

Factors influencing the decision-making of elderly acute leukemia patients in Japan regarding their treatment

- Miki Fukuyama

Nursing Department, Faculty of Life Sciences,
Kumamoto University; 4-24-1, Kuhonji, Chuo-ku,
Kumamoto City, Kumamoto 862-0976 Japan
E-mail: fukumk29@kumamoto-u.ac.jp

- Atsushi Asai

Department of Medical Ethics, Tohoku University
Graduate School of Medicine

- Taeko Hanada

Department of Nursing, International University of
Health and Welfare

- Kenji Sakai

Division of Medical Oncology, National Hospital
Organization, Kumamoto Medical Center

- Yasuhiro Kadooka

Department of Bioethics, Faculty of Life Sciences,
Kumamoto University

Abstract

Objective: This study examined the process through which elderly patients with new-onset acute leukemia make treatment decisions from the time of diagnosis, in order to identify factors influencing this decision-making process in Japan.

Methods: Semi-structured interviews were conducted with twenty-two elderly patients with leukemia. The data were analyzed using the modified grounded theory approach.

Results: The process of decision-making in elderly patients with leukemia includes three stages: Initial reactions at diagnosis, change in attitudes, and entrusting the physician with the treatment plan. Initial reactions at diagnosis were affected by interactions with others that brought peace of mind to the patients. Change in attitudes was affected by encouragement from others to undergo treatment and their own motivation to face treatment. Patients came to entrust their treatment plan completely to their physician, because they wanted to feel relief and did not want to have to grapple with difficult medical information that was relevant to decision-making about their disease and treatment options.

Conclusions: The process of decision-making in elderly patients with leukemia is affected by several factors and included three stages. Our present study findings can provide suggestions on how medical professionals might better support the process of decision-making in elderly patients with leukemia.

Introduction

In 2009, 6.3 persons (7.8 males and 4.9 females) per 100,000 population developed acute leukemia (hereafter, leukemia) in Japan, with a total of 7,900 deaths (Japan Adult Leukemia Study Group 2011). Similarly, in the United States and Sweden, acute myeloid leukemia is much more common in elderly people (Juliusson et al. 2012). The number of elderly Japanese patients undergoing treatment for leukemia is expected to increase in the future, due to progress in treatment methods for elderly patients with leukemia as well as an increase in the size of the aging population.

Against this backdrop, it is important to identify how elderly patients with leukemia make decisions to undergo treatment and what factors affect this decision-making process. Sekeres et al. (2004) reported that elderly patients with leukemia make decisions without fully understanding the treatment involved, and recommended that elderly patients acquire solid knowledge about treatment and participate in the decision-making. However, few studies have investigated this process from the perspectives of the elderly patients with leukemia when they make the decision to undergo treatment. The present study clarified the process through which elderly patients with leukemia make decisions about treatment from the time of diagnosis, and identified factors that affect this decision-making process in Japan.

The results of this study may provide useful suggestions for medical professionals as they consider how to offer support for decision-making to elderly patients with leukemia.

Materials and Methods

Ethical considerations in recruitment of subjects:

The present study was reviewed and approved by the Ethics Committees at each medical institution involved in the study as well as that of Kumamoto University (Registration Number 239, Approved December 27, 2007). We received consent from all participants before including them in this study.

Recruitment procedure:

First, the investigator asked physicians at cooperating institutions to provide an explanation of the study to elderly patients (aged ≥ 65 years). Physicians were instructed to contact the investigator if any patient indicated a desire to cooperate. The investigator then met with the patient to provide a detailed explanation about the purpose of the study, as well as ethical considerations. After obtaining a written consent, an interview was performed.

The study period was from May 2008 to March 2012 (interrupted from July 2009 to August 2010 while the investigator was on maternity leave).

Data Collection

The investigator conducted all interviews with patients face-to-face. During the interviews, patients were asked about their awareness, attitudes, and thoughts regarding leukemia and their life with medical treatment. This report includes patient narratives regarding the period from diagnosis to treatment decision. Interview contents were recorded using an IC recorder.

