

# Development of Self-Management Support Program for Elderly Patients with Lung Cancer Receiving Molecularly-Targeted Therapy

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## ABSTRACT

**Objective:** Recently, Japan has seen an increase in the number of elderly patients with lung cancer, and oral molecularly targeted therapy has become an increasingly common treatment option for these patients. Accordingly, we have developed the Self-Management Support Program for Elderly Patients with Lung Cancer who are Receiving Molecularly-Targeted Therapy. The purpose of this study is to evaluate this program based on the responses of nurses to a survey regarding the program's usability by general nurses. **Methods:** We developed the program based on our previous study and the existing literature. To evaluate the program, general nurses interested in caring for elderly patients with lung cancer or patients with other forms of cancer receiving oral agents, took part in the survey about the program's appropriateness and usefulness. **Results:** Twenty-seven nurses took part in the survey. More than 90% of nurses agreed or slightly agreed with these statements: "the purpose of the program is appropriate," "the program

is suitable for patients," "The program is useful for general nurses," and "The program is useful for nurses in providing patient support." However, some of them commented, "Nurses do not have enough time to answer outpatients' queries" and "I'm afraid that general nurses can't use this program, because they don't have enough knowledge about lung cancer patients and oral agents." **Conclusions:** The study demonstrated that the self-management support program was appropriate. Further studies are necessary to modify this program to make it useful for nurses in the clinical setting. To further examine its effectiveness, in future, the program needs to be made available to elderly patients with lung cancer who are receiving molecularly targeted therapy with oral agents in the outpatient department.

**Key words:** Chemotherapy, elderly patients, lung cancer, molecularly targeted therapy

## Introduction

Recently, the number of patients with lung cancer has been increasing worldwide due to the aging of the population,<sup>[1]</sup> and oral molecular targeted therapy has become an increasingly common treatment option for lung cancer patients. Japan has seen an increase in the number

of elderly patients with lung cancer, most of whom are treated as outpatients. Such outpatients face many issues ranging from adverse effects from treatment, cancer-related anxiety, and patients must self-manage these issues at home.

There are a number of nursing intervention and education

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programs for patients receiving chemotherapy with oral agents.<sup>[2-6]</sup> However, these interventions and educational programs are aimed at increasing patient adherence and are not tailored to the needs of elderly patients, as they focus on improving patient knowledge.

Elderly cancer patients have different needs from younger adult patients. For example, while elderly patients still want as much information about their disease and treatment as their younger counterparts, they are less interested in the fine details. It has frequently been reported that elderly patients have particular psychological needs that should be addressed, with the emphasis on emotions and coping. Moreover, there are concerns that elderly cancer patients receiving oral agents may have adherence issues and difficulty in coping with side effects due to functional and/or cognitive deficits.<sup>[7]</sup> Programs are needed to meet the needs of elderly patients based on their individual characteristics.

Our previous study<sup>[8]</sup> have shown that support based on the physical, psychological, and social characteristics of older adults undergoing chemotherapy is necessary to maintain their quality of life (QOL). In addition, our study revealed that elderly patients with lung cancer receiving molecularly targeted therapy with oral agents in an outpatient setting were able to self-manage based on their views of their own lives and the ways they wanted to live.<sup>[9]</sup> Furthermore, these patients need to receive appropriate help and information in accordance with how they wish to live their lives, which in turn makes it possible for them to manifest their strengths and maintain their lives based on personal choices. However, patients who are treated in an outpatient setting do not receive sufficient nursing support. Nurses should promote self-management in a way appropriate to elderly patients and help them to preserve a better QOL. Therefore, a systematic program to promote self-management must be devised to support elderly patients with lung cancer.

## Development of Self-Management Programs

### *Purpose of program development*

The purpose of developing the Self-Management Support Program for Elderly Patients with Lung Cancer Receiving Molecularly Targeted Therapy is to enable nurses to effectively promote self-management to patients.

### *Definition of terms*

Referring to the definition by Knobf *et al.*,<sup>[10]</sup> self-management was defined as “a process in which patients cope with side effects and other disadvantages in daily life in a way that suits them and spend their lives

during recuperation in accordance with their preferences/wishes, utilizing the support of their family and health-care providers after understanding the disease and therapy.”

### *Program development procedure*

The program was developed in the following way. First, we established the objective of the program, along with the components, timing, number and duration of interventions, and methods of intervention.

