

A family's positioning and background of the patients who are suffering from hepatic cancer resulting from hepatitis C : resulting from hepatitis C

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/2297/24777">http://hdl.handle.net/2297/24777</a>

# A family's positioning and background of the patients who are suffering from hepatic cancer resulting from hepatitis C – From the experience of the patients who are aware of their approaching death –

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## Abstract

This study was carried out for the purpose of clarifying the existence and meaning of the family in the experience of patients suffering from hepatic cancer resulting from hepatitis C who are aware of their approaching death. A qualitative analysis was conducted on 21 patients and 9 families taking care of patients. Results revealed that while the patients with hepatic cancer resulting from hepatitis C are receiving dedicated treatment from the specialists with the most advanced medical information and skills and are encouraged by other patients with the same illness and fate, which works to relieve anxiety about the disease, they do not want to discuss it with their families and have a strong desire to live out the remainder of their lives as normal people would. In addition, because they tend to hold out hope for the chance of an extension of their life expectancy through treatment, they continue to put off saying farewell to their families. Therefore, patients' families are excluded from involvement with the patients' illness until they have reached the terminal phase. The patients' families respect their wish to avoid discussing the illness to prevent a feeling of regret after death and leave everything related to treatment to the doctors. However, in the terminal phase, they feel anxious about not being able to find the best option for the patient, conflicted between respecting the patient's desire to live longer and avoiding pain from the realization that the patient cannot be cured. This study suggested the importance of medical staff involving the family in the illness before the terminal phase to prepare to part from their families.

## Key words

hepatitisC, liver cancer, cancer nursing,  
bereavement with family, repeating recurrence-treatment cycle

## Introduction

Of patients who suffer from cirrhosis that has progressed from chronic hepatitis C, 8 % per year develop hepatocellular carcinoma, which is a high frequency<sup>1)</sup>. Based on figures showing the 5-year cumulative survival rate for hepatocellular carcinoma to be 35.4%, the nurses who care for patients with hepatic cancer resulting from hepatitis C cannot help but be aware of the potential for death in the future<sup>2)</sup>. It is important in sufficiently treating and

caring for patients in an advanced stage of this illness that the patients and their families have sufficient communication in the remaining time so that the patient does not feel regret<sup>3)</sup>.

It is reported that terminal-phase patients find help in coping with their situation through interaction with family and others, and that such interaction strengthens their connections with the people around them, which promotes their growth as a person<sup>4-5)</sup>. However, according to interviews

with patients suffering from hepatic cancer resulting from chronic hepatitis C about their experience that I carried out, while many close to the terminal phase were aware of their impending death, few talked about their family<sup>6)</sup>. Other studies on patients with hepatic cancer also report that such patients tend not to speak to their family about anxiety about death in connection with the recurrence of carcinoma or the progression of hepatitis<sup>7-9)</sup>. Furthermore, some studies have reported that patients in the terminal phase have a strong desire to prepare for their death by completing life. Such patients, being aware of the finiteness of their limited life expectancy, begin to consider what would, for them, be the most desirable way to meet death by choosing how to live out the remainder of their lives<sup>10-12)</sup>. In spite of the fact that the patients with hepatic cancer resulting from hepatitis C become aware of the finiteness of their limited life expectancy when they initially develop the disease, that awareness fades as a result of the repeated extension of their life expectancy through treatment, which is different from the experience of other cancer patients. Therefore, patients with hepatic cancer resulting from hepatitis C suddenly face their terminal phase. I wondered if such patients who are supposed to face their terminal phase in such ways had the type of relationship skills that would enable them to strengthen their relationships with their families and promote their growth as human beings.

Based on such issues, this study was carried out for the purpose of clarifying the existence and meaning of the family in the experience of patients who are suffering from hepatic cancer resulting from hepatitis C and who are aware of their approaching death.

## Methods

### 1. Research participants

The subjects of the study were patients with hepatic cancer resulting from hepatitis C and who had experienced at least one occurrence of the onset and treatment of hepatic cancer. Patients who had been told their diagnosis and who were

willing to participate in the research were introduced by 4 hospitals and one association of hepatic disorder patients, for whom approval for participation in the study was obtained. For inpatients, interview dates were set at the time when the physical condition of the patients was good, and when they were emotionally stable. Also, whether the patient had hepatic encephalopathy was checked with the doctor in charge or the head nurse, and a researcher who had experience in nursing patients with the relevant disorders checked for the signs of hepatic encephalopathy by direct interview with the patients. In addition, when a sufficient description of the experience of patients had been obtained, family members of patients with hepatic cancer resulting from hepatitis C were interviewed in order to find out how they approach the experience of parting with the patient due to death from the illness. The period of research was from April 2007 to December 2009. The research participants were 21 patients and 9 family members (Tables 1, 2).

