



## Psychological Transition Characteristics of Patients Diagnosed with Asbestos-Related Mesothelioma

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**Objective:** This study aimed to explore malignant pleural mesothelioma (MPM) patients' experiences of post-diagnostic psychological transition.

**Design:** Qualitative research design was used to investigate MPM patients' experiences of transition.

**Methods:** Semi-structured interviews were conducted of five participants with MPM. A phenomenological hermeneutical method was used. Their narratives were translated to the meaning units, they were analyzed to subthemes, themes, and main themes, and identified to the transition attitudes and actions.

**Results:** Four main themes of transition attitudes were identified: "Attempting to continue independent living and to manage symptoms", "Accepting the incurability of the disease in spite of being overwhelmed", "Deciding on treatment and life through uncertainty", and "Maintaining positive relationships with family". These themes were influenced on six main themes of transition action: "Creating new self-care regime", "Gathering information about asbestos exposure and MPM", "Preparing for dying through self-experience or the experience of other patients", "Receiving emotional support from family, coworkers, care providers", "Developing positive rapport with hospital staff toward effective treatment", and "Awarding of compensation".

**Conclusions:** Psychological transition was identified as changes, disruption and reconstruction of aspects of the patients' physical symptoms management, acceptance of MPM and dying, decision making, and family relationships. A positive psychology transition may result from being able to ease symptoms, obtaining useful information resources, sharing in decision making, and receiving care, including family support. This study has established a framework of analysis, which can be applied to clinical responses and to future studies with larger statistical samplings.

**Key words:** malignant pleural mesothelioma, psychological transition, phenomenological hermeneutical method

### Introduction

Mesothelioma is a relatively rare malignant disease, usually caused by occupational and environmental exposure to asbestos for 30-40 years<sup>1) 2)</sup>. Malignant pleural mesothelioma (MPM) comprises 80% of all mesothelioma cases<sup>3)</sup>. These cases cannot be treated partially because the disease has a diffusive progression<sup>4)</sup>. Some survivors after diagnosis die within a year; others live for many years. In 2015 in Japan, there were 1,504 confirmed deaths from the disease<sup>5)</sup>. Research has projected that there

will be about 100,000 deaths in the next 40 years<sup>6)</sup>.

It has been suggested that many patients diagnosed with mesothelioma experience frequent, complex, suffering<sup>7)</sup> and difficulty<sup>8)</sup>. They have physical symptoms such as breathlessness, pain, fatigue, and cough<sup>9) 10)</sup>, and significant psychological distress such as the shock of diagnosis<sup>7)-9)</sup>, increased depression and anxiety<sup>11) 12)</sup>, anger relating to the causative factors of the disease being out of control<sup>8) 12)</sup>, and a fear of deterioration and dying process<sup>9) 12)</sup>. Japan has enacted an Industrial Accident Compensation Insurance scheme, and an

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Act on Asbestos Health Damage Relief, but the patients do not receive instant financial compensation and support, and many die before receiving funds. In addition, MPM patient care does not meet their complex needs<sup>13</sup>. For example, there is a lack of information provided to patients about palliative care services<sup>12</sup>. Nurses likewise have little understanding of mesothelioma patients' perspectives<sup>9</sup>, and there is no exploration of the long-term impact of mesothelioma on people's lives<sup>13</sup>. Prior studies have not identified how MPM patients changed from negative conditions to positive ones, nor how to set the goals of care. In this study, we explore MPM patient's whole experiences of transition through the course of the disease. Understanding the comprehensive experience of them may be derived from the specific care needs and the goals of care. The development of appropriate interventions based on their needs will improve the level of care and quality of life for them.

## Methods

### 1. Subjects

The agreed participants consisted of five patients with MPM (M=68.8 years, SD=8.3), who diagnosed 5-8 years ago, shown in Table-1. They have regular treatment at university hospital. Including criteria were: age 20 years or older, able to speak Japanese, and fitting compensation qualifications of Industrial Accident Compensation Insurance, or Act on Asbestos Health Damage Relief. Excluding criteria were any patients considered at risk of psychological and physical strain by participating in this study, and preexisting psychological illness or dementia.

### 2. Procedure

The eligible patients were selected by their physicians and interviewed in a private room after a medical examination. This study used a longitudinal approach in order to build rapport and trust, and to elicit as much detail as possible about each respondent's daily life<sup>14</sup>. Semi-structured interviews were ongoing for each patient. The participants were asked open questions related to their transitions; for example, "Would you please tell me what has happened since you were diagnosed with MPM?" or "Tell me about your recent condition, and how you are coping", "Tell me what is particularly difficult for you, and how you are handling it." They were interviewed about other topics which tend to bring on difficulty, such as their thoughts on the disease course, exposure to asbestos, and insurance or financial relief, in the context of their recent experiences. The interviewer listened without interruption and facilitated the expression of the participant's narrative. The interviews were audiotaped and carried out 6.4 times each (4-13 times), for 28.9 min each (10-59 min), from February 1, 2014 to March 31, 2016.

