

[Research Report]

Quality of life concepts important to family caregivers of advanced cancer patients undergoing treatment in Japan

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Purpose: The objective of this study was to identify important concepts of quality of life (QOL) in family caregivers of patients with advanced cancer in Japan.

Methods: Family caregivers of outpatients and inpatients with advanced cancer were recruited for semi-structured interviews (n=21).

Results: Content analysis of the interview transcripts identified 7 categories related to QOL concepts important to family caregivers of patients with advanced cancer: "being able to live while maintaining one's physical condition," "being able to face the patient with stable emotions," "having a society and personal connections with trusted persons other than the patient," "being able to manage financial health," "having relationship needs met in the family, including those of the patient," "being able to feel the importance of one's own existence," and "living daily life as unchanged since before the patient's cancer diagnosis."

Conclusion: Our findings suggested that these concepts could offer perspective on outcome evaluations of QOL in family caregivers of patients receiving treatment for advanced cancer.

Key words: advanced cancer patients, family caregiver, family quality of life, oncology nursing, qualitative study

I. Introduction

Cancer is the major cause of death in Japan and the number of patients with cancer was estimated to be 987,974 in 2015 (National Cancer Center, 2015); this number is expected to increase.

In recent years, the medical care system has shifted from inpatient care to early discharge and outpatient visits. The family of a patient with cancer often faces challenges with medical treatment in terms of daily life, during hospitalization, and after discharge. Therefore, it is important to offer

appropriate support for patients and their family. A qualitative study in Japan has reported on the experiences of family caregivers, highlighting difficulties supporting the patient with cancer (Okubo, 2013; Takeuchi, Fujino, 2012). Studies in Europe and America show that the needs and responsibilities of family caregivers increase over time (Lambert Harrison, Smith et al., 2012; Shaw, Harrison, Young et al., 2013), which affects their physical and mental health leading to problems such as sleep disorders or psychological pain.

However, few studies evaluated the present situation of family caregivers in Japan, and so there is no established family support system. One possible reason for this is that there is no established outcome standard to appropriately evaluate the quality of life (QOL) of family caregivers of patients with cancer. In Western countries, the difference between the concepts of family caregivers'

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needs and those of the patient has only recently been recognized. Because the needs of individual family caregivers are important, several instruments have been developed to evaluate QOL of family caregivers individually. Instruments developed for family caregivers of patients with cancer specifically include the Caregiver Quality of Life Index (CQLI) (McMillan, Mahon, 1994) and the Quality of Life in Life-Threatening Illness: Family Carer Version (QOLLTI-F) (Cohen, Leis, Kuhl et al., 2006), which were developed specially for family caregivers of cancer patients in palliative and hospice care. The Caregiver QOL Index-Cancer (CQOLC) (Weitzner, Jacobsen, Wagner et al., 1999), the Quality of Life-Family Version (QOL-FV) (Ferrell, Grant, 2005), and the Caregiver Oncology Quality of Life (CarGOQoL) (Minaya, Baumstarck, Berbis et al., 2012) were developed for family caregivers of patients with cancer in general.

These existing instruments were developed in Western countries. There are differences between Asian and Western societies in terms of cultural background such as family relationships, religion, and sexuality. It follows therefore that there will be differences in the concept of QOL in Asian countries (Lee, Ow, Akhileswaran et al., 2015). In Japan, outcome instruments have been necessary to address the differences in cultural background between Western countries and Japan, especially in terms of spiritual health, family roles and responsibilities, economic background based on the social security system, and religion.

Cultural background particularly affects spiritual health in a complex manner (Lee et al., 2015). There is currently no instrument originally developed in Asia. Although the CQOLC has been translated into Japanese and validated in Japan (Ando, Harata, Weitzer et al., 2013), it does not in-

clude evaluations of care burden and physical health. It is necessary to develop a QOL instrument that takes into consideration the family of the patient with cancer and reflects the cultural background of Japan to demonstrate the effects of support for the family in future.

This is a base study in the development of such an instrument. The objective of this study was to identify the concepts of QOL in family caregivers of patients with advanced cancer in Japan. This study could provide a base for outcome evaluation of family caregivers of patients receiving treatment for advanced cancer.

II. Materials and Methods

1. Participants

We recruited family caregivers of patients with advanced cancer (grade IV, stage IV, or metastases) according to the World Health Organization's classification from the outpatient and inpatient departments of our university hospital between May and November 2018. Inclusion criteria were as follows: 1) primary caregivers who are blood relatives of the patient, with whom they have a personal relationship, and who provides physical, emotional, or practical assistance and support to the patient with advanced cancer; 2) both the patient and the family caregiver have known the patient's diagnosis for more than 2 weeks since receiving notification of the cancer; 3) primary caregivers are aged 20 years or above; and 4) primary caregivers who are willing to participate. The exclusion criteria were as follows: primary caregivers who 1) experience difficulty and are unable to understand explanations of the study because of a mental disorder or cognitive impairment; 2) are unable to respond to interviews in

Japanese; and 3) bereavement.

