Scientific Research Publishing

Open Journal of Nursing, 2025, 15(10), 877-895
https://www.scirp.org/journal/ojn
ISSN Online: 2162-5344
ISSN Print: 2162-5336

Experiences of Illness and Adaptation among Patients with Multiple Myeloma in Japan: A Qualitative Study

Kumiko Morita[1], Yukiko Oue[2], Yumi Tanaka[3]

[1]Nursing Department, Faculty of Health Sciences, Kagawa Prefectural University of Health Sciences, Takamatsu, Japan
[2]Kagawa University Hospital, Kitagun, Japan
[3]Japanese Red Closs Kyoto Daiichi Hospital, Kyoto, Japan
Email: morita-k@kagawa-puhs.ac.jp

How to cite this paper: Morita, K., Oue, Y. and Tanaka, Y. (2025) Experiences of Illness and Adaptation among Patients with Multiple Myeloma in Japan: A Qualitative Study. *Open Journal of Nursing*, **15**, 877-895.
https://doi.org/10.4236/ojn.2025.1510063

Received: September 9, 2025
Accepted: October 18, 2025
Published: October 21, 2025

Abstract

Purpose: Although the treatment of multiple myeloma (MM) continues to evolve rapidly with the introduction of new drugs, it is still considered an incurable disease. Given the wide variety of symptoms and the need for continuous pharmacotherapy for MM, the purpose of this study was to explore patients' experiences with MM and their adaptation to it. **Methods:** This qualitative, descriptive design study included MM patients who had been treated with anticancer drugs for at least six months. Data were collected through semi-structured interviews and analyzed using thematic analysis. **Results:** The participants were 11 MM patients, five males and six females, with an average age of 69.7 years. Five themes were extracted with respect to the patient's experience with MM and their adaptation to it: encountering an unfamiliar illness, feelings regarding having an incurable illness, recognition of the difficulties inherent to the illness, their losses and how they harmonized with them, and their search for how to live with this illness. **Conclusion:** Five themes were identified regarding patients' experiences with MM and their adaptation to the illness. Outpatient nursing care related to MM patients' adaptation to the illness requires understanding this unknown disease and its treatment, organizing one's feelings about facing the illness, working with patients to provide strategies for coping with the limitations due to the illness, including activity limitations, and helping patients maintain a sense of normalcy and enjoyment of life.

Keywords

Multiple Myeloma, Patients' Experiences, Adaptation, Cancer Nursing, Qualitative Study

1. Introduction

Multiple myeloma (MM) is a malignant disease in which clonal proliferation of plasma cells in the bone marrow results in the production of monoclonal proteins that cause end-organ damage [1]. It accounts for 1% of all cancers and approximately 10% of all hematologic malignancies [2]. In recent decades, the incidence of MM has increased alarmingly, with approximately 86,000 cases occurring annually worldwide [3], with an incidence rate of 7 per 100,000 persons in the United States and a median age of onset of 69 years [4].

The treatment of MM continues to evolve rapidly with the introduction of several new drugs and new data from randomized trials to guide treatment [5]. The current standard of care includes conventional chemotherapy, high-dose chemotherapy with autologous hematopoietic stem cell transplantation (HSCT), and immunomodulators, which have increased the 5-year relative survival to 55.6%. However, despite these tremendous advances, MM remains an incurable disease with poor outcomes, especially in patients who are resistant to multiple drugs [6].

The characteristic end-organ damage of MM includes symptoms such as hypercalcemia, renal impairment, anemia, and bone lesions, termed CRAB symptoms [7]. with bone lesions, specially bone pain, being the first symptom reported at disease onset in 60% - 80% of cases [8] [9]. Additionally, an estimated 70% - 100% of MM patients suffer from osteolytic bone lesions [10]. MM patients often experience difficulties in maintaining their quality of life due to the chronic course of treatment with novel agents that allow management of toxicity, while living with CRAB symptoms and ongoing hospital visits. The high symptom burden and reported low quality of life in MM patients has been previously proven [11]. In fact, in a study of 16,095 cancer survivors, MM patients had the lowest scores for both health-related quality of life and physical functioning [12]. Based on these facts, we inferred that MM patients face many adaptation challenges in the process of continuing treatment after developing the disease and in adjusting to the required lifestyle changes, with difficulty in overcoming these challenges. Therefore, we decided to investigate how MM patients adapt to the difficulties associated with the disease and their experience of living with this condition.

Previous studies of MM patients' experiences of illness and treatment have included hematopoietic stem cell transplantation [13] [14], symptoms [15] [16], and caregiver experiences [17]-[19]. Among these, in contemporary MM practice, Shapiro *et al.* (2021) stated that since MM patients live longer with the chronic burden of cancer treatment, it is essential to develop supportive care interventions that maximize their quality of life and functional status [20]. In order to introduce a new perspective into nursing care in response to the evolving MM treatment and the experiences of patients undergoing it, a qualitative descriptive study was deemed necessary to gain detailed understanding of the subject's actual experience of living with and adapting to the disease.

Adaptation refers to the state of mind and body in which the person is in harmony with the environment [21]. Since patient adaptation is used as a guideline for nursing practice [22], research on MM patient adaptation will contribute to the development of guideline-based nursing for these patients. At present, however, there are only a few studies on the adaptation of MM patients, with considerably fewer qualitative studies describing the actual experiences of a Japanese population with MM.

The purpose of this study was to clarify the experiences of those affected by and adjusting to MM in Japan. This study will contribute to the development of new nursing care for Japanese patients with MM in the era of significant progresses in pharmacotherapy for the disease.

2. Methods

2.1. Study Design

This study employed a qualitative descriptive research design to gain a detailed understanding of the actual experiences of MM patients living with and adapting to the disease. This design was adopted since it recognizes the subjective nature of the problem and the diverse experiences of the participants, presents the findings in a way that directly reflects or closely resembles the terms used in the initial research questions [23], and is an excellent way to address important clinical issues [24].