### 2. Interview methods

Unstructured interviews were carried out with

Table 1 Characteristics of study population [Patients]

	Sex	Age (years old)	Disease period* (years)	The number carcinogenesis events (times)	Interview time (minutes)
1	Female	69	3	5	30
2	Male	66	15	3	57
3	Male	66	15	1	33
4	Male	70	26	1	36
5	Female	71	5	3	35
6	Male	50	5	2	41
7	Male	79	15	4	38
8	Female	71	16	2	29
9	Female	85	9	2	22
10	Female	63	7	3	41
11	Male	83	7	1	80
12	Male	68	13	2	37
13	Male	74	13	5	23
14	Male	64	5	3	31
15	Male	83	15	1	44
16	Male	72	16	5	42
17	Male	74	1	1	26
18	Male	81	6	4	33
19	Male	65	23	1	70
20	Male	72	27	1	70
21	Male	64	12	1	70

\*Disease period includes duration of hepatitis.

Table 2 Characteristics of study population [Family members]

	Family members			Characteristics of patients		
	Age (generations)	Relationship with patient	Interview time (minutes)	Age (years old)	Disease period* (years)	The number carcinogenesis events (times)
1	70	Husband	26	69	3	5
2	60	Wife	41	70	26	1
3	40	Wife	23	50	5	2
4	30	Daughter	30	63	7	3
5	80	Wife	64	83	7	1
6	60	Wife	29	74	13	5
7	70	Wife	35	64	5	3
8	40	Daughter	16	74	1	1
9	70	Wife	30	81	6	4

\*Disease period includes duration of hepatitis.

the patients. The interviews started from asking the patients about their feelings on the illness from the time they were informed about the illness until the present, and then the patients were asked to talk freely from there. When a patient narrative included discussion on how to live with the illness or discussion of the family, the discussion was deepened to encourage the patient to share details with the interviewer (Table 3).

However, in cases where there was no narrative

on the family involved in the free talk, patients were asked about their feelings toward family members. Family members were asked about their feelings toward the illness of the patient and on their involvement with the patient. During the interview, questions were asked to confirm that the approach to and the interpretation of the contents of the participant's narrative were correct. When there was consent by the participant, the interview was recorded on tape and a verbatim

Table 3 One scene during the interviews

<p>Because I am not so sensitive, I do not pay careful attention to my illness. However, when I hear something about livers, I always get nervous.</p> <p><b>[Researcher: Even when you hear people talking about the liver on the TV?] I don't really want to watch. When I initially got sick and attended the class on liver problems two years ago, I read a lot. Then, I found that my disease was following the steps described in the books, and I became more anxious about it.</b></p> <p><b>[Researcher: You probably do not want to know more about it, right?] Yes.</b></p> <p><b>[Researcher: Are you scared?] Yes, I am scared. Otherwise, I would not feel such anxiety.</b></p> <p><b>[Researcher: If you do not hear anything about the illness, do you usually not pay so much attention to the illness?] No, because there isn't anyone around me suffering from hepatic disease. I sometimes read books about it, but my knowledge is limited. Although my physician explains what I ask about, I sometimes feel so alone.</b></p> <p><b>[Researcher: Do you feel alone?] Yes, when I wonder why this happened to me. Even when I am with other people, I get tired quickly because I am not healthy. Then, I sometimes feel desperate when I start thinking about finally developing cancer.</b></p> <p><b>[Researcher: Do you have anyone who supports you?] No one. I think if I know someone who has a similar disease, I would feel more comfortable. But, my husband cannot understand my situation. Anyway, I have to deal with my disease by myself.</b></p> <p><b>[Researcher: Do you wish to know someone who is suffering from the same disease?] Yes, I always do. When I see someone in the same ward is suffering more than I am, I feel depressed. I wonder if I will be like the person and sometimes become anxious about it.</b></p> <p><b>[Researcher: Can't you consult with your husband?] No, because he does not know about liver disease. Even when I talk to him about my problem, he just tells me to see the doctor.</b></p> <p><b>[Researcher: Do you have anyone who helps you when you are feeling very sick?] No one, and my husband does not do any housework. He does not even cook rice. I sometimes wonder how much longer I will be able to live feeling this alone.</b></p> <p><b>[Researcher: When you feel alone, who would you like to talk to?] In the end, I always talk to my physician about my feelings and anxiety in detail. I have only my physician to rely on in the end.</b></p> <p><b>[Researcher: Do you have such a relationship with your physician that you can talk about your feelings?] He has taken care of me for a long time. He has taken very good care for me. I feel very lucky to have met him.</b></p> <p><b>[Researcher: Your physician helps you both physically and mentally, doesn't he?] Yes, he always tells me to feel free to come to see him at any time.</b></p>
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written record was created at a later date.

