

# A process for mitigating spiritual pain in patients with terminal cancer : the experiences of patients to help palliative care nurses

メタデータ	言語: eng 出版者: 公開日: 2017-10-04 キーワード (Ja): キーワード (En): 作成者: メールアドレス: 所属:
URL	<a href="http://hdl.handle.net/2297/10998">http://hdl.handle.net/2297/10998</a>

# A process for mitigating spiritual pain in patients with terminal cancer — the experiences of patients to help palliative care nurses —

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## Abstract

The aim of this study was to discern the meaning of experiences with a process for mitigating the spiritual pain of patients with terminal cancer in a palliative care unit. Non-structured interviews with 16 patients and 12 of their primary nurses were interpreted using a phenomenological-hermeneutic method. The findings clarified that among the 16 patients, 12 patients experienced mitigated spiritual pain from nursing care. In the process of mitigating the spiritual pain of patients with terminal cancer, patients and nurses worked together to acknowledge the patients' remaining time, and when patients were aware of "nurses' concerned words and actions" and that "physical suffering was eased", patients found positive meaning in the situation and felt happy and emotionally healed. In the process of mitigating spiritual pain, nurses' concerned words and actions triggered patients to change their perspective toward the positive. Easing patients' physical suffering is the first priority. The experiences of mitigated spiritual pain were related to patients with the greatest suffering. In nursing, nurses' care produced by nurses' concern with their patients. After their experiences, patients found the meaning of life and integrated it into the remainder of their life.

## Key words

terminal cancer, spiritual pain, mitigate, nurse

## Introduction

The human spirit is a facet of life that includes physical, mental, and social factors<sup>1)</sup>. Spiritual pain is easily triggered in patients with a terminal illness as they face death<sup>2-3)</sup>. Therefore, for terminally ill patients, spiritual care is important along with physical, mental, and social care to reduce all pain so that life might end peacefully. In Japan, in the actual practice of spiritual care in general hospital wards, palliative care units, and palliative care institutes for home care, the primary action has been to respond to expressed spiritual pain with active listening, repeating the

patient's words to affirm they were heard<sup>4)</sup>. Other modalities, such as building a relationship, art therapy, and logo therapy, have been reported<sup>5-6)</sup>. Active listening is a form of support that brings out the power of a patient, for when a patient expresses distress and reflects upon his life, his perspective is open to change<sup>7-8)</sup>. However, it is not yet clear how the mitigating of spiritual pain occurs and what role nurses may play in this process.

The purpose of this study was to clarify spiritual pain and how the mitigation of spiritual pain occurs in patients with terminal cancer and what

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nursing care may be provided for mitigating the spiritual pain of these individuals. In this study, Kawa's categories<sup>9)</sup> regarding the concept of spiritual pain were used for clarity of terms. It define a word "spiritual pain" is loss of meaning of life, loss of integration of self, religion and others, that is often experienced as the pain from gap in reality between desired and present image of oneself.

By discerning the meaning of experiences with a process for mitigating the spiritual pain of patients with terminal cancer, more comprehensive and effective care may be provided.

## **Methods**

### **The study**

Subjects were recruited for a qualitative descriptive study entitled, "The experiences with mitigated spiritual pain of patients with terminal cancer." Patients reported positive changes after the experiences—for example, positive receiving and positive activities in relation to self and others. Patients' positive changes were then interpreted by an investigator using patient narratives, nurses' observations, and medical charts.

### **Method of analysis**

The purpose of this study was to clarify the meaning of experiences with a process for mitigating the spiritual pain of patients with terminal cancer in a palliative care unit, so it was important to be able to explain how to mitigate spiritual pain and to see the interaction between each patient and a primary nurse. The results were analyzed to determine the essence of the mitigating phenomenon and the meaning of the experience to patients. The most appropriate method of analysis was the hermeneutical phenomenology approach<sup>10)</sup>.

### **Study period and subjects**

The data were collected between October 2006 and November 2007. The subjects of this study were patients with terminal cancer and their primary nurses who worked in a hospital's palliative care unit. Patients were informed of their

diagnosis, were receiving symptom management, and were able to participate in interviews. It define a word "terminal cancer" as remained period is within 6 months, and there is no cure positive any more.