2. Data Collection

A semi-structured interview format was used. Eligible participants were identified by head nurses. The head nurse considered the physical and mental state of the patient and determined whether the introduction of a particular family caregiver was suitable and appropriate. Consent was obtained after a researcher explained the study to the patient verbally, and then had the patient introduce their family caregiver. The family caregiver was then provided the study aims in writing and was invited to participate in the study. Informed consent was obtained before the actual interviews with the family caregivers were conducted. The interview guide developed from a literature review (Lee et al., 2015). The interview focused on physical, psycho-emotional, social, financial (McMillan, Mahon, 1994; Cohen, Leis, Kuhl et al., 2006; Weitzner et al., 1999; Ferrell, Grant, 2005; Minaya et al., 2012), spiritual (Weitzner et al., 1999; Ferrell, Grant, 2005), and daily life (Cohen et al., 2006; Weitzner et al., 1999; Ferrell, Grant, 2005; Minaya et al., 2012) factors. The interviewer asked about feelings considered important for the family caregiver's life and how their QOL was affected by the cancer diagnosis. 'For example, things like your physical well-being, feelings, religious beliefs, interactions with society, financial health, relationship with patients, etc. Please respond in detail regarding the examples above, or anything else.'

Because of the interview was time-restricted, family caregivers of outpatients were interviewed during wait times such as before blood test results or while waiting for actual medical examination and/or treatment. Family caregivers of inpatients were interviewed in the times on the days they visited the patient. In consideration of privacy pro-

tection for both inpatients and outpatients, we performed in a private room. There was no difference in interview time between inpatient and outpatient. After consent was obtained, all interviews were recorded using an IC digital voice recorder and transcribed verbatim. We collected interview data on the various backgrounds of the family caregivers by heterogeneous sampling.

3. Analysis

Verbatim records were produced, and parts corresponding to the contents associated with the QOL concepts important to the family caregivers were extracted, and inductive analysis was performed. To ensure the trustworthiness and scientific rigor of the qualitative data, the researchers discussed and compared the coding of the data and emerging categories and resolved any discrepancies by consensus. To ensure the analysis was adequate, 2 nurses and 4 researchers who were oncology specialists supervised the process.

4. Ethical Considerations

This study was conducted with approval from the Ethics Committee of the Research Department at the Tohoku University Graduate School of Medicine on January 12, 2018 (2018-1-12). A researcher explained the purpose and content of the study to each family caregiver in both in writing and verbally. The researcher then explained that for those who consented, participation was voluntary, they did not have to answer questions if preferred not to, they could decline participation at any time, and those who declined participation would not face any disadvantages in medical care. All obtained data were secured with lock and key. The researcher also explained to the family caregivers that the data would not be used for purposes other than the present study, and that all recorded data would be erased after the study was completed.

III. Results

1. Participants

In total, 21 (3 male and 18 female) eligible family caregivers were approached to participate in the study, all of whom consented to the study and were interviewed; each interview lasted for an average of 38 min (range, 30–90 min). The family caregivers' and patients' demographic data are presented in Table 1; 14 family caregivers were above 60 years old, 15 were spouses, 8 were employed, and 2 were religious. For cancer location, 9 patients had pancreatic cancer, 7 had brain tumor, 3 had lung cancer, 1 had head and neck cancer, and 1 had breast cancer; Eleven of the 21 patients received chemotherapy.

2. Quality of life concepts important to caregivers of patients with advanced cancer

From content analysis of the transcripts, 41 codes were retrieved. Similar codes were merged resulting into 21 subcategories, which were then grouped into the following 7 categories based on what QOL concepts important to family caregivers of patients with advanced cancer: [being able to live while maintaining one's physical condition], [being able to face the patient with stable emotions], [having a society and personal connections with trusted persons other than the patient], [being able to manage financial health], [having relationship needs met in the family, including those of the patient's], [being able to feel the importance of one's own existence] and [living daily life unchanged since before the patient's cancer diagnosis] (Table 2). Subsequently, categories will be placed in [], and subcategories in < >. The family caregivers' raw data will be written in *Italics*, and where necessary, supplementary explanations will be placed in []. Sources of raw data

will be labeled with capital letters (A–U). Examples of quotations are indicated.

1) [Being able to live while maintaining one's physical condition]

[Being able to live while maintaining one's physical condition] is composed of three subcategories: <sleep satisfaction>, <the real feeling of enjoying a delicious meal>, and <heal fatigue>.

<Sleep satisfaction> is composed of two codes: [feeling satisfied with sound sleep] and [getting enough sleep]. A feeling of not getting sound sleep was considered painful.