2.2. Participants

The study participants were individuals who had been diagnosed with symptomatic MM for at least six months, were attending a hematology outpatient hospital and receiving pharmacotherapy for MM, and were at least 20 years of age and were able to make their own decisions and express their willingness to participate in the study, provided that they were physically and mentally fit to do so.

At the hematology outpatient hospitals in this study, the physician and head nurse in charge of outpatient care were asked in advance to select candidates who met the above conditions to participate in the study. The physician and head nurse explained the study to the patients and invited their cooperation, and patients who were interested in the explanation were referred to the researchers. The researcher then explained the outline of the study to the potential research participants, and those who consented to participate in the study were selected as research participants.

2.3. Data Collection

Semi-structured interviews were used for data collection. This method was appropriate for this study since it reveals complex events, such as MM patients' experiences related to the cancer and their adaptation to it, which are highly subjective topics.

Interviews were conducted at the convenience of the study participants, in a private room in the outpatient area of the medical facility where privacy could be maintained. Each interview was designed to be 30 - 60 minutes long, so as not to be burdensome for the research participants. Interviews were conducted during the period from November 2022 to September 2023 using a questionnaire developed by the researcher (**Table 1**).

Table 1. Interview guide.

1. What has been your treatment process since you were diagnosed with multiple myeloma?
2. How were you diagnosed with multiple myeloma and what was your physical condition and feelings at the time?
3. What changes in your daily life have you experienced and dealt with since you have had this illness?
4. What personal changes and coping strategies have you experienced since this illness?
5. What physical, psychological and social problems have you had and how have you dealt with them since you have had this illness?
6. What do you feel you have lost or gained in your daily life or yourself since you have had this illness?

The questions referred to Roy's model of adaptation [25], which states that people are biopsychosocial beings who continuously interact with a changing environment, and engage in complex coping processes involving regulatory and cognitive organs to maintain adaptation to environmental stimuli; additionally, questions related to the changes due to MM and coping with it, including the physical, psychological and social circumstances, were added. During the interview process, the questions were used as a starting point, and more detailed answers were obtained by using words such as "why" and "how" in the dialogue.

The interviews were recorded on an IC recorder with the consent of the study subjects, and transcribed verbatim by the researcher.

2.4. Data Analysis

Data were analyzed using thematic analysis, as it is considered most suitable for studies that provide systematic elements and attempt to make discoveries through interpretation [26], since the aim of this study was to discover and describe the experiences of MM patients through interpretation. In this type of analysis, themes are those that capture what is important with respect to the research questions and represent some level of meaning or pattern in the data. The procedure for the analysis was based on the six phases of Braun and Clarke (2006) [27], as below:

1) Familiarizing oneself with the data: Active, repeated reading of data to look for meaning and patterns.

2) Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.

3) Searching for themes: All coded data are grouped and examined to see how the codes combine to form an overarching theme. The codes are classified into sub-themes, and further classified according to similarity to determine candidate themes.

4) Reviewing themes: The themes are refined to ensure that the candidate theme adequately captures the contours of the coded data.

5) Defining and naming themes: The relationship between themes and subthemes is identified to clarify the essence of each theme and to name them.

6) Producing the report: This involves final analysis and discussion of the data, relating it back to the study question.

In addition, we analyzed not only the completed adaptations of the participants, but also their awareness that this was an ongoing situation to which they were in the process of adapting.

As a precaution to ensure the quality of the study, data collection was conducted primarily by the principal investigator, who collected narratives as experienced by the subjects through interviews using a neutral attitude, eliminating the stereotypes for cancer patients that have been used in the past. The researchers belonged to different organizations and had a broad perspective and thinking that was not biased toward nursing care at any one facility. The fact that the researchers discussed and reviewed the data until they reached a consensus, such as data saturation, contributed to the credibility of the study. In addition, data validation by a single oncology nurse not involved in this study enhanced the credibility of the data.

Since both the research participants and the researcher were Japanese, the research processes were conducted in Japanese, and the papers were translated into English by the researcher and subsequently proofread by native English speakers. Additionally, the extracted themes were discussed and confirmed among researchers to ensure that no discrepancies in meaning arose from the translation.

2.5. Ethical Considerations

Our university ethics review committee and the ethics review committee of the cooperating facilities reviewed and approved the research before it was performed. The study complied with the ethical standards of the Declaration of Helsinki, and participants were explained orally and in writing that their participation in the research was voluntary, that they would not be disadvantaged if they did not participate, that they would not be identified when the research was published in academic journals, etc., and that they could withdraw their consent to participate in the research at any time, following which their signed consent for study participation was obtained.

3. Results

The study included 11 participants, five males and six females, with an average age of 69.7 years and an average interview duration of 46 minutes. Four of them had a history of fracture and eight had received autologous hematopoietic stem cell transplants (**Table 2**). The researchers determined that data saturation had occurred when the study had 10 participants, after which they continued data collection with one additional participant.

Table 2. Participant characteristics.

Number	Gender	Age	Duration of the disease	Transplant experience	History of bone fractures	Housemate	employment status
P1	M	70 s	8	yes	no	spouse	retirement
P2	M	70 s	10	yes	no	spouse, second daughter, grandchild	contract employee
P3	M	70 s	6	yes	no	spouse	self-employment
P4	F	60 s	3	no	yes	Spouse, eldest son	housewife
P5	M	50 s	2	yes	yes	spouse	full-time employee
P6	F	70 s	7	yes	no	spouse	housewife
P7	M	70 s	12	yes	no	spouse	part-time employee
P8	F	70 s	3	no	yes	Spouse, eldest daughter, grandchild	housewife
P9	F	60 s	3	yes	no	eldest son	full-time employee
P10	F	70 s	0.5	no	yes	spouse	housewife
P11	F	60 s	13	yes	no	no	self-employment

Sixteen sub-themes and five themes relating to the patient's experiences with MM and adapting to it were identified (Table 3). Theme 1 represents the time of diagnosis of MM as an event that required adaptation, and Themes 2 - 5 represented the participants' experiences in the process of adapting to MM.