### **Procedures and ethical consideration**

The criteria for patient participants in this study were that they had been informed of their diagnosis, were receiving symptom management, and were able to answer interview questions. The palliative care unit manager identified patients who met the criteria for study participation. The investigator obtained consent from the medical director and chief physician. Interested patient participants then contacted the investigator directly. Patients who met the criteria were informed about the objective of the study, that their participation in the study was voluntary, that they had the right to withdraw consent at any time, and how their privacy would be protected. This information was presented verbally and also provided in an explanatory paper. Patients consented to participate by signing a letter of consent. So this interview would make disturbance participants, if the participants would be unrest or excitement, investigator would report the participants to nurses, and ask to observe carefully after the interview, but there were no unrest or excitement in the participants.

### **Data collection**

Data were collected by a non-structured interview. Patients were interviewed 2–3 times. At the first interview, the patient was asked, "Please talk about your history of illness". At the second interview, Kawa's categories<sup>9)</sup> regarding the concept of spiritual pain were explained. The patient was then asked, "Please talk about the pain from the gap in reality between your desired and present image of yourself, the pain from the gap in reality between your desired and present relationships with others, and your level or anxiety" and "Please talk about experiences in which your spiritual pain was mitigated and for which you were happy for nursing care". A third

interview was conducted with patients who felt they had more to say. The interview consisted of open-ended questions and was conducted at the patient’s place of preference, either in an interview room or at the bedside. The average interview time was 38 minutes and the range was 25–75 minutes. One patient was interviewed once, 14 patients were interviewed twice, and one patient was interviewed three times. Interviews were conducted at two-week intervals, depending on the patient’s condition and cooperation.

Nurses were interviewed once with open-ended questions such as, “Please talk about how you look at your patient and how you perform nursing care”. Each nurse was interviewed in an interview room for an average of 30.3 minutes (range, 23–40 minutes). The interviews of the patients and nurses who consented to the use of a tape recorder were recorded and later transcribed into written records. The interviews were performed in the place where their privacy would be protected.

**Analysis**

Data analysis was performed with each patient and a primary nurse as one set, in accordance with the procedure developed and described by Cohen<sup>11)</sup>. The first step was to read back the interviews, extract the parts of the mitigating phenomenon in the each patient’s experiences, and then determine each part’s meaning. Then next step was to integrate the extracted groups by meaning as elements of a theme, in consideration of specific and general contexts. Similarly, nurses’ experiences were analyzed. In addition, meaning patterns were compared for similarities and differences in the interactions between each patient and primary nurse. Finally, clarification of the meaning and process by which spiritual pain was mitigated by interaction between the patient and primary nurse was supervised by an investigator who was experienced with research using the hermeneutical phenomenology approach. And it was presented to 9 participating nurses to confirm the validity of the results.

**Table1. Demographic Profile of the Participants**

Patients		Number (%)	
Sex		Marital status	
Male	7 (43.8)	Married	12 (75)
Female	9 (56.2)	Widowed	3 (18.8)
Age		Divorced	1 (6.2)
40s	1 (6.2)	Activity	
50s	4 (25)	Ambulatory	6 (37.5)
60s	8 (50)	Bedridden	6 (37.5)
70s	2 (12.5)	Wheelchair	4 (25)
80s	1 (6.2)	Metastasis	
mean	61.8years		16 (100)
	(range.40~88years)	Pain control	
Cancer site		Oral medication	8 (50)
Breast	3 (18.8)	Percutaneous absorption	7 (43.8)
Prostate	3 (18.8)	Subcutaneous injection	1 (6.2)
Stomach	2 (12.5)		
Pancreas	2 (12.5)		
Sarcoma	2 (12.5)		
Esophagus	1 (6.2)		
Kidney	1 (6.2)		
Vagina	1 (6.2)		
Malignity lymphoma	1 (6.2)		
Nurses		Number (%)	
Sex			
Male	0 (0)		
Female	12 (100)		
Experiences in Nursing			
5~ 9 years	3 (25)		
10~14 years	2 (16.7)		
15~20 years	7 (58.3)		
mean	13.6years	(range,5~19years)	
Experiences in Palliative Care			
<3 years	1 (8.3)		
3~5 years	8 (66.7)		
>5 years	3 (25)		
mean	3.8years	(range, 4months~5years)	

**Results**

Participants in this study were 16 patients and 12 primary nurses. The participants’ backgrounds were showed on table 1.

