

## Suffering Among the Families of Cancer Patients : Conceptual Analysis.

Ruka Seyama<sup>1</sup> and Kiyoko Kanda<sup>2</sup>

We clarified the construct of the suffering among the families of cancer patients based on domestic and overseas studies that had been announced up to now as original article. Referencing Walker's concept analysis, we extracted the concept of suffering by looking at the general uses of the word "suffering", suffering as viewed in psychology and studies on the suffering of families of cancer patients. We found that such, suffering consisted of two constructs unpleasant psychological pain and uncertainty about the future. Also it was considered that the precedent matters of the suffering of the families were "To understand the pain of the patients" and "To be put in a difficult situation where there was no prospect". As a result of the suffering, "Depression that made one staying indoors in oneself leading a decline in a sense of emotion and joy" and "Anger that easily raised negative feelings leading inability to maintain harmonious relations with others" was revealed. "Loss of a sense of control", "Loss", "Sense of guilt", "Incompetence" "Insensibility" and "Conflict" were also found as sub-concept of "Unpleasant psychological pain". Subconcept of "Uncertainty about the future", "Therapeutic effect, disease progressing and prognosis" "Family like style including that of patients themselves", "Life after a patient's death" and "Potential genetic predisposition to ward cancer among family members" were suggested. The clinical scenes tends to deal only empirically with family suffering as these effect family quality of life during medical treatment, so an appropriate assessment is needed to reduce suffering. This is turn makes necessary to clarify the process of suffering among the families during medical treatment and to construct of a nursing model. (Kitakanto Med J 2008 ; 58 : 71~76)

**Key Words :** Cancer, Nursing, Family, Suffering

### Introduction

A study by the Ministry of Health, Labour, and Welfare of Japan Area Cancer Registration Group estimated the survival of cancer patients diagnosed in 1993 to be 50.4%. Breast cancer and uterine cancer patient's survival exceeded 70%, reflecting advances in diagnosis and treatment. The shock of being informed of cancer and subsequent hard skip of fighting the disease inflict untold suffering on patients and their families, however necessitating stepwise nursing intervention. It is especially necessary to positively support families of the patients by considering them as subjects of nursing, rather than treating them as persons in charge of patient care. Intervention among families was classified into educational and emotional

support ; "educational support that provides family members, as the closest to patient essential knowledge and skill" and "emotional support for the mental and emotional burden the families themselves must bear". Both types of support are related to maintaining patient quality of life. Given the repeated loss experience families during medical treatment, the implementation of emotional support is a matter of great urgency.

Psychological processes of anticipatory grief and grief have been dealt with as mental problems endured by families, but nursing interventions is also needed to help families cope with the grief inevitable prognosis and the patient's imminent death. Families not actively supported in dealing with mental suffering in all stages of medical treatment experience, a problems

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1 Department of Nursing, Faculty of Nursing, Takasaki University of Health and Welfare 501, Nakaorui-machi, Takasakishi, Gunma, 370-0033 2 Department of Nursing, Gunma University Graduate School of Health Sciences 3-30-15, Showa-machi, Maebashi, Gunma, 371-8514

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Address : RUKA SEYAMA Department of Nursing, Faculty of Nursing, Takasaki University of Health and Welfare 501, Nakaorui-machi, Takasakishi, Gunma, 370-0033

in outpatient prognosis and home care because the medical treatment and setting inevitably suggest cancer as a chronic disease and increase family worries about the patient. To examine support for families by gathering results of previous studies necessitated the inclusion of the mental problems of families as suffering basic to discomfort and pain.

### **Purpose**

We examined the suffering of families of cancer patients based on results of previous research.

### **Method**

We conducted following processes to determine the suffering of families of cancer patients.

- 1) Extracting original papers on cancer nursing containing keywords such as “family” and “suffering”, “family” and “anxiety”, “family” and “grief” or “family” and “conflict”, from articles published in the ‘Journal of Japan Academy of Nursing Science’, ‘Journal of Japanese Society of Cancer Nursing’ or ‘Journal of Japan Society of Nursing Research’ between March 1983 and March 2007. These academic journals are presentative of Japanese nursing, and containing dissertations in cancer nursing domain.
- 2) Extracting original papers demonstrating suffering, anxiety, grief or conflict among the families of cancer patients by in a quantitative approach involving a search for papers containing the keywords “family caregiver” (MeSH) and “suffering or distress or anguish”, or “anxiety or fear”, “grief or mourning” or “conflict or trouble or difficulty or complication” in ‘PubMed’ and limited to ‘cancer’ using the ‘limits function’, and taking a quantitative approach by hand.
- 3) Extracting original papers containing the same words as used in ‘PubMed’ or words that having the same meaning, used in the same way as in 2) in a ‘Cumulative Index to Nursing & Allied Health Literature (CINAHL)’ stored in the OVID gateway.
- 4) Referring to the concept analysis procedure by Walker,<sup>1</sup> examining the meanings of ‘suffering’, ‘anxiety’, ‘grief’, or ‘conflict’ in general purpose and a psychology dictionaries.
- 5) Based on what was developed in 1) to 4), above, considering ways the concept of suffering is used, its characteristics, differences among related concepts, and precedents and results of suffering.
- 6) Analyzing the concept and subconcepts of the suffering based on 5), above.