"I sleep for a while. However, I feel that I cannot sleep deeply, and still feel tired when I wake up in the morning." (M3)

"I sleep early and still wake up early in the morning. Tired. I am tired even if all I do is sleep and nothing else." (J6)

The family caregivers recognized the importance of getting adequate sleep to feel rested.

<The real feeling of enjoying a meal> is composed of one code: [enjoying a meals with the patient]

"I can't eat breakfast whenever I think about my daughter. Whenever she leaves for work, I don't want to eat. I feel more alone. Whenever I'm alone, I worry that my daughter might not be able to eat in the future. I'm unable to eat with such thoughts." (U5)

The family caregiver's appetite was closely related to the illness of the patient, and was indicative of their own physical condition.

<Heal fatigue> is composed of one code: [living while relieving fatigue]

"So far, I have not rested as soon as I get home. I have to prepare meals only after lying down for a while on the sofa." (H10)

"Though I did not feel that my body was weary, I eventually had feelings of heaviness." (H16)

Table 1. Sociodemographic of the family and patient

Cases	Family						Patient							
	Sex	Age (year) a: ≤60 b: 61 ≧	Relationship to patient	Marital status	Employee	Care experience	Living together	Religion	Sex	Age (year) a: ≤60 b: 61 ≧	Type of cancer	Type of treatment	outpatients or inpatients	Employee
A	Female	b	Spouse	Married	Yes	No	Yes	No	Male	b	Brain	Combination	Inpatients	Yes
B	Female	a	Child	Unmarried	Yes	No	Yes	No	Female	a	Brain	Combination	Inpatients	No
C	Female	b	Parents	Married	No	Yes	Yes	No	Male	a	Brain	Combination	Inpatients	Yes
D	Female	b	Spouse	Married	No	No	Yes	No	Male	b	Brain	Combination	Inpatients	No
E	Male	b	Spouse	Married	No	No	Yes	No	Female	a	Brain	Combination	Inpatients	Yes
F	Female	b	Spouse	Married	No	No	Yes	No	Male	b	Lung	Chemotherapy	Inpatients	No
G	Female	a	Spouse	Married	Yes	No	Yes	No	Male	a	Brain	Combination	Outpatient	Yes
H	Female	a	Child	Unmarried	Yes	No	Yes	No	Female	b	Pancreas	Combination	Inpatients	Yes
I	Male	b	Spouse	Married	No	No	Yes	No	Female	b	Brain	Combination	Inpatients	No
J	Female	b	Spouse	Married	No	No	Yes	Yes	Male	b	Pancreas	Surgery	Inpatients	No
K	Female	a	Child	Married	Yes	No	Yes	No	Female	b	Lung	Chemotherapy	Outpatient	Yes
L	Female	a	Spouse	Married	No	No	Yes	No	Male	a	Pancreas	Chemotherapy	Outpatient	No
M	Female	a	Spouse	Married	Yes	No	Yes	No	Male	a	Pancreas	Chemotherapy	Outpatient	No
N	Male	b	Spouse	Married	Yes	No	Yes	No	Female	b	Pancreas	Chemotherapy	Outpatient	No
O	Female	b	Spouse	Married	No	No	Yes	No	Male	b	Pancreas	Chemotherapy	Outpatient	No
P	Female	b	Spouse	Married	Yes	No	Yes	No	Male	b	Pancreas	Chemotherapy	Outpatient	No
Q	Female	b	Brother and sister	Unmarried	No	No	No	No	Female	b	Pancreas	Chemotherapy	Outpatient	No
R	Female	b	Spouse	Married	No	No	Yes	No	Male	b	Pancreas	Chemotherapy	Outpatient	No
S	Female	a	Spouse	Married	No	No	Yes	No	Male	a	Lung	Chemotherapy	Inpatients	Yes
T	Female	b	Spouse	Married	No	No	Yes	Yes	Male	b	Head and neck	Surgery	Outpatient	No
U	Female	b	Parents	Married	No	No	Yes	No	Female	a	Breast	Chemotherapy	Outpatient	Yes

Table 2. Quality of life concepts important to caregivers of patients with advanced cancer in Japan