The objective of the program was “to maintain and improve QOL while alleviating adverse effects and anxiety by providing social support and empowering patients to self-manage their condition.” By promoting the self-management of elderly patients with lung cancer, this program could reduce the adverse effects, anxiety and depression, and help to maintain and improve QOL by providing social support.

In our previous study,<sup>[9]</sup> we identified the process by which elderly patients with lung cancer were able to achieve self-management. Based on the results, we examined what kinds of support were needed to facilitate the process of self-management.

Once patients were informed of their disease status and started treatment, they tried to both “Accept life with cancer” and “Maintain activities of daily living without feeling shackled by cancer”. Therefore, we considered it necessary to assess how patients perceive their disease and to gain an understanding of each individual’s life to support them. This helps patients to maintain their prediagnosis way of life without being unduly worried about cancer. To further support this, it was also clearly necessary to provide information on how to deal with the disease and the side effects of treatment. Therefore, the nurses decided that the form intervention should take needed to focus on providing information that assists the patient to clarify how he/she wants to live in the future, to reflect on his/her life up to that point, and how to cope with side effects and other inconveniences that may arise. Patients embarked on this process at the time of treatment initiation, as we thought that the first intervention should coincide with the commencement of treatment.

Furthermore, the patients had accepted living with cancer and had begun to “reexamine their own way of life to the end” while maintaining their own unique lifestyle. Patients repeated this process of self inspection throughout the treatment period because of the uncertainty surrounding the future of treatment and the heavy financial burden. Therefore, we considered that in every step of the program, the patients needed to identify how they wanted to spend their lives.

And while patients continued their treatment, they attempted to integrate treatment and daily living by engaging in a repeated cycle of trial and error and formulated their

criteria for continuing treatment. Through this repeated cycle, patients weighed both therapeutic benefits and side effects and explored how they could to continue to live their lives autonomously. To make it easier for patients to follow their own path, it is necessary for nurses to provide support in symptom management.

Obtaining help from caregivers impacted and reinforced all of the processes referred to above. We thought that nurses should coordinate relationships between the patient and others, including their caregivers and health-care providers at every step of the program. In light of the above, we devised a program that consisted of the following components: (1) helping the patient maintain his/her lifestyle in accordance with their own values, (2) providing information that is tailored to each patient, (3) assessing the daily living situation of each patient, and (4) coordinating the relationships between patients and caregivers.

We considered three sessions to be a sufficient number to implement the program. By offering the first session at the beginning of treatment, patients can prepare for how they will live their lives in the future. The second session is designed to compensate for any lack of information and provide follow-up support for the first intervention; this session is scheduled when patients receiving treatment are beginning to experience a difference in their lives. Finally, the third session is provided at the time when many patients are having side effects and beginning to experience specific disruptions to their lives. It has been designed to help patients remain autonomous and continue to self-manage their condition.

We considered that individual intervention was appropriate because the cognitive level and other functions of elderly patients vary greatly from person to person, requiring individualized attention and discussion of their views on life and living. When providing information to the elderly, we included cautions for communicating with elderly cancer patients based on interactions that help them recall information.<sup>[11]</sup> The duration of each session was set at 20–30 min, with the expectation that it would be conducted during the waiting period at the time of an outpatient visit.

Nurses communicate with the patient and assess the patient's capacity for self-management and the difficulties they encounter. To help nurses gather information and conduct assessments effectively, we have developed the Nursing Practice Guide. This guide includes examples of questions to facilitate communication with patients. We also created the Patient Handbook for patients to refer to for information on specific self-management strategies throughout the process.

The components of the program are shown in Table 1.

### **1<sup>st</sup> session: At the beginning of therapy**

In addition to guidance from doctors and pharmacists on medications and how to manage side-effects, patients participate in sessions lead by a nurse. The patients have a consultation session with the nurse, answer some questions, and develop a plan for their daily life with the help of the nurse.

