

Meaning of existence of the family for terminally ill patients

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Abstract :

The purpose of this study was to clarify the significance meaning of the family existence for terminally ill patients, because nursing for the family of terminally ill patients is important. "Terminally ill patients" in this study refer to those whose remaining life expectancy is less than six months. The subjects were eight terminally ill patients with cancer and hospitalized in a general hospital with palliative care. The subjects were given permission by their doctors and nurses to receive an interview and also gave a prior consent to the researchers for it.

Semi-structural interviews were conducted individually, collecting data of the patients' feelings and thoughts. The patients words were tape-recorded and later transcribed. These data were then analyzed for extracting relevant words and then categorized according to themes.

As a result, we found two major themes: "emotional support" and "strength against the disease". The patients explained that their families not only provided physical and psychological support but also lived their life with the disease together. Nursing for the family is just as important as nursing for patients themselves.

Key words : terminal care, existence of the family, in-patients

Introduction

Japanese family in recent years has transformed from an extended family to a nuclear one which respects for individual members' lifestyle and independence has replaced the emphasis on harmonious relationships of the whole. However, the divorce rate in Japan is still lower than that of any Western nation¹⁾. Japanese women strongly believe that the presence of children overrides their poor marital relationships with their husbands, more than women do in the Western countries²⁾. Moreover, the unmarried Japanese women live with their parents at the rate of 70-80%³⁾, and they imply that their tradition tends to respect family relationships rather than their own independence.

In most of terminally-ill cases, families are usually the first to be noticed of the disease. Even if patients want to know about their own diagnosis, the most of family try to hide the fact from patients. Although this has been changing

recently, the family decision still over-rules individual wishes.

The research team has been studying terminal care in Japan society where family decision-making is predominant. Two years ago, we conducted an interview with terminally ill patient in hospital in order to examine the psychological states. The results are summarized as follows.

The four categories are following: "pain control maintenance," "to live an ordinary life," "hope for improvement," and "the family to share the life."

The most difficult for patients to endure was harsh pain. Patients lost all their physical and mental energy to bear the extreme pain. By controlling the pain level, patients could reclaim their quality of life. Their mental condition could be improved in order to live an ordinary life and to hope for an improvement in their physical condition. Patients in the terminal phase of cancer were supported by the presence of family nearby. The families supported the patients unconditionally^{4) 5)}.

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During the interviews, we noted the lively expressions of the patients when they talked about their families. The researchers decided to analyze patients' comments in details so that we might better understand how the patients felt and thereby examine the meaning of families to patients. Another objective of the analysis was to expand the idea of including families in terminal care, according to by Kubler-Ross(1993,p.139)⁶⁾: "We cannot help the terminally ill patient in a really meaningful way if we do not include the family."

The purpose of this study was to clarify the meaning of the family presence for terminally ill patients, because nursing for the family of terminally ill patients is just as important as care for the patients. "Terminally ill patients" in this study refer to those whose remaining life expectancy is less than six months.

Methods

This study was conducted at a general hospital which contains 502 beds in Yamaguchi Prefecture, Japan. The hospital had a general medical unit for palliative care. The interviewed patients were selected in the following procedure: First, the researchers asked the doctors and nurses for names of the patients who were terminally ill with some type of cancer. These patients were prognosticated to have a limited life span because of the advanced stage of their illnesses and lack of positive results from the treatments. Then the doctors and nurses were asked to give names of the patients whose conditions were stable and strength enough to participate in an interview. The researchers conducted the interview with prior consent for an participation.

The subjects were four men and four women. Their ages ranged from 51 to 93 years with an average of 63.3. All of them had been informed of their disease condition. Three of them had gastric cancer, while the others had lung, uterine, pancreatic, renal and rectal cancers. All of the patients lived with their families except one who

lived with a very close friend. This patient also had a son living close by. Thus, all the patients had family or friend's support available.

A semi-structured interview was used as a method of gathering the data. The interviews were completed in a range of 30-60 minutes. The interviews were conducted in a carefully selected quiet place inside the hospital while taking into consideration of the patients' privacy, fatigue and endurance. The interviews were tape-recorded with the patients' consent and were later edited into a written format.

Analysis of the tape-recorded data was done in the following manner: The first stage was to extract phrases and sentences that represented the patients' family existence from the tapes. The second stage was to identify major themes for the selected phrases and sentences. The third stage was to categorize and group them according to the identified themes.

Results

The researchers found two major themes: "emotional support" and "strength against the disease".

1) Emotional support

Mrs. O, 70 years old: "If I didn't have any pain, I'd rather live at home. As if I stay in hospital, my son, his wife and their daughter still come and visit me here everyday. My daughter-in-law comes here every morning before work, my son comes at lunch time and the grand-daughter visits me after work. They all take good care of me. They provide an excellent emotional support for me." Mrs. O used to live with her son's family, who now visit regularly and make sure she does not feel lonely.