The patients were 7 men and 9 women with an average age of 61.8 years. Their average number of remaining days was 45 days. The nurses were all women. The average number of years of nursing experience was 13.6 years and the average number of years working in the palliative care unit was 3.8 years.

Of the 16 patients, 12 experienced mitigated spiritual pain (Fig. 1).

Among the remaining 4 patients, 2 gave responses that suggested emotional instability. One patient felt nausea and very lonely; the other

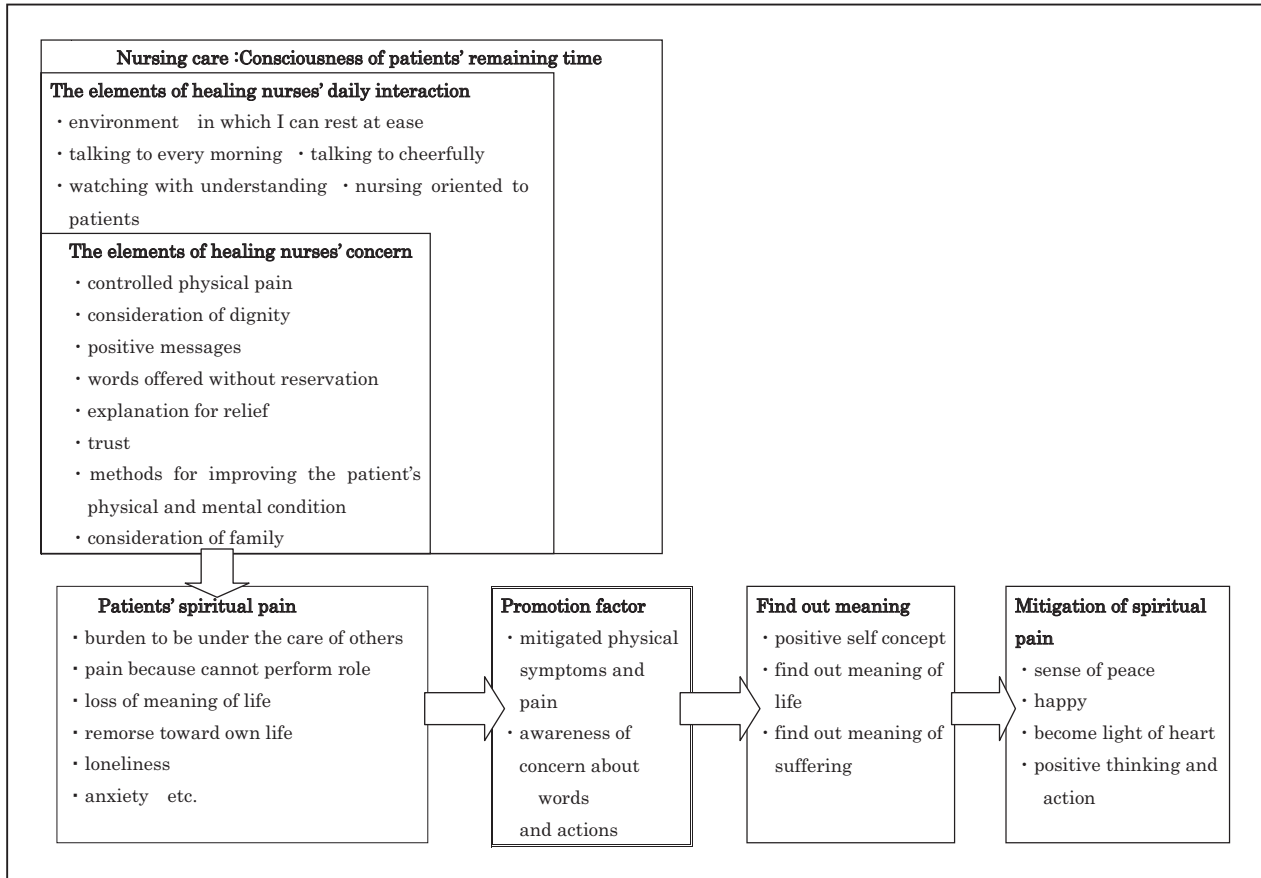


Figure 1. Process of mitigated spiritual pain in terminal cancer patients for nurses

one had recently lost the ability to walk and couldn't accept herself as a person who couldn't move.