Categories (7)	Subcategories (21)	Codes (41)
being able to live while maintaining one's physical condition	sleep satisfaction	feeling satisfied with sound sleep getting enough sleep
	the real feeling of enjoying a meal	enjoying a meals with the patient
	heal fatigue	living while relieving fatigue
being able to face the patient with stable emotions	heal reluctance	living while relieving reluctance
	emotional coping	keeping calm switching one's emotion thinking positively controlling one's emotions to ease stress
	acceptance of complex feelings	being considerate of patient's feelings in undergoing treatment
having a society and personal connections with trusted persons other than the patient	relationship with the whole family except the patient	having other family members to talk about the patient's illness
	relationship with friends	having friends to talk about the patient's illness having friends to spend one's time with
	relationship with the society and work	being supported to talk about the patient's illness in one's workplace and in society having a safe place where I can talk about this problem
	relationship with the medical staff	trusting the doctor in charge of the patient communicating effectively with the health-care staff
being able to manage financial health	income and security	not being worried about financial issues having economic security such as insurance not wanting to make the patient worried about financial issues
	time with the patient	spending time with the patient
having relationship needs met in the family, including those of the patient	relationship with the patient	always thinking of the patient thinking of the patient's issues as one's own being relieved to be with the patient being relieved to see the patient is cheerful being confident in helping the patient being thankful for the presence of the patient feeling supported emotionally by the existence of the patient thinking that it is important to communicate with the patient living while experiencing a sense of loss of the patient and the feeling lonely
	relationship with the family, including the patient	keeping bonds with family
being able to feel the importance of one's own existence	role of the self as part of the family of the cancer patient	thinking that it is natural to support the patient as a family member supporting the patient as much as possible as a family member
	importance of one's own existence	being conscious about the importance of one's own existence
	peace of mind	having peace of mind
living daily life as unchanged since before the patient's cancer diagnosis	maintaining social life	having responsibility
	meaningful time	having time for one self
	manage my health	taking care of one's own health having a doctor to consult about one's own health/physical condition living one's usual, daily life
	relief of care burden	living and coping with physical and mental burden caused by taking care of the patient

Tiredness was recognized to indicate the family caregiver's poor physical condition.

2) [Being able to face the patient with stable emotions]
[Being able to face the patient with stable emo-

tions] is composed of three subcategories: <heal reluctance>, <emotional coping>, and <acceptance of complex feelings>.

<heal reluctance> is composed of one code: [living while relieving reluctance]

“I have often stayed in the house without going out since my mother got sick.” (H17)

The family caregiver started feeling reluctant to engage in everyday actions.

<Emotional coping> is composed of four codes: 「keeping calm」, 「switching one’s emotion」, 「thinking positively」, and 「controlling one’s emotions to ease stress」. 「Keeping calm」 is expressed in the comment, *“There are various ways to keep myself calm. My husband’s physical condition may be unstable, but I try not to think about it too much. I think I can always calm myself down.”* (L6)

「Switching one’s emotion」 is expressed in the comment, *“When I heard that he had a severe illness, I was in considerable shock. My anxiety has eased now in comparison with the past because I can change my thoughts about it.”* (M5)

「Thinking positively」 is expressed in the comment, *“I just choose good thoughts that are more pleasant than thinking negatively about the future. I think I can try not to be depressed.”* (H11) The family caregiver could face the patient by thinking positively.

「Controlling one’s emotions to ease stress」 is expressed in the comment, *“If I can’t cope, I take it out on my mother. I feel stressed. I hate that I can’t communicate well with her”*. (B12)

The family caregiver practiced <emotional coping> in supporting the patient and maintained their own mental tranquility.

<Acceptance of complex feelings> is composed of one code: 「being considerate of patient’s feelings in undergoing treatment」
“On days before treatment, my daughter gets angry. She says that she doesn’t want to go. I don’t want to hear that. If she cancels her chemotherapy, I fear that the cancer may worsen in future if the treatment is delayed for 1 week. So, I don’t want to

hear such things. I want to say that it’s not just you. But, I can’t insist. I think I shouldn’t say anything.” (U7)

The family caregiver feels 「being considerate of patient’s feelings in undergoing treatment」 about the family situation surrounding the patient receiving cancer treatment.

3) [Having a society and personal connections with trusted persons other than the patient]

[Having a society personal connections with trusted persons other than the patient] is composed of four subcategories: <relationship with the whole family except the patient>, <relationship with friends>, <relationship with the society and work>, and <relationship with the medical staff>.

<Relationship with the whole family except the patient> is composed of one code: 「having other family members to talk about the patient’s illness」
“It is necessary for me to have someone on whom I can rely. With whom I can talk about anything. Though I do have friends, I can’t talk with them about such sensitive issues. I think I can only talk with my family about such things. The only people I can talk heart-to-heart with is my family.” (E12)
“I knew that I couldn’t handle this problem alone, so I told my children. I told them my husband had been diagnosed with cancer and needed treatment. I talked about wanting us all to cooperate. They all agreed and we have been fighting against the cancer as a family. I realize that my family is a blessing.” (R15)

These family caregivers emphasized the importance of family-related strength to support them and the importance of relationships with other family members.

<Relationship with friends> is composed of two codes: 「having friends to talk about the patient’s illness」 and 「having friends to spend one’s time

with].