### 3. Analysis

This study was a qualitative research design. A phenomenological hermeneutical method was the most useful for the purpose of understanding the experience from the patient's perspective<sup>15</sup>. Our team used Lindseth's and Norberg's phenomenological hermeneutical analysis method<sup>15</sup> based on Ricoeur's phenomenological hermeneutics theory<sup>16</sup>. Three methodological steps in the hermeneutical circle are described below.

Table-1 Characteristics of participants

	Gender	Age	Age at diagnosis	Family status	Type of MPM	Stage at diagnosis	Treatment	Occupation at time of asbestos exposure	Compensation qualification
A	female	65	57	widowed, with children	epithelioid	III	surgery chemotherapy	medical technician	relief
B	male	75	68	alone	epithelioid	III	surgery radiotherapy chemotherapy	electrician	compensation
C	male	61	56	married	epithelioid	II or III	surgery	banker	relief
D	male	63	58	married with children	epithelioid	III	surgery chemotherapy	clerical worker	relief
E	male	80	75	widowed, with children	epithelioid	III	chemotherapy	bookshop owner	none

- 1) A fundamental understanding of text: Text was transcribed from the patient's narrative data, which grasped the characteristics of their experiences.
- 2) Constructive analysis: The meaning units were divided from the text, which were considered as expressions related to the phenomenon of psychological transition. The units were then condensed and abstracted to form sub-themes, themes and possibly main themes on the aspects of the disease course. Each theme was compared for variation. Psychological transition was defined as recognition of changes from disruption of life phases, conditions, status and environment undergoing ordinary life, to reconstruction of new ones, based on transitional theory<sup>17)</sup>.
- 3) Interpretation of phenomenon: The text was again interpreted as a whole, to explain the meaning of experience and to convey a comprehensive understanding, using the themes of transition. In addition, influence factors of transition were described from the text.

#### 4. Trustworthiness of study

The patients needed to recognize to meaning in a transition<sup>17)</sup>, and to express their subjective experiences to better understand their internal transition process. The researcher expressed support and validated the participants' views whether the contents were grounded in the narrative or not. To ensure the accuracy of this study, researcher discussed the findings during data analysis with co-author, and two nurses in the outpatient department of the university hospital who had 12 years of experience in caring for outpatients with MPM.

#### 5. Ethics

Written informed consent for participation and permission was obtained from the participants, after explanation of the study. The participants received oral and written explanation about the purpose, content, benefit, and risk of the study, and participation was voluntary, the procedure secured confidentiality. Protection of their personal information was explained, as was the freedom to withdraw from the study at any time. This study was performed in accordance with the guidelines of the Institutional Review Board of Juntendo University Hospital (approval number: 13-174).

## Results

### 1. Expressing patient transitional attitudes

Our team identified and quantified the terms of MPM patients' transitional attitudes into 840 meaning units, 311 sub themes, 50 themes and 4 main themes. The 4 main themes are described below, and illustrated in Table-2.

#### 1) Attempting to continue independent living and to manage symptoms

MPM patients suffered from symptoms caused by MPM or the treatments, and they managed them and kept living independently. At first, some patients experienced sudden symptoms such as cough and breathlessness, and they worried about the continuation of the symptoms. They subsequently decided to see a physician in a neighbor clinic or a general hospital. The symptoms continued after diagnosis.

Four patients underwent extrapleural pneumonectomy (EPP); one patient received chemotherapy on first treatment. Some patients suffered from postoperative complications such as pain, and chemotherapy side effects including marrow repression.

In a second treatment, 2 patients underwent surgery; 3 underwent chemotherapy. The complications were pulmonary infarction and pain. The side effects were vomiting, tinnitus, and limb dysesthesia. Symptoms of MPM returned, such as dyspnea and pain. They strained to ease their heavy symptoms, to find out their own methods of health care. They were thankful for aspects of ordinary life. After second treatment, they suffered from intense distress caused by exacerbation of the disease. They tried to relieve heavy symptoms independently. They struggled to adapt to their worsening symptoms.

