



## Evaluation of care for leukemia and lymphoma patients during their last hospitalization from the perspective of the bereaved family



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### ABSTRACT

We aimed to evaluate care for leukemia and lymphoma patients during their last hospitalization from the perspective of the bereaved family. Questionnaires were sent to the bereaved family members of adult leukemia and lymphoma patients. We used the Care Evaluation Scale (CES) and asked the bereaved family members about care satisfaction and “good death” factors during the patient’s last week of life or last admission period. We distributed 177 questionnaires and were able to analyze 103 (58.2%) responses. Compared with the results of a previous study of palliative care units in Japan, the CES scores were significantly lower in 9 out of 10 domains. Assessment of the “good death” components revealed that only 33% of respondents agreed that the patient had been relieved as far as possible of pain and physical distress during the last week of life. Only 21.4% of respondents agreed that the patient had been relieved as far as possible of psychological distress, and 57% of caregivers were not satisfied with the level of care. During the last hospitalizations of leukemia or lymphoma patients, their care was insufficient and a good death was not often achieved. Improvement of end-of-life care for leukemia and lymphoma patients is needed.

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### 1. Introduction

There has been dramatic progress in treatments for some hematological malignancies. However, they are still life-threatening diseases.

Patients with hematological malignancies are likely to die in the acute care setting following escalating intervention [1–3]. Although these patients experience various forms of distress during the advanced or final phase of their illnesses [1,4–6], they are less likely than those with solid tumors to receive specialist palliative care

[1,7–10]. In the USA, Earle et al. [7], in a comparison with patients with solid tumors, revealed that patients with hematological malignancies are more likely to receive chemotherapy within 14 days of death and are less likely to receive hospice care. Our initial study reported that nurses working in hematology wards perceived that care for leukemia patients during the incurable phase of the disease was inadequate [11].

Niscola et al [12] pointed out that research is needed into the quality of terminal care in hematology settings. However, to our knowledge, there have been no detailed evaluations of the end-of-life care received by patients with hematological malignancies. It would be valuable to use a valid and reliable instrument to evaluate the structure and process of the current care of these patients so that they can receive optimal care during the final disease phase. However, it is not easy to assess patients’ opinions of care, because

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most are too ill to complete questionnaires or to be interviewed [13]. For this reason, many evaluations of end-of-life care have used the bereaved family members [14–17]. In this study, we also chose to use bereaved family members as patient proxies.

One of the most important goals of palliative care is to achieve a “good death,” or a good dying process [18–20]. Despite the need to investigate how the bereaved family perceives the process of dying in a loved one who has a hematological malignancy, to our knowledge no such study exists.

Our aims were to evaluate the structure and process of care for leukemia and lymphoma patients during their last hospitalizations—especially during the last week of life—and to investigate the achievement of a good death or good dying process for the patient from the perspective of the bereaved family.

## 2. Methods

### 2.1. Subjects

Subjects were the bereaved family members of adult patients with myelodysplastic syndrome, leukemia, or lymphoma who had died in 4 university hospitals, namely The University of Tokyo Hospital (UofT), the Medical Hospital of Tokyo Medical and Dental University (TMDU), Juntendo University Hospital (JU), and St. Marianna University School of Medicine, Yokohama City Seibu Hospital (SMU). All hospitals were participants in the Japan Adult Leukemia Study Group and performed autologous/allogeneic hematopoietic stem cell transplantation. In 2005, the number of admissions to each hospital of patients with these conditions ranged from 200 to 515, and the number of stem cell transplants performed ranged from 10 to 43. All hospitals had departments of psychiatry or psychosomatic medicine, or both. Two hospitals (UofT, JU) had inpatient palliative care teams and 3 hospitals (UofT, TMDU, JU) had pain clinics.