[having friends to talk about the patient's illness] is expressed in the comment, "*My friend told me that the burden on a family caring for a sick person is rather heavy. So, I could talk about anything with them. My friend is my main support.*" (H14)

<Relationship with society and work> is composed of two codes: [being supported to talk about the patient's illness in one's workplace and in society] and [having a safe place where I can talk about this problem].

[Being supported to talk about the patient's illness in one's workplace and in society] is expressed in the comment, "*I have care leave. My company assured me of financial support and supported me. They adjusted consecutive holidays for me to be able to come to the hospital. I feel very thankful.*" (B9)

[Having a safe place where I can talk about this problem] is expressed in the comment, "*I talked with a consulting service. I can manage this, and I can do something. I decided that I don't need to worry.*" (R7)

<Relationship with the medical staff> is composed of two codes: [trusting the doctor in charge of the patient] and [communicating effectively with the health-care staff].

[Trusting the doctor in charge of the patient] is expressed in the comment, "*When we first saw the doctor, the doctor patiently listened to all my mother had to say. He said that he would work with us all and together we would decide on the best treatment.*" (H8)

[Communicating effectively with the health-care staff] is expressed in the comment, "*I want to ask the doctor some questions and I want a clear explanation about my husband's illness. I don't understand how it progresses. I want the doctor to ex-*

plain this well. I want smooth communication with the doctors because I hate that I can't understand the details of my husband's illness." (K11)

4) [Being able to manage financial health]

[Being able to manage financial health] is composed of one subcategory: <income and security>.

<Income and security> is composed of three codes: [not being worried about financial issues], [having economic security such as insurance], and [not wanting to make the patient worried about financial issues].

[Not being worried about financial issues] is expressed in the comment, "*When I make time to go to hospital with my husband, I must be absent from work. I need to look for flexible work to ensure job security. Because of this, there's nowhere I can work in the long term. I have to make do with short-term contracts. My husband doesn't work himself, so the burden of treatment costs is large. He's not being paid his full income, and so the financial burden is great.*" (M4)

The family caregiver states that lack of employment continuity makes it difficult for her to support the family budget in view of the decreased income of her husband who is himself ill. She wished that there was no financial stress.

[Having economic security such as insurance] is expressed in the comment, "*I worried about what would happen to our finances. However, I was relieved because I enrolled in medical insurance and cancer insurance. So, the benefits were made available at the time of the first operation.*" (S5) The family caregiver secured economic stability by receiving financial security such as insurance.

[Not wanting to make the patient worried about financial issues] is expressed in the comment, "*My husband says that keeping him alive costs money. I don't want him to worry about money. So, I tell*

him that the money is sufficient." (U4)

5) [Having relationship needs met in the family, including those of the patient]

[Having relationship needs met in the family, including those of the patient] is composed of three subcategories: <time with the patient>, <relationship with the patient>, and <relationship with the family, including the patient>.

<Time with the patient> is composed of one code: [spending time with the patient].

[Spending time with the patient] is expressed in the comment, "*I make it my first priority to make time to be with my wife. I go home early and don't work overtime.*" (G3)

"I feel uneasy about how long he has left to live. But, we don't put this into words to each other. I value the time I have with him." (L5)

<Relationship with the patient> is composed of nine codes: [always thinking of the patient], [thinking of the patient's issues as one's own], [being relieved to be with the patient], [being relieved to see the patient is cheerful], [being confident in helping the patient], [being thankful for the presence of the patient], [feeling supported emotionally by the existence of the patient], [thinking that it is important to communicate with the patient], and [living while experiencing a sense of loss of the patient and the feeling lonely]. [Always thinking of the patient] is expressed in the comment, "*Every morning as soon as I wake up, I always have this uneasiness about his illness all the time. So, I don't feel refreshed.*" (F4)

[Thinking of the patient's issues as one's own] is expressed in the comment, "*Even though foreigners think about individual family members, in Japan I think of the family as one unit.*" (F9)

[Being relieved to be with the patient] is expressed in the comments, "*I always make sure to*

be there for my wife. Because I have enough time. I think that it is important to take care of her and check her condition myself." (E1)

[Being relieved to see the patient is cheerful] is expressed in the comments,

"When my wife eats delicious food and looks happy, my heart feels warm." (H3)

[Being confident in helping the patient] is expressed in the comments, "*I will do anything to help my mother get well.*" (H2)

"The environment in my house was really different because my mother's influence disappeared." (H5)

[being thankful for the presence of the patient] is also indicated. The family caregiver thought that she took her mother's presence for granted before the cancer diagnosis, but appreciated her mother anew afterward.