#### 2) Accepting the incurability of the disease in spite of being overwhelmed

Patients were told of their mesothelioma diagnosis, the shortened life expectancy, and the connection of the disease to asbestos exposure. They were shocked and commonly expressed responses of "I didn't think it could happen to me", and "I had awareness of the crisis because treatment had not been established" (Mr. C). However, patients who received a recommendation to undergo an

Table-2 Transitional process of MPM patients

Main theme	Time of diagnosis MPM		Time of treatment	
	Time of appearance of symptoms (several months)	Time after diagnosis (several weeks)	1st treatment~PD (17-60 months)	2nd treatment~PD (2-33 months)
Attempting to continue independent living and managing symptoms	Worrying about continuing symptoms	Understanding cause of symptoms	Suffering from serious treatment damage	Sustaining damage from treatment and symptoms of MPM
	Seeing a physician due to clear symptoms		Trying to alleviate the therapy-related symptoms and to improve life	Straining to maintain prior health and pace of life
Accepting the incurability of the disease in spite of being overwhelmed	Being surprised by the reality of asbestos exposure	Being surprised by the reality of asbestos exposure	Thinking negatively and being seized with inevitability of recurrent disease	Feeling shocked at the unavoidable progression and deterioration
	Reminding oneself of the reality of asbestos exposure	Sense of crisis about rapidly progressive, incurable disease	Pursuing the connection between outbreak of MPM and asbestos exposure	Being constantly haunted by anxiety about deterioration and death
Deciding on treatment and life through uncertainty	Remaining undiagnosed despite intensified suspicion of MPM	Not preparing for decisions despite being pressured	Resentment toward asbestos exposure	Striving to think positively
	Trying to receive firm diagnosis from a specialized hospital	Trying hard to look for a physician who has MPM therapeutic experience	Being relieved to receive treatment by experienced physician	Accepting unavoidable deterioration and death
Maintaining positive relationships with family	Feeling sorry for asking family members to search for a specialized hospital	Accepting family advice and wishes for treatment and cure	Anxiety that physician has limited therapeutic experience	Hesitating about physicians' recommendations for therapy
	Being grateful for family help	Deciding treatment based on family wishes	Finding satisfactory medical treatment	Trying to be satisfied with their own decisions
			Preparing for palliative care	Wishing to receive treatment even if it shows minimum efficacy
			Gaining courage through family encouragement	Feelings of isolation between patient and family
			Acting calmly to please the family	Struggling with illness together with family
				Feeling stress about family relationships
				Keeping a comfortable distance with family
				Providing advance inheritance and succession directions to family

□: disruption themes of transition ■: reconstruction themes of transition

operation said “I was fortunate in receiving a surgery, which is the only curable treatment”. The others who received chemotherapy, expressed with regret “I could not get the necessary medical attention at an earlier stage”.

After first treatment, the patients who underwent surgery said “I worried about when and how the same thing would happen on the opposite side”, but they kept a positive outlook based on their physician’s advice. A patient who received chemotherapy, had negative thoughts and said “I didn’t want to deteriorate more”. In addition, some patients researched the causes of MPM, and became angry about the use of asbestos. Many developed feelings of self-guilt and responsibility toward asbestos exposure. When they were told of the progression of MPM after first treatment, some patients who received surgery were shocked at the inevitable recurrence, while other patients searched for the best treatment from an experienced physician.

During second treatments from 2 to 33 months, all patients were haunted by anxiety about deterioration, recurrence, and death. However, some patients drew strength from stories of others, and controlled their emotions to accept the unavoidable outcome. Mr. C. said that one attitude he kept in mind was “I liked the history of Japan, especially the last days of Tokugawa Shogunate. Samurai had the good grace to die because they guarded the Shogun against enemies. I thought they were brave men with great mental vigor”.

After progression of the disease, their anxieties about incurability intensified. All of them wanted to continue ordinary living, Mr. E said “I was not afraid of death, but I was not suffering more”. They wished to be free from MPM. Some also showed acceptance at stopping treatment and palliative care, and they developed a full realization of the death that they would face. Others wished to continue their treatment; Mr. B said “I wanted an effective medicine to come out quickly”. In addition, some expressed shock that asbestos was used even after health risks were discovered.

### 3) Deciding on treatment and life through uncertainty

Some patients received ample medical examinations, but lacked clear diagnosis in spite of intensified suspicion of MPM. This led them to seek

out special hospitals. Mr. C said “I thought about changing to a specialized hospital, so my wife found the next hospital where I am now. The physician examined carefully my lungs and pleura; he diagnosed it as MPM and recommended surgery”. However, they struggled to obtain adequate information, and to make the decision to operate in a short time. All of them who decided on the operation were relieved to receive it by the physician with therapeutic experience of MPM. Others were anxious physicians having little experience of MPM, and sought out other hospitals.