Method of analysis

Data were analyzed using the modified grounded theory approach (Kinoshita 1999 & 2003). In this study, the analysis theme was as follows: "From the time of diagnosis to treatment initiation, how do elderly patients make decisions? What factors affect the process of decision-making?" To analyze data, an analysis worksheet comprising the columns for concept name, concept definition, examples, and theoretical memo was used. Verbatim records were carefully reviewed, while paying attention to data related to the analysis theme. Data were recorded in the example column. Next, the data were interpreted from the viewpoint of elderly patients, and ideas that emerged during the analysis were recorded in the theoretical memo column. The concept definition and the concept name were created, followed by comparative analysis based on the concept definition to seek out other similar/contrasting examples from the data. Other concepts were created in the same way as described above. An analysis worksheet was created for each concept. The relationship between each concept was examined and categories were created from the relationships between multiple concepts. Finally, the mutual relationships between categories were examined, yielding a map of categories.

Results

Participants

Twenty-two elderly patients agreed to be interviewed. Nine of the participants were in their 60s, ten in their 70s, and three in their 80s. Fourteen were male and eight were female. Two had been diagnosed with acute lymphocytic leukemia and twenty with acute myeloid leukemia. The interview duration ranged from 29 to 79 min, with a mean of 55 min. Patient information is shown in Table 1.

Overall results

The process of decision-making in elderly patients with leukemia comprised three stages: Initial reactions at diagnosis, change in attitudes, and entrusting the physician with the treatment plan.

Table 1: Participants' information

case	Sex	Age	Disease	Treatment
A	M	70s	ALL	Remission induction therapy→4 courses consolidation therapy
B	M	80s	AML	3 courses CAG (quiloside, aclacinon, G-CFS) therapy
C	M	70s	AML	Remission induction therapy→3 courses consolidation therapy
D	M	70s	AML	2 courses CAG
E	M	70s	AML	5 courses CAG
F	M	60s	AML	Remission induction therapy→consolidation therapy→1 course intensification therapy
G	M	60s	AML	RIT IDA AraC (rituxan, idamycin, quiloside)→CAG→VP (vepesid)+3 courses CAG
H	M	70s	AML	Remission induction therapy→3 courses consolidation therapy
I	M	60s	AML	Remission induction therapy, 1 course CAG
J	F	70s	AML	4 courses CAG
K	F	60s	AML	2 courses CAG
L	M	80s	AML	2 courses CAG
M	F	70s	AML	3 courses CAG
N	F	60s	AML	Remission induction therapy→consolidation therapy
O	F	60s	ALL	Remission induction therapy→consolidation therapy
P	M	70s	APL	Remission induction therapy→consolidation therapy
Q	F	70s	AML	2 courses CAG
R	M	60s	AML	CAG twice, MIT-Arac (novantron, quiloside) 2 nd course of vidaza
S	M	60s	AML	Remission induction therapy, 1 course CAG
T	F	70s	AML	Remission induction therapy, CAG, MIT-AraC, DNR-AraC (daunomycin, quiloside), CAG
U	F	60s	AML	Remission induction therapy, 3 courses CAG
V	M	80s	AML	4 courses CAG