### Experiences of patients with mitigated spiritual pain

In the experiences of 12 patients with mitigated spiritual pain, two themes were found: healing nurse's concern and healing nurse's daily interaction. In "healing nurse's concern", these elements were found (Fig.1) : "controlled physical pain", "consideration of dignity", "positive message", "words offered without reservation", "explanation for relief", "trust", "methods for improving the patient's physical and mental condition" and "consideration of family". In "healing nurse's daily interaction", these elements were found: "environment in which I can rest at ease", "talking to every morning", "talking to cheerfully", "watching with understanding", and "nursing oriented to patients". Finally, two characteristic patterns of meaning were found: "feeling the nurse's intention and concerned words and actions

for me" and "feeling the nurse's consideration, although the nurse didn't intend daily interaction". Of these two patterns of meaning, the former point to "the elements of healing nurses' concern", the latter point to "the elements of healing nurse's daily interaction" (Fig.1).

Figure 1 showed the process of mitigated the spiritual pain in terminal cancer patients. In the process, nursing care related to mitigation of the spiritual pain in patient participants.

#### 1) Feeling nurse's intention and concerned words and actions for oneself

For example, one patient participant said, "I cried with happiness at the end of the year because I got Christmas cards and in one, a young nurse had written, 'I wish to be present beside the patient, rather than to do anything else.' I was impressed with the words this young nurse had written! (with tears in his eyes)... This is consolation, to keep in the back of the mind. ... Ultimately, I was still lonely. Then, the words 'I

*wish to be present beside the patient' impressed me. I am happy that the nurse was concerned that I would like this!"*

Another patient participant said, "*Nurses have been caring very well ... When I said, 'I have no meaning of life with this condition', the nurse said, 'Your family said you are ok only being'. I am happy and encouraged ... When I said, 'I have been troubled by my husband when he wants to work in the garden', the nurse said, 'When you have been helpful to your family, your turn comes next to be helped by your family.'*

*When I thought, 'so, my turn comes next to be helped by my family', I became light a little ... When I felt tiredness in my legs, I called for a nurse, and one came and massaged my legs. I feel tiredness in my legs after even a little time in the same position. Nurses massage my legs. I am happy."*

Another patient participant who had discomfort in the arms said, "*When I first came here, I told a nurse that my right arm was asleep. The nurse said, 'We will receive all, including it.' I was really surprised and happy! I had been unwilling to ask anyone to do anything for me, but at this explanation, my feelings changed 180 degrees."*

## **2) Feeling nurses' concern through their daily interactions**

A participating patient said, "*Nurses talk to me kneeled down instead of standing over me, saying, 'How are you?' I was surprised the first time. I am happy ... Every morning, nurses check on me during rounds and ask 'How are you today?' Then they said, 'We will keep up!' (laugh)* She said that nurses talked to her to encourage every day.

Thus, the patient participants felt the nurses' concerned words and actions, and mitigated physical symptoms and pain, then changed their perspective toward positive, and find out meaning of life. And the patient participants felt happy, and became light of heart, so mitigated spiritual pain. In this process, mitigated physical symptoms and pain, and patients' awareness of nurses' concerned words and actions preceded and triggered off find out meaning. That were named Promotion factor.

And the process was named Process of mitigated spiritual pain in terminal cancer patients for nurses (Fig.1).

## **3) Patients feeling the most suffering reported experiencing the most happiness**

Experiences of feeling happy reported by patient participants contained concerns about elimination care, shower, and massage expressed by patients who were feeling the most suffering. For instance, a patient participant who felt an acute loss of dignity said, "*I have resistance to anyone doing anything for me and the nurses knew it, yet they exerted their influence. I appreciate their care in the shower too*". Another patient participant who felt lonely said that he was impressed by the words that a nurse had written in a Christmas card, '*I wish to be present beside the patient'* and he had been consoled by the words.