They were told by the physicians about the progressive nature of the disease, but some hesitated about the next stage of therapy because of lack of information and severe symptoms. They searched sources such as medical journals, internet sites, newspapers, other MPM patients. At the same time, they collected information about palliative care units near their homes.

### 4) Maintaining positive relationships with family

The patients adapted to wishes of other family members to reach treatment decisions. In addition, they felt a sense of obligation to receive treatment at the request of family members. Mrs. A said, “My son did not give up on recovering from this disease, he wanted me to have the operation. So, I decided to be operated on.”

Some patients felt that their family members were unconcerned about their condition and treatment, and kept a distance from their family. They tried to behave naturally, not wanting to worry their families. In addition, they made practical plans for death, put their affairs in order, and gave instructions for succession of property, so that their families would not to be troubled after their death.

## 2. Expressing patient transitional actions

After documenting the expressions of patient transitional attitudes, our team identified patient transitional actions within 29 sub themes, 14 themes and 6 main themes from their narratives. The main themes were: “Creating new self-care regime”, “Gathering information about asbestos exposure and MPM”, “Preparing for dying through self-experience or the experience of other patients”, “Receiving emotional support from family, coworkers, care providers”, “Developing positive

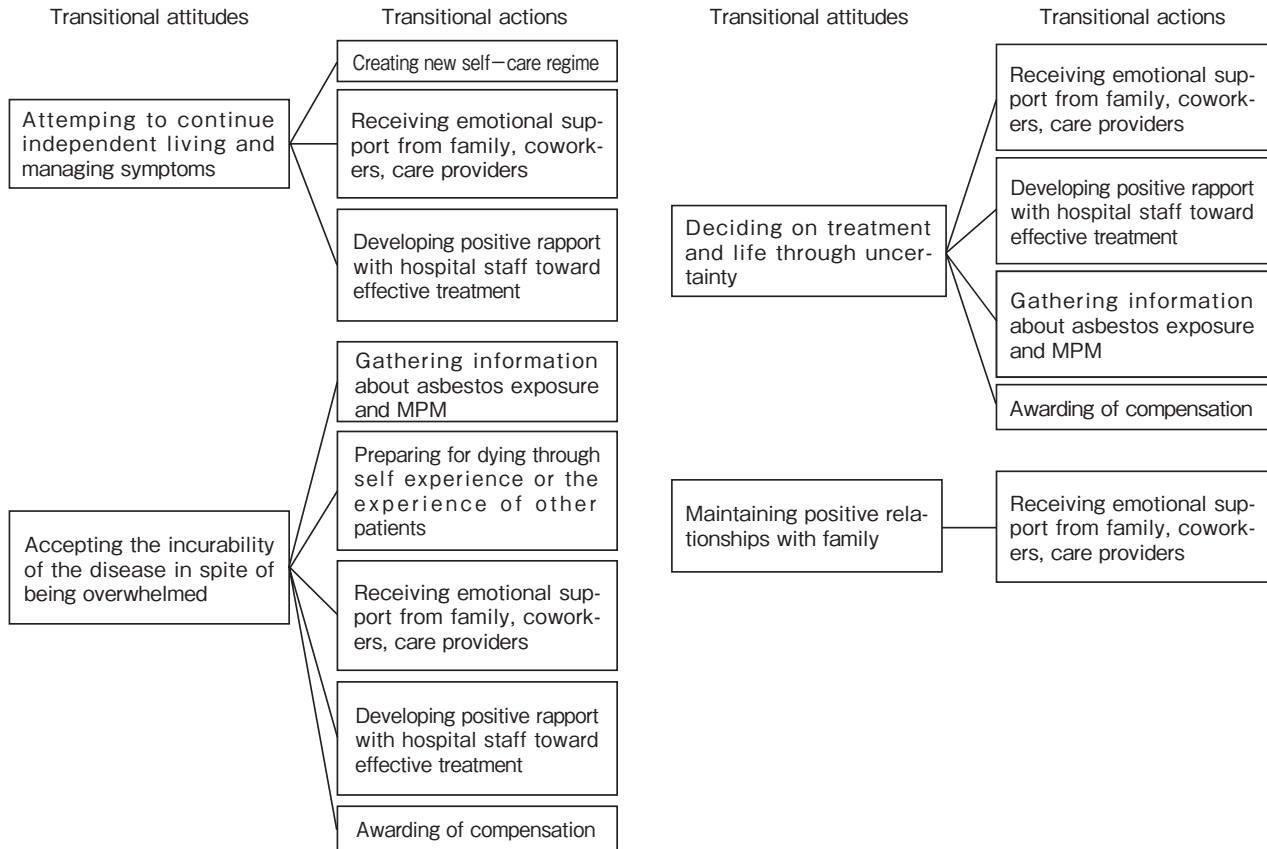


Figure-1 Influence factors of MPM patients' transition

rapport with hospital staff toward effective treatment”, and “Awarding of compensation”.