※60s ; 65 years and older

※ALL ; Acute lymphocytic leukaemia; AML: acute myelogenous leukaemia

APL ; Acute promyelocytic leukaemia

※M: male; F: female

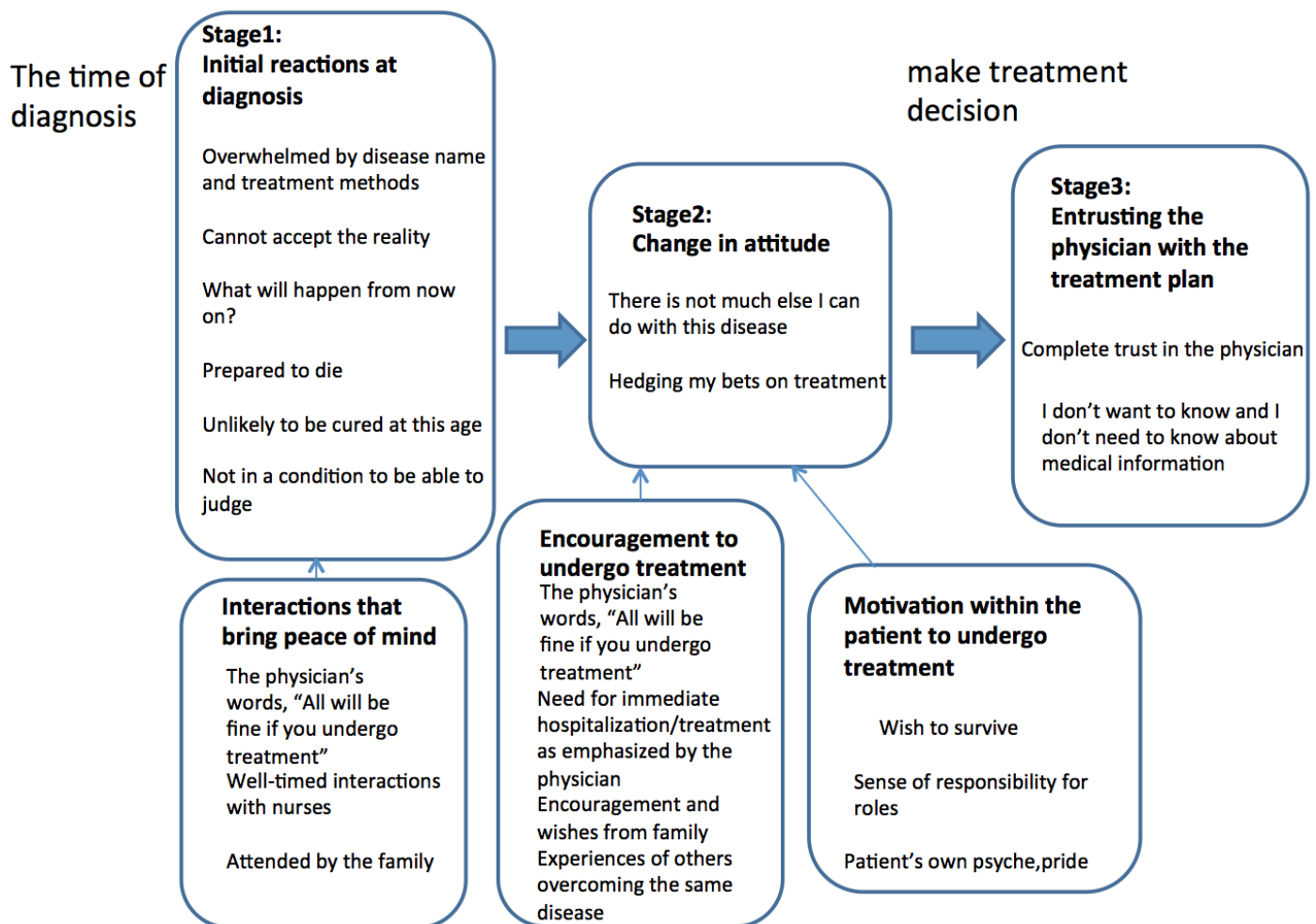


Figure 1: The decision-making process and associated factors in elderly patients with acute leukemia in Japan

Patients' initial reactions at diagnosis comprised negative feelings, but interactions with others brought them peace of mind. Patients changed their attitudes toward the disease through encouragement from others and their own motivation to undergo treatment. Patients came to entrust their treatment plans completely to their physicians, because they wanted to feel relief and did not want to have to grapple with difficult medical information pertaining to decision-making about their disease and treatment. Overall results are shown in Figure 1.