Mrs. I, 53 years old housewife: "Oh, what well care my husband and my children showed me when I was in hospital! My family is the very solace of my heart." Mrs. I. Considered the minute care provided by her family as tremendous.

Mrs. S, 61 years old: " On an outing day, my

family always got together to take me out to eat." Whenever Mrs. S went out, she felt secure remembering her way of life before hospitalization.

Mr. K, 52 years old: "I tell my wife not to come to the hospital, because she has work and kids to look after. But she comes here anyway (laugh)." Mr. K was in his middle age and had financial concerns for the family. However, his wife worked to provide regularly visited him after work. She was his great emotional support.

Mr. N, 71 years old: "My wife comes to see me everyday. Because she is working, she comes here in the evenings. She visits me because she cares for me. She's my wife any way." In Mr. N's life, his wife played truly a significant role.

These were the words which the patients shared during the interviews and expressed the thought of family as a great emotional supportor.

2) Strength against the disease

Mr. N: Mr. N said that he did not notice changes himself but recognized by his wife's words such as "Your eczema is going away" and "You'll get better soon."

Mr. E: "My wife was also hospitalized because she had a surgery on her gallbladder. She's not young anymore, you know. She has a hearing problem, too." Mr. E talked about his wife rather than himself with showing more concern about her. Although his wife had been discharged and visited him every now and then, he often showed consideration about his wife's health. They encouraged each other to fight the disease. While Mr. E was very conscious of his role of protecting the family -saying "I'm most worried about my family"- he was at the same time relieved to know that his children would come a long distance to take care of minute household affairs. He said, "While I am away, my children come all the way from Tokyo or Kanazawa and take care of the house hold."

Mrs. S: Mrs. S had a uterine cancer with a metastasis bone tumor, suffering from severe pain throughout her body. She said that she had not been able to receive an effective palliative care at

the previous hospital. This fact made her sons decide to put her in the current hospital where has a palliative care system. Mrs. S was thankful for alleviation of the pain and for her sons' quick action with saying "My sons brought me here because this hospital has a doctor who can take away pain from me. I didn't even know that what kind of hospital was."

Mrs. I: "I don't want to look back. I only want to look ahead to the future because I've been blessed with the support and care from my family and friends. I will learn to live with this disease and live my life fully."

The above words showed both the patients' and their families' will to battle the disease together. We found two categories in the terminally ill patients' words in terms of the "meaning of the family": "emotional support" and "strength against the disease". These two categories seem similar to each other; however, the former refers to the family as "something that accepts the patient as he/she is" while the later sees the family as "someone who tries to overcome an illness together."

Discussion

The interviews of this study focused on the patients who had good relationships with their families visiting them and providing a strong support to the patients. Therefore, the results of the study may not apply to all cases of the terminally ill patients; For example, a family which had problems before the patient is hospitalized, and family which might have no particular problems before the patient's hospitalization but might malfunction afterwards.

Some of the patients in this study, expressed their wish to attain self-realization rather than just to live their daily lives in hospital. Mrs. I who said that she wanted to "look ahead to the future" because she had "been blessed with the support and care" from her family and friends and she wanted to "learn to live with this disease and live" her life to the fullest. Family might

have a potential to exert an effect beyond support for the sick.

In conjunction with this, the researchers mention a valuable piece of literature *Structure of Dependence*⁷⁾, which speaks of a unique aspect of the Japanese family. Japanese family relationships are immersed in dependence and there is no room for reservation. Relationships with others, on the other hand, involve much of reservation and worry as well as concern for the possibility of being disliked, causing an uptight psychological state.

This psychological state may seem difficult for non-Japanese to understand but is frequently observed in Japanese clinical situations. For example, a patient in severe pain expresses his/her anger and frustration to the family, where we can observe his/her "dependence" on the family for pain alleviation. To the doctor or nurses, on the other hand, the patient does not express the same feeling. A gap is caused between the family and the medical staff. Therefore, a family which has close relationships with patients may paradoxically experience a great deal of mental exhaustion when a member becomes sick because of "dependence" on each other. This fact makes it important for nurses to observe and support the family relationships so that the family can their support to the patient. The family also shares the patient's joy, pain, confusion and frustration and wishes for help from someone else. However, many families feel embarrassed to share such feelings with medical staff. It is therefore the nurses' role to sense their feelings and to extend assistance to the family whenever needed. This makes it possible for the family to care for the patient with confidence and comfort. As a result, it enable the patient, the family and the nurses to experience joy of sharing the life together till the end of the patient's life.

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