### 3. Methods of analysis

This study shows the feelings that patients suffering from this illness who are aware of their approaching death have toward their families, and the degree of involvement that these patients have with them. Therefore, a qualitative and descriptive study using a phenomenological approach in which Heidegger's concept that "Being and time determine each other reciprocally, but in such a manner that neither can the former, Being, be addressed as something temporal nor can the latter, time, be addressed as a being" was applied<sup>13-17</sup>. Colaizzi's method was referred to in the analysis. Colaizzi's method of analysis states that the ordinary, in terms of attitudes, beliefs, behaviors, expectations, desires, goals, evaluations, theories, feelings, tendencies, etc., is all radically re-structured; everything is called into question, nothing is any longer taken for granted. There is the recognition that every single moment can reveal the inexhaustible richness of life and existence<sup>18-20</sup>.

The procedure is as follows:

1) After the interview, the section with the strongest impression within the participants' narrative and behavior was reflected upon and notes were taken on the section and impression.

2) The whole of the patients' narratives that were made into a verbatim written record were read closely, then the narratives relating to how the patient deals with the illness while being aware of approaching death were extracted, and then the words that were factors which make up the meaning of how they do so were selected.

3) In the same manner as in 2), the narratives of patients in which they were aware of parting from their families due to death were extracted.

4) An attempt was made to interpret how the way patients live and their feelings about parting with their family, as extracted in 2) and 3), impact the involvement of the patients with their families. While doing this, the background of the patients, such as the state of the illness, changes in treatment, or changes in the patient lifestyle were focused on. During this process, impressions of the section in 1) were also included in the

interpretation of the reasons that the researcher had such impressions with an explanation of the researcher's feelings and existing knowledge, and the words extracted in 1) as factors making up meanings were also given careful consideration. This process was carried out for individual participants (Figure 1).

5) Common meanings from 4) were sought out and organized into themes. During this process, with regard to the terms used commonly by several participants, the researchers reviewed the patients' original descriptions, their backgrounds, and the impressions that the researchers had during previous interviews to confirm whether it was appropriate to interpret the terms as having a certain meaning, and whether participants did not use those terms to express different meanings. In addition, to address the possibility that interviewers might interpret different descriptions as having similar meanings due to impressions during the interviews, the researchers gave careful consideration to the meanings of terms used by participants through a review of their original descriptions and confirmed whether the interpretations were consistent with what the participants meant.

6) To confirm that themes sought out in 5) were appropriate, the groups of themes were compared to the original description given by the patient, the explanation of the structure of themes was refined, and an overall description was made.

The above procedures 1)-6) were used in the data analysis.

7) From the complete narrative of the family, narratives that corresponded to the themes of the patients were extracted, and a similar analysis was carried out on how the families feel about the patient's relationship with the family and how they approach parting with them due to their death.

Throughout the entire period of research, opinions of a supervisor and a clinical nurse who were very experienced in the care of patients with hepatic cancer resulting from hepatitis C were consulted in order to maintain the validity of the research.