Stage 1: Initial reactions at diagnosis

In this study, elderly patients described six feelings including psychological distress that they experienced immediately after diagnosis. First, patients were overwhelmed by the name of the disease and its treatment methods. This occurred immediately after diagnosis, as many elderly patients had stereotypes associated with leukemia due to the influence of the media, e.g., that leukemia is an incurable disease. Some elderly patients formed an image of leukemia based on the experience of a close friend or acquaintance with leukemia from several decades ago.

"About 40 years ago, my wife's mother died of leukemia. Her doctor at the time said that leukemia was an incurable disease. This experience has been stuck in my head."

Second, elderly patients had difficulty accepting the reality, and some were unaware of leukemia, particularly among those with few subjective symptoms. Moreover, some patients were not convinced that they had developed leukemia, as they could not think of any cause.

"When I was told directly by my physician that [I had] myeloid leukemia, I said: Why? Really? Then I said: I'm in such good health. I really was healthy. No dizziness. So, I kept saying: No way, no way..."

Third, at initial diagnosis, patients were worried about the nature of disease progression and treatment to undergo in the future because they could not understand the relevant information.

"What treatment will be conducted? Will the treatment be painful?"

Fourth, in preparing for death, some elderly patients became strongly conscious of death, felt depressed, or became very reflective as they looked back on their lives.

"I have lived for 80 years already, and it's not like I have a family, or kids, so I'd say that if I were to die, it would be OK."

Fifth, some elderly patients felt that their disease was unlikely to be cured at their age.

"I felt pessimistic, thinking that, at my age, if I get sick with a disease like that, I would probably not get better again."

Finally, they were in no physical or mental state to listen to physicians' explanations or make any judgment concerning treatment decisions.

"When I was told that [I had] acute myeloid leukemia, I plainly asked: What is it, doctor? He said: It's a cancer of the blood. Then my mind just went completely blank, and while my doctor explained various things, I asked (my family): Please listen (to the doctor's explanations) on my behalf."

Interactions that brought peace of mind

Immediately after diagnosis, the distress that elderly patients experienced was alleviated to some extent through interactions that brought peace of mind. In particular, the physician's words calmed the distressed patients.

"My doctor said: It's a big deal to undergo anti-cancer therapy, but if you do, you will get better. We will cure you."

Furthermore, well-timed interactions with nurses also helped the anguished patients.

"When I said: I wonder if I will get through this New Year. I wonder if I will get through...; a nurse cheerfully said to me: Oh, everyone gets better and goes home. I remember how happy that made me."

Family members accompanying the patient also helped reduce the distress.

"My husband was always by my side."

Stage 2: Change in attitude

Elderly patients managed to change their attitudes while going through a number of hardships. They accepted their leukemia development as their fate, with the mindset that nothing can be done about it because they already have the disease, and tried to focus on treatment.

There's nothing that can be done about the fact that I got leukemia. I just need to do my absolute best to be a faithful patient and follow all that the doctor is recommending for treatment.

Some elderly patients prepared to take on this fate by hedging their bets on treatment, even though they were uncertain of the efficacy.

"As I had already resigned myself to the fact that I might not get better, I was in a position where I felt like taking a chance with treatment, even if it cost me my life."

Encouragement to undergo treatment

Encouragement from others to undergo treatment influenced elderly patients to change their attitudes. Many patients mentioned the physician's words; the only thing that elderly patients remembered clearly was physicians saying that they will try their best to cure them. This quote was noted in the context of 'Interactions that bring peace of mind.'

Moreover, the physician emphasizing the need for immediate hospitalization and/or treatment also greatly motivated elderly patients to move towards treatment.

"You only have one month to live. We can't just leave you in a state where the airplane is going straight down, [my doctor] said."

The family's encouragement and wishes, including the gathering of the family to make decisions, the collection of active information, and asking the physician instead of other patients, also pushed patients to undergo treatment.

"Two of my daughters and my son-in-law, who is a doctor, said: Nowadays, even with a leukemia diagnosis you can get better if you undergo proper treatment, so you should do it."