Table 3. Experiences of illness and adaptation among patients with multiple myeloma.

No.	Theme	Subtheme
1	Encountering an unfamiliar illness	Body pains, fractures and blood abnormalities make this illness noticeable No real sense of illness as it was completely unexpected
2	Feelings regarding having an incurable illness	Discouragement that the disease cannot be cured, but trying to come to terms with it The arrival of new drugs leads to hope and relief Desire to continue treatment despite uncertainty about getting well Giving up on a cure, and living with the illness
3	Recognition of the difficulties inherent to the illness	The disease and treatment are out of my control Transplantation performed, but treatment still continues Attention needed to ensure safe living Multiple inconspicuous symptoms Not getting the effect I want
4	Losses and how they harmonized with them	Finding out how to deal with the illness Compromising, but regaining one's former self
5	Searching for how to live with this illness	Living life putting myself first Interacting and conversing with others Getting support from family members

Characteristic narratives of the selected subjects are described below in quotation marks. The number at the end of the sentence indicates the corresponding participant.

3.1. Encountering an Unfamiliar Illness

Participants' pathways to the diagnosis of MM differed, largely due to the presence or absence of subjective symptoms.

This was reflected in the participants' experience of unexpectedly encountering an unknown malignant disease at the time of diagnosis, since, in some cases, the participants had not considered that their unrelieved bone pain and fractures were symptoms of MM, and, in other cases, the disease was discovered when they were told to have a thorough blood test without significant subjective symptoms. In both situations, their diagnosis of malignancy was unexpected. This theme consisted of two sub-themes.

3.1.1. Body Pains, Fractures and Blood Abnormalities Make This Illness Noticeable

Participants who had bone symptoms when they were diagnosed with MM understood that their symptoms were caused by the disease. In addition, participants who were diagnosed with MM based on abnormal blood tests were puzzled by the discovery of a hidden disease, but recognized that they were fortunate to have this disease discovered sooner, rather than later.

This theme was elucidated in the participants' words, as:

"*MM, so my bones are probably weak…so when I stumbled, it resulted in the most crushed fracture I've ever seen. In hindsight, I figured that was the cause.*" *P*4

"*A few years ago, I went to the hospital for a blood test because I thought I had a heart problem, since I kept fainting and falling. Although my heart was fine, blood tests revealed myeloma. The diagnosis of myeloma was totally unexpected, since I only thought I had a bad heart.*" *P*8

3.1.2. No Real Sense of Illness, as It Was Completely Unexpected

At the time of the diagnosis, none of the participants had any knowledge of MM. Since the disease was unfamiliar and unknown to them, they did not appreciate its implications, even when bone symptoms were present or abnormal blood tests were noted.

In the participants' words:

"*I went to a nearby clinic with the intention of getting blood pressure medication, with no subjective symptoms except for light-headedness. But when I was told to go to a hematologist, I thought, "Are my symptoms because of such a disease?" And when they did some tests and talked about a transplant, I realized that it was bad.*" *P*9

3.2. Feelings Regarding Having an Incurable Illness

Based on the doctor's explanation, the participants were discouraged by their affliction with an intractable malignant disease, but they accepted it and attempted to transform their feelings in order to achieve psychological stability. This theme consisted of four sub-themes.

3.2.1. Discouragement That the Disease Cannot Be Cured, but Trying to Come to Terms with It

Although the participants were discouraged by the MM and its intractable nature, and they almost lost purpose and meaning in life, they tried to deal with the disease by not fixating on the intractable nature of MM and, instead, intentionally coming to terms with the disease.

In the participants' words:

"*I looked up MM on the internet with no good results, only bad…no cure.*" *P*2

"*Don't get too depressed because you have myeloma, if you don't get better, that's okay.*" *P*4

"*The doctor casually told me that this disease could not be cured. At that time, I realized that there was no cure. However, I thought that my life expectancy would be the same as that of a normal person my age, about* 10 *or* 20 *years.*" *P*9

3.2.2. The Arrival of New Drugs Leads to Hope and Relief

The treatment of MM has improved significantly over the past two decades, with the development of therapeutic agents such as proteasome inhibitors, immunomodulators, and monoclonal antibodies [28]. Against this backdrop, many of the participants were treated with several different regimens, and although the MM was refractory, the availability of multiple treatments gave them hope and reassurance that they would not die yet, since more medical treatments for MM would also likely be developed in the future.

To quote a participant:

"*I was wondering why I had such a disease when I found out that there was no cure for it, but I heard that new and better medicines were being developed, so I felt that I should not give up hope.*" *P*3

3.2.3. Desire to Continue Treatment Despite Uncertainty about Getting Well

Participants were uncertain how well their MM would respond to anticancer drug treatment and how long they would live, but still requested that they continue to receive treatment.

As one participant said:

"*I've taken the necessary treatment rather than focusing on whether the disease is getting better or not, and now will take it as it comes.*" *P*8

3.2.4. Giving up on a Cure, and Living with the Illness

Participants realized that they could not change the fact that MM was intractable, and they gave up aiming for a cure. They began to think that they could live with the disease by taking treatment, although without fighting it aggressively.

In the participants' words:

"*I have to live with the medicine now. I have given up on being cured. I think I* *have to live with the disease.*” P1

“*I've already got this disease, so I'm resigned to it, and will live with the disease while taking medicine.*” P4

3.3. Recognition of the Difficulties Inherent to the Illness

In addition to the widely recognized physical pain due to bone involvement, MM patients experience other aspects of the complex pain, including social and psychological pain [29]. This theme indicated the participants' experience of recognizing that life with MM involves holistic suffering, and that the disease is not as straightforward and is more formidable than they would like it to be. This theme consisted of five sub-themes.

