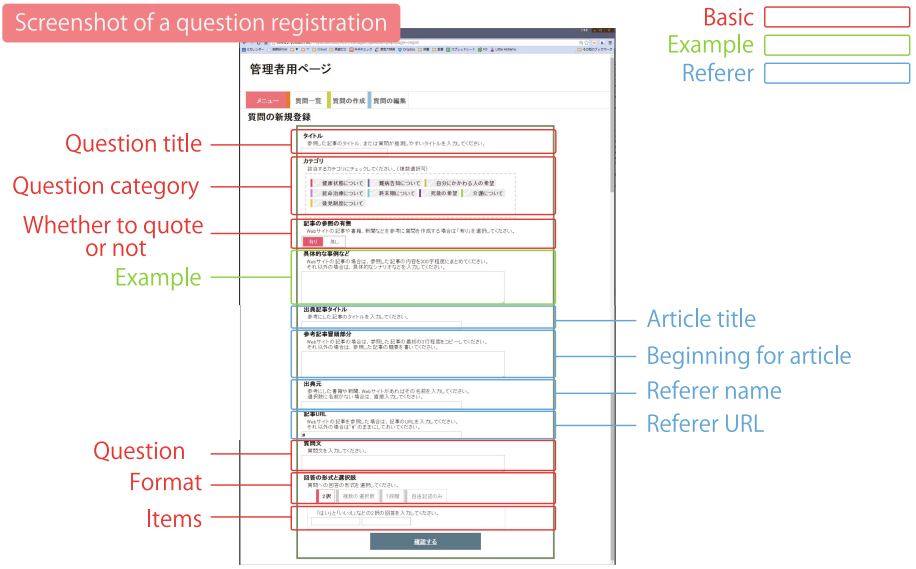

Fig. 6. Question registration screen.

- Choice (multiple selection)
- Seven-point scale
- Only description

The choices for the answers are input at the same time a question without "Only description" is added. An actual case is a one that occurred at a medical site, while the situation was developed by an information provider. We assume that the presentation of the situation in detail prompts a respondent to take self-choice more seriously.

6.2 Question Registration Screen

Figure 6 shows a registration screen of a question.

An information provider inputs the data in this screen, which is described in subsection 6.1. The red framed part shows the basic items of the question. The green framed part is an input part where an actual case is shown in detail to the respondent. The blue framed part is the quoted reference. The parts within the red and green frames are the required items.

7 Conclusion

We have developed an advance care planning support system. The proposed system is designed for changing self-choices. We plan to evaluate our system in the near future.

References

1. Ministry of Health, Labour and Welfare: Integrated Community Care System, 20 February 2015. http://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushikaigo/kaigokoureisha/chiiki-houkatsu/
2. Ogusu, N.: The possibilities of life story recollection by the elderly to understand their desires in the last stage of their life. Jpn J. Nurs. Sci. **28**(2), 46–54 (2008)
3. Ministry of Health, Labour and Welfare: The first national guideline on terminal care and withdrawal of treatment in Japan, 20 February 2015. http://www.mhlw.go.jp/shingi/2007/05/s0521-11.html
4. Thomas, K., Lobo, B.: Advance Care Planning in End of Life Care, pp. 4–24. Oxford University Press, New York (2010)
5. Abe, Y.: Advance care planning featuring shared decision-making. Palliat. Care **22**(5), 416–419 (2012)
6. Fatima, I., Fahim, M., Guan, D., Lee, Y.-K., Lee, S.: Socially interactive CDSS for u- life Care. In: Proceedings of the 5th International Conference on Ubiquitous Information Management and Communication, vol. 95 (2011)
7. Matsumura, Y.: Development of a clinical decision support system using clinical laboratory test data. Clinicopathological **59**(5), 512–518 (2011)
8. Itai, k.: What is medical information system as "Patient's Decision making Support System:PDSS"?, Information ethics collection book, vol. 2, pp. 84–97. FINE Project of Kyoto University (2000)
9. Green, M.J., Levi, B.H.: Development of an interactive computer program for advance care planning. Health Expect **12**(1), 60–69 (2009)
10. Takeshima, M., Kita, C., Kato, T., Yoshino, T., Yamamoto, S.: Construction of creation ending note support system. In: The 77th national convention of IPSJ (2015)