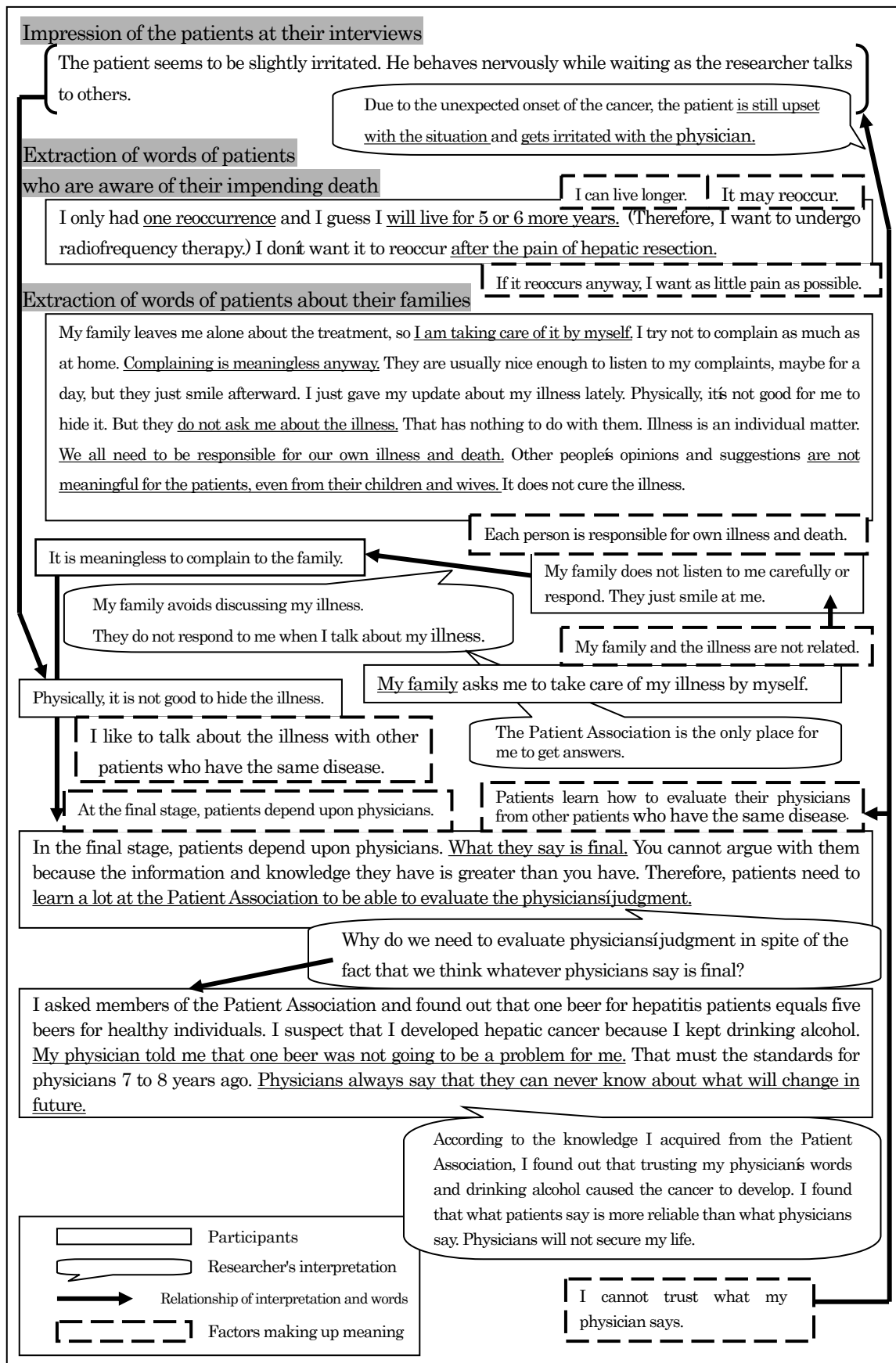


Figure 1 A sample of process of case analysis

#### 4. Ethical considerations for this study

This study was carried out with approval of the Medical Ethics Committee of Kanazawa University. Further, this study underwent an ethical review by the hospitals which were asked to cooperate in the study. In hospitals which did not have ethics review committees, a review by the head of the hospital, the head of the appropriate department and the nursing department were carried out. Subjects participated of their own free will and their intention to participate was checked at the time of request for research participation, as well as before and after the interview. A document explaining the study, which included contact information for the researcher, was given to the participants, so that they could withdraw from the study at any time. Also, the participants were assured that choosing whether to participate in the research or not would have no effect on future treatment. Participants were assured that the information obtained was not to be used outside the purpose of the study, and that individual participants were not to be specified in the event that the study were published as a paper or in other form. The fact that all information obtained was to be discarded upon withdrawal from the study was explained both orally and in writing, and consent for participation in the research was defined by the signing of the study participation consent form.

#### Results

The following describes the themes and the meaning of the families' existence in the patients' experience with hepatic cancer resulting from hepatitis C who aware of their approaching death. A family's existence was explained by the family's positioning and background (Table 4).

**1. Every time there is a relapse of the cancer and treatment is carried out, the patients cannot give up the hope that the doctor can find a treatment that will cure them and postpone their death a bit longer.**

Knowing that the effectiveness of hepatic cancer treatment is increasing due to the development

of new treatment methods, and that localized treatments which require a high level of technology, such as transcatheter arterial embolization or radiofrequency ablation have become mainstream, patients realize that they themselves cannot do anything about the cancer, and need to leave the treatment to the specialists who have the latest knowledge and techniques. Currently, only a few regions have hospitals offering radiofrequency ablation therapy, and most patients who live in these areas receive treatment in hospitals where there is a specialist in hepatic disorders with good treatment results. However, the patients felt constant anxiety as to whether the doctor treating them was conducting the latest and most ideal treatment and observed the words and actions of doctors carefully. Also, the patients felt relief that the utmost efforts were being made in treating them when the doctors showed an earnest attitude, such as explaining to them in a way that was easy for them to understand, or when the doctors made efforts to make the treatment as painless as possible. This is an important point in patients accepting their fate, in that the best efforts have been made in order to prolong their lives. A negligent attitude or inadequate treatment led directly to mistrust of the doctor and the fear that their life was shortened due to it. Being told by the doctor that the localized treatment for hepatic cancer was not possible after self-reported symptoms become more obvious, the patients realized that their death was impending. However, due to trust toward the doctor cultivated up to that point, patients were able to sustain their expectations for the prolongation of life as long as the doctor recommended life-prolonging treatment.

**2. Getting to know patients who have the same disorder and who have received the same treatment from the same doctor eases the loneliness of patients who bear the burden of having hepatic cancer resulting from hepatitis C, and this gives them strength and encourages them to continue to bear this burden.**

As mentioned above, patients being treated for this illness tend to go to the same hospitals. When

**Table 4** Themes of the families' existence in the patients' experience with hepatic cancer resulting from hepatitis C who aware of their approaching death, and the narratives of the participants.