Furthermore, having seen or heard of patients who had overcome the same disease prior to diagnosis also served as motivation for elderly patients to summon their courage.

"My friend had acute lymphatic leukemia. He, though it's been 4 years already, has gotten considerably better. Seeing the way he is now makes me want to push myself, and hang in there a little more."

Motivation within the patient to undergo treatment

Some elderly patients were able to change their attitudes with motivation they found within themselves to undergo treatment. These elderly patients first felt the desire to survive, and this led them to switch their attitudes toward receiving treatment.

"I was filled with the idea that I must break myself away from this illness."

With regard to the sense of responsibility for their roles, there were patients who stepped into treatment with a strong sense of relationship between themselves and family or society.

"If I can live, I must live [for my family] as long as I can. After all, that's what caring for my family is about, I think."

Other elderly patients decided to undergo treatment by becoming conscious of their own psyche and pride.

"I want to be able to live my own life. Nothing bothers me. I've always kept a spirit of 'que sera, sera.'"

Stage 3: Entrusting the physician with the treatment plan

After changing their attitudes, elderly patients embarked on the first round of treatment by leaving treatment plans entirely up to their physicians. Patients placed complete trust in their physicians. In particular, the degree of reliance on the expertise of physicians at a hospital treating leukemia and doing chemotherapy tended to be high from the very beginning.

"I was still worried but I felt peace of mind because I was hospitalized and trusted my physician. This entrustment made me feel good."

The elderly patients did not need detailed information about their disease and treatment. Some of them even tried to limit their intake of such information, which may have increased their anxiety.

"I don't really want to know about the efficacy of drugs and what is involved in this disease. "

(Regarding supply of books about leukemia): *"I couldn't look at them at all. I was afraid that if I read those books, the knowledge about the disease entering my mind would make me more anxious."*

Discussion

Initial reactions at diagnosis

The elderly patients of this study experienced several kinds of distress, as described in previous reports (Friis et al. 2003; Koenigsmann et al. 2006; Meenaghan & Dowling 2010; Rodin et al. 2013). Also, the elderly patients' reaction to their onset of leukemia took into account their age. For example, they felt that their disease was unlikely to be cured at their age, or they began to prepare for death. In addition, we found that they were unable to listen to the physicians' explanations or make any judgments about their treatment. Their Initial reactions at diagnosis were based on stereotypes that had developed based on information from the media as well as their own experiences from several decades ago.

In Japan, TV dramas, documentaries, and films often feature patients who battle leukemia. Many elderly patients were exposed to instances in which

effective treatment for leukemia was not established. Interactions with others brought elderly leukemia patients peace of mind. In particular, physicians' words alleviated their psychological distress. LeBlanc et al. reported that many patients with leukemia described blunt communication between medical professionals that lacked emotional support, resulting in feelings of disappointment, fear, and even abandonment (LeBlanc et al. 2016). Therefore, we would propose that healthcare professionals can improve patients' initial reactions by exploring and correcting their outdated assumptions about leukemia, as well as through verbal communication that provides emotional support.

Change in attitude

A change in attitude came about when elderly patients managed to change how they perceived the fact that they developed leukemia. This change in perception likely resembles one of the coping strategies described by Lazarus et al., emotion-focused coping, in which one seeks to find a different meaning in an incident that he or she encountered and deemed stressful, by changing how the cause of this stress is interpreted (Chaen 2006). In this study, patients' change in attitude was influenced by encouragement from their physicians, family members and other leukemia patients. Some elderly patients found within themselves the motivation to undergo treatment, which led to a change in attitude. This motivation was driven by their desire to survive, patient's psyche, pride, and a sense of responsibility toward fulfilling their roles.

Physicians' words in particular appeared to have a major impact on patients as they considered undergoing treatment. In this study, the wish to live was expressed by many elderly patients. For elderly patients with such thoughts, a physician's encouragement evoked a feeling of great hope that they could undergo treatment, which led to a change in attitude. Puts et al. reported that chemotherapy, as the last resort to prolong life, was one of the most important reasons to face treatment (Puts et al. 2017). We surmise that the physician's explanation significantly influenced this change in attitude of patients.