## **Results**

A literature search turned up 34 Japanese articles (6 on suffering, 19 on anxiety, 7 on grief, and 2 on conflict), and 87 non-Japanese articles (48 on suffering, 23 on anxiety, 15 on grief, and 1 on conflict). Results of analysis of these articles and has the concept of suffering was used generally and in psychology were as follows:

### **1. General concept of suffering**

#### **1) General application of suffering**

The Oxford English Dictionary defines “suffering” as to “undergo, experience, be subjected to (pain, loss, grief, defeat, change, punishment, wrong, etc)”.<sup>2</sup> The Japanese Kojien dictionary, it defines as “a pain, worry, psychical pain”.<sup>3</sup> These thus define suffering a unpleasant psychical pain such as loss, grief, incompetence, loss of a sense of control, and guilt.

#### **2) Suffering in psychology**

V.E. Frankl stated that suffering was what was asked.<sup>4</sup> L.M. Wright defined suffering as involving agony that was physical, emotional, and spiritual, the pain and grief of heavy illness that would change ones’ past and relationships with others.<sup>5</sup> In other words, suffering was psychologically to hold agony, grief, pain, and conflict due to the inability of families to find an answer to problems that changed their life and relations with others.

#### **3) Suffering in cancer nursing**

Many studies in Japan, mention the suffering of patients. Kaneko et al., for example, held that the suffering of cancer patients was negative pain sometimes experienced in exceeding the categories of the sense of control of oneself. Patients suffered pain by thinking negatively about problems that would occur during medical treatment.<sup>6</sup>

In Europe and North America, the suffering of the families of cancer patients was widely verified. Pam et al. discussed the suffering of the families of cancer patients as that of being unable to believe reality, denying reality, and being in an insensitive state.<sup>8</sup> Marie T et al. regarded suffering as a conflict between spiritual feelings and reality.<sup>9</sup> Shigeko et al. regarded it as feelings raised by contradiction.<sup>7</sup> Hinds concluded that the suffering of families involved fear of isolation and uncertainty for the future.<sup>10</sup> The suffering of families, including that of Japanese, was thus a state of denying reality, feeling too much uncertainty about the future, and being insensible and having conflicts.

### **2. Characteristics of suffering**

Our examination of previous studies suggested to us that suffering was characteristics for two aspects;

“Unpleasant psychical pain” (such as loss, grief, incompetence, loss of a sense of control, feeling of guilt, agony, loneliness, and denial) and “Uncertainty about the future”.

### 3. Relations and difference from similar concepts

As we did with “suffering”, we selected 3 concepts suggesting families’ psychic problems arising when informed of a cancer diagnosis, and analyzed comparatively these concepts.

#### 1) Anxiety

Psychology holds that anxiety involves feeling worry, uneasiness, and a sense of fear a vague not specified.<sup>11</sup> In nursing, Faye et al. held that anxiety among families of cancer patients emerged as a physical symptom that appeared before a definitive diagnosis was reached.<sup>12</sup> Pam et al. proposed however that the worry of families consisted in accepting the reality of the patient having cancer, acquiring a method to deal with fear and stress of the uncertainty involved, and thereby being at a loss as to whether they could lead a positive life even in an economic ally.<sup>8</sup> Van et al. proposed that the families of cancer patients felt uneasiness at the possibility of recurrence and physical aftereffects,<sup>13</sup> i.e., anxiety involved elements such as suffering, but showed worry, concern, and fear of not clearly knowing the reason for worry.

#### 2) Grief

The Kojien defines grief as to mourn.<sup>14</sup> In psychology, it involved things containing 6 processes; insensibility, longing, protest, confusion, depression, and recovery.<sup>15</sup> In the medical setting, Kübler-Ross clarified the psychology of grief as 5 processes; denial, anger, dealing, depression, and acceptance.<sup>16</sup> A similar concept resulted from the process of grief in Japanese cancer families.<sup>17</sup> Grief thus consisted in part of elements similar to those of suffering, not

referring to one specific point but to a process that included psychological change. Hirayama emphasized anticipatory grief as a mental state that lessened grief, holding that the property of anticipatory grief was the same as that of grief.<sup>18</sup> In other words, the property of grief resembled suffering, but suffering expressed one specific point, whereas grief and anticipatory grief showed a process and, moreover, the psychology of recovery and acceptance in the final stage of grief was not itself included in grief.