Theme	Narrative of participant
Every time there is a relapse of the cancer and treatment is carried out, the patients cannot give up the hope that the doctor can find a treatment that will cure them and postpone their death a bit longer.	<p>I do not know what is a perfect treatment, but I hear that this hospital provides a treatment method that is as close to perfect as you can get in this area.</p> <p>The doctor leads the way in curing the disease, and the medications, injections and other things help with it. Whether appropriate treatment is being given depends upon how I feel within this experience.</p> <p>Because when I asked the doctor at the outpatient clinic how much longer I had to live, he told me that I would be ok for a few more years.</p>
Getting to know patients who have the same disorder and who have received the same treatment from the same doctor eases the loneliness of patients who bear the burden of having hepatic cancer resulting from hepatitis C, and this gives them strength and encourages them to continue to bear this burden.	<p>I am lonely, and I have never felt like this before. A person who I was talking to at the hospital with the same disorder and around the same age as me said their state of their condition was about the same as mine, and they passed away last year.</p> <p>The trouble is who to talk to. I don't talk about these things with the family because it makes the conversation a bit down. It is like counseling for me talking if the hospital or people who know the facts of the case listen to me.</p>
The patients wish the family spent time with them as a normal person (not a patient with hepatic cancer resulting from hepatitis C) in order to make the remaining time more meaningful.	<p>I seem to be relatively active compared to the other patients, so I go anywhere I like, forgetting about the illness. I guess you can't help it once you get hepatitis C, you just have to go about it. I don't know how many years longer I will be able to do everything by myself, but if I lived with my daughter, I do not know if I would be moving as much as I do now. I think it will weaken me if I allow my daughter to help me.</p> <p>I basically decided to stop things that are a burden on the liver. Then I decided to only do what I like. I am doing a bit of water-color painting and sketching from time to time. Maybe if I left the experience as a written record, I might be able to write a novel on it.</p>
Leaving the time of death to fate, the patient is preparing to be away from their family, so they do not cause them too much trouble. However, because they trust that the doctor is carrying out life-prolonging treatment, they believe that they do not need to say goodbye to their family yet.	<p>I think it may be about time, but I have not been able to tell my husband. I told my children, thinking I have to leave everything in their hands.</p> <p>There is a given-up kind of feeling, like thinking getting up today is already enough. I am thinking of going back to my family when I have been told there is nothing left to do and there is only my final strength left in me, but I do not know if it will work that well.</p>
The family members think it is their duty to do fulfill the patient's wishes if they cannot be cured. However, they are troubled by the conflict of whether or not it is good for the patient to go through pain and suffering with treatment through to the end despite knowing that it is not going to be cured. This feeling does not reach the patient until the terminal phase.	<p>I feel bad in holding him back from everything, so to a degree he does what he likes, but within limits. It is like watching over him. Daily life seems to not cause any particular problems, and it is not at the stage of requiring care. I want to be cheerful when he is at home.</p> <p>I wanted to respect his motivation to fight the disease, and we do what we can to respect his desire. Fortunately, I am so glad that we could work together for the better.</p> <p>It's not like it is possible to live long even if they survive, so I am not sure whether this treatment is actually a good idea. So I told my father whether this can be done without pain in a place like a hospice. The family says to leave it to him, but of course he wants to live on, and hearing that causes trouble.</p>

a patient went for regular outpatient treatment or to a ward for inpatient treatment, they often found patients with the same disorder. By talking to such patients about how they were being treated and how painful the treatment was, the patient felt prepared for the treatment they were to receive. Also, they were able to find out about the doctors to who they were handing their lives over to. From the state of patients with more progressed disease, they were able to see themselves in the

near future and were able to feel grief in advance. The patients were sometimes unable to show their weakness due to their illness to doctors or to their families in order to protect themselves; however, they did not have to pretend with other patients with the same disorder and were able to show themselves as a patient. For patients who could only carry the burden of illness alone, the presence of patients with the same disorder and who carried the same burden helped them to understand the



burden, gave strength and encouraged them when it was hard to cope.

**3. The patients wish the family spent time with them as a normal person (not a patient with hepatic cancer resulting from hepatitis C) in order to make the remaining time more meaningful.**

In order to delay relapse of the cancer, patients made the effort to do everything that could be done at home with help from their family, such as not drinking alcohol, not smoking, resting, paying attention to their diet, and reducing stress. However, for patients who could do nothing but leave the treatment of the cancer to the doctor, discussing the illness with family members who had no knowledge of the illness only led to increasing anxiety for their families and themselves because it was seen as a waste of breath as there was no resolution possible. This is why the patients believed that they should not talk about their illnesses with their family. Also, patients felt apologetic that repeated relapse of the cancer caused the family to worry and caused them trouble. The patients dealt with their own illness

so as to cause less trouble for their family. When at home, patients sometimes suffered from fear of death or pain; however, the patients waited for this to subside without mentioning it to their family.