#### **Examples of questions from nurses**

*“Did you receive explanations from your healthcare professional about your illness and treatment?”*

*“Were the explanations you received from medical professionals on your illness and drugs easy to understand? Were you able to receive explanations in a way that suited you?”*

*“How do you plan to live your daily life while taking your medication and taking steps to prevent side effects?”*

*“Is there anyone who can help you? What kind of help do you feel you need?”*

*“How do you want to spend your time on a daily basis? What things would you like to continue doing on a daily basis? We will help you to do the things that are important to you.”*

### **2<sup>nd</sup> session: 3 weeks to 1 month after the start of treatment**

The patient has a second consultation session with the nurse. In this session, the patients assess their daily life with the nurse and reflect on whether they have been able to deal with any problems that arose and whether or not they have been able to maintain their chosen lifestyle in accordance with their own values and hopes. If the patient has problems, the nurse will refer to the nursing support guidebook and consider measures with the patient that address the problems.

#### **Examples of questions from nurses**

*“Has anything unexpected occurred in your daily life? Let's consider how we can go about solving your problem.”*

*“At the first session, I asked a question about what you would like to continue doing on a daily basis (e.g., enjoying hobbies, spending time with the family). Have you been able to do this? How have you been spending your time at home?”*

*“Are you getting help from your caregivers or friends when you encounter problems? Are you talking to your doctor or nurse when you need to? If you don't have any immediate problems or concerns, would you be able to consult them if problems were to arise?”*

### **3<sup>rd</sup> session: About 2 months after the start of treatment**

The patient meets with the nurse and answers some statements.

#### **Examples of questions from nurses**

*“Two months have passed since treatment began. Are you experiencing any problems in your daily life? Are things going well without any changes since treatment began, and are you satisfied with what you initially planned?”*

Table 1: Components of the self-management support program

The objective of the program			
“To maintain and improve QOL while alleviating adverse effects and anxiety by providing social support and empowering patients to self-manage their condition”			
Timing of intervention	1 <sup>st</sup> session	2 <sup>nd</sup> session	3 <sup>rd</sup> session
	At the beginning of therapy (before discharge or outpatient visit within 2 weeks of treatment)	3 weeks to 1 month after the start of treatment	About 2 months after the start of treatment
The objective	The patient is able to set life goals while expressing his/her thoughts on disease and treatment and can consider how he/she would like to spend time after leaving the hospital The patient can identify the tasks that he/she will have to perform and think about ways to handle them	The patient can think of ways to alleviate the undesirable effects of treatment The patient can talk to medical staff about issues that he/she cannot solve alone	The patient understands the methods and support that can be utilized to maintain his/her own lifestyle The patient can express his/her wishes for treatment by seeking assistance from families and medical staff when necessary The patient can continue to self-manage
Content and method of intervention	To help the patient maintain his/her lifestyle in accordance with their own values	Assess the patient's feelings in relation to disease and treatment Assess the patient's lifestyle in accordance with the patient's values	Assess whether the patient is able to maintain his/her lifestyle in accordance with his/her own values If the patient is unable to do this, consider the reason why this is so and how to deal with the problem Sympathize with the patient's feelings and provide positive feedback on his/her efforts
	To provide information in a way tailored to each patient	Determine which method of information provision is suitable for the patient depending on the patient's capacity to understand and the patient's preferences and provide the information using the method decided upon Assess the extent to which the patient understands the information on treatments/medicines provided by doctors, pharmacists, ward nurses, etc.	Reconfirm that the method of providing information is without problems Evaluate whether patients can utilize information on self-management from the handbook and drug pamphlets
	To assess the daily living situation of each patient	In conjunction with the patient, discuss symptom management in relation to the lifestyle desired by the patient Describe methods of symptom management, symptom monitoring, and oral administration using materials such as the patient's self-management handbook and medication brochure Explain the evaluation and corresponding side effects based on the patient's capacity to understand	Observe symptoms and provide information on effective countermeasures Assess what kind of things the patient is having trouble with in his/her daily life and, in conjunction with the patient, consider how these difficulties can be dealt with
	To coordinate the relationships between patients and caregivers	Find out who will be able to help the patient with their medical care, and who the patient can consult regarding disease and treatment If needed, cooperate with his/her attending doctor and outpatient nurse and share information about patients	Communicate with other medical personnel according to the patient's needs Assess the social support situation of patients and the burden on their lives and discuss whether it is necessary to utilize new social resources
Intervention environment	The ward nurse or outpatient nurse participates in this session The nurse gathers information and assesses the patient throughout the hospital stay Sessions are conducted in an environment where privacy is protected If the patient wishes, family members and caregivers can also attend the session	The outpatient nurse participates in this session Sessions are conducted in an environment where privacy is protected If the patient wishes, family members and caregivers can also attend the session	