[Feeling supported emotionally by the existence of the patient] is expressed in the comment, "*I want you to live longer.*" (F1)

After overcoming many difficulties facing the patient, a family caregiver indicated [thinking that it is important to communicate with the patient] in their comment, "*I talk with my husband almost every day. Because we confide in each other, we can talk about anything.*" (Q7) Moreover, another family caregiver stated, "*Before, we couldn't confide in each other in our relationship. His mental condition changed. We had a big argument after which we are now able to confide in each other.*" (Q9)

Another family caregiver said, "*I am conscious of my relationship with my wife. When I consider that I could lose her in the future, my sense of loss is huge. These kinds of thoughts flash through my mind; I think of this often.*" (E2) This comment indicates [living while experiencing a sense of loss of the patient and the feeling lonely].

<Relationship with the family, including the pa-

tient> is composed of one code: 「keeping bonds with family」.

A family caregiver mentioned, “*My family needs my support the most; that is, my husband and my child. Not keeping secrets from each other and sharing opinions. I’m careful not to incite a big argument even if we have a small quarrel.*”. (M10)

6) [Being able to feel the importance of one’s own existence]

[Being able to feel the importance of one’s own existence] is composed of three subcategories: <role of the self as part of the family of the cancer patient>, <importance of one’s own existence>, and <peace of mind>.

<Role of the self as part of the family of the cancer patient> is composed of two codes: 「thinking that it is natural to support the patient as a family member」 and 「supporting the patient as much as possible as a family member」.

「Thinking that it is natural to support the patient as a family member」 is expressed in the comment, “*I was helped, too. We are a couple. I told my husband I would help him.*” (D8). The family caregiver firmly believed that it is natural for a family member to support the patient.

Another family caregiver had regrets about her husband not being able to work. However, she recognized her role as important while also reaching out for possible support, based on the code 「supporting the patient as much as possible as a family member」. She commented, “*Actually, I wanted him to go back to work again.*” (F16)

<Importance of one’s own existence> is composed of one code: 「being conscious about the importance of one’s own existence」. A family caregiver was conscious about her life existence in the present, stating, “*I worry about my life. If I die, what would happen?*” (Q6)

<Peace of mind> is composed of one code: 「having peace of mind」. This is expressed by the comment, “*I am non-religious. However, I have special water that I replace every morning, and I burn incense and worship my ancestors. I do this every day. I feel that this is a form of support for the heart.*” (F13)

7) [Living daily life as unchanged since before the patient’s cancer diagnosis]

[Living daily life as unchanged since before the patient’s cancer diagnosis] is composed of four subcategories: <maintaining social life>, <meaningful time>, <manage my health>, and <relief of care burden>.

<Maintaining social life> is composed of one code: 「having responsibility」. One family caregiver maintained their social life by spending time at their workplace every day, fulfilling their responsibilities through work.

“*My work is my responsibility. Work is not possible without my clients. I never trouble my clients. Also, I am responsible for managing the lives of my employee’s families. I have a conscious.*” (N2)

<Meaningful time> is composed of one code: 「having time for one self」. This is expressed by the comment, “*I made a place to blow off steam and relax, and I take this time whenever my husband takes a rest.*” (L8)

<Manage my health> is composed of three codes: 「taking care of one’s own health」, 「having a doctor to consult about one’s own health/physical condition」, and 「living one’s usual, daily life」. One family caregiver said that it is important to be able to keep a healthy daily life in the comment, “*My dietary habits are alright. But sometimes I lose my appetite. Because I should stay healthy, I make it a point to eat.*” (K4)

<Relief of care burden> has some influence on

daily life, as shown above. <Relief of care burden> is composed of one code: [living and coping with physical and mental burden caused by taking care of the patient].

A family caregiver mentioned, "*I prevent myself from telling my husband how I honestly feel overburdened. With all the side-effects of the anticancer agent, it's impossible for him to have coped by himself so far. I work and go home to care for him. My fatigue has increased considerably because I've been taking care of my husband in addition to doing regular housework*". (M1)

IV. Discussion

This is a base study in the development of an instrument. Semi-structured interviews were conducted to identify the QOL concepts in family caregivers of patients with advanced cancer in Japan.

Content analysis revealed 7 categories that were similar to the concepts of existing instruments that had been developed in Europe and America. Subcategories and codes comprising the categories were the results of characteristics that reflected the values and the beliefs of Japan's cultural background. We focused on the subcategories and codes in this study and considered differences between this study and existing instruments.

