

# Quality of End-of-Life Care in Adolescents and Young Adults with Cancer in Japan

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## Introduction

- Cancer is the leading cause of nonaccidental death among adolescents and young adults (AYAs; 15-39 years old) in Japan.
- About 4% of all cancer occurs in AYA population in Japan. Although much is known about experiences of older adults who die of cancer, far less is known about experiences of AYAs.
- Confronting end-of-life (EOL) during AYAs is the antithesis of the usual tasks of AYA; it creates a paradox that makes discussion of EOL issues extremely challenging among AYA patients, family members, and health care providers.
- Quality of EOL care in this population varies among different nationalities or cultures.

## Objectives

We aimed to evaluate quality of EOL care in Japanese AYA patients.

## Methods

- We retrospectively reviewed electric medical record of AYA patients died from Jan 2013 to Dec 2017 in our hospital. Patients were eligible if they were aged 15-39 years at the time of death.

### Quality of EOL care

- We evaluated the quality of EOL care using the measure of the EOL care intensity developed by Earle et al.
- We compared EOL care intensity with those in previous studies including children, AYAs, and adults in other country.

### EOL discussion

- EOL discussions were identified in medical records; there was documentation of discussion about end of aggressive treatment and resuscitation.
- For this analysis, we were focused on the following points: whether the patient was involved in EOL discussion and how many days they discussed preferences of EOL care before death.

## Results

### Characteristics of AYA patients (N=114)

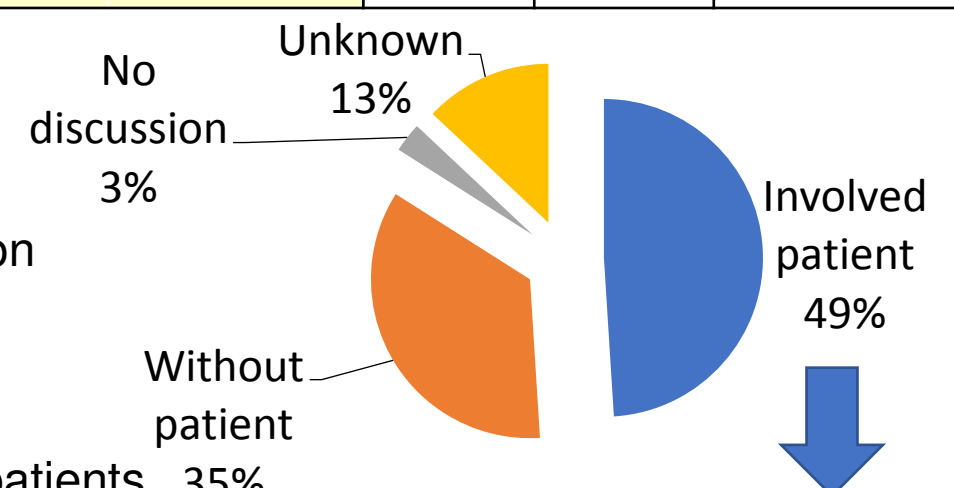
| Characteristic        | n (%)      |
|-----------------------|------------|
| Median age (IQR)      | 32 (28-34) |
| <b>Gender</b>         |            |
| Male                  | 50 (44)    |
| <b>Marital status</b> |            |
| Married               | 46 (40)    |
| Non-married           | 68 (60)    |
| <b>Cancer type</b>    |            |
| Leukemia/lymphoma     | 5 (4)      |
| Bone/soft tissue      | 23 (20)    |
| Gastrointestinal      | 23 (20)    |
| Genitourinary         | 14 (12)    |
| Lung                  | 8 (7)      |
| Breast                | 6 (5)      |
| Brain                 | 10 (9)     |
| Other                 | 25 (23)    |
| <b>Place of death</b> |            |
| Home                  | 6 (5)      |
| Palliative care unit  | 19 (17)    |
| Acute care unit       | 82 (72)    |

### Quality of EOL care

| EOL care intensity measure, %                               | (N=114)   | AYA (US) Mack et al, 2015 | Adult (US) Earle et al, 2005 | Children (US) Kassam et al, 2018 |
|---|-----------|---------------------------|------------------------------|----------------------------------|
| Chemotherapy within 14 days of death                        | 20 (n=23) | 11                        | 10                           | 8                                |
| ICU within 30 days of death                                 | 3 (n=3)   | 22                        | 4                            | 22                               |
| >1 ER visit within 30 days of death                         | 45 (n=50) | 22                        |                              | 9                                |
| Hospitalization within 30 days of death                     | 85 (n=97) | 62                        |                              | 18                               |
| In-hospital death, %  | 72 (n=82) |                           |                              | 43                               |
| Median days spent at home in the last 30 days of life (IQR) | 5 (0-17)  |                           |                              |                                  |

### EOL discussion

- Most patients were informed of their cancer diagnosis and disease condition when they started treatment.
- 96 (84%) of cases with the EOL discussion took place by the before death, and 56 (49%) cases included patients. 35%



Preference of EOL care was discussed in 37 (33%) of patients before the last 30 days of life.

## Conclusion

- For AYA patients who received cancer treatment at the cancer center in Japan, the proportion of patients receiving chemotherapy within 14 days of death was relatively high, and the proportion of hospitalization within 30 days of death was relatively high. Differences in the medical system and clinical setting by the country ought to be taken into consideration.
- There was a little population who could discuss EOL care in advance based on AYA patients' wishes.
- Better understanding of EOL care is necessary in both health care providers and family members to improve quality of EOL care in AYA population.