QOL: Quality of life

*“Do you think that it will be possible to continue doing the things at home that you wanted to continue doing?”*

*“Are you getting help from your caregivers or friends when you encounter problems? Are you talking to your doctor or nurse when you need to?”*

*“Do you feel capable of continuing with self-management in your daily life?”*

#### **At the end of 3<sup>rd</sup> session**

At the end of the 3<sup>rd</sup> session, the nurse will assess whether patients can continue to manage themselves autonomously. If the nurse concludes, based on the assessment, that a patient can continue self-management, the nurse continues to provide normal nursing care. If it is difficult for the patient to continue self-management autonomously, the nurse should consult with a resource nurse at the hospital, such as a certified nurse specializing in oncology or cancer chemotherapy, and together plan a support program for the patient.

To obtain advice on the program, nurses with expertise in caring for elderly patients with lung cancer (certified nurse specializing in oncology or cancer chemotherapy, head of the nurse in respiratory medicine ward) were surveyed, using a focus group interview approach.

The program was modified based on the interview feedback from nurses. Nurses with a high level of expertise regarded the modified program as clinically applicable. However, some nurses with expertise commented, “This program is useful for us. However, it requires knowledge of cancer and treatment, so it may be difficult for generalists to use.”

Accordingly, we evaluated the program based on the responses of nurses to a survey regarding the program’s usability by general nurses.

## **Program Evaluation**

### **Purpose of the study**

The purpose of this study is to evaluate the Self-Management Support Program for Elderly Patients with Lung Cancer who are Receiving Molecularly Targeted Therapy based on the responses of nurses to a survey regarding the program’s usability by general nurses.

### **Program evaluation procedure**

#### **Participants**

Study participants were nurses interested in caring for elderly patients with lung cancer or cancer patients who are treated with oral agents. We recruited participants who were working in the respiratory wards, respiratory outpatient departments, and chemotherapy centers of the sentinel hospital for cancer therapy in Osaka prefecture, and participants were also recruited from the Japanese Society of Cancer Nursing Conference. At the hospital, we approached

the head nurses of the relevant departments, explained our research and its objectives, and asked them to distribute materials on the research project to general nurses. General nurses made contact with us by letter. We held a seminar for interested parties, and those nurses who wished to collaborate with us in the research were contacted by email.

#### **Timing of data collection**

Data collection was conducted from February to August 2019.

#### **Data collection method and content**

Participants read the outline of the program, the Nursing Practice Guide, the Patient Handbook, and evaluated the content according to the survey.

This questionnaire was developed with reference to a study that developed the Oral Agent Teaching Tool.<sup>[12]</sup> The survey included 14 statements about the program’s appropriateness and usefulness. The appropriateness of the program’s content was evaluated based on such statements as “The purpose of the program is appropriate” and “The program is suitable for elderly patients with lung cancer who are receiving molecularly targeted therapy with oral agents,” and the usefulness of the program was evaluated based on such statements as “this program is suitable for use in clinical settings,” and “The program is useful for nurses in providing patient support.” Participants were asked to answer using a 5-point scale: agree, somewhat agree, neither agree nor disagree, somewhat disagree, disagree.

#### **Statistical analysis**

The responses to the statements in the survey were tabulated for each statement; data were assessed by descriptive statistics. The description in the free text column is coded in units of semantic content, and categorized based on similarity.

#### **Ethical approval**

This study was approved by the committee for research ethics at Osaka Medical College Approval Approval (No.109-2632).

## **Results**

### **Participants**

Twenty-seven nurses responded to the survey [Table 2]. They were working in the respiratory ward or outpatient department or belonged to the palliative care team.

In the following, “**Bold**” indicates statements, “*Italic*” indicates comments.

### **The program’s appropriateness**

In terms of the appropriateness of the content [Figure 1], more than 90% (24 or more) nurses agreed or slightly agreed

with these statements, **“the purpose of the program is appropriate (27/27),” “the program helps patients review their daily lives (27/27),”** and **“the program is suitable for elderly patients with lung cancer who are receiving molecularly targeted therapy with oral agents (24/27).”**

However, for the statement **“The program is easy for patients to understand”**, ten participants (37.0%) replied Neither agree nor agree, or Somewhat disagree or Disagree. For **“The program is suitable for use in wards and outpatient setting”** five participants (18.5%) replied, Neither agree nor agree.