1. Emotional coping skills in this study

An important category identified by this study appeared to be [Being able to face the patient with stable emotions]. The family caregivers mentioned difficult experience in the interviews. However, they also stated positive aspects such as [keeping calm], [switching one's emotion], [thinking positively], and [controlling one's emotions to ease stress]. They practiced positive emotional coping

skills to support the patient, and maintained their own mental tranquility. Family caregivers of patients with cancer have both positive and negative experiences in the process through which the patients deal with cancer (Kristanti, Effendy, Uparini et al., 2019). Family caregivers share tasks and make sacrifices (Kristanti et al., 2019). The positive value of caregiving is related to willingness to continue care (Balducci, Minch, Mckee et al., 2008). The CQOLC involves the caregiver's positive emotions domains (Weitzner et al., 1999). This phenomenon suggested family resilience, which is the ability to overcome difficulties and is a positive coping skill in crises, such as when a loved one develops cancer. Family resilience is the family's capacity to cultivate strength to positively meet life challenges (Silliman, 1994) and may depend to some degree on their cultural background (Hawley, DeHaan, 1996). Therefore, the category [Having relationship needs met in the family, including those of the patient] may relate to resilience. In this way, the QOL concepts in the family caregiver are not independent, but influence each other reciprocally.

2. Managing financial issues in this study

[Being able to manage financial health] is considered a financial aspect in existing instruments. Japan has a comprehensive system of national public health insurance established by the Ministry of Health, Labour and Welfare. All citizens are required to take out a medical insurance policy and can receive medical care by paying part of the medical expenses. Furthermore, the burden of insured persons over 70 years of age has been markedly reduced by the introduction of a medical system for the elderly since 2008. The burden of cost limits for monthly expenses is decided based on income. In addition, the medical expenses burden has been reduced by an expensive

medical charge system. There is also an “Invalidity Claim Benefit” that guarantees income for company employees who take leave for medical treatment. Medical expense costs incurred by cancer treatment are a burden on patients and their family. To decrease economic burden during such illness, many Japanese individuals take out private life insurance policies before illness onset. In this study, family caregivers attached importance to receiving security such as insurance. They tended to make concerted efforts to prepare ahead of an emergency. Furthermore, they were considerate of the patient’s feelings so as to not add to their worries about finances. This was reflected by family caregivers’ desire for patients to receive treatment without worrying about finances. Thus, emotions and family relationship were included as the concerns family caregivers had for patients in addition to improved finances. This may be a characteristic of the Japanese culture that is connected to the family relationship.

3. Spiritual mind in this study

Asian and Western societies differ in terms of cultural background. Therefore, cultural background has a huge impact on the QOL concept of spiritual health in Asians (Lee et al., 2015). In this study, [Having relationship needs met in the family, including the patient] and [Being able to feel the importance of one’s own existence] were considered important concepts equivalent to the concept of spiritual health. This may have been due to the specific present situation facing the family of the patient with cancer. These two concepts were the most discussed concepts in these interviews, and were extracted from 15 codes. Also found was a sense of values and faith that expresses the strong ties of Japanese family relationships in terms of always thinking of the patient,

keep bonds with the patient, and thinking that it is natural to support the patient as a family. This study found cultural differences compared with existing instruments. It is a remarkable difference category with the existing instruments. It is not just the relationship of patient and family is good or bad, the cancer patient-family relationship is very sensitive. In addition, a strong bonds appears in the relationship. These were largely reflected in the spiritual aspects. There is no existing instruments that makes patient-family relationships delicate like this study. This can be considered as a representation of the Japanese family relationships, and the specific circumstances of the family of cancer patients. Previously, “belief in caregiving” was clarified as the core phenomenon in the experience of family caregivers of patients with cancer in Asia (Kristanti et al., 2019). In the present study, these two concepts were equivalent to the spiritual aspect and may be the central concept that constitutes the QOL of the family. The two concepts comprise a spiritual side, and involve not only the self as a family member of the patient with cancer, but also the existence of the self as a human being. Among Chinese family caregivers of patients with advanced cancer in Singapore, Spiritual Health comprised three themes: making sense of the patient’s condition, making sense of the caregiver role, and self-transformation (Lee et al., 2015). In the present study, the common concept structure that produced the self was family caregivers who recognized patients and themselves as human beings. Religion describes the existence of God and has taken root among people of Western culture. Therefore, spiritual support by religion has been included in existing instruments (Ferrell, Grant, 2005). Generally, the Japanese people have no specific religion. However, some worship ances-

tors at the family Buddhist altar and hold memorial services to thank the ancestors; both are also cultures or customs of Shintoism. Although there are differences in manners and customs in both religions, the life existence of ancestors is recognized as continuing into the present day (Iwata, 2006). Against this background, <peace of mind> was reflected as a culture that values the non-physical existence. Everyone may potentially feel the need to pray for the recovery of a patient regardless of culture or religion.

Also, there was no difference in interview result between inpatient and outpatient, because we think that we collected interview data on the various backgrounds of the family caregivers by heterogeneous sampling.