3.3.1. The Disease and Treatment Are out of My Control

Participants repeatedly recognized that although they hoped that the disease would not progress further than its current state, this was, of course, not under their control.

In the words of some participants:

“*Although I kept taking the medicine, its effect gradually diminished, so the medicine was changed several times. I've been doing well with that medicine so far, but I have to try the next new medicine to see if it is right for me.*” P6

“*The doctor said, “There will definitely come a time when it will get worse again.” I wonder when it will get that bad again.*” P4

“*Even if I have information about the treatment, I cannot decide for myself which treatment is best.*” P3

3.3.2. Transplantation Performed, but Treatment Still Continues

Although HSCT is considered a curative treatment for many hematologic malignancies, the outcomes after transplantation vary depending on the type of disease, remission status at the time of transplantation, type of donor, and other factors [30]. HSCT can lead to fatal complications, including side effects associated with conventional chemotherapy, such as infections related to extreme immunosuppression immediately after transplantation [31]. Eight of the study participants had undergone autologous HSCT, and although the harshness of the treatment had given them the feeling that they would be able to overcome the MM if they could withstand this treatment, their experience was contrary to their expectations.

To quote the participants:

“*I thought I would be cured after a stem cell transplant, but after about* 3 *months, my blood test numbers went back up.*” P1

“*I thought I would be cured now that I had a stem cell transplant, but in fact I was wrong.*” P6

“*I was told by the doctor that I would have to be on maintenance therapy for about* 2 *years after the transplant. It's now been over* 2 *years, so I said, “I'd like to stop the medication*”, *but he said, “No, you can't stop it*”. *So it's still ongoing.*” P9

3.3.3. Attention Needed to Ensure Safe Living

Participants were limited in their activities of daily living due to bone symptoms and adverse reactions to medications, and were at risk of injury if they were not careful. They were aware of many of these risks and took measures to ensure their safety and comfort.

To quote the participants:

"*I can't lie on my back because of the pain. I can't sleep on my back, I have to bend over to walk, I get short of breath when I walk. That's a bit of a problem.*" *P*5.

"*I had a collection of china dishes, but they were a little too heavy for me to carry, would fall and break, and my joints hurt anyway.*" *P*11

"*I think my bones are still weak and that's why I'm afraid to cough. I have to sit down gently, if I sit down with a thump, I'm in trouble.*" *P*4

3.3.4. Multiple Inconspicuous Symptoms

Adverse reactions to outpatient pharmacotherapy are less frequent and less severe, and are basically within the patient's ability to self-manage. Although this might lead others to believe that they are living a life comparable to that of healthy people, the participants had multiple symptoms, although they appeared to be "unremarkable" at first glance.

In the participants' words:

"*I always stay home and don't go anywhere for two days after the infusion, because my immunity is lowered and I'm prone to infection. It's scary.*" *P*1

"*I take dexamethasone (adrenal corticosteroid) on Thursday, wake up perfectly. The side effects are hand cramps, slight hoarseness of voice, and constipation.*" *P*7

"*Sometimes I'm slow because I'm tired, sometimes I'm frustrated because I can't move.*" *P*4

3.3.5. Not Getting the Effect I Want

The participants had many hopes that they would be cured as a result of continued drug therapy, or that their doctors would tell them that their disease had stabilized and that they no longer needed drug therapy, even if achieving a cure for MM was difficult, but they felt disappointed that the actual outcome was not what they had hoped for.

As stated by the participants:

"*I have been on various anti-cancer drugs, but eventually it came back again and I was not cured. I have been treated with the same drug for 2 months to up to one year at a time, depending on the drug.*" *P*1

"*Because the medicine doesn't suit everyone's body and I don't know if it will suit me, every time the medicine changes, I wonder how it will be this time.*" *P*6

3.4. Losses and How They Harmonized with Them

This theme illustrates the experience of participants who had to forgo many of their targets with respect to their physical behaviors and life plans due to the MM, but who made compromises and took steps to adapt to the situation rather than continue to grieve about their condition. This theme consisted of two sub-themes.

3.4.1. Finding out How to Deal with the Illness

The participants were able to tolerate the physical aspects of the disease and its treatment, such as reduced range of activities due to physical symptoms caused by MM and adverse reactions to medication, and found specific ways to live with them and maintain a life that they were comfortable with.

To quote the participants:

"*I've already learned how to work when it's tough, so I don't feel that the job is that hard.*" *P3*

"*I can no longer move freely. But I try not to think about it too much. I go to work and come back home, and my life is normal.*" *P5*

"*I'm trying to figure out how to do this while cutting corners in my life's activities. I've become lazy in the eyes of my family, but I don't care if I'm lazy anymore.*" *P8*

3.4.2. Compromising, but Regaining One's Former Self

One participant's identity was shaken in part by the fact that he was no longer able to engage in some of the functionally independent life activities he had been engaged in before he developed MM, which used to be an important aspect of his identity.

However, patients were able to come to terms with and reach a compromise in areas where they could not return to their pre-morbid lifestyle behaviors, and once they acknowledged that they were still the same person they were before the illness, they gradually regained a sense of self.

As stated by some participants:

"*I can't move even though I would like to move a little more. Still, I'm gradually getting back to my old life.*" *P4*

"*For now, my family does the housework, so I live the same way I did before.*" *P6*

3.5. Searching for How to Live with This Illness

This theme represents the experience of participants accepting MM as one of the factors that make up their lives, exploring how to live this life, and in doing so, reflecting on and finding what is of value to them in their immediate lives, using this as a guide for living.

This theme consisted of three sub-themes.

