## How do in-patients with advanced terminal cancer feel?

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## Abstract:

The purpose of this study was to know how in-patients with advanced terminal cancer feel, thereby, determining ways that nurses in the hospital who care for patients who are terminally ill can improve their care for patients who are terminally ill. A descriptive research design was selected for this study. It was decided that patients would be interviewed to find out their major concerns. The subjects of this study were four men and four women with advanced stages of cancer in Yamaguchi Prefecture in Japan in a 502 bed general hospital's medical unit with palliative care beds. The patients' ages ranged from 51 to 93 years with 63.3 years the average age. This study revealed four major areas of concern of patients who were terminally ill: pain control, living an ordinary life, hope for improvement of physical condition and the need to be near family. The expressed concerns of these patients provide data for nurses to explore avenues to improve care given to patients who are terminally ill.

Key words: terminal care, advanced terminal cancer, in-patients

Nurses working with patients who are terminally ill devote themselves to maintain their patients' original quality of life and want to respect the patients' wishes as far as possible. To do this, it is essential to fully understand the patients' views on quality of life during hospitalization.

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A descriptive research design was selected for this study. It was decided that patients would be interviewed to receive their views and concerns about their illness, needs and concerns.

The subjects of this study were four men and four women with advanced stages of cancer. The patients' ages ranged from 51 to 93 years with 63.3 years the average age. All of the patients

had been informed about their disease. Their life expectancies were less than six months. Three of them had gastric cancer, while the others had lung cancer, uterine cancer, pancreatic cancer, renal cancer and rectal cancer. All the patients had families. The patients were in stable condition and permission was given by the doctors for each of them to be interviewed. Consent by each of the patients for an interview was obtained prior to each interview.

A semi-structured interview was used as the tool for gathering data. The conversation was tape recorded with the patients' agreement and later it was edited into a verbal record.

Analysis of the tape recorded data was done using the following process: 1) Select phrases and sentences representing patients' thoughts during hospitalization were isolated from the tapes. 2) Group the phrases and sentences by the contents. 3) Categorize the groups. Prior to doing the research, an anticipated concern was the fear of pain. Other themes that were revealed during the analysis of the data were as follows: the desire to lead an ordinary life, hope for improvement of

the physical condition and to have family nearby.

The data analysis revealed four categories or themes in the thoughts of the study patients.

- 1) The first data category was "to maintain pain control." This category had three subcategories:
  - a) "Fear of unbearable pain" was found in this statement, "When I was at home, I screamed out at night because of the pain." The fear of the pain continued even after the pain was relatively alleviated in the hospital.
  - b) "Joy from the palliation of pain" was found in the statement, "I am most delighted when the pain has gone." In an environment where pain could be controlled, the statement was made, "As long as I am in the hospital, I can fee safe."
  - c) "Healing pain" refers to the feelings coming from their experiences of on coming pain and the idea "the only thing I can do is take pain killer" to control the pain. Patients would then ask nurses for pain killers in advance so that they would be more effective
- 2) Statements that reflected the second theme-"To live an ordinary life," were placed in four subcategories:
  - a) Life activities -- "Joy from the satisfaction with the need of ordinary life" was found in the statements: "I'm thankful to have had my hair shampooed," or "I can eat at a table when I wear a corset."

The joy and gratitude were expressed sincerely from their heart.

b) Economic concerns -- "Economic anxiety" was found in the statement: "I'm concerned about my hospital expenses and living expenses of my family as I have been hospitalized for a long time. I wouldn't care about the expenses if my stay in hospital were shorter."

Patients who had been hospitalized many times felt economic anxiety due to long hospitalization. In addition, they wished they could have gotten public financial aid.

c) Family concerns -- Statements that reflected these concerns were: "My spouse isn't in good condition." "I'm concerned if the important documents are made and kept in order or not."

The patients far from their homes were concerned about the health condition of the their families and their roles at home. They had vague anxiety and frustration of the failure to fulfill roles at home.

d) Hope to continue their jobs -- This concern was reflected in the following statements: "I wish I could go to work even for a short while." "I will go to the office at least twice or three times a week when I get well."

The patients had been living with their cancer up to then with a cycle of medical leave and returns to work. The patients understood very well that they would have been working if they were in good condition.

 Hope for improvement of physical condition was the third concern reflected in the interviews.

A female patient who was gradually regaining her appetite was delighted with her improved condition and said, "I will make an effort to maintain this improved condition." She also said positively, "I'm not going to look backwards, I want to live with the disease with all my strength, and maintain my quality of life as a human being." The patients found the hope for further improvement by way of treatment and nominal signs of improvement, while understanding their conditions.

4) To have family nearby was the fourth theme reflected in the data.

The patients talked about their families, especially their spouses who supported and were beside them. "I always overcame hard times with my family. My family is nothing less than the support of my heart." They

convinced support from their families and showed gratitude for them. "The presence of a spouse as a partner to live with through my times of struggle against disease is indispensable to me." They appreciate their families' support very much.

The hardest thing for patients to endure is harsh pain. Pain intensity is also related to patient's psychological status<sup>1)</sup>. Patients lose all their physical and mental energy to bear the extreme pain. By maintaining pain-control, patients can reclaim their own quality of life as a human being. Their mental state can be improved to live an ordinary life and to hope for the improvement of physical condition. Moral support from family is very important to the patient<sup>2)</sup>. Patients who are in the terminal phases of cancer are supported by the existence of the family nearby was identified by these patients as the greatest support.

This study provides several suggestions for improving the care given to patients who are terminally ill.

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