The present study also revealed that the families of the elderly patients were active participants in the decision-making process. In Japan, patients and their families often desire to make decisions following a consultation with both the physician and the family present (Ito et al. 2010). In fact, some elderly patients in the present study decided to undergo treatment after obtaining information from their family members. Thus, involvement of

the patients' family members as mentors greatly impacts the changes in patient attitudes.

The present study revealed that experiences of others overcoming the same disease served as encouragement to elderly patients. Yogaparan et al. reported that family, friends, other patients, and the Internet were uncommon sources of information (2009). Peer support is a flexible concept used in healthcare across diverse areas to describe the activities of individuals acting in a non-professional capacity offering support to others with whom they have some experience in common (McLeish & Redshaw 2015); in recent years, peer support has become widespread in clinical practice for cancer (Kawakami et al. 2014). A report on peer support for patients with breast cancer found that patients were relieved to see others with the same disease doing well and that their true inner feelings were heard by others (Osaka et al. 2011). In this study, some patients experienced a desire to overcome the disease after listening to the experiences of other patients. Interactions with other patients who had overcome the same disease seem to contribute greatly toward the changes in attitude in patients.

The elderly patients' sense of responsibility toward fulfilling their roles also influenced changes in attitude. With regard to their responsibility toward their family members, some patients thought that receiving no treatment would make their family feel regret. This thought may be influenced by Confucianism, which values blood relationships, and collectivism, which not only considers individuals to be consistently part of a larger group, but also expects them to downplay their own personal goals relative to those of the group (Kaji 2015; Ishikawa & Yamazaki 2005). In fact, elderly patients of this study reported that they thought about how their decision affected their family, and chose to undergo treatment not only for themselves, but for their family as well.

The present study also revealed that patients' psyche and pride contribute greatly to changes in attitude among patients. One patient expressed that she had an unwavering mindset of "*que sera, sera*". Other patients took pride in themselves due to their past discipline (mental and physical), as well as their experience in overcoming many difficulties. For elderly patients, these types of psychological predisposition and pride can serve as sources of power that enables them to overcome difficulties and encouragement that can lead to a change in attitude. With regard to decision-making about treatment for elderly patients, some researchers have emphasized the need for sufficient consideration of treatment risks (Klepin 2015), while others have clarified that some elderly patients turn the decisions over to their family members (Miyama 2016). However, we would

suggest that a patient's psyche, pride, and sense of responsibility in fulfilling their various roles should also be taken into consideration when making decisions about treatment.

Entrusting the physician with the treatment plan

The present study revealed that elderly patients suffering from leukemia often opted to entrust the physician completely with their treatment plan. Underlying such a posture may be complete trust in the physician for their peace of mind, the lack of desire to obtain medical information, and the difficulty to understand such information.

With regard to complete trust in the physician, Nissim et al. reported similar patient attitudes as their psychological response (2013). Specifically, they found that patients with leukemia expressed a strong sense of trust in their health care providers, which provided a sense of "safety" in the midst of the chaotic and traumatic experience of the illness. In this study, after elderly patients changed their attitude and decided to receive treatment, they were still worried about their disease. Some patients stated that they entrusted their physician completely with their treatment plans so that they might eliminate the anxiety and feel relieved.

Previous studies on leukemia patients' need for information have reported that patients did not want to know detailed medical information, such as numerical data or potential side effects (LeBlanc et al. 2016; Puts et al. 2017). The elderly in particular expressed no desire to receive further medical details about their disease (Friis et al. 2003). Elderly patients of this study also exhibited little desire to obtain medical information. Some patients limited their intake of medical information in order to avoid anxiety. Friis et al. reported that avoiding information in this manner could be explained as a strategy to maintain hope, and that most patients more readily sought after information on problems affecting their everyday life and how other patients had coped with their disease (Friis et al. 2003). Similarly, some elderly patients of this study found themselves asking, "What will happen from now on?" Medical professionals who are interested in why patients are not eager to obtain medical information, or what kinds of information the elderly patients desire, may benefit from providing information consistent with patient preference.