3.5.1. Living Life Putting Myself First

Since one's lifetime is finite and the remainder of one's life is uncertain, the participants found direction in life by putting themselves first, with the desire to live their lives with conviction despite their illness.

In the participants' words:

"*Everyone's life has an endpoint. I was thinking about how many more years I have left to live, and I decided to do what I want to do.*" *P*2

"*Do what you want to do, eat what you want to eat, you have to go with it now, even though you can't do everything* 100 *percent.*" *P*8

3.5.2. Interacting and Conversing with Others

After reflecting on how they could spend their lives with MM and what was important to them in their lives, participants realized once again that they would benefit from interaction and conversation with others, and considered it as something they needed to do.

As some of the participants stated:

"*I talk to a lot of people to keep up my spirits, that way I feel at ease.*" *P7*

"*I write about my day on my blog, the theme is like a group of people with myeloma. There is one person I have become close to through the disease. I traveled to see that person.*" *P9*

3.5.3. Getting Support from Family Members

Participants realized that their families were considerate about the limitations imposed on their lives by the MM and its treatment, and did not interpret this as a burden. This helped them adapt to MM with the help of their families in a natural way, aiming for a stable life.

To quote one of the participants:

"*Basically, I am alone. If I have to, I ask my oldest son to come over. I have three children, and if I need something, I just send them an email and they help me with what I need. I really rely on my oldest son a lot, but I'm getting by.*" *P*11

4. Discussion

This study led to the extraction of five themes related to the patients' experience of MM morbidity and their adaptation to it. Our findings will serve as a powerful resource for the development of outpatient nursing care for MM patients in Japan, since the study was conducted on patients currently receiving drug therapy in outpatient clinics. Below, we discuss the experience of MM from a Japanese patient perspective, along with the scope of outpatient nursing care for MM patients, focusing on each of the themes identified.

First, MM patients "encountered an unfamiliar disease" at the time of diagnosis. Some participants were aware of unrelieved pain and delayed the MM diagnosis by first seeing an orthopedic surgeon. Some of the participants suspected other diseases and went to see a doctor and had blood tests done, which revealed MM. Rowland *et al.* [32] MM patients were confused because they did not know that multiple myeloma was cancer before being diagnosed, Cuffe *et al.* [33] reported that most patients with MM were confused about the diagnosis because none of them had anticipated having this disease, and because of the relatively intangible nature of MM compared to solid tumors, such as breast cancer, resulting in it being more emotionally traumatic. Indeed, solid tumors are generally easy to visualize since they have more specific presentations based on the organ affected, and subjective symptoms are likely to raise the suspicion of cancer in that organ. In comparison, MM patients are prone to presenting with more general symptoms, such as bone pain or other symptoms, so that they are less likely to suspect MM. Since MM is a rare cancer, its symptoms are generally not well recognized by the general public [34]. Therefore, it is important for nurses to provide the patient with the appropriate amount and quality of knowledge and information about MM at the time of its diagnosis in the outpatient setting, based on the assumption that the patient is not likely to have prior detailed knowledge about MM, and depending on the patient's ability to understand the disease.

In addition, since lack of early detection and referral to an oncologist might lead to delay in the diagnosis and inadequate symptom control [35], nurses play an important role in educating the public about anemia, fatigue, bone pain, and other symptoms that may be caused by MM.

Second, coping with MM includes the psychological aspect of adapting to living with MM, along with the "feelings regarding having an incurable illness". The main reason participants were discouraged by MM was that, in addition to being a malignant disease, it was also refractory to treatment. Dahan *et al.* [36] reported that MM patients "must accept living while dying." In this context, Viitala *et al.* [37] stated that incurable cancer patients have no choice but to accept their disease and, over time, develop a positive attitude, similar to MM patients' "Feelings about the incurable illness". MM patients should not continue to mourn the incurable aspects of MM, but rather find their own way of "accepting" and "coping" with the illness, which is one of the factors that will help them to adapt. Nurses should deal with the patients' emotions as they try to come to terms with MM, provide opportunities for them to sort out their feelings about facing their illness, and continue to monitor and support their psychological changes and behaviors as they adapt.

In addition, the development of new and effective therapeutic agents has given MM patients hope for life and motivation for treatment. Although the efficacy and benefit of treatment in MM patients is uncertain, the hope is that they will continue to use this uncertainty as a strength and be willing to accept treatment, since uncertainty is said to be the gateway to possibility [38]. Therefore, nurses who support their hope of living over the long term naturally need to be sensitive to trends in MM treatment.

Third, MM patients' experiences of adjusting to their illnesses included "recognition of the difficulties inherent to the illness." This experience is due to the current situation in which the goal of treatment is stabilization of the patient's condition, or for the patient to be in a situation where he or she will be able to complete drug therapy once the condition is stabilized, but that goal is not reached. Patients who have undergone autologous HSCT, in particular, have high expectations of the treatment because of its intensity and adverse drug reactions, assuming that the severity of treatment is an indication of its efficacy, and will enable them achieve the desired outcomes. However, they are made aware of the toughness of MM when the outcome does not meet these expectations. These experiences make it difficult for MM patients to set clear goals for their treatment, and leaves them with the feeling that the disease and its treatment are not something they can manage on their own, depriving them of the motivation to undergo treatment and fight the illness. In addition, while adverse reactions, such as peripheral neuropathy and infection, might not be obvious or pronounced, living with these persistent symptoms is a challenge that only patients can understand. Rubins *et al.* [39] state that the symptoms themselves tend to trigger more complex emotions, that perpetuate the difficulties of experiencing illness.

It is important for nurses to understand the physical pain and complex psychological aspects of the patient's MM treatment characteristics, to be supportive when it is in their capacity to help control these symptoms, and to help patients feel confident about the treatment.