The relationship actions were divided into 6 main themes, and their intersection with the transitional attitudes tabulated (Figure-1).

### Discussion

Transitions are associated with an identifiable marker critical point and event<sup>17)</sup>. In this study, it is point of the diagnosis, treatment, and the progressive nature of the disease. Transition includes changes of disruption and reconstruction on the aspects of patients' physical symptoms management, accepting to MPM and dying, decision making, and family relationship. And the recognition of meaning in a transition is essential to deal with the consequences<sup>18)</sup>, their transitional attitudes were associated with transitional actions are the consequences.

Severe symptoms such as pain and dyspnea, due to MPM and treatment damage found frequently. MPM patients have to learn to adapt to restrictions imposed by symptoms and this adjustment in itself

appeared to contribute to anxiety and stress<sup>12)</sup>. Especially they almost spent time at home when the symptoms could manage adequately, and they thought to spend the remainder of their life usefully. Therefore, they attempted to continue relieving the symptoms independently and to create new self-care regime at home. It is necessary to obtain information and technique of self-care about symptom relief.

The participants had emotional distress such as shock of diagnosis<sup>7)-9)</sup>, anxiety<sup>11) 12)</sup>, crisis, anger and self-responsibility related to exposure to asbestos<sup>8) 12)</sup>. However, the participants who received surgery at first treatment felt relieved because surgery was only curable treatment and was performed by an experienced physician. Apart from the procedure, they had always been overwhelmed, and felt fear of deterioration and terminal diagnosis for more than five years. The longer one lives beyond the prognosis, the more ambiguous and uncertainty life becomes<sup>19) 20)</sup>. Uncertainty results when an adequate cognitive schema cannot be found with which to interpret the meaning of illness related events, it leads to psychological

distress<sup>21)</sup>. The MPM patients' uncertainty occurred by a lack of accurate information of disease, diagnosis, treatment<sup>19) 22)</sup>, dying trajectory, and award of government/insurance. In addition, some patients welcomed the opportunity to talk to others in a similar situation to themselves<sup>12)</sup>, others were afraid of that they upset sharing experience, and that they died one patient after another. However, they tried to control positively their emotions by their own way, to accept the incurability of the disease and to prepare for dying through self-experience. Especially it needed to develop positive rapport with experienced physicians toward effective treatment, so that they could reduce uncertainty through gathering the information. The nature of the patient-physician relationship is a key part of decision making concerning the withdrawal of anticancer drugs towards the end of life<sup>23)</sup>. Despite they accepted the inevitable death, they had hope of being cured. Living with an incurable illness does not mean living without hope, it is inexhaustible<sup>24)</sup>. Therefore, it is necessary to support to foster hope, but also to inform adequately harms and benefits associated with treatment, and to develop positive rapport in shared decision making from diagnosis.

According to Arber, it needs the opportunity of a home visit with a specialist/palliative care practitioner soon after the diagnosis<sup>19)</sup>. It doesn't need to inform useful resources such as a hospice, a home visiting service, and MPM patient association, but also to support continuously as an interdisciplinary team<sup>25)</sup>. In addition, it needed to receive emotional support from others. They maintained positive relationships with family, and it was influenced on their decision and life. However, their family has a psychological burden of caring, it is important to make the patients within their family the unit of care<sup>26)</sup>. There is also a financial burden because of payment for long-term care services costs, it is necessary to eliminate the payment like the medical insurance.

We recognize some important limitations of the study. This study may not be generalizable to the experience of MPM patients, because the goal of this study is to understand the individual and their interpretation of the world. The sample size is determined by the intensity of the contact on hermeneutic phenomenological research. As the intensity of the contact increases in terms of both

length of time and frequency of contact, the sample size will necessarily decrease<sup>14)</sup>. Because MPM is a rare disease and shortens life expectancy, and patients will die during the process, determining the sample size to follow is difficult. There is little agreement on what happens for patients with MPM, and this study needs smaller sample interviews that are conducted more closely and frequently, to gather sufficient data regarding the transitional process.

This study has established a framework for analysis which can be applied to clinical responses, and to future studies with larger statistical sampling. In addition, nursing practices for MPM patients are needed in order to facilitate positive transitions and improve quality of life and dying process.

#### Conflict of interest statement

The authors declare no conflict of interest associated with this manuscript.

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