#### 3) Conflict

The Kojien defines conflict as a state of being troubled by differences.<sup>19</sup> In nursing, Hatakeyama held that conflict for families of cancer patients included “not accepting the death of the patient”, “wanting to forget about cancer”, “not receiving reality”, “regretting the past”, “worrying after death” and “loneliness”.<sup>20</sup> Priscilla et al. stated the conflict for families was a combination of grief and guilt.<sup>21</sup> It became clear that conflict included psychology of a property similar to that of suffering but was used in a narrower sense.

By compiling elements of related concepts of suffering, connections with suffering a shown in Figure 1.

### 4. Precedents and results of suffering

Walker et al. stated that the examination of precedents and results of suffering was useful for clarifying premises of suffering and possible variables surrounding the phenomenon and making a model for the concept of suffering.<sup>1</sup> Based on this idea, we made the following analysis :

#### 1) Precedents matter of suffering

Roberta et al. pointed out precedents of suffering among families as symptoms impossible to control.<sup>22</sup> Priscilla et al. noted precedents as physical weakening and visual symptoms.<sup>21</sup> Andresse et al. stated it

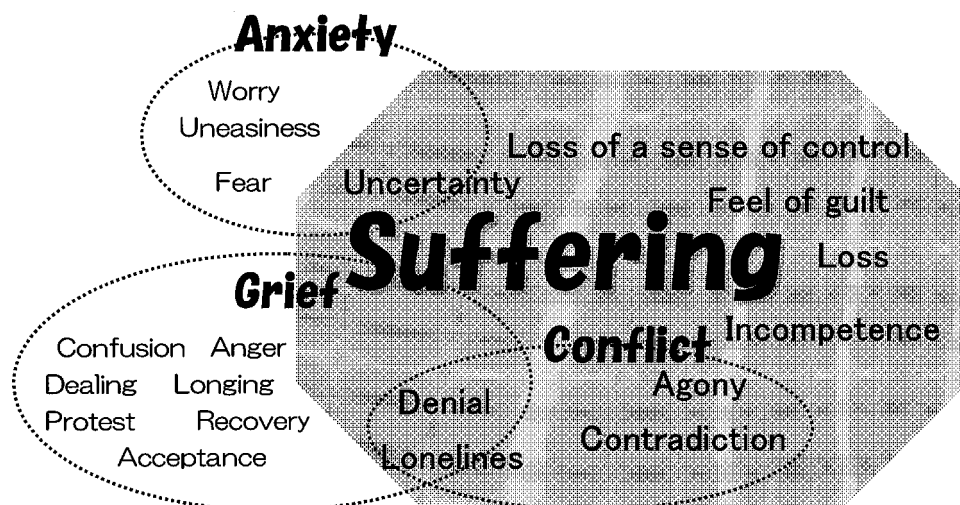


Figure 1 Related concepts of suffering

uncertainty,<sup>23</sup> and Catherine et al. as repetition of a difficult situation.<sup>24</sup> We thus concluded that precedents in suffering among families was the “recognition of the pain of the patient” and “being put in a hopeless situation”.