The process of adaptation by MM patients also includes a feeling of "losses and how they harmonized with them". MM patients lose variable degrees of their physical, psychological, and social identity, including developing fractures and susceptibility to fractures, reduction in social activities due to adverse reactions to treatment, and knowing that they will be unable to achieve their vision for their future. Monterosso *et al.* [40] also reported that MM patients experience feelings of loss because the illness and its treatment have changed their lives. In such a situation, MM patients are able to open up and harmonize with their loss as they come to accept the loss, and understand how to deal with the illness. Additionally, despite knowing that they might not be able to return to their pre-affliction physical selves, they will regain themselves if they realize that some parts of themselves have not changed.

This is related to what Weerahandi *et al.* [41] says about MM patients experiencing a transformation of identity, where they discover a new self while maintaining their old self. Nurses should provide a holistic perspective to MM patients, so that while there is a sense of loss, they can be aware of the parts of themselves that have not been lost. Molassiotis *et al.* [42] noted that MM patients have considerable difficulty accepting their reduced activity levels, including frustration with their inability to do things and difficulty accepting their decreased autonomy. In order to cope with the reduced scope of activities, it is desirable to provide specific information on how to make up for the reduction in daily activities and resources, with safety as the top priority. We believe that incorporating such information into the patients' daily life will enable them to realize that they have not changed, and will make it easier for them to adapt to the changes in their lives.

Finally, as MM patients adapted to MM, there was a "search for how to live with this illness". LeBlanc *et al.* [43] state that the relentlessness of active treatment is what differentiates modern MM treatment patterns, the course of this chronic illness and its treatment involves much uncertainty, with the patient groping through trial and error in dealing with the changing physical and mental condition of the body and mind due to the pathology, its treatment and symptoms. In this search, it is important to be sensitive to the patient's confusion and distress, and to help the patient find some measure of resolution, since their own resources and energy might not be adequate. Participants in this study viewed family cooperation as beneficial, and family members were an important part of the patient's life with the illness. However, the lives of family members themselves can be disrupted, which might also add to the patient's stress. de Wet *et al.* [44] reported that the support of family and friends is important to many MM patients, although they also reported additional anxiety about being a burden on their loved ones.

Therefore, it is important to consider the relationship between MM patients and their families, directly interview the families during outpatient visits about their living conditions and feelings toward the patient, and to provide support for the patients and families, so that problems, if they arise, can be resolved promptly. Parsons *et al.* [45] also reported that what MM patients wanted most from their treatment was help in maintaining as normal (and enjoyable) a life as possible. It was mentioned by participants in this study that enjoyment in life is often derived from interaction with others. It is important to support these social interactions appropriately, keeping in mind that the maintenance of normalcy and enjoyment for the patient contributes to his/her adaptation to life with MM.

5. Limitations and Future Issues

The participants in this study were patients at two Japanese hospitals, so selection bias is undeniable and the study cannot be said to be a comprehensive description of the entire experience of MM patients in Japan. We would like to continue to explore this topic with an even wider range of participants in the future. Future work should use this study as a foundation to develop an outpatient nursing model for MM patients, should test the usefulness of this model in actual clinical practice, and contribute to the practice of more advanced nursing care for MM patients.

6. Conclusions

MM patients need to adapt to this unfamiliar and intractable disease and find ways to live with it. In the process of continuing treatment, they recognize the toughness of the disease when the treatment outcomes do not meet their expectations. Although they experience certain losses and limitations in their daily lives, they seek ways to live with and harmonize with the illness in their own unique ways.

Our study suggests that outpatient nursing care that facilitates MM patients' adjustment to their illness, helps them to understand this unknown disease and its treatment, helps them understand their feelings about their illness and sort out their feelings about facing their illness, that works with them to develop and provide strategies to help them accept their loss, including activity limitations, and helps them maintain a sense of normalcy and enjoyment of life, is much needed.

Acknowledgements

We would like to express our deepest gratitude to all study participants, physicians, nursing administrators, and all others who cooperated with us in conducting this study.

Funding

This study was supported by JSPS Grants-in-Aid for Scientific Research.

Author Contributions

Kumiko Morita conceived the study, collected and analyzed the data, and drafted the paper; Yukiko Oue and Yumi Tanaka provided suggestions for writing of the paper and advice on the analysis. All authors read and accepted the final manuscript.

Conflicts of Interest

There are no conflicts of interest related to this study.

References

[1] Palumbo, A. and Anderson, K. (2011) Multiple Myeloma. *New England Journal of Medicine*, **364**, 1046-1060. https://doi.org/10.1056/nejmra1011442

[2] Rajkumar, S.V., Dimopoulos, M.A., Palumbo, A., Blade, J., Merlini, G., Mateos, M., *et al.* (2014) International Myeloma Working Group Updated Criteria for the Diagnosis of Multiple Myeloma. *The Lancet Oncology*, **15**, e538-e548. https://doi.org/10.1016/s1470-2045(14)70442-5

[3] Becker, N. (2011) Epidemiology of Multiple Myeloma. *Recent Results Cancer Research*, **183**, 25-35. https://doi.org/10.1007/978-3-540-85772-3_2

[4] SEER (2023) Cancer Stat Facts: Myeloma. https://seer.cancer.gov/statfacts/html/mulmy.html

[5] Rajkumar, S.V. and Kumar, S. (2020) Multiple Myeloma Current Treatment Algorithms. *Blood Cancer Journal*, **10**, Article No. 94. https://doi.org/10.1038/s41408-020-00359-2

[6] Dima, D., Jiang, D., Singh, D.J., Hasipek, M., Shah, H.S., Ullah, F., *et al.* (2022) Multiple Myeloma Therapy: Emerging Trends and Challenges. *Cancers*, **14**, Article 4082. https://doi.org/10.3390/cancers14174082

[7] Michels, T.C. and Petersen, K.E. (2017) Multiple Myeloma: Diagnosis and Treatment. *American Family Physician*, **95**, 373-383. https://www.aafp.org/pubs/afp/issues/2017/0315/p373.pdf