## **Experiences of patients with didn't mitigated spiritual pain**

In the experiences of four patients with did not achieve mitigated spiritual pain, two themes were found: the nurse's concern and experiences of distress. In "nurse's concern", these elements were found: "words offered without reservation", "explanation for relief", "trust", and "methods for improving the patient's physical and mental condition". In "experiences of distress", these elements were found: "physical pain and symptoms", "loneliness", and "difficulty with acceptance of changes in oneself". The patient participants who did achieve mitigated spiritual pain felt happy on the one hand for the nurses' concerned words and actions. However, they were less distressed with physical pain and symptoms, loneliness, and acceptance of changes in oneself.

A patient participant said "*Nurses accept anything, so when I came here, I was happy ... However, I became distressed when nausea developed ... I became distressed when I couldn't sleep, so I had to be given an injection of a sedative ... and I am very lonely ... I thank my family for their presence, actually."*

## **Nursing care**

The primary nurses of the 16 patients learned

the backgrounds of their patients, history, age, family, character, and psychological state. In nursing care interviews was found the theme “consciousness of remaining time” (Fig.1) and this theme contained the following elements: 1) to show concern for patients; 2) to build a relationship for ease of asking; 3) to make deliberate use of time; 4) to listen and give positive messages; 5) to support role playing; 6) to protect the patient’s dignity; 7) to explain for reassurance; 8) to show regard for hope and consideration of the most safe and comfortable way to do things; 9) to show respect for the patient’s life; and 10) to use intuition and show support for the family.

Nurses showed concern for their patients and consideration of their patients’ backgrounds and conditions, were conscious of the patients’ remaining time, and supported each patient’s life. For example, a nurse said, *“I think that on the palliative care unit, no matter how many years old a patient is, the little parts of life are important, so I become concerned with how patients have lived and their life history until now, so I ask about it while I’m wiping their body ... So I had known one man would be interested in a particular television program when it was broadcasting in the lounge, and I told him about it so he could enjoy it and he did.”* The nurse provided her patient with pleasure from something she knew he would enjoy. Another nurse said, *“The patient would be conscious of her remaining time. Whatever she hopes to do, I will respect it.”* One patient with paralysis in the lower half of her body from cancer metastasis felt like a burden to others who were providing care. The primary nurse listened to her every day and gave her affirmative words such as, *“At other wards, there are 40 patients, but there are only a few in this ward, so you don’t feel like such a burden”* and *“Your family said you are ok only being.”* At the same time, the nurse massaged a patient’s legs when she felt discomfort even after a short time in the same position.

Another primary nurse who cared for a patient who didn’t achieve mitigated spiritual pain said, “He wishes to not feel any pain, so we should meet

his wishes”. Nurses tried to manage his pain and symptoms every day.

Thus, the primary nurses concerned their patients’ physical, spiritual pain, and provided care with consciousness of their patients’ remaining time.

## Discussion

### Background

It has been reported that the spiritual pain of terminally ill patients arises from loneliness from near-death awareness, regret from leaving work unfinished, remorse at the life led, sorrow for leaving people, and guilt at feeling like a burden under the care of others<sup>7-8)</sup>; this study’s participants expressed the same feelings.

This study’s participating nurses had significant clinical experience and prominent nursing skill. This would be related to the quality of patient care.

### Patients whose spiritual pain was not mitigated

In the participants, 4 patients were not mitigated. It seemed no relationship with generation and disease. Mitigation of spiritual pain has been found to be connected with management of physical pain<sup>12)</sup>. The results of this investigation were same. And it would need a lot of time that person would receive change in own body.

### The experiences of patients with mitigated spiritual pain

Participating patients reported experiencing happiness when they heard nurses’ words, watched their actions, and felt their concern in their daily interactions. Before receiving positive messages and sensitive actions from the nurses, patients reported trying to cope with regrets, loneliness, and anxiety. From the results, mitigated physical symptoms and pain and nurse’ concerned words and actions triggered a change in patients’ perspectives toward the positive. As a result, patients found a positive meaning in their situation and felt happy, then mitigated spiritual pain.

### Nursing care

The nurses’ concern that was perceived by their patients was strengthened because nurses understood their patients’ background, was conscious

of patients' remaining time, supported their hopes, and extended concerned words and actions to them. Nursing care that includes knowledge of a patient's background and consciousness of a patient's remaining time is characteristic of palliative care. However, nursing care that includes eye contact, being on the same level as the patient while talking, and asking their condition every morning seems to make a significant difference in palliative care for mitigating spiritual pain.