When a patient is diagnosed with cancer, family caregivers feel a responsibility to always support the patient as they face the various influences of everyday life, similar to the patient. It is important for the family to support the patient. There is the aspect of the family who supports the patient. On the other hand, even they are one person who lives. QOL in family caregivers of patients with advanced cancer was based on these two aspects. We interviewed only Japanese family caregivers of patients with cancer in our study because the focus was Japanese culture. Therefore, our results cannot be generalized to other ethnic groups. However, this study contributes to the development of QOL instruments for family caregivers of patients undergoing treatment for advanced cancer in Japan.

V. Limits and Problems of the Research

In this study, the aspect of sexuality was not emphasized as much as in existing Western in-

struments. Asians seem to avoid discussions of sexuality (Lee et al., 2015), and this appeared to be true for the Japanese people in the present study. This may have been an effect of the participants' ages, and how urogenital cancer was not included as a cancer location in the patients. Thus, one limitation of our study is that it is uncertain whether sexuality is indeed an unimportant issue for the family caregivers or it is a Japanese social construct to avoid discussion on this topic. This is a limitation of the short interview survey and the first meeting that could be considered as being due to a sense of shame.

VI. Conclusion

From content analysis of transcripts, we identified 7 categories concerning QOL concepts that are important for family caregivers of patients with advanced cancer: "being able to live while maintaining one's physical condition," "being able to face the patient with stable emotions," "having a society and personal connections with trusted persons other than the patient," "being able to manage financial health," "having relationship needs are met in the family, including those of the patient," "being able to feel the importance of one's own existence," and "living daily life as unchanged since before the patient's cancer diagnosis."

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Author Contributions

H.S. contributed to the conception and design of the study and the entire study process. All authors supervised the study and analysis.

Conflicts of Interest

The authors declare no conflicts of interest.

References

- Ando, S., Harata, M., Weitzner, M. A. et al.: Reliability and validity of Japanese version Caregiver Quality of Life Index—CKristantiOLC), *Palliative Care Research*, 8(2): 286–292, 2013
- Balducci, C., Mnich, E., McKee, K. J. et al.: Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers, *Gerontologist*, 48: 276–286, 2008
- Cancer Registry and Statistics. Cancer Information Service, National Cancer Center, Japan
- Cohen, R., Leis, A. M., Kuhl, D. et al.: QOLLTI-F: Measuring family carer quality of life, *Palliative Medicine*, 20(8): 755–767, 2006
- Ferrell, B., Grant, M.: Quality of life—family version (QOL-FV), National Medical Center and Beckman Research Institute, 2005.
- Hawley, D. R., DeHaan, L.: Toward a Definition of Family Resilience: Integrating Life-Span and Family Perspectives, *Family Process*, 35(3): 283–298, 1996
- Iwata, S.: Jinsei jinseigireikenkyuu no genzai, *nihon-minzokugaku*, 247: 66–100, 2006
- Kristanti, M. S., Effendy, C., Utarini, A. et al.: The experience of family caregivers of patients with cancer in an Asian country: A grounded theory approach. *Palliative Medicine*, 1–9, 2019
- Lambert, S. D., Harrison, J. D., Smith, E. et al.: The unmet needs of partners and caregivers of adults diagnosed with cancer, *BMJ Supportive & Palliative Care*, 2: 224–230, 2012
- Lee, G. L., Ow, H. Y. L., Akhileswaran, R. et al.: Quality of life domains important and relevant to family caregivers of advanced cancer patients in an Asian population: a qualitative study, *Quality of Life Research*, 24: 817–827, 2015
- McMillan, S. C., Mahon, M.: The impact of hospice services on the quality of life of primary caregivers. *Oncology Nursing Forum*, 21(7): 1189–1195, 1994
- Minaya, P., Baumstarck, K., Berbis, J. et al.: The CareGiver Oncology Quality of Life questionnaire (CarGOQoL): development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer, *Eur. Cancer*, 48: 904–911, 2012
- Ministry of Health, Labor and Welfare: health insurance. (Cited 16 November 2019.) Available from URL https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryuu/iryuhoken/iryuhoken01/index.html.
- Okubo, S.: Gannkanjano ryouyoupuosesude haiguusyaga taikennsita konnnann, *Hospice and Home Care*, 21(1): 29–35, 2013
- Shaw, J., Harrison, J., Young, J. et al.: Coping with newly diagnosed upper gastrointestinal cancer: a longitudinal qualitative study of family caregivers' role perception and supportive care needs, *Support Care Cancer*, 21: 749–756, 2013
- Silliman, B.: Rationale for resilient families concept paper, National Network for Family Resiliency, 1994
- Takeuchi, S., Fujino, F.: Gairaikagakuryouhou wo uketeiru gannkanjano kazoku no taikenn, *Journal of Japanese Society of Human Caring Research*, 3: 17–24, 2012
- Weitzner, M. A., Wagner, H. et al.: The Caregiver Quality of Life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer, *Qual Life Res*, 8: 55–63, 1999