During most of the period when there was no relapse, the patients felt no physical weakness due to the illness and were able to live like a healthy person. The patients that realized the poorness of their prognosis thought about the end of their lives and decided to spend this time living without regrets. Although they cared for their bodies in order to prolong life, patients were actively involved in a hobby or in work so that they would not regret that they had not done a particular thing and fulfilled their role as a family member. Such days when the patients made the effort to make each day fulfilling and not show their illness to the family made the patients feel thankful that they were alive (Figure 2).

**4. Leaving the time of death to fate, the patient is preparing to be away from their family, so they do not cause them too much trouble. However, because they**

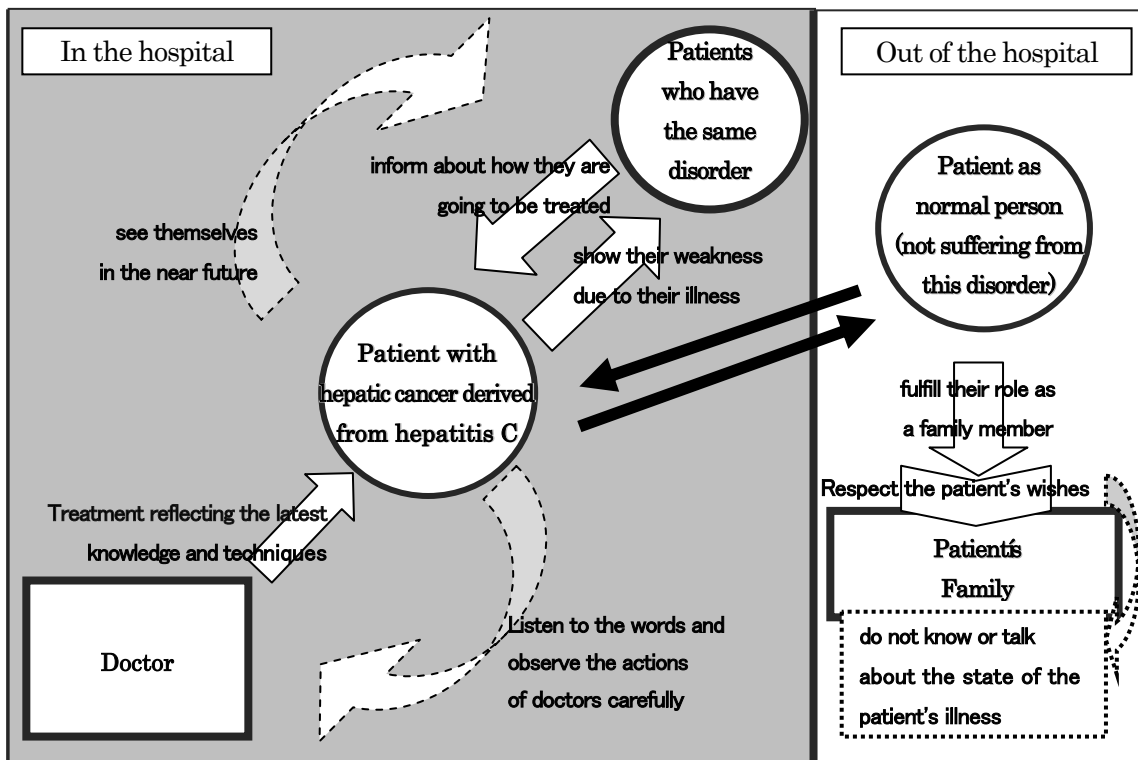


Figure 2 Relationship that gives patients with hepatic cancer resulting from hepatitis C strength and encourages them to continue to bear this disorder. (during periods of repeated treatments)

**trust that the doctor is carrying out life-prolonging treatment, they believe that they do not need to say goodbye to their family yet.**

Patients who had been told by their doctor that localized treatment of hepatic cancer was not possible because the illness had progressed and the symptoms had become too apparent knew that their death was impending. Until that point in time, the patients witnessed the death of other patients with the same disease. Thinking that it was finally their turn, they wished to approach death calmly, leaving it to fate. Since the patients knew that they would not recover to live as a healthy people, they organized their family business as they wished and talked to their family members little by little so that their role would be taken over. There were patients who requested their family arrange their funeral in a particular way. However, patients also believed that as long as hope for the prolongation of life was sustained through chemotherapy and radiotherapy, they felt that would not die immediately. Patients believed that there was time to say farewell to their families between the time

they had been told that no more treatment was possible (and therefore that it was impossible to prolong their lives) and their death.