Taylor reported in a study of nursing requirements that it is important that before spiritual care, nurses must show kindness and respect to the patients and a skill for developing rapport<sup>13</sup>. Conner et al. reported that the nursing skills that were most helpful for satisfying the spiritual needs of patients were first praying together, reading the Bible, and participating in religious activity. Next were attitudes of sympathy and kindness, followed by touch and massage<sup>14</sup>. In this study, participation in religious activity was not a finding, probably because many people in Japan don't have a particular religion. However, patients in both the West and East want nurses to provide kindness, respect, and sympathy. The patients with the most suffering seem to benefit the most from especially sensitive nursing care. Gauthier reported on barriers to healing for terminally ill adults and indicated that facilitators were maintaining relationships, holding a unique perspective of hope, and returning to spiritual roots<sup>12</sup>. In this study, strong suffering was a barrier to healing. Nurses responded with concern and an attempt to ease the suffering; patients would feel this concern and come to trust the nurses, which would lead to a change in perspective.

Heidegger said, "Considerate open action is partnership present with another."<sup>15</sup> In the process of palliative care for patients with terminal cancer, the patient and the primary nurse are in a partnership thrown into the world. The nurse is concerned for the patient, learns the patient's background until now, and considers individual needs. In this process, when the patients were aware and accepted the nurses' concerns,

including "considerate words and actions for me", the patients found a positive meaning in their situation and felt happy, with mitigated spiritual pain.

### **Conclusion**

This study involved 16 patients with terminal cancer in a palliative care unit and their 12 primary nurses. Of these 16 patients, 12 had mitigated spiritual pain as a result of nursing care. These patients reported feeling the concern of the nurses, expressed through considerate words and actions, and this gave positive meaning to their condition. In this process, physical pain was controlled and patients' awareness of nurses' considerate words and actions would operate promotion factor in finding out meaning and to change their perspective toward the positive. Patients with the most suffering seem to respond the most to sensitive nursing care. The experiences of mitigated spiritual pain are connected to finding the meaning of life and living the remaining time in a meaningful way. Nurses are needed for their skill in relationships with patients and their penetrative care of terminally ill patients in their remaining time. The findings and originality of this investigation were clarified the process of mitigated spiritual pain from patients' inside, and substances of nurses' concerned words and actions and mean of nursing care for patients developed.

### **Limitation of the study**

This study was conducted to clarify aspects of mitigated spiritual pain of patients with terminal cancer in a palliative care unit, cared for by primary nurses. However, in this initial study, it couldn't present to patient participants to confirm the validity of the results for the patients were terminally ill. And the sample size was too small for the results to be applied generally. Further studies with larger patient populations, middle age and old age are necessary to validate these findings.



## Acknowledgment

The author thanks the willing participants in this study and the manager and director of the hospice care team.

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## 終末期がん患者のスピリチュアルペインが緩和される過程 －看護により癒される体験から－

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### 要 旨

本研究の目的は、終末期がん患者のスピリチュアルペインが、看護により緩和される体験の意味と過程を明らかにすることであった。緩和ケア病棟に入院している終末期がん患者16名と12名の担当看護師を対象として非構成的面接を行い、語られた内容を解釈学的現象学的に分析した。その結果、明らかにされたことは、研究に参加された終末期がん患者16名のうち看護師の関わりによりスピリチュアルペインが緩和された者は12名であった。終末期がん患者のスピリチュアルペインが緩和される過程では、患者と看護師は、投企された世界に共同存在しており、看護師が「残された時間を意識したケア」を個別に配慮をしながら関わっている中で、患者が「身体的苦痛の緩和」と「自分のことを気遣ってくれている言葉や行動」と認知した時に、状況を肯定的に意味づけし、嬉しく思い、癒されていくことが明らかになった。このことから、「身体的苦痛の緩和」が前提として重要であることと、理解した上での患者への「配慮された言葉かけや行動」が患者の見方を変化させ、意味を見出す契機となっていることが示唆された。看護師の関わりでは、患者への「関心」が患者への「配慮」を導いていた。患者にとって癒された体験として語られた内容は、患者が最も辛いと感じていることに関連していた。スピリチュアルペインが癒される体験は、その後の残された時間を生きる意味を見出し、人生を統合していくことに繋がっていた。