[8] Kyle, R.A., Gertz, M.A., Witzig, T.E., Lust, J.A., Lacy, M.Q., Dispenzieri, A., *et al.* (2003) Review of 1027 Patients with Newly Diagnosed Multiple Myeloma. *Mayo Clinic Proceedings*, **78**, 21-33. https://doi.org/10.4065/78.1.21

[9] Miller, J.A., Bowen, A., Morisada, M.V., Margetis, K., Lubelski, D., Lieberman, I.H., *et al.* (2015) Radiologic and Clinical Characteristics of Vertebral Fractures in Multiple Myeloma. *The Spine Journal*, **15**, 2149-2156. https://doi.org/10.1016/j.spinee.2015.05.026

[10] Patel, M.S., Ghasem, A., Greif, D.N., Huntley, S.R., Conway, S.A. and AL Maaieh, M.

(2018) Evaluating Treatment Strategies for Spinal Lesions in Multiple Myeloma: A Review of the Literature. *International Journal of Spine Surgery*, **12**, 571-581. https://doi.org/10.14444/5070

[11] Ramsenthaler, C., Osborne, T.R., Gao, W., Siegert, R.J., Edmonds, P.M., Schey, S.A., *et al.* (2016) The Impact of Disease-Related Symptoms and Palliative Care Concerns on Health-Related Quality of Life in Multiple Myeloma: A Multi-Centre Study. *BMC Cancer*, **16**, Article No. 427. https://doi.org/10.1186/s12885-016-2410-2

[12] Kent, E.E., Ambs, A., Mitchell, S.A., Clauser, S.B., Smith, A.W. and Hays, R.D. (2015) Health-Related Quality of Life in Older Adult Survivors of Selected Cancers: Data from the Seer-Mhos Linkage. *Cancer*, **121**, 758-765. https://doi.org/10.1002/cncr.29119

[13] Walpole, G., Clark, H. and Dowling, M. (2018) Myeloma Patients' Experiences of Haematopoietic Stem Cell Transplant: A Qualitative Thematic Synthesis. *European Journal of Oncology Nursing*, **35**, 15-21. https://doi.org/10.1016/j.ejon.2018.05.002

[14] Naegele, M., Kirsch, M., Ihorst, G., Fierz, K., Engelhardt, M. and De Geest, S. (2017) Symptom Experience of Multiple Myeloma (syMMEX) Patients Treated with Autologous Stem Cell Transplantation Following High-Dose Melphalan: A Descriptive Longitudinal Study. *Supportive Care in Cancer*, **26**, 833-841. https://doi.org/10.1007/s00520-017-3897-z

[15] Chen, F., Leng, Y., Ni, J., Niu, T., Zhang, L., Li, J., *et al.* (2022) Symptom Clusters and Quality of Life in Ambulatory Patients with Multiple Myeloma. *Supportive Care in Cancer*, **30**, 4961-4970. https://doi.org/10.1007/s00520-022-06896-9

[16] Patel, M.N., Nina, A., Branchaud, B., Herring, K.W., Johnson, S., Scott, J., *et al.* (2024) Symptom Experience of Patients Undergoing Treatment for Multiple Myeloma: A Longitudinal Real-World Electronic Patient-Reported Outcomes Study. *Supportive Care in Cancer*, **32**, Article No. 802. https://doi.org/10.1007/s00520-024-08985-3

[17] Morris, M. and Marshall-Lucette, S. (2017) The Experience of Myeloma Caregivers during Home-Based Oral Chemotherapy Treatment: A Qualitative Study. *Seminars in Oncology Nursing*, **33**, 362-371. https://doi.org/10.1016/j.soncn.2017.05.010

[18] Quiñoa-Salanova, C., Porta-Sales, J., Monforte-Royo, C. and Edo-Gual, M. (2019) The Experiences and Needs of Primary Family Caregivers of Patients with Multiple Myeloma: A Qualitative Analysis. *Palliative Medicine*, **33**, 500-509. https://doi.org/10.1177/0269216319830017

[19] Borregaard Myrhøj, C., Novrup Clemmensen, S., Sax Røgind, S., Jarden, M. and Toudal Viftrup, D. (2021) Serious Illness Conversations in Patients with Multiple Myeloma and Their Family Caregivers—A Qualitative Interview Study. *European Journal of Cancer Care*, **31**, e13537. https://doi.org/10.1111/ecc.13537

[20] Shapiro, Y.N., Peppercorn, J.M., Yee, A.J., Branagan, A.R., Raje, N.S. and Donnell, E.K.O. (2021) Lifestyle Considerations in Multiple Myeloma. *Blood Cancer Journal*, **11**, Article No. 172. https://doi.org/10.1038/s41408-021-00560-x

[21] The Japan Academy of Nursing Science. Steering Committee for Scientific Nursing Terminology(n.d.) JANSpedia: Adaptation (in Japanese). https://www.jans.or.jp/english/glossary/adaptation/

[22] Duffy, M.E. (1998) The Concept of Adaptation: Examining Alternatives for the Study of Nursing Phenomena. *Scholarly Inquiry for Nursing Practice*, **12**, 163-186.

[23] Bradshaw, C., Atkinson, S. and Doody, O. (2017) Employing a Qualitative Description Approach in Health Care Research. *Global Qualitative Nursing Research*, **4**, 1-8. https://doi.org/10.1177/2333393617742282

[24] Chafe, R. (2017) The Value of Qualitative Description in Health Services and Policy

Research. *Healthcare Policy|Politiques de Santé*, **12**, 12-18. https://doi.org/10.12927/hcpol.2017.25030

[25] Roy, S.C. and Andrews, H.A. (1999) The Roy Adaptation Model. 2nd Edition, Appleton & Lange.