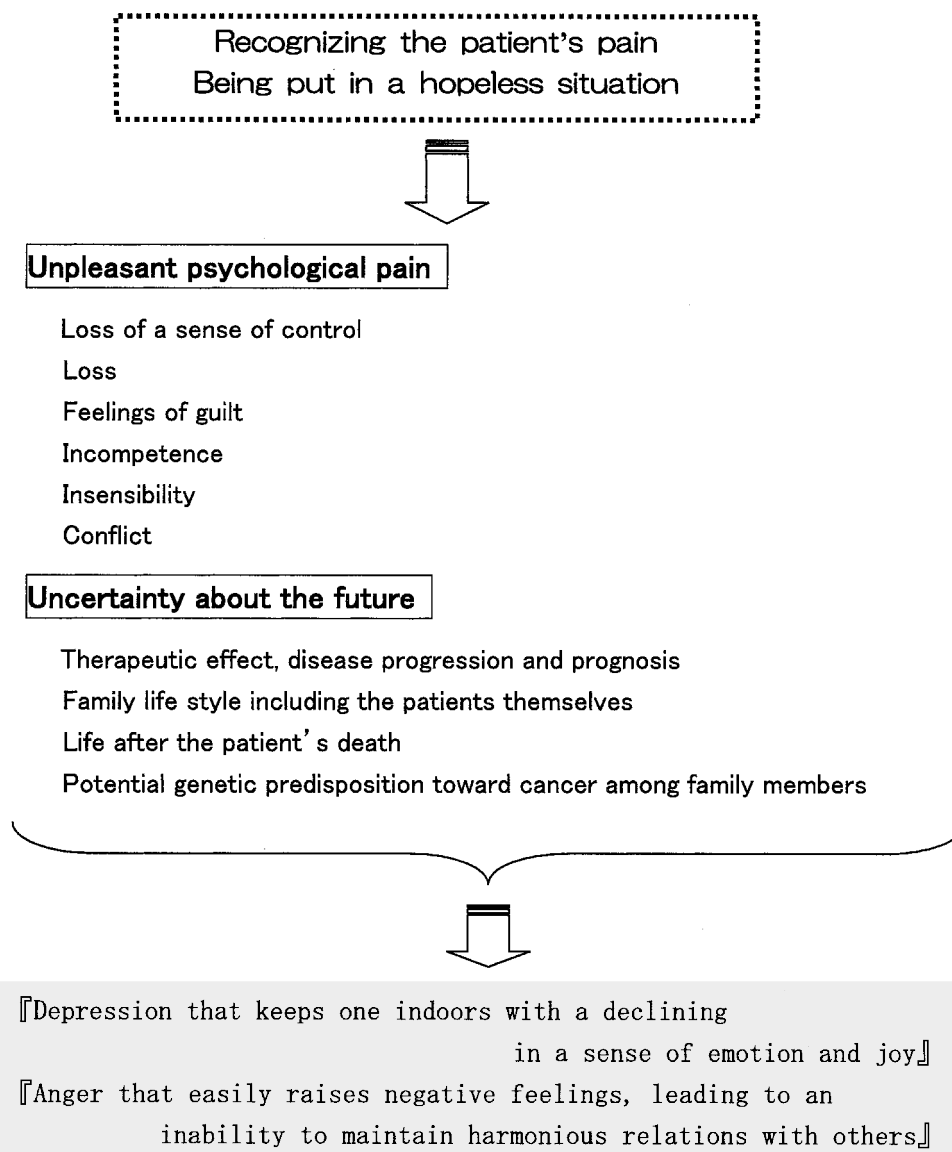
**2) Results of suffering**

Van et al. stated that the family of the cancer patient became depressed as a result of suffering.<sup>13</sup> Wright argued that the result of suffering induced anger in imagining how life could have been without illness.<sup>25</sup> Lynn et al. clarified a similar concept.<sup>26</sup> Their concepts included “Depression that kept one indoors with a declining sense of emotion and joy” and “Anger that easily raises negative feelings leading to an inability to maintain harmonious relations with others”.<sup>23,27</sup>

**Considerations**

The construct of the suffering of the families of cancer patients was made by integrating characteristics and elements of family suffering Figure 2.

The construct of suffering clarified by concept analysis of suffering was characterized by “Unpleasant psychological pain” and “Uncertainty about the future”. The subconcept of “Unpleasant psychological pains” suggested “Loss of a sense of control”, “Loss”, “Feeling of guilt”, “Incompetence”, “Insensibility” and “Conflict”. The subconcept of “Future uncertainty” suggested “Therapeutic effect, progress of disease and prognosis” “Family life styles including that of patients themselves”, “Life after a patient’s death, members” and “Potential genetic predisposition toward cancer among family”.



**Figure 2** The construct of family suffering of cancer patient

## Discussion

Our concept analysis of the suffering of the families of cancer patients made clear the following became clear.

1. The suffering of families of cancer patients consisted of two constructs “unpleasant psychological pain” and “uncertainty about the future”.
2. The precedents of suffering of families were “recognizing the pain of the patient” and “being put in a hopeless situation”.
3. The result of suffering included “depression that kept them indoors with a declining sense of emotion and joy” and “anger that easily raised negative feelings leading to an inability to maintain harmonious relations with others”.
4. The subconcept of “unpleasant psychological pain” suggested “loss of a sense of control”, “loss”, “feeling of guilt”, “incompetence”, “insensibility” and “conflict”. The subconcept of “future uncertainty” suggested “therapeutic effect, disease progression and prognosis” “family life styles including that of patients themselves”, “life after patient’s death” and “potential genetic predisposition toward cancer among family member”.
5. Anxiety and grief that were concepts related to suffering had elements in common with suffering, but differed from suffering in that anxiety contained concerns of not clearly knowing the reason for worry, and grief was the psychology of process including acceptance. Conflict was suggested as a subconcept of suffering.

## Conclusions

Family suffering is partially and empirically observed only among nurses close to patients and the family. Suffering is an important concept in helping the family maintain good mental health. Intervention to ensure care that maintains and improves the family quality of life. Comprehensive studies on the psychology of the families of cancer patient should thus be promoted immediately and care measurements developed that could be used in a medical.

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