The inclusion criteria for potential participants were: (1) they were primary family caregivers of patients who had died at one of the participating hospitals within a period of 6–30 months before the initial mailing of the questionnaire; (2) there was one family member aged 20 or more (20 being the age of adulthood in Japan) who was capable of replying to a self-reported questionnaire; (3) the patient was aged 20 or more and had stayed in the hospital for at least 7 days; (4) no serious psychological distress had been recognized in the family caregiver during patient’s last hospitalization by the primary care physician; and (5) the family caregiver had not been enrolled in any pilot study. We selected the period of 6–30 months after patient death to send the questionnaires in consideration of the social customs of grieving among Japanese bereaved and in accordance with the period used in a previous Japanese study [21].

### 2.2. Study design

Inpatient deaths were identified from individual hospital records. The survey was mailed out from November 2005 to May 2006. The institutional review board of each hospital confirmed the ethical and scientific validity of the study. In accordance with the instructions of each institutional review board, we used two methods: 1) In the case of 2 of the hospitals (TMDU, JU), before the survey, a letter explaining the study aims and methods was mailed from each hospital and the respondents were asked to return the consent forms to our research center. After we had obtained consent we mailed the questionnaire to the respondents. 2) In the case of the other 2 hospitals (UofT, SMU), a letter explaining the aims and methods of the study was mailed from each hospital together with the questionnaire. Completion and return of the questionnaire

were regarded as consent to participate in the study. If the questionnaire was not returned within 1 month, a reminder was sent. If the respondents did not want to participate in the survey, they were asked to mark the questionnaire with “no participation” and return it, and a reminder was not mailed.

### 2.3. Questionnaires

#### 2.3.1. Evaluation of care during last hospitalization

**2.3.1.1. Care evaluation.** We used the Care Evaluation Scale (CES), which is a valid and reliable instrument for measuring a bereaved family’s perceptions about the need to improve the structural and process aspects of end-of-life care [22]. In the current study, the reliability of this scale was shown by the excellent internal consistency of the data (Cronbach’s alpha coefficient 0.82–0.96). The CES was developed for use not only in palliative care units but also in general wards and home hospice care. Nationwide surveys in Japan have used the CES to evaluate the quality of hospice and palliative care [22–24].

The CES comprised 28 items on 10 subscales, namely physical care by physicians, physical care by nurses, psycho-existential care, help with decision-making for patients, help with decision-making for families, environment, family burden, cost, availability, and coordination and consistency. (Examples of questions are given in the [Appendix A](#).)

The questions were designed so that the respondents evaluated the need for improvement of each item on a 6-point Likert-type scale: “improvement is highly necessary (1),” “quite necessary (2),” “necessary (3),” “slightly necessary (4),” “hardly necessary (5),” or “not necessary (6).” If respondents had no need for an item, they were asked to select “not applicable.” An average score was calculated for the items on each subscale, and the total score was calculated as an average of the subscale scores. All scores were adjusted to range from 0 to 100; higher scores indicated a lower need for improvement. We asked the respondents to evaluate care during the last week of life for all subscales except 2, namely cost and availability, which were instead evaluated throughout the entire last admission period.

**2.3.1.2. Care satisfaction.** We asked respondents to rate their satisfaction with the level of care provided during the patients’ last hospitalization, on a scale ranging from 1 (very dissatisfied) to 8 (perfectly satisfied).

#### 2.3.2. Evaluation of good death

We asked the respondents to rate the levels of achievement of 6 components of “good death” during the last week of life or last admission period, on a scale ranging from 1 (“agree”) to 4 (“disagree”), along with “unsure.” These components were extracted from previous qualitative and quantitative studies exploring good death in Japanese cancer care [21,25]. Examples of the components were “Being free from pain and physical distress,” “Being free from psychological distress,” and “Spending enough time with one’s family.” Some of the expressions were modified to fit the situation of leukemia and lymphoma patients, but the main context was not changed. For details of the components see Section 3.

#### 2.3.3. Characteristics of respondents

The questionnaire included demographic information and information on the respondent’s health status and economic status at the time of the patient’s last hospitalization.

#### 2.3.4. Characteristics of patients (decedents)

With the respondent’s consent, information was collected from the patient’s medical records on demographic characteristics, dura-

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