**5. The family members think it is their duty to do follow the patient's wishes if they cannot be cured. However, they are troubled by the conflict of whether or not it is good for the patient to go through pain and suffering with treatment through to the end despite knowing that it is not going to be cured. This feeling does not reach the patient until the terminal phase.**

The family members thought that they would not going to have any regrets after the patient passed away, and wanted to fulfill the patient's wishes while they were still alive. The reason why they did not talk to the patients about the illness was because the patients did not touch upon the subject when talking to them.

The family members never knew the actual state of the patient's illness. However, because the patients trusted their doctor, the family members also trusted the doctor and agreed to the recommended treatments that the patients had

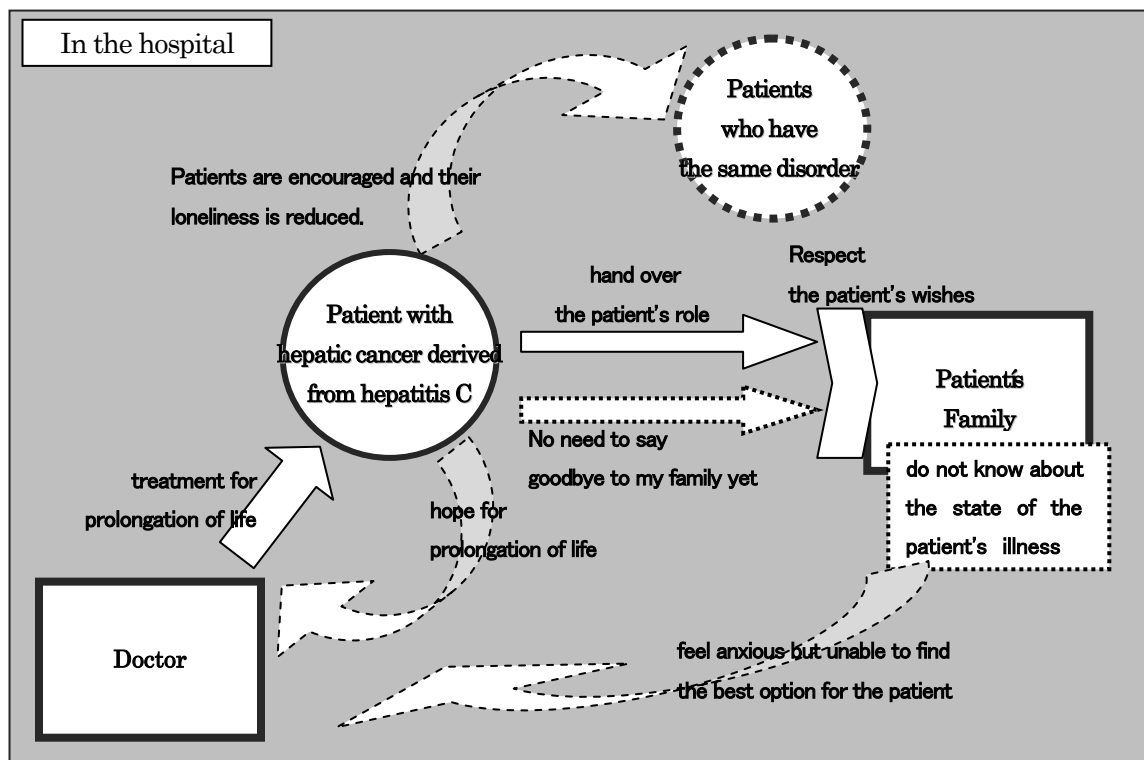


Figure 3 Relationship that prepares patients to be away from their families. (after the patient realizes that their death was impending)

agreed to. When the patient's illness reached the terminal phase and the symptoms became more apparent, the family members realized for the first time how serious the patient's condition was and they were shocked, regretting that they were not closely involved with the patient's illness until then. Family members, knowing that the patient wanted to live as long as possible, could not suggest to the patient to transfer to palliative care, even having witnessed how the patients suffer from the illness. Also, they felt that to discuss the transfer to palliative care with doctors recommending life-prolonging treatment would make the doctor feel bad, and have a negative effect on their relationship with the doctor. The only thing that the family could do was to feel anxious about being unable to find the best option for the patient (Figure 3).

### Discussion

This study reveals that patients with hepatic cancer resulting from hepatitis C did not see their families as going through the illness with them, and they believed that parting with their family through death was not likely to happen soon.

It is thought that these were the reasons the families were not involved in the patients' narratives. The reasons the patients have attached meanings to their families in this manner are discussed in relation to the characteristics of treatment of hepatic cancer resulting from hepatitis C. Also, issues related to the preparation for parting through death arising from the families' wishes not reaching the patient until the terminal phase will also be discussed.