[26] Alhojailan, M.I. (2012) Thematic Analysis: A Critical Review of Its Process and Evaluation. *West East Journal of Social Sciences*, **1**, 39-47. https://faculty.ksu.edu.sa/sites/default/files/ta_thematic_analysis_dr_mohammed_alhojailan.pdf

[27] Braun, V. and Clarke, V. (2006) Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, **3**, 77-101. https://doi.org/10.1191/1478088706qp063oa

[28] Jung, S., Koh, Y., Kim, M.K., Kim, J.S., Moon, J.H., Min, C., *et al.* (2025) Evidence-based Korean Guidelines for the Clinical Management of Multiple Myeloma: Addressing 12 Key Clinical Questions. *Blood Research*, **60**, Article No. 9. https://doi.org/10.1007/s44313-025-00055-9

[29] Quinn, B., Ludwig, H., Bailey, A., Khela, K., Marongiu, A., Carlson, K.B., *et al.* (2021) Physical, Emotional and Social Pain Communication by Patients Diagnosed and Living with Multiple Myeloma. *Pain Management*, **12**, 59-74. https://doi.org/10.2217/pmt-2021-0013

[30] Barrett, A.J. and Battiwalla, M. (2010) Relapse after Allogeneic Stem Cell Transplantation. *Expert Review of Hematology*, **3**, 429-441. https://doi.org/10.1586/ehm.10.32

[31] Potter, M. and Kerridge, I. (2004) Bone Marrow and Stem Cell Transplantation. *Medicine*, **32**, 46-49. https://doi.org/10.1383/medc.32.6.46.36658

[32] Rowland, S., Forbes, R., Howell, D., Kelly, H., Haghayegh, A., Cardinale, M., *et al.* (2023) Psychosocial and Supportive Care Needs of Individuals with Advanced Myeloma. *Canadian Oncology Nursing Journal*, **33**, 215-222. https://doi.org/10.5737/23688076332215

[33] Cuffe, C.H., Quirke, M.B. and McCabe, C. (2020) Patients' Experiences of Living with Multiple Myeloma. *British Journal of Nursing*, **29**, 103-110. https://doi.org/10.12968/bjon.2020.29.2.103

[34] Stephens, M., McKenzie, H. and Jordens, C.F.C. (2014) The Work of Living with a Rare Cancer: Multiple Myeloma. *Journal of Advanced Nursing*, **70**, 2800-2809. https://doi.org/10.1111/jan.12430

[35] Dvorak, C. (2006) Common Complaints, Difficult Diagnosis: Multiple Myeloma. *Journal of the American Academy of Nurse Practitioners*, **18**, 190-194. https://doi.org/10.1111/j.1745-7599.2006.00122.x

[36] Dahan, J.F. and Auerbach, C.F. (2006) A Qualitative Study of the Trauma and Post-traumatic Growth of Multiple Myeloma Patients Treated with Peripheral Blood Stem Cell Transplant. *Palliative and Supportive Care*, **4**, 365-387. https://doi.org/10.1017/s1478951506060470

[37] Viitala, A., Saukkonen, M., Lehto, J.T., Palonen, M. and Åstedt-Kurki, P. (2018) The Coping and Support Needs of Incurable Cancer Patients. *Journal of Hospice & Palliative Nursing*, **20**, 187-194. https://doi.org/10.1097/njh.0000000000000427

[38] Beghetto, R.A. (2020) Uncertainty. In: Glăveanu, V.P., Ed., *The Palgrave Encyclopedia of the Possible*, Springer International Publishing, 1-7. https://doi.org/10.1007/978-3-319-98390-5_122-1 https://link.springer.com/referenceworkentry/10.1007/978-3-319-98390-5_122-1

[39] Rubins, Z., Gibson, B.J. and Chantry, A. (2022) What Can Patient Narratives Reveal to Us about the Experience of a Diagnosis of Myeloma? A Qualitative Scoping Re-

view. *Journal of Patient Experience*, **9**, 1-11. https://doi.org/10.1177/23743735221079133

[40] Monterosso, L., Taylor, K., Platt, V., Lobb, E., Musiello, T., Bulsara, C., *et al.* (2018) Living with Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care. *Journal of Patient Experience*, **5**, 6-15. https://doi.org/10.1177/2374373517715011

[41] Weerahandi, A., Sinclair, S., Raffin-Bouchal, S., Watson, L. and Lemieux, L. (2024) The Experiences of Living with Multiple Myeloma and a Palliative Approach to Care: A Grounded Theory Study. *Canadian Oncology Nursing Journal*, **34**, 539-549. https://doi.org/10.5737/23688076344539

[42] Molassiotis, A., Wilson, B., Blair, S., Howe, T. and Cavet, J. (2011) Living with Multiple Myeloma: Experiences of Patients and Their Informal Caregivers. *Supportive Care in Cancer*, **19**, 101-111. https://doi.org/10.1007/s00520-009-0793-1

[43] LeBlanc, M., LeBlanc, T., Leak Bryant, A., Pollak, K., Bailey, D. and Smith, S. (2021) A Qualitative Study of the Experiences of Living with Multiple Myeloma. *Oncology Nursing Forum*, **48**, 151-160. https://doi.org/10.1188/21.onf.151-160

[44] de Wet, R., Lane, H., Tandon, A., Augustson, B. and Joske, D. (2019) ‘It Is a Journey of Discovery’: Living with Myeloma. *Supportive Care in Cancer*, **27**, 2435-2442. https://doi.org/10.1007/s00520-018-4502-9

[45] Parsons, J.A., Greenspan, N.R., Baker, N.A., McKillop, C., Hicks, L.K. and Chan, O. (2019) Treatment Preferences of Patients with Relapsed and Refractory Multiple Myeloma: A Qualitative Study. *BMC Cancer*, **19**, Article No. 264. https://doi.org/10.1186/s12885-019-5467-x