The following comments were made, *“I think this program will be an opportunity to think about problems such as patients’*

*daily life, their key person, and self-management,”* and *“The nursing practice guide contains detailed guidance and it is helpful, and makes it easy to provide support to patients to think and act independently.”*

Some of them commented *“It’s difficult for elderly patients to understand how to use the program. They will need to have the program explained to them by nurses,” “Nurses do not have enough time to answer outpatients’ queries”* and *“I’m afraid that general nurses can’t use this program, because they don’t have enough knowledge about lung cancer patients and oral agents”*.

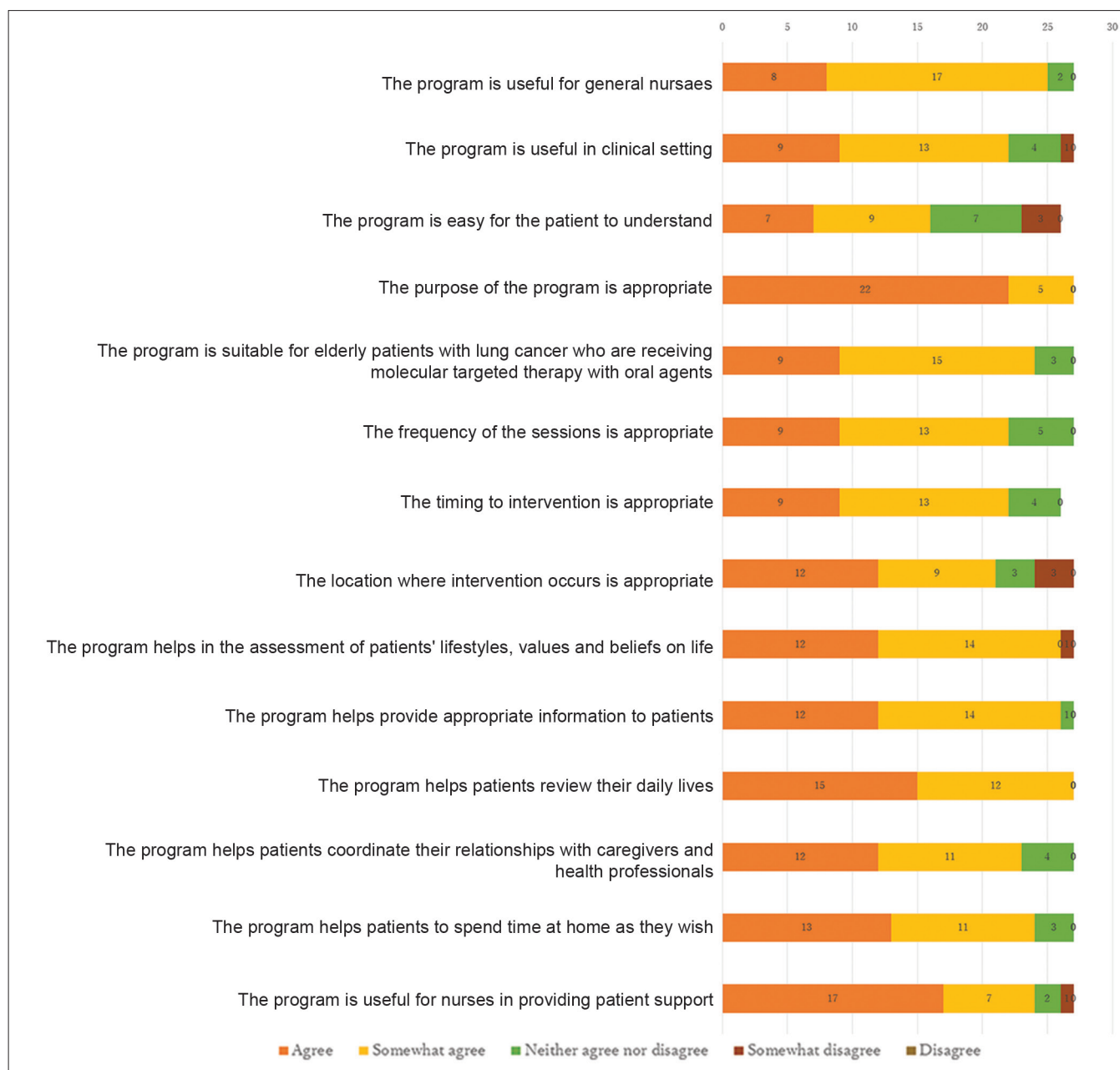


Figure 1: The program’s appropriateness

Table 2: Characteristics of participants (n=27)