#### **1. The role of rapidly-advancing treatment methods for hepatic cancer resulting from hepatitis C in contributing to patients' expectations that the parting with their family will be delayed, and the roles of other patients with the same disease and who have the same fate.**

Since patients witnessed closely how the treatment of hepatic cancer provided by the specialists with the most advanced knowledge and skills progresses, they could not give up hope that

a treatment method that would cure them would be developed within the next few years. Patients also obtain information and advice from patients with the same illness in the same hospital for the same treatment by the same doctor. This is thought to function as a prospect for the patients and enhance their sense of self and bring about confidence that they can prepare appropriately in terms of their illnesses<sup>21)</sup>. This expectation and confidence regarding treatment are thought to have led to patients having the confidence that they are not going to die yet, even in the terminal phase, and have led to them continue to put off saying farewell to their families.

#### **2. The everyday life of patients with hepatic cancer resulting from hepatitis C, divided into periods as a patient and as a normal person due to the special nature of hepatic cancer treatment, where only mild systemic invasiveness and short-term hospitalization are required.**

The localized treatment of hepatic cancer involves little systemic invasiveness and relatively minor side effects after operations, so the hospitalization period usually lasts 1-2 weeks. The patient can live as a normal person with their family, aside from the hospitalization period, which occurs once every six months to one year. It is believed this made patients feel that the family being involved in their illness is a special occasion, leading to them feeling guilty about troubling their family with their illness. Also, not talking about the illness during periods without relapse is thought to ease the psychological burden of patients facing death and their families<sup>22)</sup>.

#### **3. The direction of care support for families who are only passively involved with the patient's illness**

The families were well aware of the fact that they were going to part with the patients due to their death, and wished to be involved so that they would not feel regret. However, respecting the patient's wishes prevented any appreciable involvement in the process of care following the onset of the disease. This resulted in the family suffering pain because of the patient's choices

regarding how he or she would live out the rest of his or her life. The patients planned to say farewell to their families only after the limit of life-prolonging treatment has been reached, and when they realized that death could no longer be postponed or delayed. Since this illness has a high chance of a sudden turn for the worse in the terminal phase, such as hemorrhage or hepatic encephalopathy, it is highly likely that patients will not have a sufficient chance to sufficiently communicate with their families about parting. Saunders & Baines reported that the families of terminal stage cancer patients refrained from being involved in consideration of medical staff, and that they were anxious that they would not be able to obtain appropriate explanations from staff at appropriate stages<sup>23</sup>. It has also been reported that in caring for terminal patients and families the nurses always take the patients' side<sup>24-25</sup>. The families of patients with hepatic cancer resulting from hepatitis C tend to hide their feelings in order to respect the desire of the patients, who do not want to show families how much they suffer, unless medical staff actively becomes involved through interaction with the family from an early stage. With only a few short hospitalizations per year, medical staff and patient families do not have sufficient opportunities to interact. I believe that it is important for medical staff to provide an environment in which the families of the patients can express their feelings about patient care before the terminal phase so that they are not left to regret having respected the patient's choice. It is considered important that medical staff involve the family in the illness from an early stage, and that they help patients recognize that it is normal for the family to be involved in the treatment.

### **Limits of this study**

The results of this study are the understanding of phenomena from experiences narrated by research participants. Therefore, there are limits in applying these results to all patients with hepatic cancer resulting from hepatitis C. Also, because of the bias due to the high number of participants from nearby residential areas, it is

possible that regional character is reflected in the attitude toward treatment and lifestyle.

### **Acknowledgements**

I sincerely would like to thank all informants of the present research, all the individuals who have given me great help, especially Professor Michiko Inagaki who directly supervised me throughout the entire process of the research and helped me to develop the proper way of thinking and attitude based on a logical and ethical point of view. I also would like to thank Professor Kiyoko Izumi and Professor Keiko Shimada for supervising my thesis.

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## C型肝炎由来肝癌患者における家族の位置づけとその背景 —死を意識しながら生きる病みの体験から—

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### 要 旨

本研究は、死を意識するC型肝炎由来肝癌患者の病の体験における家族の存在とその意味を明らかにすることを研究目的とした。患者21名と患者を持つ家族9名を対象に質的分析を行った。C型肝炎由来肝癌患者は、自分の死を先延ばすために最新の医療情報と特別な治療技術を持つ専門医による熱心な治療を受け、自分と同じ病の運命を持つ同病者によって一人で病気を背負う辛さを支えられている一方、家族には自分の病に関わることを求めず、残された時間を普通の人としての自分と共に生きることを強く望んでいることが表された。また、終末期に至っても、患者は特別な医師の治療によるわずかな延命を期待し、今すぐは死なないだろうと思うことができるため、家族への別れを先送りしていることが表された。そのため、家族は終末期まで患者の闘病においては蚊帳の外になっていた。家族は死別後に後悔しないように患者の思いに沿い治療を医師に任せるが、終末期になり、生き延びたい患者の思いと、治らないのに患者に痛い思いをさせたくないという自分の思いに挟まれて、よりよい治療法の選択ができず、思い悩んでいた。したがって、患者が家族との死別に向かう準備のためには、終末期より前に、医療者が家族を治療に巻き込むケアが必要であることが示唆された。