With regard to the difficulty of understanding medical information, LeBlanc et al. argued that patients with leukemia face a particularly daunting task in trying to understand and contextualize incredibly complex information (LeBlanc et al. 2016). In addition, because the subjects of this study were elderly patients, declined cognitive

function was likely to increase this difficulty (Uldry et al. 2013).

In addition to a low desire to obtain medical information, participants of this survey exhibited complete trust in their physicians. In Japan, such an attitude is known as *omakase*, a traditional Japanese approach to medical decision-making (Specker Sullivan 2017). The term means to entrust decisions to another person, and is often heard in restaurants in Japan, where asking for the *omakase* set is to have the chef determine the contents of one's meal (Specker Sullivan 2017). In medical settings, it implies that a patient wishes to leave the decisions up to the physician (Specker Sullivan 2017). One reason why Japanese patients prefer *omakase*, Specker Sullivan argues, goes back to the importance of trusting relationships in the Japanese society, which may explain why they do not prefer to make decisions alone and take responsibility for these (2017). In this study, elderly patients placed a high value on their relationship with their physicians. To this end, they chose to entrust their physicians with their treatment plans.

Limitations

First, the sample size was small, and it was difficult to describe the process of decision-making for all Japanese elderly patients with leukemia. There may be other contributing factors in addition to those identified in this study.

Second, given the background of the study participants, recruitment was limited. Many of the participants had a decent support system. It will be necessary to study decision-making in elderly patients with various backgrounds.

Finally, the present study did not adequately compare decision-making in elderly patients with leukemia from a cultural perspective. In the future, similar studies in other cultures might help clarify the extent of involvement of certain Japanese cultural factors.

Conclusions

This study examined the thought processes of Japanese elderly patients with newly-onset acute leukemia from the time of diagnosis to decision-making on treatment, and identified factors that affected decision-making. Based on our findings, medical professionals should acknowledge the significance of their role in influencing patients and their decision-making; in particular, words from the physicians were reported to calm patient distress and encourage them to change their attitude. Second, medical professionals should pay attention to patient characteristics such as their sense of responsibility toward fulfilling their roles, their psyche, and pride, as these characteristics can bring about positive changes in a patient's attitude

toward treatment. Third, families of patients play a major role in the decision-making process, so medical professionals should offer support to the families as stakeholders. Finally, medical professionals should proceed with their decision-making regarding treatment for elderly leukemia patients knowing that the patients may seek relief in the form of entrusting their treatment plans to the physician and not obtaining detailed medical information.

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Eradicating Mosquitoes? The Promise and Peril of Gene Drive Technologies

- Bang-Ook Jun, Ph.D.

Professor, Department of Biology,
Gangneung-Wonju National University,
Gangneung, Republic of Korea
Email: bojun@gwnu.ac.kr

Abstract

This paper discusses the ethical issues associated with genetic modification of mosquito species that are human disease vectors. The Oxitec genetically changed mosquito—a variant of a species called *Aedes aegypti*, OX513A, is taken as an example. The benefits and risks are discussed, and questions need to be discussed in public prior to release of this gene drive system.

Introduction

Mosquitoes are high-impact disease vectors with the capacity to transmit pathogen agents that cause diseases such as malaria, yellow fever, chikungunya, dengue, and most recently Zika (Overcash 2015). Mosquitoes kill an average of 725,000 people every year. Since scientists first made the connection between malaria and mosquito bites, the mosquito has been the subject of important research, and also the vector of at least a dozen fatal diseases (Dawson 2016).

There are as many as 3,500 different mosquito species, of which 30 spread malaria, which kills more than 400,000 people, mostly children, every year. Zika virus, closely associated with birth defects and severe neurological symptoms, has

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