Characteristics	n
Years of experience in cancer nursing	
1-4	1
5-9	7
10-14	8
15-19	3
20	7
No answer	1
Position	
Staff nurse	19
Head nurse	2
Chief nurse	5
Certified nurse specialist	2
Certified nurse	4
Department	
Ward	5
Outpatient	11
Outpatient chemotherapy center	8
Other	3

### The program's usefulness

More than 90% (24 or more) nurses agreed or slightly agreed with these statements, **“The program is useful for general nurses (25/27),”** **“The program is useful for nurses in providing patient support (24/27).”**

And some of them commented, *“Nurses couldn't continuously be involved with outpatients who are treated with oral agents. I think that we can effectively interact with patients by using this program.”* *“Elderly patients need the time and opportunity to talk closely with nurses, just as this program provides.”* *“Because the number of elderly cancer patients is increasing, I think that it is a useful intervention for patients who receive other treatments too.”*

## Discussion

### Appropriateness of the program

Our results confirmed that the program was appropriate. However, some comments suggested that the program may be difficult for elderly patients to understand. The reason may be that the amount of information in the patient handbook has increased because the Handbook includes numerous methods for dealing with adverse events and possible problems in life. Most patients, before program sessions with nurses begin, receive basic medication guidance from a doctor or pharmacist using existing drug pamphlets. Getting too much information can confuse patients. It is necessary to avoid further complicating the situation for patients by not cramming more information into the patient handbook or by using existing drug pamphlets.

It was also indicated that outpatient nurses were too busy to take advantage of this program and did not have

enough time to respond to patient inquiries. Furthermore, general nurses may have insufficient knowledge regarding lung cancer patients and oral medications, making it difficult for them to participate effectively in the program. The standard staffing ratio for outpatient nurses in Japan is one nurse to 30 patients, which has not changed since 1948.<sup>[13]</sup> However, the number of outpatients is growing and diversifying due to advances in treatment methods but with shortening hospital stays. This means that outpatient nurses need to have a range of knowledge and skills, from dealing with the adverse effects of treatment to supporting decision-making and utilizing social welfare systems. Moreover, outpatient nurses need to acquire or have access to specific methods and information to facilitate multi-disciplinary collaboration such as how to engage with pharmacists on providing explanations about drugs, how to interact and consult with social workers on social resources, etc., in order to effectively care for patients, even in busy situations. The program needs to be enhanced to provide information and knowledge effectively.

### The program's usefulness

In our study, the program was rated by the participants as useful, with good results being achieved. However, in outpatient settings, some participants thought it may be hard to use the program due to nurses lacking the time to communicate with patients and insufficient knowledge on the part of general nurses. To make this program more accessible to general nurses, it is necessary to reconsider the information included in the nursing practice guide. To make it possible for general nurses to use the program, it is also necessary to have an opportunity to given them an outline of the program and explain specific methods of support.

Elderly patients, especially those treated with oral anticancer agents, may have more psychological needs as they are away from the hospital. Despite this, the outpatient consultations for those receiving oral treatment tend to be of the short time, and they have few opportunities to engage with nurses. We thought that implementing this program would create an opportunity for busy outpatient nurses to interact with patients and enhance the quality of outpatient nursing.

### Limitations and future issues

The evaluation by nurses suggests that the program may be appropriate and useful. However, the program has not been evaluated by patients. In the future, it would be useful to have the patients themselves evaluate the program and ascertain if they think the program helps them with self-management and assists them in maintaining and improving their QOL.

## Conclusions

The study demonstrated that the self-management support program was appropriate. Further studies are necessary to modify this program to make it useful for nurses in the clinical setting. To further examine its effectiveness, in future, the program needs to be applied to elderly patients with lung cancer who are receiving molecularly targeted therapy with oral agents in the outpatient department.

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## Conflicts of interest

There are no conflicts of interest.

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